## "An Opportunity of This Kind": The Milbank Memorial Fund and the U.S. Public Health Service Study of Untreated Syphilis in Tuskegee

#### A REPORT TO THE MILBANK MEMORIAL FUND

#### Susan M. Reverby, PhD

Marion Butler McLean Professor Emerita in the History of Ideas and Professor Emerita of Women's and Gender Studies, Wellesley College, Wellesley, MA

Editor, Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study (2000), and author, Examining Tuskegee: The Infamous Syphilis Study and Its Legacy (2009)

#### **TABLE OF CONTENTS**

EXECUTIVE SUMMARY
REPORT7
Brief Background History 1905-19357
Medical Economics/Politics, "Pure Medical Research," and Controversy in the 1930s9
Syphilis, the U.S. Public Health Service, and the Fund (Part 1): The Medical Research Questions13
Syphilis, the U.S. Public Health Service, and the Fund (Part 2): Syphilis in the South17
Autopsies, "Burial Insurance," and the Fund20
The Fund and the Study between 1935 and 1972: The Missed Chances to Ask Questions27
The Media, the Lawsuit, the Fund, and "Culpable Ignorance"
The Study, the Fund, and Historical Memory34
Summary and Conclusion
ACKNOWLEDGMENTS AND CONNECTIONS TO MILBANK43
APPENDIX 1: KEY NAMES
APPENDIX 2: MONIES PROVIDED BY THE FUND
AMOUNTS APPROPRIATED and TITLE OF GRANT/GRANTEE PROVIDED BY THE FUND TO THE TUSKEGEE INSTITUTE, 1935-1973
SCHEDULE OF PAYMENTS TO THE TUSKEGEE INSTITUTE
EXAMPLE OF THE APPEAL IN 1936
APPENDIX 3: AUTOPSIES: PRELIMINARY CDC DATA AND PROCEDURE
CDC 1971 DATA ON AUTOPSIES AND DEATHS53
NURSE RIVERS LAURIE EXPLAINS THE AUTOPSY PROCEDURE, AUGUST 197053
NOTES

#### **EXECUTIVE SUMMARY**

In June 2021, the Milbank Memorial Fund engaged the author to conduct historical research to answer the following questions about the relationship between the Fund and the U.S. Public Health Service's study of "Untreated Syphilis in the Male Negro" in and around Tuskegee, Alabama, 1932-1972. Because many of the archives that contained the primary materials about this relationship were closed or restricted due to the COVID pandemic, it took the author several months to get into the appropriate archives to do the research.

#### Questions the Milbank Memorial Fund Asked to Be Answered by the Historical Analysis

- 1. What were the circumstances under which the Fund initially engaged in the Study, who approved it, and who monitored it over the effective period?
- 2. How and to what extent (qualitatively and financially) did the Fund engage in and support the Study; and what value did the Fund receive from the Public Health Service Study of Untreated Syphilis.
- 3. What opportunities did the Fund have to influence or react to the Study as it was conducted?
- 4. Since the conclusion of the Study, what opportunities has the Fund had to examine its role in the Study, to publicize or suppress it; and why did it make the decisions that it did in those circumstances?
- 5. What are possible implications of the findings for Fund decision-making and programmatic activities, given the Fund's mission?

#### What were the circumstances under which the Fund initially engaged in the Study, who approved it, and who monitored it over the effective period?

The U.S. Public Health Service (PHS) conducted a study of "Untreated Syphilis in the Male Negro" (the Study) in and around Tuskegee, Alabama, between 1932 and 1972 (finally closing it officially in 1973). Over the years, approximately 624 men were recruited (427 men with the disease in one arm of the Study, and 197 men without syphilis in the other). In order to prove the scientific validity of the Study, the PHS determined it needed autopsies of the men both subjects and controls. While no informed consent was required for the Study, signed permission was necessary for the autopsies under Alabama law. Nurse Eunice Rivers Laurie, who served as the go-between the PHS and the men, had as one of her duties to obtain these agreements.

The PHS approached the Rosenwald Fund in 1934 to pay a "burial insurance" to the families of the men in the Study who died to induce them to sign for the autopsies, after a family member of a deceased man suggested to them that there should be some kind of payment. Rosenwald, because of lack of funds at the height of the Depression and with its focus on education for African Americans in the South, turned the PHS request down. The U.S. Surgeon General Hugh Cumming then approached the Milbank Memorial Fund in 1935 with the same funding inquiry. The Fund had close relationships with federal health officials, especially within the PHS. This appeal for funds came just after the Fund had come under severe criticism from organized medicine for its active role in studying medical economics, medical access, and the need for some form of national health insurance. Thus this foray into "medical research" with public health implications must have been seen by the Fund's boards and staff as both within keeping of the Fund's mandate and somewhat politically benign.

The grant continued year after year with the approval of the Fund staff, its Technical Board, and the Board of Directors. Every year, under the signature of the Surgeon General, the request for funds for the "burial insurance" would come in. A Milbank Memorial Fund grant was budgeted for the Study every year, but the actual amounts spent depended upon the Fund receiving notice from the PHS that the autopsies had been done. The PHS staff visited the Fund staff from time to time, and the records of this are in the Fund archives.

#### How and to what extent (qualitatively and financially) did the Fund engage in and support the Study; and what value did the Fund receive from the Study?

The Fund budgeted \$35,500 over the years for the "burial insurance," but actually only recorded \$20,150 in expenditures for the actual autopsies. The Centers for Disease Control and Prevention (CDC) records indicate that 234 autopsies were performed out of 428 men who had died by 1971, although analysis of the men's actual medical records show autopsy information for 353 men: 256 men with the disease and 97 who were considered controls. I cannot explain the reason for this disparity since I did this research on the medical records 20 years ago. I think the 234 number is closer to what the Fund actually paid for.

All of the Fund's checks were sent to the treasurer at the Tuskegee Institute. Once the Fund sent the money to Tuskegee, the Institute wrote checks to the doctor performing the autopsy and to the hospitals for use of their facilities, to the county health officer for his paperwork and efforts to get the bodies, to Nurse Rivers if she brought the body to their attention or assisted, to the undertakers to pay for the burial and service, and sometimes a bit more to the families after 1940, especially the poorer ones.

This grant kept the Fund connected to the PHS and the CDC (which formed after World War II and took over supervising the work), especially as various Surgeon Generals during the course of the Study's forty years participated on the Fund's Advisory Board or the Technical Board and, in the case of former Surgeon General Leroy Burney, served as the Fund's executive director and president from 1970 to 1977. Burney himself had worked on the Study in the 1930s when he was a young PHS officer. Thus, because the Fund wanted to influence policy to improve public health, various Fund administrators and board members must have believed that granting monies, however small, to a PHS and later CDC project mattered in advancing this goal. In addition to the programmatic connections, the Fund's journal, *The Milbank Quarterly*, published one article about the Study, accepted articles written by PHS officials, and helped pay for and then ran a positive review of Surgeon General Thomas Parran's 1937 book, *Shadow on the Land: Syphilis*.

## What opportunities did the Fund have to influence or react to the Study as it was conducted?

Regular reports were sent to the Fund staff and boards on how many autopsies were done and articles published, and PHS and CDC officials met from time to time with Fund staff. The PHS published 13 articles about the research in public health and venereal disease journals that at least Thomas Parran, a Technical Board member for decades, a public health physician and author of the 1930s major book on the public health aspects of the disease, and a Surgeon General, would have known about. One article appeared in *The Milbank Quarterly* in 1954. In 1965, the CDC suggested that the Fund might want to provide a single grant to wrap up its contributions, but the Fund determined to continue paying for the autopsies as they came in. In 1966, after Harvard physician Henry Beecher published a critique of research ethics by leading physicians, there was a presentation to the Technical Board on the issues of such problems and then further discussion on issues of equity and the two-class medical system. However, the Study in Tuskegee was never mentioned in the Fund's review.

After San Francisco-based sexually transmitted disease contact tracer Peter Buxtun made persistent criticisms of the Study, the CDC called a meeting in 1969 to discuss whether the Study should be continued. The Fund's Clyde Kiser attended the meeting. In his report to the Fund afterwards, Kiser discussed some of the scientific limits of the Study, but made no mention of the moral or ethical ones. The Fund continued its grants.

# Since the conclusion of the Study, what opportunities has the Fund had to examine its role in the Study, to publicize or suppress it; and why did it make the decisions that it did in those circumstances?

When the Study became widely public in July 1972 (after Buxtun told the story to a journalist friend that led to publication by the Associated Press), there was discussion at the Fund's October Board of Directors meeting. The Fund president Leroy Burney told the board that a federal investigative report was pending, and that the Fund had provided "burial expenses" and sent the checks to the Tuskegee Institute. In July 1973, Alabama-based famed civil rights lawyer Fred Gray filed *Pollard v. U.S. et al.* and named the Fund as one of the defendants for its "knowledge or with culpable ignorance" of the lack of informed consent and danger of the nontreatment. The Fund's liability was dismissed on technical grounds, and Gray focused only on the U.S. government when the case was settled out of court. There was no further discussion by the Fund's board on its role. The Fund's former vice president for technical affairs Clyde Kiser published a history of the Fund in 1975 and made no mention of the Fund's role in the Study.

Twenty years later, in 1992, two documentary films were made about the Study, one in the U.S. and one in the U.K. The producer of the U.S. film, developed by Boston's public television's *Nova*, contacted the Fund's president, Daniel M. Fox, who sat on the *Nova* scientific advisory committee. Fox suggested that the Fund's board might want to draft a paper on the current ethical status of the issue. However, the board appears to have deferred to the

arguments about the complicated science of the Study made by former Harvard medical school dean and former Fund president Robert Ebert. Ebert also told the board the Fund had not been "…involved in the experiment, only in paying the burial expenses. But [emphasis in notes] we would be misunderstood." Finally, as Alan T. Wenzell, a retired investment banker on the board, concluded: "Don't borrow trouble but be prepared with a statement in reserve.' Just don't volunteer it." No paper was written.

In 1996, a Legacy Committee organized with others including the Black Congressional Caucus to get a formal federal apology for the Study from President Bill Clinton, which happened on May 16, 1997. The Fund was never asked by the committee to apologize, and Fund staff and its board did not know about the apology till it was in the news. Nothing further was done. In 2005, when it was the Fund's 100th anniversary, the Fund published a centennial report; *The Milbank Quarterly* published a historical article by President Dan Fox about the Fund in 2006; and several key articles from *The Milbank Quarterly* were reprinted. The Study was not mentioned.

#### What are possible implications of the findings for Fund decisionmaking and programmatic activities, given the Fund's mission?

While it might seem obvious now that there was a conflict of interest, the Fund's Technical and Advisory Boards in the past had members who were direct or indirect beneficiaries of the decisions made for grants. In such circumstances, programmatic oversight is compromised. The Fund's need to be relevant to federal, state, and local health officials may have made it hard to turn down their requests for funding.

The Fund should understand who is affected by program activities and the assumptions that are made. Since the checks for the Study were sent to the Tuskegee Institute, not the PHS nor the CDC, it is possible that any concerns about racism were assuaged because this important historically Black college was key to the relationship of the Fund to the Study. Furthermore, while it was assumed that the money for the "burial insurance" was important to the families' participation, it should also be considered that making such a study seemingly more "scientific" also kept the PHS/CDC researchers involved.

The reliance on the physician/scientists on the various Fund boards and leadership may have also blinded the Fund from seeing the programmatic implications of its funding. While the presence of representatives of more ethnic and racially diverse groups is no guarantee of differing viewpoints (as this history of the Study demonstrates), it would perhaps help raise questions for consideration that others on the board or staff might overlook.

Understandings of how to respond to ethical dilemmas in medicine change over time, as the history of the development of bioethics demonstrates. Similarly, in terms of governance policy, the decision in 1992 to avoid discussion of the Fund's connection to the Study does not seem appropriate in the light of current politics in 2022. It would make sense as the

Fund moves on in its important work, especially now in the midst of the current COVID/public health crisis, to acknowledge publicly its role in the Study in Tuskegee, and to negotiate appropriate reparations with the organization of the descendants of the men in the Study. Apologies of course only cover what happened in the past, but such public acknowledgment of the history is part of a contribution to restorative justice. What happens next is what matters as the Fund determines how to work to promote trustworthiness, not mistrust, of the health care system, promotes efforts to undermine the racism that shapes health outcomes, and supports efforts toward equity in health care.

#### REPORT

"I am particularly interested in fostering preventive and constructive social measures for the welfare of the poor..., as distinguished from relief measures affecting particular individuals and families." Elizabeth Milbank Anderson to a New York City welfare organization in 1912.<sup>1</sup>

"I have confidence...in the stimulating challenge of facts." Edgar Sydenstricker, 1931.

"An opportunity of this kind is not presented in many places in the civilized world today. For this reason it is urged that the Milbank Memorial Fund continue to support this study to the extent of providing for a maximum of ten autopsies per year at \$50.00 each, or a total of \$500.00. The Public Health Service expends approximately \$1,800 per annum on this project...." Surgeon General Hugh S. Cumming to Albert G. Milbank, Chair of the Board of Directors of the Milbank Memorial Fund, November 1935.

"The brittle thread of life having been cut this morning, old man [name redacted] was launched into eternity....He has fulfilled his destiny. As a last tribute of our affection for our deceased brother; as a demonstration in the strongest possible manner of the sincerity of our past esteem for him, and in conformity to the usual procedure, an autopsy will be performed at 1 o'clock this afternoon, after which, sections of the vital structures will be mailed to the National Institute of Health while his cold and lifeless body...will be resolved into its original elements." Murray Smith, Macon County Health Officer and Special Expert V.D. for the U.S. Public Health Service, to Dr. R.A. Vonderlehr, U.S. Public Health Service, March 1940.

#### Brief Background History 1905-1935

In 1935, when U.S. Surgeon General Hugh Cumming wrote to the Milbank Memorial Fund (the Fund) to ask if it would support the U.S. Public Health Service's study of "Untreated Syphilis in the Male Negro" in Tuskegee (the Study), he had every reason to expect a positive reply.<sup>2</sup> The amount of monies he was requesting was for a purpose that fit within the Fund's concern with demonstrated "economy and efficiency" in public health, and linked to its history of cooper-

ation with federal, state, and local public health officials.<sup>3</sup> Neither Cumming nor the Fund's board and staff could know then that this grant would go on for another 38 years and cost the Fund \$20,150, a very, very small percentage of the Fund's giving. Nor could they probably have imagined that the Study would become the symbol of unjust and racist public health/medical research that would echo through the decades.

The Milbank Memorial Fund did not start with a concern with syphilis, or public health issues that focused on African Americans. In 1905 philanthropist Elizabeth Milbank Anderson began one of the first American foundations, called the Memorial Fund Association. Its earliest awards were to support prevention measures, not mere charity, in "child welfare and public health work, including mental hygiene," primarily in New York's poor communities.<sup>4</sup> With Mrs. Anderson's death in 1921 and additional bequests from her will, the name of the foundation became the Milbank Memorial Fund and the Fund's beneficence expanded with an asset base of approximately \$10 million.<sup>5</sup> Between 1921 and 1935, the Fund's directors concentrated on grants for "projects on carefully defined populations, diseases, and services so that the goals would be clear and the results measurable," as its former president and historian Daniel M. Fox labeled them.<sup>6</sup> Reports were published in what would become the renowned Milbank *Quarterly* (under several different titles over the years and called the Quarterly hereafter), with summaries and press releases sent out to leading health services administrators, prominent doctors, and health departments.<sup>7</sup>

The Fund was operating in its first decades at a time when the tensions and boundary disputes between public health and organized American medicine, in the form of the American Medical Association (AMA) and its state/local affiliates, were high.<sup>8</sup> In the 19th century, elite physicians often supported sanitarian public health measures and the creation of public health departments linked to social reforms for the poor, working class, and immigrants, while the AMA had little power.

By the early 20th century, growing acceptance of germ theory "uncouple[d] disease from its social roots" and led to the rise of scientific/laboratory-based training for almost exclusively white male physicians.<sup>9</sup> Elite doctors tended to move into specialties and hospitals while separating their public health efforts, if they occurred at all, from what was often seen as the "maternalist" work of well-meaning lay "charity" women and social reformers.<sup>10</sup> Physicians, in academic medicine and private practice, remained ever dubious about both the political nature of public health and the public hospitals with their links to politicians who handed out jobs to local constituents supposedly without training.<sup>11</sup> General practitioners in private practice feared that prevention of primarily infectious diseases and required reporting, assumed to be the bailiwick of public health, could cross over into medical care and thwart their efforts, limit their income, or destroy their patients' privacy.<sup>12</sup>

Aware of these difficulties and never politically naïve, the Fund's board and staff tried to balance the possible opposition of private physicians and their organizations with measurable public health reform goals. In 1920s, many of the Fund's grants proposed by its own staff focused on demonstrations in a New York rural county, small city, and metropolitan area on the cure and prevention of infectious diseases and coordinated public health and education.<sup>13</sup> Armed with statistical data, the demonstrations were set up to prove that more efficient organization would positively affect health outcomes. As *The Survey* magazine noted in 1935, "... the Fund has gained an enviable reputation for grappling with difficult and important public questions, chiefly in the broad field of public health, and laying them open to dispassionate, informed and scientific study."<sup>14</sup> The science of medicine focused on individuals was to be met with grants from the Fund to improve the science of public health focused on populations.

The Fund also set up a Technical Board and an Advisory Board in 1922 to make sure medical, social reform, and public health experts assisted in the Fund's efforts.<sup>15</sup> Both boards' membership was a "who's who" of elite health care leadership, including Hugh S. Cumming, the U.S. Surgeon General; William H. Welch, one of the Johns Hopkins Medical School's "great doctors" and dean of its School of Hygiene and Public Health; and leading statisticians, health commissioners, and directors of various disease voluntary associations.<sup>16</sup> Welch declared that the Technical Board, which met monthly, "was the most valuable body of its kind meeting in the whole country."<sup>17</sup> With careful political maneuvering, attention to detail, constant work at community health outreach, use of public health nurses, and support for health departments, the Fund's projects attempted to measure outcomes and to assuage the fears of what a local medical society labeled the "pernicious 'interference' of lay groups."<sup>18</sup> Above all, the Fund's efforts had to contend with medical groups that would argue for decades that no one should come between doctor and patient, and that meant primarily any representative of the government and its requirements.<sup>19</sup>

The border between medical care and public health, always contested and porous, was becoming more so, and the Fund did not always find itself on the public health side alone. As Thomas Parran, a crucial member of the Fund's Technical Board and Commissioner of Health in New York State, wrote in 1935: "Prevention and control of disease cannot be separated from care and treatment by any but an artificial boundary line."<sup>20</sup> Despite the Fund's efforts to stay above the fray in these border disputes, by the late 1920s and early 1930s it found itself under attack from representatives of organized medicine; the attack would grow even worse as it ventured into studying the reasons behind Americans' poor health and their inability to pay for medical care.<sup>21</sup> These battles would go on to affect what projects the Fund would, and would not, support.

#### Medical Economics/Politics, "Pure Medical Research," and Controversy in the 1930s

Organized medicine's concern with the Fund began simply enough. Well aware that financial difficulties limited access to medical care and thus the public's health, the Fund, along with seven other foundations, backed what would become a five-year study between 1927 and 1932 by the Committee on the Costs of Medical Care (CCMC), run by a carefully curated group of private physicians, medical school faculty, and public health reformers.<sup>22</sup> Unable to make a definitive set of recommendations within the divided committee, the Fund then supported I.S. Falk, a bacteriologist/public health reform advocate who had been the CCMC's associate

director for research, and Edgar Sydenstricker, a well-known economist/statistician on loan from the U.S. Public Health Service (PHS) as the Fund's scientific director, to look into "the plans that the [CCMC] had left unsolved."<sup>23</sup> They developed a proposal for compulsory health insurance and sent their recommendations on to President Franklin Delano Roosevelt.<sup>24</sup> This focus was a logical outcome of the Fund's concern with public health and the difficulties many Americans had paying for their health care.

Despite efforts to assuage physicians that such proposals would be of little harm to their practices, organized medicine, with its private general practitioner base, did battle against the recommendations.<sup>25</sup> The AMA's anger became focused on the Fund for its support of the CCMC, the continued work of Falk and Sydenstricker, and above all the writings and speeches of the Fund's executive secretary, John Kingsbury. Kingsbury had come to the Fund in May 1922 with a long history as an administrator in organized charity work for voluntary associations and the city of New York. Although he later described himself as a "Roosevelt Republican," Kingsbury's own poverty-filled youth and years of experience in charity work and research led to his increasing radicalization and sense of urgency for real structural changes in the organization of medicine and public health.<sup>26</sup> He coauthored a Fund-sponsored 1933 volume with English health advocate Sir Arthur Newsholme on state medicine in the Soviet Union, with the unfortunate, if accurate, title of Red Medicine, complete with a big red star on the book's spine.<sup>27</sup> While Kingsbury made clear he did not think that the "state medicine" in the Soviet system would work in the United States, the book's positive support for governmental involvement in the funding and structuring of health services, along with Kingsbury's tours to support his position all over the country between 1934 and 1935, was enough to bring him under attack. He was seen as part of what an editorial in the right-wing Hearst-owned newspapers called the "brain trust' of the 'Reds' in America."28 While Kingsbury was calling for a system of compulsory health insurance, not what was labeled "state or socialized medicine" or governmental control of health delivery, the obvious differences between these two positions were often lost.<sup>29</sup>

Ever fearful of the reforms being discussed and Franklin Delano Roosevelt's programs that were pushing through Congress, organized medicine increased its pressure politics. It was literally about the possibility of spilt milk since the Milbanks as a family, and the Fund as a foundation, had considerable holdings in the Borden's Condensed Milk Company that Elizabeth Milbank Anderson's father, Jeremiah Milbank, had financed beginning in 1857. In the 1930s, his grand-nephew, Albert G. Milbank, served as the chair of the boards of directors of both the Fund and the Borden Company, and had long been active in social welfare concerns. The doctor groups threatened to tell the country's doctors to tell mothers not to buy Borden's products to use in their infant formulas unless the Fund backed off its support for national health insurance.<sup>30</sup>

Albert Milbank and John Kingsbury had been in the social policy trenches together for decades, editing one another's pronouncements and seeing eye to eye on reform efforts. Now Milbank, however, was caught and had to balance his strongly held social reform principles, class interests, and financial responsibilities. Pressure was being put on him from within Borden's board of directors too, as Kingsbury saw it, "to call me off." Kingsbury reported that the Borden executives were telling Milbank that the Fund should "transfer our interests to pure medical research [underlining added], putting our monies in the hands of the various medical societies, and withdraw, temporarily at least, from the field of medical economics, and particularly from health insurance activities."<sup>31</sup>

In June 1934, Albert G. Milbank, along with Louis J. Auerbacher, the director of medical relations for the Borden Company, came to see Kingsbury in his Fund office. Kingsbury claimed Auerbacher reiterated the position that the Fund should "put our money into medical research, telling me that by doing so we could create a great monument to ourselves and eventually secure the good will of the medical profession." An angry exchange ensued. Milbank, later that day, assured Kingsbury he would continue to support the efforts for insurance and other reforms, even if it cost them "thousands."<sup>32</sup>

Milbank still was committed to the work on social reform of health care delivery/funding and understood the importance of the Fund to this effort. By a Board of Directors meeting that fall, however, the pressure was building, as the minutes report: "[1]t would be unwise at this time for the Fund's staff to speak before large audiences, although it might be desirable to continue meeting with small groups of doctors for the purpose of discussing the problem of health insurance."<sup>33</sup> Such a nuanced position was, however, becoming impossible.

If the changes being investigated and proposed by the Fund's staff had just stayed within the health policy intellectual world, it would probably not have been so threatening to organized medicine. Kingsbury, however, had mentored FDR's commerce secretary Harry Hopkins. Others within the Fund had similar ties and could write, call, or meet easily with federal executive branch leaders as the social and political ties between private philanthropic organizations and the Roosevelt administration ran deep.<sup>34</sup> Kingsbury's efforts could have become national policy as elements of the social security bill were being worked out in Congress.

Despite pressures on Roosevelt to add national health insurance to his proposals, however, Roosevelt and Secretary of Labor Frances Perkins were also flooded by "tens of thousands of [physicians'] telegrams...in opposition to health insurance."<sup>35</sup> FDR's administration eventually backed off any support for the insurance, concerned that the opposition of the country's doctors could have done in the social security plans they deemed essential to New Deal policy. Divisions within FDR's cabinet, the lack of labor support, debates among even reform-minded physicians, and a focus on gradualism also figured in the demise of the insurance schemes. Thus, social security, without a provision for health insurance, made it into the final bill and passed Congress on April 19, 1935.<sup>36</sup>

Albert G. Milbank now had the problem of what to do about his conflicting responsibilities to his own commitment to social reform in the health care arena, protection of the Fund and the Borden Company, acceptance that health insurance would not be proposed at the federal level, and the necessity to deal with his friend and compatriot John Kingsbury. Aware of the ever

growing criticism of the Fund's work, Milbank crafted and gave an invited speech in Indianapolis to organized doctor groups on January 27, 1935. The speech went through multiple drafts and was vetted by the Fund staff, including Kingsbury, and eventually by Milbank's doctor contacts.<sup>37</sup> A press release issued the next day by the Fund highlighted his key points, and the whole speech was published three months later in the *Quarterly* and the *Indiana Medical Journal*.

Tracing the Fund's history of constant support from its physician advisors, Milbank assured his critics that they were not proposing any form of socialism, nor expecting doctors to give up their control of their practices. Skillfully assuaging the physicians' fears, both financial and political, Milbank threaded a careful line, promising that insurance was not the same as "state medicine," while encouraging the doctors to consider the role of government in financing medical needs. Finally, he concluded by reminding his audience how much the Fund had given for medical research work on tuberculosis, diphtheria, and cervico-vaginitis that far outweighed any time or monies spent advocating policy changes for health insurance.<sup>38</sup>

Milbank continued to carry on his theme of cooperation with private doctors at the annual meeting of the Fund's Advisory and Technical Boards two months later on March 28, 1935, as he "urged" what the *New York Times* report the next day called "harmony…in health field." His views were reiterated at the meeting by U.S. Surgeon General Hugh Cumming, who argued that both the medical profession and the leaders of public health had "mutual responsibilities" to come together before "the public may become impatient and step in with some one solution that may be disastrous and detrimental to all concerned…."<sup>39</sup> The conciliatory speeches did not prove enough, as the organized physicians seemed to think that some form of social-ism, or even communism, was now pressing at their gates.

The pressure on Milbank to do something about the Fund's executive secretary finally became too much. Three days later, on April 1, 1935, the support Milbank had promised Kingsbury a year earlier had evaporated. He called Kingsbury into his office and gave him a two-hour lecture on their differences, a talk Kingsbury did not expect. Two weeks later, Milbank asserted to Kingsbury: "The issue between you and the Board is not health insurance, nor the consequences of the hostility of certain groups in the medical profession toward you and toward the Fund, but lies much deeper and is bound to develop into conflicts that will impair the usefulness of the Fund in the future."<sup>40</sup>

In a sense Milbank was right. He was focused on how the Fund presented itself in public, and how it negotiated the boundaries between public health and private medical practice. Fund historian and former president Dan Fox argued in his analysis of these difficulties that Milbank was also concerned about then ongoing legislative investigations into the workings of foundations and the Fund's grants for research on such controversial topics as fertility and birth control.<sup>41</sup> A week after their meeting, Kingsbury realized his position was untenable: he sent in his "resignation" and Milbank wrote him a letter acknowledging a political divorce based on "irreconcilable differences."<sup>42</sup> As Kingsbury saw it, Milbank was giving "first consideration to the medical profession" while he was focused on "the public."<sup>43</sup> On April 20, 1935, the Fund sent out a press release that explained that Kingsbury "had severed his connection with the Fund owing to difference of opinion as to policy."44

Rumors flew about the inner circle of health reformers and medical experts that the Fund was also going to fire Falk and Sydenstricker and "give up its health insurance studies and enter the field of medical research." Four days later, Kingsbury assured one of his harshest critics, lago Galdston at the New York Academy of Medicine, that this "rumor" he thought Galdston had started was not true.<sup>45</sup> Kingsbury's fellow reformers rallied around him, as when *The Survey Graphic* editor Paul Kellogg telegraphed: "Here's to you John your integrity courage and service to America."<sup>46</sup> Despite Kingsbury's efforts to explain his position both in public and in private correspondence, his work with the Fund was over.<sup>47</sup>

One month later, the Fund agreed to give the U.S. Public Health Service funds for medical research in Tuskegee.

#### Syphilis, the U.S. Public Health Service, and the Fund (Part 1): The Medical Research Questions

Kingsbury's dismissal and the pressure on the Fund not to work on social reform and medical economics but to turn to what seemed at the time to be a simple medical research project with public health implications was *not* the only reason the Fund would become willing to provide monies for the Study in Tuskegee. Other parts of the Fund's history made this a distinct possibility, especially when the amounts asked for proved small relative to other grants.

The physicians and public health officials on the Fund's Technical and Advisory Boards understood, as Albert G. Milbank had told the Indiana physicians, that new ways of treating infectious disease fell within the wide purview of the Fund's policy for funding and research with its public health focus. Some of the early grants had focused on diphtheria, which had killed Elizabeth Milbank Anderson's son, and more prominently on tuberculosis, the leading cause of death after pneumonia, in the first half of the 20th century. Syphilis, a sexually transmitted or congenitally transferred infection, had a harder time garnering research support from the Fund and elsewhere.<sup>48</sup>

Famed physician Sir William Osler had asserted to physicians in 1904: "Know syphilis in all its manifestations and relations, and all other things clinical will be added unto you."<sup>49</sup> Osler was referencing the facts that syphilis could affect every part of the body: eyes, brain, heart, skin, nerves. It had therefore much to teach physicians. The disease affected one out of every 10 Americans by the 1930s and cost "the taxpayer more than any other infectious disease."<sup>50</sup>

Yet syphilologists and their allies spent much of the first third of the 20th century struggling to take syphilis out of secrets and silences to make the public, health authorities, and physicians realize the importance of discussing and treating it appropriately. Syphilis care was never easy. As key Johns Hopkins syphilologist Joseph Earle Moore put it succinctly, syphilis was a stigmatizing disease of "vice, prostitution, and penitentiaries."<sup>51</sup> The disease was treated quietly for those with money in private doctors' offices and by public health clinics for everyone else, if it was diagnosed and treated at all.

One infamous story captured the problem of stigma and enforced silence. When he was New York State's Health Commissioner and two years before he became the U.S. Surgeon General, Thomas Parran demanded in November 1934 to be allowed to use the words "syphilis" and "gonorrhea," rather than the euphemism "social diseases," for a CBS radio program on public health. CBS executives refused to let him be on the air, and he was stopped from speaking.<sup>52</sup> Parran, who served on the Fund's Technical Board for 41 years beginning in 1920, was especially concerned with making syphilis control part of public health education and medical care practice. His focus on what was then called venereal diseases, and especially syphilis, was the hallmark of his career and for what he would be remembered.<sup>53</sup>

Research on syphilis and other venereal diseases was needed because there was much uncertainty about treatments by the late 1920s. Syphilis had three stages, the first two were considered contagious and the last more potentially dangerous for its suffer. The early promise of the use of heavy metals like mercury (an older treatment) coupled with the newer neoarsphenamine and bismuth was being questioned, especially for those who had survived to the third stage or late latency of the disease and were supposed to be no longer contagious.<sup>54</sup> Therapeutic concerns at the time focused on what kind of drugs were appropriate, at what stages in the disease they ought to be given, and in what amounts and regularity. Even if patients showed syphilis on the blood tests, they sometimes did not have clinical symptoms. Those in the latency stage without symptoms but positive tests were also of concern: should they be treated? Furthermore, specialists believed that private doctors did not know how to handle the difficult-to-use arsphenamines, and there was little uniformity in treatment. Joseph Earle Moore was certain there was way too much dangerous overuse of neoarsphenamine in particular, and he continually pushed for studies to evaluate various treatment and prophylaxis drugs.<sup>55</sup> He discussed these concerns repeatedly with Thomas Parran and other syphilologists throughout the world in the 1930s and till his death in 1957.56

Given the danger of the haphazardly provided heavy metals, the adage among syphilologists went: "If the patient has had syphilis for 25 years without clinical disease, he is to be congratulated not treated."<sup>57</sup> A retrospective report referred to in the medical literature as the Oslo Study, done with white patients in Norway around the turn of the century with some of the older treatment modalities, had shown that many patients did not need treatments and could live with the disease.<sup>58</sup> Costs were an issue as well. Health economists in the early 1930s found "eighty percent of the population could not afford the cost of adequate care...from private physicians."<sup>59</sup> Even care in the public clinics proved expensive.

Race, too, figured in the calculations of what to do about syphilis. It was assumed at the time, even though this proved wrong, that the disease was different in Black and white people: with neurological changes affecting white people and cardiovascular deficits in African Americans.<sup>60</sup> As the PHS's Raymond Vonderlehr put it bluntly: "[0]ur present information indicated definite biologic differences in the disease in Negroes and whites."<sup>61</sup>Community-wide surveys using the Wassermann test for syphilis in the rural South showed particularly high prevalence rates among African Americans, although comparative studies of white people in the same area and with the same socioeconomic status were not done. In the vernacular of the

time, the authors of a 1930 survey done by the PHS and the Rockefeller Foundation in three Mississippi Delta counties concluded: "[S]yphilis is probably the major public health problem among rural Mississippi negroes [small n in original] today." To explain this finding, their contemporary racism led them to assert: "The rural negroes [sic] of Mississippi are unmoral and prodigal. As a group these negroes are carefree, happy and peaceable; crimes of violence unassociated with a sexual background are rare; their prodigality is inordinate and their sex appetite is enormous."<sup>62</sup>

The Fund had not ignored syphilis as a public health problem, and it could not have with syphilis care champion Thomas Parran on its Technical Board. Syphilis was never central, however, to the Fund's giving either. Grants were provided here and there on venereal diseases in the 1920s and early 1930s for specific research projects, but many were turned down. At the annual conferences in the 1930s, syphilis control was often discussed at the various round-tables along with other concerns. Given the social status of discussion of syphilis in public, these open considerations were themselves controversial, as Dan Fox has argued.<sup>63</sup>

Mostly the Fund officials seemed to think that strictly medical research ought to be carried out either by medical schools and/or with governmental funds.<sup>64</sup> When Joseph Earle Moore asked in March 1935 for funds for a study at Johns Hopkins of cardiovascular syphilis, for example, he was told his study "does not strictly lie within the present field of interest of this foundation." Moore considered appealing by contacting others he knew on the staff and Technical Board but realized it would not have helped.<sup>65</sup> The same year, the Fund turned down requests from New York Hospital, New York University Medical School, and Vanderbilt Medical School for various kinds of venereal disease studies.<sup>66</sup>

Parran, in contrast, convinced the Fund to provide money for the Cooperative Clinical Group Study on Syphilis that was examining treatment in multiple medical school clinics, paid for primarily by the PHS and a philanthropist for five years beginning in 1927. Parran made his successful pitch by emphasizing the need to have this information for public health.<sup>67</sup>As the Depression deepened, however, while we have "great interest in the syphilis studies," the Fund's Edgar Sydenstricker told the PHS's Taliaferro Clark that there had to be "bone cuts" to the budget and limits to their contributions.<sup>68</sup> In December 1933, when the PHS tried again to get several thousands of dollars more in financing to tabulate the Cooperative Clinical Group findings, Sydenstricker thought funding "clerks" to do this kind of work was not the best use of the Fund's money and "not a very exciting venture, to say the least." Instead, the Fund provided just a few hundred dollars to wind that project down.<sup>69</sup>

In turning down the larger PHS application for support, however, Sydenstricker did not rule out money for syphilis research. Writing to Parran, who was still the health commissioner for New York and had headed the Cooperative Clinical Group, for advice on the PHS's request, Sydenstricker remarked that "there might be an opportunity to aid in an actual community program of venereal disease control in some small locality which might serve as an experiment or an illustration in administrative methods." And, he told Parran, "we might consider some other use of the fund of three or four thousand dollars which might be found in our budget for venereal diseases."<sup>70</sup>

Sydenstricker was very clearly focused on public health, not just medical research. Turning down a funding request for a venereal disease clinic at Cornell Medical School, he informed Parran moreover: "I am very much afraid that the public health aspects of such a clinic would be neglected and it would be too much of a research clinic." Sydenstricker was clear, how-ever, that if a project could fit within the rubric of what he labeled "practical administrative research" that "represents scientific inquiry into the application of data already at hand," the Fund would consider it.<sup>71</sup> As the Fund's board discussed what to fund, Livingston Farrand, physician, tuberculosis research expert, and Cornell University president, in contrast reminded his fellow board members that "pure research would at times be necessarily involved."<sup>72</sup>

One of the last things John Kingsbury did for the Fund was head an experts' discussion on syphilis. On January 24, 1935, he convened a roundtable to discuss funding "further work along the lines of more intensive form of treatment for syphilis," among other issues concerning the disease. Most of it focused on how the Fund might be of use to the Health Department in New York City since cases had gone up at least 10% in the previous year and the needs in both Harlem and East Harlem were considered the direst. Some of the concern was whether the needed clinics should focus on the "whole burden" of syphilis or, as was being done in Baltimore, "just the infectious early cases."

The debates at the roundtable give a sense of how much, in the face of limited funds, the issue of whether treatment for those in the later stages of the disease ought to be a high priority, especially since it turned out that New York City regulations restricted "use of welfare funds to the treatment of patients confined to bed." In contrast, while discussing what ought to be done, Kingsbury read part of a letter from his coauthor Sir Arthur Newsholme in England "suggesting that the United States <u>offer free treatment to all ters</u> [underlining in original] as a means of solving the venereal disease problem."<sup>73</sup> At the Technical Board meeting the following April, these issues were returned to as Kingsbury, at his last meeting, suggested the Fund would have to decide what kind of programs in venereal disease it was willing to support.

A month after Kingbury's departure, Sydenstricker was the Fund's scientific director and acting head of the Fund when he took up the concern with syphilis. At a meeting of the Technical Board on May 16, 1935 he reported to the Board of Directors there had been "consideration to the best form of...contribution which could be made by the Fund in the field of syphilis control; that there was some difference of opinion as to the type of work which might best be undertaken...[and] the Technical Board would give further consideration to the subject and report back with recommendations at a later date."<sup>74</sup> As Sydenstricker had told Parran the year before, he was concerned with "the whole question of experimentation in public health procedures and methods and of ways of measuring the effectiveness of such procedures and methods." And, as he reminded Parran, "you have already spoken to me about the possibility of trying out some methods of syphilis control...using established health departments, where the health officers are sympathetic and competent, as field laboratories."<sup>75</sup> A few months later the Fund was again considering whether it ought to support studies on intensive treatment, although the Fund's Technical Board staff member syphilologist Ralph E. Wheeler thought "it is doubtful whether the Milbank Fund is necessarily the agency to assist the work."<sup>76</sup>

Over the next year there would be more discussion at the Technical Board meetings on what kind of syphilis programs they might fund: more money for public education, for training of physicians, supporting local health departments, or finding ways to evaluate intensive treatment programs.<sup>77</sup> Parran in particular argued that one of the "certain unsolved problems of syphilis – notably the question of duration of infectivity – recurred repeatedly and were badly in need of solution."<sup>78</sup> The Fund, in particular, followed much of Parran's advice, and even provided him with \$2,000 to publish his groundbreaking and best-selling book *Shadow on the Land: Syphilis*, which appeared in 1937.<sup>79</sup>

It was clear that more focus on syphilis, although never a major part of the Fund's work, was beginning to happen.

### Syphilis, the U.S. Public Health Service, and the Fund (Part 2): Syphilis in the South

The Fund's relationship to the PHS was crucial to what followed. After all, the success of the Fund's grants over the years was because of its careful and close relationships to leaders in public health at the local, state, and federal levels.<sup>80</sup> While it never financed everything a governmental agency (including the PHS) might ask for, it looked very seriously at those requests, especially because a number of these officials served on their boards, even though final decisions on funding were made at the Board of Directors level. At the national level, the PHS was key because before 1946 and the creation of what would become the Centers for Disease Control and Prevention (CDC), the PHS served as the primary public health arm of the federal government.<sup>81</sup> Begun as the Marine Hospital Service in 1778 to aid sick merchant seaman, by the early 1900s it was involved in medical research, quarantine, examination of immigrants at the borders and in Europe, and the control of infectious diseases from flu to syphilis.

Often in contention with private physicians who thought the federal agency was overstepping its boundaries, the PHS leadership had to work with other public health reformers and foundations to sustain many of their efforts and to build local health departments.<sup>82</sup> Hugh S. Cumming, the Surgeon General and head of the PHS from 1920 to 1936, served for years on the Fund's Advisory Board. As a relatively conservative and eugenic-minded physician trained at the University of Virginia Medical School, he opposed the findings of the CCMC and ran twice unsuccessfully for president of the AMA but did serve as president of the American Public Health Association in 1931. He also thought focusing on syphilis in African Americans in the rural South mattered.<sup>83</sup> Syphilis was only part of the PHS's work, but the PHS provided much of the staff for the studies in the 1930s. After the Cooperative Clinical Group project, the PHS worked with the Rockefeller Foundation on prevalence research in Mississippi and then more closely with the Chicago-based Julius Rosenwald Fund to develop a model syphilis control study in six Southern counties, including Macon County in Alabama, in the early 1930s. One sixth of the Alabama county's Black population — men, women, and children — showed up for the surveys and treatment in schoolyards, churches, stores, and crossroads. The PHS was delighted to find, in the condescending and racist words of one of the doctors in charge, that the Black population was "susceptible to kindness."<sup>84</sup> Despite the effort, the amount of unmet need for treatment of syphilis and other major ills was enormous, and their treatment program even for the venereal diseases fell short.

Michael M. Davis, the Rosenwald Fund's health czar, hired physician H.L. Harris to examine the project, New York State health commissioner and syphilis expert Thomas Parran to evaluate the work, and sociologist Charles Johnson to research the social and economic conditions in Macon County.<sup>85</sup> Their studies proved that there was a need for syphilis control, and that treatment could be carried out successfully in the rural South with the cooperation of employers on plantations, the health departments, and even the local white physicians who were not threatened by a public program for Black patients.<sup>86</sup> The demonstrations, however, could not be a substitute for the real rural health department that was actually required because the needs were so great and the economic distress enormous.<sup>87</sup>

In an exchange of letters among leaders running the Rosenwald demonstrations, it was clear they thought the next step had to be finding the funds for expanding treatment in differing locations.<sup>86</sup> The needed expenditures to do so were small, even for that time, as Parran told the Rosenwald Fund: "[T]he cost of an adequate demonstration approximates \$1.00 per Negro inhabitant or \$5.00 per infected case per annum."<sup>89</sup> Parran thought the demonstrations so successful that he "expect[ed] to recommend...that they continue the demonstrations in the counties in which they have been started and that these studies should be continued for another three years....I am sure that these demonstrations are potentially the most significant health projects undertaken in the south in recent years."<sup>90</sup>

Unfortunately for what was to follow, an extensive Southern syphilis treatment plan was deferred by the Rosenwald Fund as the Depression deepened. Hard hit by falling stock prices by 1931, the Rosenwald Fund decided to eliminate most of its funding on what Michael M. Davis labeled anything "outside of our special interests in Negro school education."<sup>91</sup> The demonstrations were closed. Any hopes of the Rosenwald Fund would create a model of rural health care delivery for syphilis control or anything else medical in the South for mainly African Americans was dashed.

In the PHS's Venereal Disease Division, however, the concern with what to do with all the "data" they had collected remained an issue, and their concern with syphilis did not abate. It seemed to them a shame to let it all go. Alabama's Macon County was of especial interest because there had been high rates of prevalence and not much treatment. Tuskegee, the small city

that was the county seat for Macon, also had the John A. Andrew Memorial Hospital on the Tuskegee Institute campus, and an adjacent Veterans Administration Hospital that could be part of any study, given segregated medical facilities throughout the South.

Historians are still debating whether the initial idea for what would become known as the "Tuskegee Study" came from the PHS's Taliaferro Clark and Surgeon General Hugh S. Cumming, or from the then New York State Health Commissioner Thomas Parran.<sup>92</sup> In examining the results of the Rosenwald Fund demonstration in Macon County, Parran speculated in his January 15, 1932, report: "If one wished to study the natural history of syphilis in the Negro race uninfluenced by treatment, this county [Macon] would be an ideal location for such a study. Little is known also concerning the nature and extent of physical impairment caused by untreated syphilis. This also might be studies in this population with an untreated control group and a comparable treated group."<sup>93</sup> Eight months later, however, the PHS's Venereal Disease Division head Taliaferro Clark wrote to the Alabama state health officer that since so few people in Macon County had really been treated, they had "an unparalleled opportunity of studying the effect of untreated syphilis on the human economy."<sup>94</sup>

Plans began to be worked out to study "untreated syphilis in the Male Negro" for those in late latency of the disease and assumed to be no longer contagious. Only men would be studied since they could more easily give a history of when a visible chancre on their genitalia appeared (to date the origin of infection and therefore their stage of the disease), and it lessened any chance of congenital syphilis that women could pass on to their fetus at birth.<sup>95</sup>

By September, having met with the PHS's Taliaferro Clark, Eugene H. Dibble, the medical director of the hospital on the Tuskegee Institute campus, was telling the Institute's principal about the possible project. In Dibble's words, "the U.S. Public Health Service...is very anxious to extend its research...so that they can find out just what effect syphilis is having on people who have been untreated over a period of years....The cost of the treatment of this disease is very high, so that it would be of worldwide significance to have this study made." Dibble also promised the Institute "would get credit for this piece of research work...[and] the results of this study will be sought all the world over."<sup>96</sup> Three days later the Surgeon General added his request to R.R. Moton, the Institute's principal, by reiterating Clark's words that it would be "an unparalleled opportunity" that would have "a marked bearing on the treatment, or conversely the non-necessity for treatment of cases of latent syphilis."<sup>97</sup> For Dibble, both a "race" and "science" man, the idea that the expenditure of funds for treatment in the latent stages of the disease might not be needed was clearly appealing under the dire economic and medical straits of the people he served, and he accepted the supposed medical wisdom that the disease might be different in African American and white people.<sup>98</sup>

As was common at the time, there was no real research proposal or protocol set up for creating such a study. Instead, the doctors within the PHS's Venereal Disease Division wrote and spoke to one another, checked with other leading syphilologists, gained support from the health departments in Macon County and Alabama and with the local white physicians, and connected with Dibble. Whatever role Parran played in suggesting that a study might

have a treatment and nontreatment arm did not come to fruition. Instead, Clark and Cumming worked out a program in 1932 that began with an inadequate amount of treatment (received by 40% of the men with syphilis) that within the year, because there was so little money, became a study with two arms: those supposedly in latency who were to remain untreated and a control arm of those who did not have the disease.<sup>99</sup>

The recruitment began as the promise of free treatment for "bad blood" spread across the county's churches, schools, and fields. While the term "bad blood" implied syphilis, it could have meant a number of other diseases as well. The men were never told specifically they had syphilis. Nurse Eunice Rivers Laurie (known primarily as Nurse Rivers before she married later in the 1950s), a Tuskegee Institute graduate with public health nursing experience, was hired to link the PHS doctors and Dibble to the recruited subjects and controls. Armed now with just aspirins, vitamins, and tonics, and even the lie that the diagnostic spinal taps were "free treatment" coupled with the periodic physical examinations and x-rays, the Study went on and on.

#### Autopsies, "Burial Insurance," and the Fund

Fairly quickly it became clear to the Study's PHS leadership that autopsies had to be key to what they hoped to accomplish. Autopsy, the word derived from the Greek meaning "the act of seeing for oneself," was considered the best way to understand what had caused a death. Explaining in 1933 to 0.C. Wenger, one of the PHS's leading public health/physician experts on syphilis control, the new Venereal Disease Division head Raymond Vonderlehr (who replaced Clark) reported that the evolving plan was "the continuance of the observation of the Negro men used in the Study with the idea of eventually bringing them to autopsy."<sup>100</sup> Writing back, in a phrase that has haunted the history of the Study ever since, the always blunt Wenger said, "As I see it, we have no further interest in these patients <u>until they die</u> [underlining in original]."<sup>101</sup> In the harrowing words of medical historian Susan Lederer, "Vonderlehr and his PHS colleagues identified bodies for dissection while the individuals were still alive."<sup>102</sup>

The PHS knew that blood draws, subjects' recollections of their ills, and clinical observations were not enough to really understand the effect of syphilis on the bodies of the Study's infected men. Having discussed their focus on syphilis-induced heart disease with a leader and then a specialist committee at the American Heart Association, the PHS researchers were told their mere observations, even x-rays, were not sufficient to prove syphilis's cardiovascular damage. Anxious to make this a good scientific project and already having dealt with criticism from peers, especially in the eyes of the ever-critical syphilis taskmaster Joseph Earle Moore at Hopkins, they felt that getting the families to agree to the autopsy was essential to the developing practices in the Study.<sup>103</sup> The scientific credibility of the PHS's research rested therefore on the pathological postmortem examination of the men's organs and tissues to have more irrefutable proof of the damage syphilis could do, or not do, without treatment.<sup>104</sup>

The procedures for the autopsies were set in motion. PHS officials met with local physicians and the health department in Macon County and at the state level to set the effort up, and

wrote follow-up letters making sure the doctors, health departments, and the hospital on the Tuskegee campus would let them know when a man was terminal or had died.<sup>105</sup> Dibble and R.R. Moton, the Institute's principal, were told the autopsies mattered so that "pathological confirmation may be made of the disease processes."<sup>106</sup> The PHS and Dibble detailed Nurse Rivers to convince the families of the importance of the autopsy.<sup>107</sup> With the roentgenologist (radiologist) and pathologist James Jerome Peters on staff at the federal Tuskegee Veterans Administration Hospital, there was also someone local skilled enough to do the postmortems. Dibble could help and supervise, and Rivers could assist if needed.<sup>108</sup> Vonderlehr even thanked Dibble for going to smaller towns in the county to "do the autopsies on those who die without coming to your hospital."<sup>109</sup> After the autopsies were completed, it was the job of Nurse Rivers to pack up the samples, put them on ice, and send them on to a pathologist at the National Institute of Health.<sup>110</sup>

In horrific irony, no permission was dictated by law to get the men into the research project. Consent from families for an autopsy, however, was legally required because of anatomical practice laws that made "unauthorized autopsy of a dead human body...a tort" that could have led to lawsuits.<sup>111</sup>The PHS hoped to get notified by the families, doctors, or funeral directors upon the deaths so that the dissections could happen before the embalming destroyed some of the tissues and organs or the body's deterioration had set in. Sometimes it went slowly, as Dibble told Vonderlehr in January 1934: "Both Miss Rivers and myself have been keeping a vigilant watch for any further possible autopsies. Have heard nothing further, however."<sup>112</sup> Other times, as the county health officer Murray Smith wrote in his cavalier language to the PHS: "Old man [name redacted] died a few minutes ago. [Name] was one of the faithful positive cases of the untreated study. The ambulance is on the way for him. Dr. Peters has been notified, and Nurse Rivers will be available to assist with the post at 5 P.M. You should have a report of the findings on this patient within a few days."<sup>113</sup>

In attempts to work these procedures out, the PHS came up against African American burial practices. Seen as a "homegoing" (a return to the Lord), the funeral was an occasion when dignity mattered, with open caskets that allowed for visitations if the family could afford the costs of a decent funeral.<sup>114</sup> Many families planned for this inevitability by buying burial insurance, the only kind of insurance many could afford to keep up. Even this was difficult in the Depression, when, as Mr. Herman Shaw, one of the men in the Study, explained, he and his friends borrowed one another's license plates to drive their trucks off the land and "cash money" was scarce.<sup>115</sup> One Macon County woman told the sociologist Charles Johnson: "Didn't have nothing to keep hit up and they don't pay you nothing. A poor man died right over there whose been paying his dues for years and they didn't even bury him. Ain't nothing to some of these insurances."<sup>116</sup> And often, the families without the funds to pay for a reasonable funeral had their loved ones buried before a physician or health department official could even be notified for the death certificate.<sup>117</sup>

The autopsies began *before* the families were offered any funds, probably in early 1934, since Cumming later told the Fund in November 1935 that they had been doing them for 18 months.<sup>118</sup> The concept of paying the families for the autopsies, historian James H. Jones's research revealed, came from one of the family members. Jones found that "the idea seems to have originated in a request for a cash payment from the widow of the first subject on whom an autopsy was performed. According to Nurse Rivers, the woman asked 'for a hundred and fifty dollars for her husband's body as we performed an autopsy.' Though the request was politely refused, Dr. Vonderlehr was quick to perceive in burial stipends an excellent means of enticing the families."<sup>119</sup>

There appeared no way within the federal budget to have the PHS cover this expense, presumably because it was a form of insurance and the payment went to individuals, not institutions.<sup>120</sup> As a first step, the PHS officials thought the Rosenwald Fund might be able to supply the monies given the Rosenwald Fund's previous work in Macon County. In October 1933, Vonderlehr wrote to Rosenwald's Michael Davis and explained that they needed to see if the findings of cardiac involvement seen on clinical examination were there in the heart tissue.<sup>121</sup> A year later, Surgeon General Hugh S. Cumming asked the Rosenwald Fund if it would contribute \$50 each for 10 "burial stipends" every year into the future. With this money, Cumming thought nearly "100%" of the men's families would agree to the autopsies. He even promised Davis that the Rosenwald Fund could "hide the Fund's name if they wanted," but there is no explanation as to why. Davis explained again that the foundation was not supporting additional proposals, but added, "I hope very much that there is some way in which the \$500 can be secured for carrying through the projects."<sup>122</sup> Even this amount was not very much in terms of foundation grants: \$500 in 1932 translates to \$10,144.09 in 2020-2021 dollars.<sup>123</sup>

It would have made sense then for Cumming to reach out to the Milbank Fund after Rosenwald turned him down. He already had a relationship to the Fund, Parran was on the Technical Board and was about to replace Cumming as Surgeon General, and the Fund had a history of grants for some syphilis work in communities. The grants for the postmortem examinations would have been reasonable for the Fund to consider because this was presumably "nonpolitical" medical research that would not be objected to by organized medicine. The funding, too, would do what Sydenstricker wanted: work with local and state health departments in Alabama as well as the federal PHS to show the need or lack of need for treatment of latent syphilis, with the results then available to guide future public health administrative practice in venereal disease control.

The PHS made its first request to the Fund in May 1935. From the records, the Technical Board minutes read: "From the USPHS for financial aid in the study of syphilis in Negroes. Five hundred dollars is asked annually for several years. In cooperation with the Alabama State Board of Health, the effect of untreated syphilis in the Negro is being studied by clinical and physical examinations, and when death occurs, by autopsy."<sup>124</sup> There was no discussion of this seemingly small grant on the part of the Technical Board in the minutes, even though they discussed other syphilis projects in the same time period. Nothing about the discussion appears in the Board of Directors' records either.

In November 1935, Cumming wrote a long letter to the Fund explaining the procedures, how the blood draws were done, and the cardiovascular consequences visible through physical

and x-ray examinations. He again reiterated the PHS's position that "it was early appreciated that the study was open to the objection that all of the evidence was based upon clinical observation. Measures were therefore instituted to bring the individuals included in the study to autopsy in the event of death." As Cumming explained: "[T]he individuals included in the study have been told that a philanthropic organization has agreed to be responsible for their burial insurance in the event of death, provided their family communicates before burial of the patient, with the County Health Officer." He noted that they only got "18%" of the autopsies before the funding, and "66%" after the funds were made available, although the numbers of actual autopsies done at that point were very small and the percentages statistically insignificant. And then he closed with the words: "An opportunity of this kind is not presented in many places in the civilized world today. For this reason it is urged that the Milbank Memorial Fund continue to support this study...."<sup>125</sup>

And so, it began.<sup>126</sup> Every year the Surgeon General or the head of the Venereal Disease Division of the PHS would send its appeal for the grant to the Fund, detailing what they had done that year with the surveys, testing, and publications and then estimating how many autopsies they expected in the coming year, given what they knew of the ages and medical conditions of the Study's men. The letters were usually no more than a page or two.<sup>127</sup> Parran, after he became Surgeon General, explained in 1939, for example, that "due chiefly to the prospective nature of this project, its value is incalculable." He reiterated the importance of the autopsies and the Fund's support, reminding them that "funds appropriated to the Public Health Service cannot be used for obtaining necropsies on individuals in this study," although he, too, never explained why beyond this.<sup>128</sup> After 1957, the CDC (newly formed after World War II) took over the PHS's venereal disease programs and the appeals came from the CDC.<sup>129</sup>

The procedure for the autopsies was the same year after year.<sup>130</sup> After either Rivers or the County Health Officer or both were notified of a death, Rivers would make sure they had a signed permission from the family and the death certificate. Once the body was picked up and examined by the pathologist and a report was sent to the PHS, Rivers would pack up the tissues and organs in the jars the PHS supplied and send them, on ice, to a pathologist at the National Institute of Health. The PHS would then write to the Fund and ask that the monies be sent to the Tuskegee Institute, which was in charge of disbursal. Once an autopsy was done, the PHS asked the Fund for money for the next post-mortem. Vonderlehr wrote to Tuskegee Institute treasurer Lloyd Isaacs on May 8, 1937, for example, to say: "Information has been received that the sixteenth autopsy has been made in our study of untreated syphilis. We have, therefore, requested the Milbank Memorial Fund to forward you a check for \$50.00 to cover the cost of the next or seventieth autopsy."<sup>131</sup>

Sometimes the request changed a little. In 1940, the PHS wanted more money to be sent since the number of autopsies had increased that year, but Catherine A. Doran at the Fund made clear they did not have any additional funds to appropriate beyond what was budgeted, and concluded, "I am extremely sorry that this is the case, and hope you will succeed in securing the necessary additional funds elsewhere."<sup>132</sup> By 1952, however, the Fund agreed to spend \$100 per autopsy and that, if more was needed, the PHS should ask.<sup>133</sup>

Over the years, the PHS and then CDC Venereal Disease Division directors kept careful track of the autopsies, deeply concerned that the tissues and organs were preserved properly and of use to their objectives of discovering whether there was syphilitic damage to the bodies. It was not always easy to do. In 1937, the pathologist James Jerome Peters admitted he had done two postmortems on bodies that were "pretty badly degenerated, so much so that I felt that the examinations to be of no scientific value."<sup>134</sup> Concerned about this turn of events, the PHS's Vonderlehr reminded C.A. Walwyn, who had become Tuskegee's medical director after Dibble went to do the same work at the Tuskegee VA: "I...hope that it will be possible to obtain consent for the autopsy of deceased patients included in our study of untreated syphilis at an earlier date after death in the future. If earlier autopsies cannot be obtained the patient should be embalmed as soon as possible. If the body is disintegrated it is quite useless to subject it to autopsy since the examination of the specimens which are obtained yield little information of value."<sup>136</sup>

Sometimes other difficulties made their efforts harder, or even thwarted them. In 1937, the county's health officer reported there were "additional expenses....In one case the family refused to turn the body over to me until I paid them \$15.00. This man [name redacted] had burial insurance and the family did not want him 'cut on.' Nevertheless I got the bodies."<sup>137</sup> As late as 1965, however, Nurse Rivers explained to Anne Yobs, the CDC's head of medical research, "I am sure you are wondering what has happened to the frozen specimen. Well, it is still in the freezer. I have to get the ice from Opelika [28 miles from Tuskegee]. The driver who has been delivering it for me is on vacation and it seems that I can't get through to the relief persons. I hope to get something accomplished shortly."<sup>138</sup> Rivers also reported in 1965 that she was out of town taking care of her sister and "could not get anyone to do an autopsy" on one of the "patients." After Rivers requested that the widow be given the "contribution usually made to the family of the deceased" because it was not the family's fault no pathologist was then available, the PHS told the Institute to send the widow the sum of \$50.00 to keep up the "rapport."<sup>139</sup>

The disbursed funds did not just go to the undertakers to pay for the funerals. Instead, once the Fund sent the money to Tuskegee, the Institute wrote checks to the doctor performing the autopsy and the hospitals for use of their facilities, to the county health officer for his paperwork and efforts to get the bodies, to Nurse Rivers if she brought the body to their attention or assisted, and sometimes a bit more to the families after 1940, especially the poorer ones.<sup>140</sup> While the amounts that went out other than to the funeral directors were small, the funds helped to keep everyone apprised of what was happening and invested in the procedures.

The letters among the PHS/CDC, the Institute, and the Fund were formulaic. In one of the last letters in 1972, J.D. Millar, then head of the Venereal Disease Division of the CDC, told Tuskegee Institute treasurer Harold K. Logan: "Information has been received that the 223rd autopsy has been performed in our study of untreated syphilis in Macon County. We have requested the Milbank Memorial Fund to forward you a check for \$250.00." And again a few months later John Baugh, the Milbank's executive vice president for administration, was telling Tuskegee's president Luther H. Foster that they were "enclosing \$100 to cover expenses as a contribution for funeral."<sup>141</sup>

Every year the Fund would report on the amounts it was budgeting and sending under differing titles in its own records, although the monies actually given out depended upon the number of autopsies (see Appendix 2). The notifications make clear over the years that this was a study of untreated or what they sometimes labeled the "natural" course of the disease without explaining that the PHS had, of course, made it "natural." In the list of grants for 1957-1958, for example, the Fund stated: "Tuskegee Institute Study of the Natural Course of Syphilitic Infection, \$2,400. This is a long-range study of the natural course of syphilis in which the Public Health Service is cooperating with State and local health departments, In spite of the great progress made in combating syphilis, there are still many gaps in our knowledge, and the disease is still a most serious health problem."<sup>142</sup> Any Fund board member reading this might have imagined the Study was being done by the Tuskegee Institute as the primary investigator.

The actual number of autopsies is a bit unclear. The numbers vary slightly depending on whether the records of the requests to the Fund, the reports within the CDC/PHS, and then the data compiled from the men's actual medical records are analyzed. The CDC claimed there were 234 autopsies out of 428 men who died by 1971, or about 54.67%.<sup>143</sup> When I worked with a biostatistician using the men's medical records 20 years ago, we found that by 1973 the percentage of those autopsied went up to 66.2%.<sup>144</sup> It suggests that at least one third of the families then refused the autopsy, or could not be reached in time to make it happen.

Even as early as 1937, the county's health officer admitted he knew about a man's death "and put forth every effort to obtain the body for an autopsy, I was unsuccessful."<sup>145</sup> In 1947 the PHS told the Fund that "over the fifteen-year period [1932-1947] 144 deaths have occurred and 103 autopsies have been obtained."<sup>146</sup> However, in Nurse Rivers's published report six years later, she claimed there had been only one autopsy refusal, and that she had obtained 145 autopsies by that time. She does not report the number of deaths in total. Because some of the men left the county and died out of state, or were embalmed or buried before the authorities were notified, her ability to get the autopsies was hampered and her "only one autopsy refusal" number does not really show what was happening, especially over time.<sup>147</sup> However, her article, rather than the actual numbers, is usually cited, and this has caused the problem of interpretation that more autopsies were done than actually were.

Historians have argued that the bribe of burial insurance kept the men in the Study as one final way for them to care for their families' financial and emotional needs. No one asked the families, in the aftermath of the public exposure of the Study, if the burial insurance made a difference to their agreement to allow for the postmortems. By the late 1960s, the PHS/CDC had to admit to the Fund that it was becoming "increasingly difficult...obtaining permission for autopsy from the families concerned."<sup>148</sup> By 1969 the PHS/CDC was told by the Alabama

state health officer that "most of the patients now have burial insurance," suggesting the payments were seen now more as a compensation for their participation than an insurance scheme.<sup>149</sup>

Rivers's presence may have mattered more for what else she did for the families, and the government researchers knew it. Her continued role as the men's and their families' almost private public health nurse, whom they could call when they were ill in any way, was essential to all the work and keeping the families connected to the Study. Indeed, the PHS worried as early as 1952 that if anything happened to her there could be problems. PHS officer John Cutler laid out the conundrum bluntly: "[I]f she were to go there is no one available who could easily step in and take over her work and responsibility even occasionally."<sup>150</sup>

Yet another explanation also needs to be considered for why obtaining the autopsies was so important: they made the PHS researchers into supposedly excellent scientists with data above reproach. And they were loath to give up their "data." Indeed, in one renewal letter to the Fund they made clear that except for the Study in Oslo and another autopsy study of syphilis patients by Connecticut pathologist Paul D. Rosahn in the 1940s, there were no other studies like this in the medical literature.<sup>151</sup> The money that made these autopsies possible could then have been even more important to the PHS/CDC researchers than to the families themselves.

The Fund was thus apprised of what was happening with the Study and the autopsies every year. The PHS's John Cutler also thought Nurse Rivers's article on her work ought to have been sent to the Fund's *Quarterly* "in view of their continued financial support over these many years and of the fact that we shall continue to ask for funds from them to pay for autopsies as long as any single patient still remains alive."<sup>152</sup>

The connection between the PHS/CDC and the Fund was not merely in the letters and requests. When PHS officials were in New York, they also came to see the Fund's leadership. In 1952, the PHS's Stanley Schuman reported he had telephoned and then met with the Fund's secretary Catherine A. Doran. He reported: "She knew all about the Tuskegee project and...I was able to answer some of her questions about Tuskegee and show her the complete photograph album of the recent survey. She seemed very interested in all aspects of the study and her chief request was that we be sure to send her 50 copies of any paper we publish."<sup>153</sup>

Four years later John Cutler explained to his superiors in the PHS that he had met with Fund staff, and had "discussed the general aspects of our Tuskegee study with the Assistant Secretary, Mrs. Helen McGuire [Doran's replacement]....I also discussed the study with Dr. Frank Boudreau, the Executive Secretary. He, of course, has followed it for many years with much interest. I gather that he has no intention of discontinuing the Foundation support in as much as he said that the actual cost is so little that it represents no serious burden to the Foundation. They recognize the scientific importance and validity of the study and feel that this is one area in which they can continue to be helpful to us."<sup>154</sup> Such a viewpoint was reiterated in 1964 when the Fund's then executive director Alexander Robertson assured the chief of the CDC's Venereal Disease Division: "I should be most happy if you could come to see me sometime during 1965 so that we might discuss programs and your plans for the final report on this historic contribution to the natural history of disease."<sup>155</sup>

What the Fund did not seem to know, and the PHS or the CDC certainly did not tell it, were the flaws in much of the work. The Fund was never told that the controls who became syphilitic were still counted as controls even when autopsied, and some of the controls were even admitted into treatment programs as early as 1937 that came to Macon County separate from the Study.<sup>156</sup> Those whose serologies were positive for syphilis, but who showed no syphilitic damage on autopsy, were never switched into the control arm. Although historian James H. Jones and I disagree on this, there is evidence that Nurse Rivers Laurie worked to tell some of the men what they had and to get them to treatment either in Macon County or elsewhere.<sup>157</sup> And as the antibiotic era expanded, many of the men seeking medical care for other ills, both in Alabama and elsewhere, were given the drugs that might have affected the course of their infections. Mr. Herman Shaw, for example, got pneumonia in the early 1950s and was treated in a hospital a few miles outside of Tuskegee with IV penicillin.<sup>158</sup> None of this evidence changes, however, what the PHS *intended* to have happen.

## The Fund and the Study between 1935 and 1972: The Missed Chances to Ask Questions

Since there is no real discussion of the importance of the Study over the years in the Fund archives except for the few sentences in the correspondence, it is difficult to say what was achieved by the grant. An analysis of the historical evidence provided here leads to a conclusion that follows Boudreau's words that suggest the Fund did "recognize the scientific importance and validity of the study," even though the Fund lacked information on the Study's limitations.<sup>159</sup> Unlike the Fund's involvement in the CCMC studies of medical economics, this one seemed, ironically of course, to be about medical or public health research and thus non-controversial, at least to organized medicine. The racism of the Study in only studying African American men and failing to offer treatment, and its emphasis on the supposed biological differences in the disease by race, was never discussed by the Fund in the board meetings or correspondence.

It is also important that this grant kept the Fund connected to the PHS and the CDC, especially as various Surgeon Generals during the course of the Study's 40 years participated on the Advisory Board or the Technical Board and, in the case of former Surgeon General Leroy Burney, served as the Fund's executive director and president from 1970 to 1977. Thus, because the Fund wanted to influence public health policy to improve public health, various Fund administrators and board members must have believed that granting monies, however small, to a PHS and later CDC project mattered in advancing this goal.<sup>160</sup> Even in the years when the Fund's attention moved more toward mental health, fertility concerns, demography, and various fellowship programs, it continued the small amounts it was giving to the Study year after year. There were critical inflection points over the years of the Study, in addition to the yearly grants, when the Fund's officers and board members could have raised concerns but did not. Even as penicillin was proven to be a cure for early syphilis by the mid-1940s and even for latent syphilis in some cases by the mid-1950s, and efforts at rapid treatment programs with the older drugs were tried, the Study continued. Indeed, in writing to the Fund to ask for the annual grant in 1943, Surgeon General and Technical Board member Thomas Parran was blunt if a bit evasive over how successful they had been: "This study, with its careful and complete physical examinations and subsequent observation up to and including autopsy at death, forms a necessary control against which to project not only the results obtained with the rapid schedules of therapy for syphilis but also the costs involved in finding and placing under treatment the infected individuals."<sup>161</sup>

Members of the Fund's Technical Board might have read some of the publications about the Study, and the leadership clearly read the annual appeal letters sent in by the PHS and then the CDC, and spoke with government officials from time to time. At the very least, it is most probable that Thomas Parran, because of his focus on syphilis, the publications from within the PHS, and his role as the Surgeon General, did read them all. From 1936 to 1973, 13 articles about the Study were published, mostly in venereal disease and public health journals, although one authored by PHS researchers and statisticians, entitled "Untreated Syphilis in the Male Negro: A Prospective Study of the Effect on Life Expectancy," appeared simultaneously in the PHS's Public Health Reports and a month later in the Quarterly in 1954. After comparison of the controls and the men with syphilis, the not surprising conclusion of that article was that "the life expectancy of an individual 25-50 years of age with syphilis, for which he has received no appreciable amount of therapy, is approximately 17 percent less on the average than that of an individual in the same age interval of a non-syphilitic population."<sup>162</sup> Neither whoever read and approved the article for the *Ouarterly* nor the editor from the Fund's technical staff appears to have asked any questions about how the men had been recruited for the Study or why they were being left untreated in this era after the discovery of penicillin's effectiveness for syphilis.

The Fund's board members and its staff were not alone in ignoring the moral concerns that the Study raised. Except for several rare cases documented by historians, almost no one objected to the Study.<sup>163</sup> Indeed, speech communications scholar Martha Solomon argued in her examination of the Study's published articles, "Rhetorically, the generic conventions of scientific writing not only encouraged neglect of ethical questions but also played an important role in the study's continuation...[as] the reports of the study functioned rhetorically to diminish and obscure the moral issues involved."<sup>164</sup> And by the later articles, the men were being called "volunteers."

The Fund might have made its final contribution in 1965. That year the pathologist James Jerome Peters retired and his assistant took over the work, but left for another university very soon thereafter. To attract another doctor for the autopsies, the PHS asked if the Fund would give \$175 for each procedure, with \$100 of it going to the pathologist and the rest for the burials.<sup>165</sup> Alexander Robertson, the Fund's executive secretary, raised the possibility that

the Fund would make a larger last grant.<sup>166</sup> The CDC's William J. Brown suggested that the Fund consider "a grant for possibly a longer period would be more realistic than a final grant... maybe \$10,000 to 12,000," and he provided some numbers on how many men were still alive. But after discussing it with his Executive Committee, Robertson told Brown the Fund would continue to fund the Study in the same way it had in the past, promising, "I believe you can feel confident that the Fund will see this study through."<sup>167</sup> No questions were raised about the ethics by the Fund.

Even those whom you might expect to object to the Study did not do so. Two examples of public health activists who did not see the problem reflect what appeared to be normative around the Study. In 1969, the outspoken George A. Silver, a public health advocate physician, Yale professor, and former deputy assistant secretary for health and scientific affairs for the federal department that was then called Health, Education, and Welfare, was on the Technical Board. The Fund's vice president for administration sent a letter to the Technical Board members in January 1969 to tell them of the grants approved at the previous December's Board of Directors meeting. Underlined for Silver, and in his papers in the archives at Yale, is the grant to him for \$140,000 over four years "to head up development of Urban Coalition Task Force on Health." On the next page, under Research Grant, it says clearly: "Tuskegee Institute, Tuskegee, Alabama, Further Research Grant to continue Study of Untreated Syphilis, payable from 1969 income....700."<sup>168</sup> It is hard to imagine that Silver didn't see this, but it did not yet register as a problem to him.

Silver is important because 20 years later, when one of the PHS researchers who had worked in Tuskegee coauthored an article, "Venereal Disease Control by Health Departments in the Past," in the *American Journal of Public Health*, the researcher never mentioned the Study as he called for the PHS's Raymond Vonderlehr to be honored for all he had done. Silver objected to the omission and wrote to the journal that "...not to remember is to forget, and to forget is a disservice to those who suffered the indignities."<sup>169</sup>

Similarly, in 1989 historian Susan L. Smith interviewed famed Howard University public health and medical leader Paul B. Cornely, the first Black president of the American Public Health Association. Ruefully, Cornely recalled he knew about the Study and even taught it at Howard's medical school. Neither he nor his students objected. "I have guilt feeling about it, as I view it now,' he explained, 'because I considered myself to be an activist. I used to get hot and bothered about injustice and inequity, yet here right under my nose something is happening and I'm blind."<sup>170</sup>

Thomas Parran, who was the U.S. Surgeon General from 1936 to 1948, wrote to gain support for the Study from the Fund and clearly approved the work. There is no reason to expect he would have any second thoughts about it, especially since he also approved other equally ethically challenged sexually transmitted disease studies that occurred under his watch.<sup>171</sup> Former Surgeon General Leroy Burney never raised any real questions either between 1970 and 1972 when he was the executive director and president of the Fund. There may be an explanation for this: in the 1930s Burney himself had been detailed by the PHS to work on the study in Tuskegee, and he had been a PHS "lifer."<sup>172</sup> Over the years of the Study, Surgeon Generals Leonard A. Scheele and William M. Stewart also served on the Fund's Technical Board.<sup>173</sup>

Another chance for the Fund's board and staff to have considered their role in the Study came in the late 1960s. In June 1966, Harvard physician Henry K. Beecher published his shattering "Ethics and Clinical Research" article in the *New England Journal of Medicine*, arguing that even well-known and respected physicians were making serious ethical mistakes in their research.<sup>174</sup> Four months later, the Fund's Technical Board brought in University of Toronto expert Kenneth L. Clute to speak to them about issues of law, medicine, and ethics. Discussing some of the famous cases in the newly emerging field of bioethics, Clute told the Technical Board there could be "conflict of values between the needs of research and the rights of the individual patient." Most of the discussion focused on medicine and law issues. No one raised the Study in Tuskegee.<sup>175</sup>

It was not as if the Fund's various boards were unaware of the racism in the health care system and its two-class nature. At the Technical Board's December 1968 meeting, and several months after the uprisings at Columbia University and across the country over racism after the murder of Martin Luther King Jr., George Silver, now working for the Urban Coalition's health task force, spoke to his fellow board members about the problems of the two-class medical system. Two years later, George Lythcott, then the associate dean for community affairs at the Columbia Medical School, was brought in to lead a discussion on the tensions between Columbia University and Harlem. In 1971, there was even a concern with equity in health care and how to make sure the *Quarterly* was publishing relevant articles. Again, no one seems to have made any connections between these social/political issues about racism and the continued funding of the Study.<sup>176</sup>

The biggest chance for a reappraisal by the Fund was missed in 1969. By that time, San Francisco-based former sexually transmitted disease investigator and now law student Peter Buxtun had been raising questions about the ethics of the Study with the CDC and the PHS for several years. In 1969 his concerns led then CDC director David Sencer to call an ad hoc committee meeting on February 6 to discuss whether the Study should be continued or terminated.<sup>177</sup> The Fund's Clyde Kiser was asked by the head of the CDC's Venereal Disease Division to attend. Kiser was on the Fund's technical staff from 1931 to 1970, was the vice president for technical affairs, and was the author of the only book on the Fund's history.<sup>178</sup> Kiser was a sociologist whose major focus was on fertility, birth control, eugenics, and demography.<sup>179</sup>

Everyone who attended, except for Kiser, was a physician or statistician. As historian James H. Jones summarized the attendees: "No one with training in medical ethics was invited to the meeting, none of the participants was black, and at no point during the discussions that followed did anyone mention the PHS's own guidelines on human experimentation or those of other federal agencies."<sup>180</sup> Only Gene Stollerman, chair of the medicine department at the University of Tennessee Medical School, objected to the Study. As one of the PHS officials put in his files, Stollerman thought: "[T]his appears...to be a 'hot potato' from many standpoints – racial, public relations, etc. Wondered if we could be sued for withholding treatment. He thinks we should 'go all out to get this worked out as soon as possible."<sup>181</sup>

Sencer was aware that the Study might now be a "political problem." William J. Brown, then head of the Venereal Disease Division at the CDC, read the autopsy records and told the meeting attendees that "syphilis was a primary cause of death in only seven [study subjects] as shown at autopsy," although he admitted that many of the autopsies were inaccurate because of the condition of the men's bodies.\* Kiser, according to the minutes where his name is misspelled as Kaiser, was surprised that the men were supposedly "doing so well," and that white executives being examined for the famed Framingham Study had more heart disease. Kiser, as a sociologist, was asked by Sencer about the "racial and political overtones" of continuing the Study. According to the minutes of the meeting, Kiser told him: "This is not a Study that would be repeated now. The public conscience would not accept it. If you combined treatment with the present study, I am impressed with the plan – but I don't know whether the Fund would up the ante."

Over the course of the three-hour meeting, the more technical medical questions of the dangers of penicillin were discussed, and Sencer asked over and over if treatment was now appropriate. Many of the specialists worried about the Herxheimer reaction, which occurs when a drug kills off the spirochetes that cause syphilis and releases toxins that can endanger the human host. Sencer in particular was troubled by how the Study would be seen if they did not treat. In the end, Sencer sent two public health advisors to speak to the Macon County health officer and the by then almost all African American Macon County Medical Society. What actually transpired when they spoke to the physicians in Tuskegee is unclear (the document is missing from the archives), but the Study did not end. Sencer believed that the local medical establishment and health department were on board and that there was no way in the federal budget to now pay for treatment or the burial insurance.<sup>182</sup> Sencer made the decision to keep the Study going, in part because he could not figure out how to honor the commitment to the families without the Study staying in place.<sup>183</sup>

When he got back to New York, Kiser reported on the meeting in a three-page memo to the Fund's executive director, Alexander Robertson.<sup>184</sup> Kiser's notes are similar to those of the CDC official minutes, but he added that someone at the meeting stated that the state required "informed consent," but that "the educational level of the Negroes in the Study is so low that it would not be possible to explain 'informed consent' to them." He noted the Fund's contribution "has always been modest....\$16,500 for the years 1935-1965."

Finally, the Fund was being made aware of the Study's scientific limitations while ignoring the moral ones. Kiser emphasized the failed science of the Study. He explained that "during the course of the years some controls contracted syphilis and almost all of the syphilitic subjects had at least some type of treatment on their own." Furthermore, the PHS admitted "that some of those originally classified as having cardio-vascular involvement were probably misclassified." But the justifications for continuing it included the difficulty of getting treatment in

\*Brown's claim of only seven deaths from syphilis does not comport with records of the death certificates in the men's medical records, which show 15 deaths with syphilis as the major cause by 1969. Other syphilis-related causes of death, aortitis or other forms of heart disease, and neurological complitions are also noted; see examiningtuskegee.com for this data and its limitations. the early years, the lack of penicillin, and that there "probably would have been resistance to treatment on the part of the poorly educated rural Negro males in Alabama."

Nowhere in this statement did he raise, or more likely he did not know, that there had been a syphilis control project back in Macon County by 1936, and that since penicillin had been available now for nearly 25 years it ought to have been given when needed. The assumption of the "resistance to treatment" of course meant that the PHS and CDC doctors had no idea how to explain their work and to provide public health in a rural and poor Black setting, even though they thought talking to the local Black doctors would be the right thing to do. No one seemed to know about a letter from Nurse Rivers to Raymond Vonderlehr from three decades earlier that explained that "quite a number of the patients included in the control group have come out for treatment," in the special venereal disease clinic that was being run in the county in parallel to the Study.<sup>185</sup>

Finally, Kiser thought the Fund should continue what it was doing. Sencer believed, Kiser reported, that the contributions to the men's families for the autopsies should not be increased because it "might raise dissent in the community rather than satisfaction. He would prefer using any additional money to get another nurse or to pay a bonus to doctors who do the autopsies." After the meeting, the Fund continued to participate at the same level for the next few years.

The discussion did not end within the PHS/CDC in 1969. Internally, some of researchers involved in the Study were trying to balance their sense of the commitment over the years to the work and the moral dilemmas they thought the Study raised. In July 1970, 16 months after the ad hoc meeting, research chief Anne Yobs told CDC's director David Sencer that she thought "there have been changes at the program level in attitude, in level of interest, and in sensitivity to (potential) criticism," and therefore she recommended that "this study be closed."<sup>186</sup> Two months later, however, James B. Lucas, the assistant chief of the Venereal Disease Division, was concerned it had become an "emotionally charged subject," and he attempted to make the perspective more "reasonable." His assessment made clear that more of the men had been treated over the years, not just from "happenstance," and thus the scientific quality of the data was suspect. He cited a study done by famed ophthalmologist J. Lawton Smith in 1967 using the data from the Study that actually showed little difference between the controls and those with syphilis in terms of "neurologic and ophthalmological defects." As Lucas put it bluntly, "[N]othing learned will prevent, find, or cure a single case of infectious syphilis or bring us closer to our basic mission of controlling venereal disease in the United States." But because there were still 149 men alive in 1970, Lucas thought they could not wait for the all the deaths to occur before ending the study. Given that a new nurse (Mrs. Helen Kennebrew) had been hired, he recommended the Study be "continued along its present lines with periodic clinical observation and serologic surveillance."187

Other than what was discussed at the 1969 meeting, nothing more about the limits of the science, not to mention the ethics, was transmitted to the Fund's board. After the 1969 meeting, the Fund's grants continued as they had in the past, responding to the federal requests and sending the checks to the Tuskegee Institute. Then, on July 26, 1972, the story of the Study left the confines of the PHS/CDC and the public health world to splash across the headlines.

#### The Media, the Lawsuit, the Fund, and "Culpable Ignorance"

In San Francisco, Peter Buxtun got tired of waiting for the PHS and CDC to respond to his moral qualms about the Study that he had been raising in letters and meetings for several years. He told the story of what he knew, yet again, to his friend Edith Lederer, who worked for the Associated Press (AP). Finally, Lederer got it. Her editor thought she was too green a reporter, so he gave the details to more seasoned AP journalist Jean Heller. She did her research.

Everything began to change when Heller's story on the Study, entitled "Syphilis Victims in U.S. Study Went Untreated for 40 Years," went out on the AP wire and made the front page of the *New York Times*. Suddenly, what Wisconsin Senator William Proxmire then called "a moral and ethical nightmare" was in media accounts across the country, although there was no mention of the Fund's role in the initial stories.<sup>188</sup> To respond to the uproar, President Richard Nixon appointed a federal ad hoc committee to look into what had happened. Ted Kennedy's "Quality of Health Care" Senate hearings pivoted and began to hear testimony about the Study over the next year, but no one from the Fund was called to appear.<sup>189</sup>

After the initial story broke, the first discussion at the Fund appeared in the Board of Directors minutes on October 17, 1972, although what might have been discussed privately among Fund officials between July and October is unknown. Leroy Burney told the board the federal ad hoc report was due the next month. As the minutes put it, "he mentioned that the Fund's grant had always been made to Tuskegee Institute." He explained that the families expected the Fund's money to cover part of their "burial expenses" and that they had come to rely upon it as a form of "insurance."<sup>190</sup> Between July 1972 and July 1973, the Fund sent its final \$1,250 to the Tuskegee Institute for what was called in the minutes "appropriate benefits to the families of the participants in the Tuskegee Study."<sup>191</sup> It is possible that since the checks went to the Tuskegee Institute the Fund members were assured that a leading historically Black college had approved of the Study, helping to take away any taint of racism in their minds. In the context of Black politics in the early 1970s, it might have made the Fund directors and staff feel it had less culpability over the years.

In Alabama, the response was about to mean a lawsuit. Macon County resident and farmerlandowner Charlie Pollard, reached in a Montgomery horse trading auction by reporters, realized the day the story broke that he had been part of the Study.<sup>192</sup> The next morning, he went to see Fred Gray, his lawyer in Tuskegee and a famed Alabama civil rights attorney. Gray started to put a lawsuit together on behalf of the surviving men and the families of the deceased participants, suing not only the U.S. government, but the state of Alabama, some of the individual doctors who ran the Study, and also the Milbank Fund, but none of the Black health personnel nor the Tuskegee Institute.<sup>193</sup> Gray began the work, finding the men and their families as plaintiffs, getting legal assistance, building his argument, and even mortgaging his own home to pay the expenses. Gray purposefully made his legal analysis very black and white, with the racism central to his case. On July 24, 1973, a year after the public exposure, the lawsuit was filed. In the words of Gray's September 1973 Amendment to Complaint in what became known as *Pollard v. U.S. et al.*, Gray explained why the Fund was being sued: "On information and belief it encouraged and abetted the conduct complained of herein with knowledge, or with culpable ignorance, that no consent had been given to the experiment and that injuries and death for patients was a predictable result."<sup>194</sup> A month later the Fund was served in part because Gray claimed it was "not qualified to do business in the State of Alabama," but had been doing so.<sup>195</sup>

The Fund turned to its lawyers at Milbank, Tweed, Hadley and McCloy, and spent \$17,181.58 defending itself.<sup>196</sup> Staff at the Fund had to go through their files, find the appropriate documentation that was being demanded, and respond to the interrogatories from Gray and the lawyers helping him.<sup>197</sup> Clyde Kiser, who by then had been retired from the Fund for two years, explained that his role at the 1969 meeting had been that "of an observer."<sup>198</sup> No mention, at least in the archival record, was made of the visits of the PHS officials to the Fund or what had, or had not, been discussed at the board meetings.

When the lawyers were able to get the complaint dismissed on technicalities of whether the Fund could be sued for doing business in Alabama, Gray did not appeal. As he put it: "I thought the government was the real defendant and the others helped it. So I spent my time on it."<sup>199</sup> By February 1975, Gray settled the case out of court, receiving compensation from the U.S. government of \$37,500 for each survivor and \$15,000 to the living controls. The estates of those who had syphilis received \$15,000, and the families of the controls received \$5,000.

In New York, at least in the extant records and minutes, there was no further discussion by the Fund's Board of Directors about what it had meant to support the Study, and whether the Fund ought to do more about it. Legal advice might have made this the most prudent action. If there were private meetings, calls, and whispers, they are not documented. When the Fund's former executive Clyde V. Kiser published the history of the Fund in 1975, Milbank's role in the Study was never mentioned.<sup>200</sup>

These silences were not limited to the Fund staff, boards, or official history. As the federal ad hoc committee member and Yale bioethicist Jay Katz put it, "I note sadly that the medical profession, through its national association, its many individual societies, and its journals, has on the whole not reacted to this study except by ignoring it. One lengthy editorial appeared in the October 1972 issue of the *Southern Medical Journal* which exonerated the study and chastised the 'irresponsible press' for bringing it to public attention."<sup>201</sup>It would not, however, remain forgotten.

#### The Study, the Fund, and Historical Memory

As the news of the Study faded from media accounts and was buried by medical associations, it never exited from historical memory within the African American and bioethics communities. Coupled with other examples of egregious medical research projects, the federal government's Belmont Commission issued its report in 1978 that enunciated the principles of respect for persons, beneficence, and justice that should underlie ethical human subjects research and have become the basis for regulations for federally funded research.<sup>202</sup> The Study began to be taught as a way to understand how not to do research and how to see the racism in medicine. It appeared in many Institutional Review Board training programs and documents. By 1981, James H. Jones published his book *Bad Blood: The Tuskegee Syphilis Experiment*, and it became the definitive text on the history of the Study for the next decades. He described the Fund's role in paying for the autopsies, footnoting the information from the CDC records.<sup>203</sup> The Study became harder to ignore, even if rumors about what happened, in particular the assumption that the government had given the men their syphilis, circulated.

With awareness of the spread of the HIV/AIDS epidemic into the African American communities in the early 1990s, other researchers began to make the link between the Study and the hesitancy in such communities to trust the government.<sup>204</sup> Around the same time, playwright and emergency room physician David Feldshuh began to write what would become his play, and then eventually an HBO movie, called *Miss Evers' Boys*, which fictionalized the story of the Study and starred Alfre Woodard and Laurence Fishburne.<sup>205</sup> Jazz player Don Byron produced his first album, entitled *Tuskegee Experiments*, which included a track about the Study with a mournful and angry spoken poem set to a wailing saxophone.<sup>206</sup> The Study even showed up in a *Saturday Night Live* routine as just the words "Tuskegee" were used to explain a black patient's distrust of the medical system.<sup>207</sup> The Study in Tuskegee had found its place in popular culture and memory.<sup>208</sup> None of these venues, however, mentioned the Fund.

The Fund was pulled back into some discussion of the Study within its own board in 1992. As the 20th anniversary of the widespread public exposure of the Study was coming around, a number of documentary filmmakers and television reporters began to consider bringing the Study into public attention in a new way. The first was a 15-minute segment on ABC's *Prime-time Live* news show that focused on Atlanta physician Sidney Olansky, who had run the Study in the 1950s and who still did not seem to have any sense of what had been wrong.<sup>209</sup> In England, one of the television networks produced a film called dramatically, and incorrectly, *The Secret of Bad Blood*.<sup>210</sup> In the United States, ABC television reporter George Strait, unable to get support at his home network, convinced Boston's WGBH/PBS *Nova* unit to film an episode that would be called "The Deadly Deception" and was broadcast in January 1993.<sup>211</sup>

In both the U.S. and U.K. films, several of the PHS/CDC doctors still alive who spoke seemed to have no remorse. The PHS's John Cutler told the audiences in both films that the Study had been "grossly misunderstood" and that since "we have no compunction about sending our youth away to war when it is in the national interest," he concluded we were at war with a deadly disease and that the men in the Study had "served their race."<sup>212</sup> While he never said it, Cutler seemed to imply that he might have been a general in such a war against syphilis, and that he and other PHS/CDC doctors had the right to make such decisions to draft unsuspecting people into the battle.<sup>213</sup> In the PBS film, the existence of the autopsy is dramatized, but by using excerpts from the fictional play *Miss Evers' Boys* on this point, the source of the funding for the so-called burial insurance for the autopsy is made to seem as if it comes from the government. The Fund is never mentioned.

As the WGBH/PBS film was being developed, Denisce Dilanni, PBS's *Nova* producer, reached out for advice to the Fund's president and historian, Dan Fox, who was also on the *Nova* scientific advisory board.<sup>214</sup> Fox spoke to Dilanni, watched a fine cut of the documentary, and added his comments. He reported to the Fund's Board of Directors about this in May 1992, as well as on other subjects of controversy including an article on lead poisoning and the history of Kingsbury's work. In his discussion of the upcoming *Nova* film, Fox told the board his advice on the film was that it should make clear "that unexpected ethical transgressions will continue to occur in medicine...and that a balanced historical interpretation of the Tuskegee study should be placed on the record...."<sup>215</sup>

The board watched, according to the draft minutes, "a brief selection from an ABC Television program on the Tuskegee experiment." This led to a discussion of whether or not the Fund ought to have a "written policy" on how to respond to controversies. The minutes make clear it was decided that "the Fund needs to monitor on a regular basis the moral implications of the work it supports."

What followed was a discussion on whether something proactive ought to be done before the PBS film appeared. The draft minutes of the meeting reads: "In anticipation of the controversy being reopened by WGBH's documentary on Tuskegee, Dr. Fox said that he and the film's producer had discussed joint WGBH-Fund sponsorship of a meeting of experts to draft a paper on the current ethical status of the issue. Other members rejected this suggestion, agreeing that such a paper would draw attention to the Fund's involvement and still not ensure that the Fund's role would be made clear."<sup>216</sup>

These lines, however, were deleted from the final minutes.<sup>217</sup> The approved minutes left out the word "instead," since it referred to the rejected suggestion, and read: "They proposed [instead] that the Fund be prepared to respond to controversies as they arise but not volunteer a response to an anticipated controversy."<sup>218</sup> The resulting policy statement acknowledged that the Fund might have "activities that it has sponsored or their results will sometimes be criticized. The Fund is committed to moral and intellectual integrity in all of its activities. The Board will monitor the moral and intellectual implications of the Fund's commitments on a regular basis."

The statement went on to promise that the Fund would "respond to criticism of it and of the work it sponsors. These responses will be factual statements prepared by the President in consultation with the Chairman. Statements responding to [attacks] criticism of the Fund will be reviewed first by appropriate legal counsel and then by each director. The Fund will not initiate a controversy or call attention to controversial activities in the past. But on occasion it may be prudent to prepare a factual statement in anticipation of criticism."

The handwritten notes taken by Kathleen Andersen, then the board secretary, at this meeting expand on the discussion. The Fund's former president and former Harvard Medical School dean Robert Ebert raised the treatment questions for syphilis of both the older metals and whether penicillin would have helped the men in the Study who were at the advanced stage

of the disease. Noting that the Study took place before informed consent and randomized controlled trials, he was putting the Study in what he called "the context of the time." Ebert thought that "it is important for the Board to get informed of issues we're involved in and have funded to keep track of changes in knowledge that would affect our decisions." Fox again reiterated his suggestion that there be a "position paper," written with WGBH, "on how we approached the [Tuskegee study] problem."

As noted in the final minutes, the board did not take Fox's suggestion and made it clear, at least in Andersen's notes, that "we don't want to draw attention to our involvement," with no attribution to who said this. Ebert commented the Fund had not been "...involved in the experiment, only in paying the burial expenses. <u>But</u> [emphasis in notes] we would be misunderstood." As he was the only physician on the board, Ebert's view of the medicine must have been compelling. Finally, as Alan T. Wenzell, a retired investment banker on the board, concluded: "Don't borrow trouble but be prepared with a statement in reserve.' Just don't volunteer it." In sum, the board decided to respond in the future to any issues, but not to discuss proactively or apologize for anything that had happened in the past. The story of the Fund's involvement in the Study, therefore, was buried.

Finally, two more occasions in the 1990s brought attention again to the Study that could have, but did not, involve the Fund. In 1995, President Bill Clinton nominated Henry Foster to be the Surgeon General. An obstetrician-gynecologist, Foster had been working at the John A. Andrew Memorial Hospital on the Tuskegee campus when CDC Director David Sencer sent the two public health advisors to meet with the Macon County Medical Society, to which Foster belonged. Because Foster had done abortions and sterilizations, his nomination came under attack by Congressional Republicans. Part of the questioning focused on whether or not Foster had been at the meeting with the CDC representatives and also knew about the Study. In tracking down the information (as Foster denied any knowledge of the meeting or the Study before 1972), historians of the Study (this author included) were contacted by White House officials and the FBI. Dan Fox, then the president of Milbank, was also asked if he knew anything about Foster's involvement, but he did not.<sup>219</sup> Clearly the federal investigators had read enough about the Study to know how the Fund was involved, but this did not come up in Foster's failed nomination hearings.

In January 1996, a group of historians, bioethicists, African American health advocates, and concerned others met at Tuskegee University to discuss the failure of the federal government ever to apologize formally for the Study. The meeting was triggered by both President Clinton's apology for the U.S. government's radiation studies on citizens and soldiers in 1995 and because the PHS/CDC officials in the early 1990s documentary films had not been repentant nor apologetic for the Study. A Legacy Committee (this author included) was formed and spent the next year writing a position paper and lobbying, along with others, for Clinton to issue the apology.<sup>220</sup> It was done with great fanfare on May 16, 1997, in the East Room of the White House, with five of the six remaining men from the Study present.

In the discussions and request to the White House we wrote, none of us thought of asking the Milbank Fund, the state of Alabama, the Macon County Health Department, or Tuskegee University to apologize too. We were too focused on the role of the federal government to consider this. Others in Tuskegee worked to get a similar apology from the State of Alabama. No one on the Fund staff or board thus knew about the federal apology until the day it occurred and was covered in the media. No further mention of the Study appears in the Fund's board minutes.

Finally, in preparation for the Fund's 100th anniversary in 2005, Dan Fox wrote a historical analysis, published a year later, of the importance of the Fund's impact on health policy over the century. He did not, however, mention the Study. None of the articles reprinted in the *Quarterly* or online to celebrate the Fund's centennial referenced the Study, nor did the centennial report, nor was the one report of the Study that had been published republished either.<sup>221</sup> Furthermore, between 2009 and 2018, two articles came into the *Quarterly* that were about the Study and cited the Fund's involvement. They were both rejected for editorial reasons, not because of their mention of the Fund's role.

This silence began to change two years ago. During 2020, in reaction to all the responses reinforcing the call that *Black Lives Matter* in the wake of the murder of George Floyd and other extrajudicial killings, the Fund began an examination of how it might address structural racism in its work. An internal team to focus on diversity, equity, and inclusion was formed, and the Fund hired an outside consulting firm.<sup>222</sup> This was happening at the same time as interest in the Study reappeared, as it was noted in thousands of media accounts covering COVID and vaccine resistance in African American communities.<sup>223</sup>

Concern within the staff and board of the Fund about its role in the Study picked up by December 2020. That month, the Fund's communications director, Christine Haran, shared with other staff members a reference to the Fund's involvement in the Study in one news article. In February 2021, Fund president Christopher Koller asked staff member Gail Cambridge to compile references to the Fund's role from the Board of Directors minutes. This was shared with several of the board members. Legal concerns were raised with the Fund's lawyers about what it might mean to acknowledge this past.<sup>224</sup>

In March 2021, the Fund received an inquiry from Diane Louise Rowley, a physician and professor of the practice of public health at the University of North Carolina and the widow of epidemiologist Bill Jenkins. Jenkins had tried to stop the Study in the late 1960s, but failed. He then became the manager at the CDC of the health program for the Study's men and their families.<sup>225</sup> Rowley raised the question of whether the Fund had ever apologized for paying for the autopsies. A response was sent to Rowley, who did not respond.

Her concerns led to further discussion within the Board of Directors about the Fund's experience with the Study and what it ought to do now. A short historical report was written by two board members. In the next months, the Fund created an ad hoc committee that did the following: "plan for an apology to affected families, plan for a public disclosure, and identify a historian to compile the record." After that the Fund engaged a historian (this author) to do the research, made contact with the organization of the descendants of the men in the Study, and offered a formal apology, a gift, and plans for ongoing relations with Voices for Our Fathers Legacy Foundation and other programmatic changes.<sup>226</sup>

This report is part of that process.

### SUMMARY AND CONCLUSION

For 117 years since 1905, the Milbank Memorial Fund has focused on various ways to use its grants and publications to create efficiency, or now evidence-based choices, to influence the policy decisions of health care leaders and federal, state, and local government agencies and officials focused on public health. This has been a complex, sometimes fraught, history that led to its involvement in the Study. In its efforts to push for national health insurance in FDR's social security bill in 1935 that failed for multiple reasons, the Fund found itself in a lopsided battle against organized medicine's resistance to such efforts. A few months later, it granted a very small request from the U.S. Surgeon General to provide the "burial insurance" to help obtain the postmortems for the subjects and controls in the Study. At the time, it must have been seen as a noncontroversial form of medical research that had implications for the efficient use of public health funds in the height of the Depression. Blinded by the arguments made by the Surgeon General and reeling in part from the criticism of their seemingly more political efforts at national health insurance, no one on the Milbank board or staff saw any-thing wrong with this.

The monetary award to the PHS was for very little, compared with other Fund grants, and remained minimal over the entire course of the decades of funding. Year after year the request came in, and the Fund continued to provide the monies, asking (at least from the archival record) no real questions, even when the opportunities to do so occurred. The fact that this happened in an era when at least the legal demand for written informed consent for research was not required, even if "do no harm" had existed for a millennium, may have mitigated concerns.<sup>227</sup> When the published papers called the men "volunteers," it might never have occurred to Fund directors or even the physicians on its Advisory or Technical Boards to be worried about how they had been recruited. The racism of the Study, who was studied, the assumptions underlying the work, and the failure to treat never raised hackles on the Fund's boards, nor anywhere else, with exceptions.

The fact that no questions were asked over the decades is critical to understanding why the Fund continued this grant. First, numerous U.S. Surgeon Generals sat on the Fund's Advisory and Technical Boards, and one even served, after his tour of duty, as the Fund's president. With someone as powerful as New York Health Commissioner, then Surgeon General, and then University of Pittsburgh Public Health School dean Thomas Parran on the Technical Board for decades, it would have been hard for the Fund to turn the PHS down over the years. The Fund, too, gave Parran the money to complete multiple printings of his well-used and famous book Shadow on the Land: Syphilis and then followed it with a positive review in the *Quarterly*.<sup>228</sup> Second, the Fund needed carefully cultivated relationships with federal, state,

and local public health departments to effect the changes and reforms its boards and staff thought necessary. While not every proposal from such offices was funded, there was a political as well as scientific reason to honor such requests to make sure new policies were implemented. Third, the final decisions on funding were made by the Board of Directors with some advice from the Executive Committee, staff, and Technical Board. Of the 30 men (and they were all men and I presume white) who served on the Board of Directors between 1935 and 1974, only seven were doctors (three of whom were the executive secretaries or presidents on the staff) and none were syphilis specialists.<sup>229</sup>

While no medical degree is needed to understand the ethics of the research and to at least question its underlying racist assumptions, it is possible the lawyers, financiers, charity administrators, and social scientists on the Board of Directors could have been swayed by medical information on the lack of treatment pre-penicillin, and then the questionable use of penicillin for the men in the disease's late latency stage, that could have persuaded them that nothing was wrong. Even as late as 1992, for example, the medical concerns raised by former Fund president and former Harvard Medical School dean Robert Ebert seemed to have helped move the board not to go on record about the Fund's role in the Study, nor to follow president Dan Fox's suggestion for a program of experts as part of the programming for the Nova documentary. At the same time, the desire to protect the Fund and not open it up to criticism from the past prevailed.

Fourth, since the checks were sent to the Tuskegee Institute to distribute, if the board and staff members were at all concerned about the racial issues this might have assuaged them. After all, it must have looked as if there was no racism involved since the Institute, as a famous historically Black college, was a critical part of the Study.<sup>230</sup>

Most historians, including me, have argued implicitly or explicitly that the Milbank money made the autopsies possible because it served as burial insurance and kept the men in the Study. Many of us have used the 1954 article by Nurse Rivers in which she said she had only one autopsy refusal to make it look as if almost every man in the Study had been sent to post-mortem. This reconsideration at least suggests that the money that led to the postmortems may have become less important over time to the families and actually *more important* to the PHS/CDC researchers. It made possible their sense that with the analysis from the autopsies they were doing good science, and would be contributing an unusual and excellent piece of longitudinal research on syphilis that they knew could never be repeated.

If the families did not need the money as an inducement but the the researchers needed the autopsies for their science, there is another question to ponder. If the Fund had stopped the payments at some point over questions and the PHS could not find any other foundation or organization to take them over, would the Study have continued, especially after penicillin became widely used? For without the autopsies, the PHS knew its more observational data would have been questioned by peers.

There is, of course, the issue of the politics of apology and how that changes over time. When the Fund was dropped from the lawsuit in the 1970s, there would have been every reason for the Fund to be quiet about its participation although there was no nondisclosure agreement signed. When the film documentaries and play/movie appeared in the early 1990s that brought the Study back into some popular consciousness, there was the opportunity to participate in a public discussion of why the Fund had participated in the ways it had. The board voted to not to participate in such an event that was never organized. And when the Legacy Committee wrote its report to demand an apology for the Study a few years later, the focus was on persuading President Clinton to do so because it was a federally sponsored study. The Fund was not included, nor did it take this time to publish or speak out about its role once the apology became public.

While the Fund has had lawyers since its inception, it did not have a crisis management specialist on its staff or board. Since the Tylenol poisoning episode in the fall of 1982, crisis management strategies had evolved to propose that institutions under such duress speak more publicly about their concerns and regrets to get ahead of the damaging publicity.<sup>231</sup> The businessmen and lawyers on the Fund's board in 1992, however, thought it was prudent to be quiet about the Fund's role in the Study, especially since there really was no crisis at hand.

Since 1992, other political events made thinking about how to acknowledge the Fund's role in the Study possible. After the change of the apartheid government in South Africa in the early 1990s, Truth and Reconciliation processes were developed there and in other countries as part of the work of transition from authoritarian and racist regimes to ones based on democratic rule. While some of these processes focused on transitional justice, others tried to consider, as the Canadians did with respect to First Nations people, a form of restorative justice where both sides in a crime meet to repair the harms.<sup>232</sup> Since then it has become more common, although not that often, to have governments apologize for their crimes of the past. For example, when I gave information about the PHS's inoculation syphilis research in Guatemala in 1946-1948 to CDC officials in 2010, the formal apology from the Obama administration to Guatemala happened within six months.<sup>233</sup>

In the last several years, concerns about the honors bestowed posthumously on medical leaders have come under question as other medical associations have faced their racist past. Dr. J. Marion Sims, considered the "father" of American gynecology and inventor of the speculum and a surgical cure for vaginal fistulas, who experimented on enslaved women, was honored with a statue on Fifth Avenue next to Central Park, across from the New York Academy of Medicine and in East Harlem. After protests, the statue was moved recently to his burial site in Greenwood Cemetery in Brooklyn, and a monument to Anarcha, Betsey, and Lucy, the women he experimented upon, is being put up. Similarly, after questions about Thomas Parran's role both in the Study in Tuskegee and then in the research project in Guatemala were raised in numerous quarters, the American Sexually Transmitted Diseases Association's membership voted to remove his name from their major award, and the name of the main building at the University of Pittsburgh School of Public Health, where Parran was the first dean, was taken down after student requests and a reconsideration process. In 2008, the American Medical Association's immediate past president apologized for a century of the organization's exclusion of African Americans and did several other reports on this issue.<sup>234</sup>

At a time when our country is riven with division, the question of reparations for slavery have again been debated, and many colleges and universities are acknowledging the ways in which the enslavement of Africans and African Americans funded their very existence.<sup>235</sup> The arguments over the *New York Times's* support for its *The 1619 Project*, which has reexamined the founding of this country and its principles in the light of slavery, demonstrate the hard thinking we need to do to face our past and the resistance that exists to doing so.<sup>236</sup>

It would make sense then, as the Fund moves on in its important work, especially now in the midst of our current COVID/public health crisis, to publicly acknowledge its role in the Study in Tuskegee and to negotiate appropriate reparations with the organization of the descendants of the men in the Study. Apologies of course only cover what happened in the past. What happens next is critical.

This analysis also suggests the Fund might examine who sits on its boards and makes decisions. More diverse voices might help raise questions from differing perspectives, but they are not a guarantee that this will happen, as this history of the Study shows. As former Fund president Dan Fox told the board in 1992, "unexpected ethical transgressions will continue to occur in medicine." They may not look like what happened in Tuskegee, but they will happen. Perhaps a careful examination of the ethical concerns in research needs to be part of the Fund's review process for both articles published in the *Quarterly* and other actions the Fund supports.

It is also inevitable that the Fund as an institution will want to protect itself. This report suggests ways questions could have been raised, and examines other decisions made over the last 87 years since 1935 when the Fund became involved with the Study. There are many ways to protect an institution, and it has become increasingly clear that silence is often not the most ethical, or even the best, one. When the Tuskegee Institute's Eugene Dibble promised the Institute's leader that "the results of this study will be sought all the world over," alas, he was right in ways he could never have expected.

This July is the 50th anniversary of the public exposure of the Study. I hope this report becomes part of our understanding of why and how it happened, and that it becomes part of the Fund's process of self-reflection. As any good historian can tell you, new facts, reexaminations of old ones, and a differing perspective can change how we come to explain the past. It matters.

# ACKNOWLEDGMENTS AND CONNECTIONS TO MILBANK

In 1975-1977, my doctoral work in medical history in the American Studies Program at Boston University was funded in part by the Milbank Memorial Fund. I was in the Milbank Multidisciplinary Program in Health Services Research under a Fund grant to Professor John McKinley in the Department of Sociology. The only direct ties I had to the Fund were when its vice president and *Quarterly* editor David Willis came to visit to learn what the graduate students were doing, and a report about my activities was part of McKinley's annual review for the Fund. For this report, the Milbank Memorial Fund paid for my research and writing, but left me to do the work unimpeded.

Trying to do this research in the middle of the pandemic that closed archives was a challenge. I am grateful to dean Maureen Lichtveld and former dean Donald Burke of the School of Public Health at the University of Pittsburgh, who made my access to the Pitt archives possible. Former School of Public Health dean and Fund board member Paul Cleary, Yale historians of medicine Naomi Rogers and John Harley Warner, and the librarians at Yale had the Fund papers moved from the main Yale archives to a private room in the history of medicine library so I could access them as a non-Yale person. It took six months for me to get into the National Archives in Morrow, Georgia, and I am grateful to Rob Richards, the head archivist, for making my visit possible when they finally reopened and let only a few researchers in at a time. Because of COVID, the archives actually closed again a week after I was there. I did not revisit the National Archives in Washington, DC, but relied upon my notes taken from previous trips when I was doing the research for my two Tuskegee books

Professors Naomi Rogers and John Harley Warner in New Haven and Kylie Smith in Atlanta put me up in their homes and fed me so I could more easily do the research and discuss history with them in the evenings. The interlibrary loan librarians at both Wellesley College and the Boston Athenaeum also made the research possible.

I am indebted to Chris Koller, Dan Fox, Kathleen Andersen, Tara Strome, Gail Cambridge, Bob Harvey, Peter Gottsegen, and Tony Milbank at the Fund, who left me unrestricted to do this work, provided assistance in finding crucial documents, responded to my interview queries, made excellent editorial suggestions for revision, processed the paperwork, and supported this effort. Chris Koller's edits and comments for the Executive Summary were particularly insightful. I am honored to have been asked to do this and appreciate, too, that it made me rethink the analysis I had proffered before to understand this history.

# **APPENDIX 1: KEY NAMES**

PHS/CDC

Hugh S. Cumming Thomas Parran Raymond Vonderlehr Taliaferro Clark O.C. Wenger John Cutler David Sencer Anne Yobs Leroy Burney William J. Brown J.D. Millar Leonard A. Scheele William M. Stewart James B. Lucas Sidney Olansky

#### MACON COUNTY HEALTH DEPARTMENT Murray Smith

MILBANK MEMORIAL FUND STAFF, RESEARCHERS, AND BOARDS Elizabeth Milbank Anderson Albert G. Milbank Daniel M. Fox William W. Welch I.S. Falk Edgar Sydenstricker John Kingsbury Sir Arthur Newsholme Catherine Doran Ralph E. Wheeler James Baugh Helen McGuire Frank Boudreau Alexander Robertson Leroy Burney George Silver Clyde Kiser

SYPHILOLOGIST Joseph Earle Moore

ROSENWALD FUND Michael M. Davis

TUSKEGEE INSTITUTE, TUSKEGEE VETERANS ADMINISTRATION HOSPITAL

Eugene H. Dibble James Jerome Peters R.R. Moton Eunice Rivers Laurie Helen Kennebrew

WHISTLEBLOWER Peter Buxtun

LAWYER FOR THE PARTICIPANTS Fred Gray

# **APPENDIX 2: MONIES PROVIDED BY THE FUND**

AMOUNTS APPROPRIATED and TITLE OF GRANT/GRANTEE PROVIDED BY THE FUND TO THE TUSKEGEE INSTITUTE, 1935-1973

and

# SCHEDULE OF PAYMENTS TO THE TUSKEGEE INSTITUTE

and

# EXAMPLE OF THE APPEAL IN 1936

NOTE: Amounts budgeted in the grants and amounts sent to Tuskegee differ because each check sent came after notification of deaths/autopsies, while grants were prospective for the coming year.

<u>December 20, 1935</u>; Folio 507: Tuskegee Institute - study of untreated syphilis in the Negro \$500

<u>October 16, 1936;</u> Folio 526: Tuskegee Normal and Industrial Institute - for study of untreated syphilis in the Negro in Macon County, Alabama \$500

<u>December 16, 1936;</u> Folio 536: Tuskegee Normal and Industrial Institute - study of untreated syphilis in the Negro \$600

<u>December 17, 1937;</u> Folio 564: Tuskegee Normal and Industrial Institute - Study of Untreated Syphilis \$600

December 16, 1938; Folio 591: Tuskegee Normal and Industrial Institute \$600

December 15, 1939; Folio 617: Tuskegee Normal and Industrial Institute - Syphilis Study \$500

<u>October 18, 1940</u>; Folio 632: A request was presented for continued support of a study of untreated syphilis in the Negro in Macon County, Alabama, which has been carried on by the United States Public Health Service since 1935, in cooperation with the Tuskegee Normal and Industrial Institute, the Macon County Health Department and the Alabama State Board of Health. \$500 or as much thereof as may be necessary, ...to the Tuskegee Normal and Industrial Institute—Syphilis Study, \$600

December 19, 1941; Folio 662: Tuskegee Normal and Industrial Institute - Syphilis Study, \$600

December 18, 1942; Folio 688: Tuskegee Normal and Industrial Institute - Syphilis Study, \$600

December 17, 1943: Folio 715: Tuskegee Normal and Industrial Institute - Syphilis Study \$600

December 15, 1944; Folio 743: Tuskegee Institute \$600

December 21, 1945; Folio 770: Tuskegee Institute \$600

December 20, 1946; Folio 809: Tuskegee Institute - Syphilis Study \$600

December 19, 1947; Folio 837: Tuskegee Institute - Syphilis \$600

December 17, 1948; Folio 862: Tuskegee Institute \$600

<u>December 16, 1949;</u> Folio 892: Tuskegee Institute - Study of Untreated Syphilis \$600

December 20, 1950; Folio 923: Tuskegee Institute - Study of Untreated Syphilis \$600

December 19, 1951; Folio 946: Tuskegee Institute - Study of Untreated Syphilis \$600

<u>October 15, 1952;</u> Folio 966; An additional 1952 grant of \$450 to Tuskegee Institute for the Study of Untreated Syphilis in the Negro in Macon County, Alabama

December 17, 1952; Folio 978: Tuskegee Institute - Study of Untreated Syphilis \$1,800 December 16, 1953; Folio 1001: Tuskegee Institute - Study of Untreated Syphilis \$1,600 December 15, 1954; Folio 1028: Tuskegee Institute - Study of Untreated Syphilis \$1,600 December 21, 1955; Folio 1061: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 19, 1956; Folio 1091: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 18, 1957; Folio 1091: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 18, 1957; Folio 1113: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 17, 1958; Folio 1135: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 16, 1959; Folio 1154: Tuskegee Institute - Study of Untreated Syphilis \$1,000 October 13, 1960; Folio 1173: Tuskegee Institute - Study of Untreated Syphilis \$1,000 December 8, 1960; Folio 1177: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 14, 1961; Folio 1204: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 13, 1960; Folio 1204: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 13, 1962; Folio 1204: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 13, 1962; Folio 1204: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 13, 1962; Folio 1204: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 13, 1962; Folio 1204: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 13, 1962; Folio 1268: Tuskegee Institute - Study of Untreated Syphilis \$1,200 December 12, 1963; Folio 1268: Tuskegee Institute, Tuskegee, Alabama - Research grant for 1964 to continue the Tuskegee Study of Untreated Syphilis \$1,200

<u>December 10, 1964;</u> Folio 1300: Tuskegee Institute – Research Grant to the Institute for the continuation of the Tuskegee Study of Untreated Syphilis \$1,200

<u>December 9, 1965;</u> Folio 1333: Tuskegee Institute - Research Grant to the Institute for the continuation of the Study of Untreated Syphilis \$1,200 <u>December 8, 1966</u>; Folio 1364: Tuskegee Institute, Tuskegee, Alabama \$1,200 - to continue the Tuskegee Study of Untreated Syphilis

<u>December 14, 1967</u>; Folio 1395: Tuskegee Institute, Tuskegee, Alabama \$700 - for the continuation of the Tuskegee Study of Untreated Syphilis

<u>December 12, 1968;</u> Folio 1431: Tuskegee Institute, Tuskegee, Alabama - to continue Study of Untreated Syphilis \$700

<u>December 11, 1969</u>; Folio 1467: Tuskegee Institute, Tuskegee, Alabama - to continue study of Untreated Syphilis \$700

<u>December 10, 1970;</u> Folio 1510: Tuskegee Institute, Tuskegee, Alabama - to continue study of untreated syphilis \$1,400

<u>October 19, 1971</u>; Folio 1544: Tuskegee Institute, Tuskegee, Alabama \$1, 000 to cover autopsy expenses through the remainder of 1971

<u>December 14, 1971</u>; Folio 1565: Tuskegee Institute, Tuskegee, Alabama to continue study of untreated syphilis \$1,250

October 17, 1972; Folios 1618-19: The President reported on the present status of the longitudinal study of syphilis in Tuskegee and summarized briefly some of the comments which had appeared in the press in various parts of the country. He informed the Board that the Secretary of Health, Education and Welfare had appointed a Committee to review and make recommendations as to the action that should be taken with regard to this study. Doctor Burney said that he understood the Committee's report would be submitted by November 1, 1972. He mentioned that the Fund's grant had always been made to Tuskegee Institute, one of the four sponsors of the initial study. The Institute had discontinued the provision of autopsies but is continuing to use the Fund's small grant to assist the families of the deceased in defraying in part the cost of burial expenses. Doctor Burney said that as the participants in the study and their families have come to look upon this benefit as an insurance, he felt that the Fund should continue to honor this expectation, if possible through a continuation of the grant to Tuskegee Institute.

<u>March 20, 1973</u>: Folios 1649–50: Tuskegee Institute, Tuskegee, Alabama. For a special grant of \$1,500 to enable the Fund to continue extending financial aid to the Tuskegee Institute to assist it in continuing to provide appropriate benefits to the families of the participants in the Tuskegee Study. Referring to the award to the Tuskegee Institute Doctor Burney mentioned that the longitudinal investigation of the medical consequences of untreated syphilis known as the "Tuskegee Study" had been terminated by agreement of the officials and scientists responsible for the conduct of the study. Until the recommendations of the scientific and governmental bodies reviewing the study were issued, however, it was desirable for the Fund to continue extending the aid for which the award was given. To aid the institute in continuing to provide appropriate benefits to families of the participants in the 'Tuskegee Study' - 1972-1973 (This grant was previously described as 'Study of syphilis, 1972'), amount awarded in 1971 \$1,250

# MILBANK MEMORIAL FUND

# SCHEDULE OF ACTUAL PAYMENTS TO TUSKEGEE INSTITUTE, PER CASH BOOKS

YEAR	AMOUNT
1973	400
1972	1,600
1971	1,750
1970	550
1969	450
1968	150
1967	150
1966	450
1965	200
1964	900
1963	400
1962	800
1961	700
1960	1,300
1959	100
1958	700
1957	1,000
1956	800
1955	600
1954	600
1953	200
1952	650
1951	300
1950	300
1949	50
1948	200
1947	450
1946	50
1945	150
1944	600
1943	200
1942	350
1941	500

1940	500
1939	300
1938	500
1937	600
1936	500
1935	150

Total: \$20,150

Box 20, Folder 3, Milbank Memorial Fund Records, Yale University Archives, New Haven, CT.

# **ABSTRACT OF APPEAL**

ORGANIZATION	TUSKEGEE NORMAL AND INDUSTRIAL INSTITUTE Tuskegee Institute, Alabama
OFFICERS	Lloyd Isaacs, Treasurer
NATURE OF WORK	The continuation of a study of untreated syphilis in the Negro in Macon County, Alabama, which has been conducted by the U.S. Public Health Service for about four years, in cooperation with the Tuskegee Normal and Industrial Institute, the Macon County Health Department and the Alabama State Board of Health. In this study, a comparison is made of a group of untreated syphilitic Negro males with a group of Nonsyphilitic males and measures have been insti- tuted to provide necropsy work relating to this study.
	Pathological studies of these cases by necropsy should not only confirm or disprove the original clinical diagnoses but it is planned to reexamine the living individuals at intervals of five years in order to note the progress of the syphilitic infection when no treatment is administered. The control cases will also be observed in order that the effects of such conditions as arteriosclerosis and hypertension may be noted in this race.
APPEAL	A supplemental grant for 1936 of \$500. This sum will provide ten autopsies at \$50 each.
PREVIOUS DONATIONS	\$500. appropriated in 1935 but only \$150. called for; \$500. in 1936.
BUDGET	\$1800. is expended yearly on this project by the U.S. Public Health Service, and small contributions in the form of personnel service are made by other organizations. The John A. Andrew Memorial Hospital provides free hospitalization to seriously ill patients.

Box 6, 1936 Record Book, Milbank Memorial Fund Records, Yale University Archives, New Haven, CT.

# APPENDIX 3: AUTOPSIES: PRELIMINARY CDC DATA AND PROCEDURE

# CDC 1971 DATA ON AUTOPSIES AND DEATHS

and

NURSE RIVERS LAURIE EXPLAINS THE AUTOPSY PROCEDURE, AUGUST 1970

#### TUSKEGEE PARTICIPANTS

Total Participants in Study:	625	
Total Deaths	428	
Autopsies	234	
Death Certificates	162	
Neither	32	
Patients last examined in 1971 and		4
presumed to be living		
Patients last examined in 1970 and	100	
presumed to be living		
Patients last examined in 1968 and	17	
presumed to be living		
Patients last examined prior to 1968	10	
and presumed to be living		
Patients with no known address	66	
Total		197

Box 9, Folders 1970, 1971, CDC Venereal Disease Division Records, Tuskegee Syphilis Study Administrative Records, RG 442, National Archives Southeast Region, Morrow, GA.

#### PROCEDURE FOR AUTOPSY

- 1. Contact family immediately for a signed permit for autopsy.
- Call: Dr. Robert B. Adams ----- Telephone: 288-2100 Pathology Laboratories Blount F, Davidson Medical Plaza Montgomery, Alabama 36111
- 3. Notify Undertaker of the autopsy and hour.
- 4. Prepare two pint jars with formalin. One plastic bag for frozen specimen. Two specimen are sent to Atlanta - one formalin and the frozen one. The sections to be frozen are placed in the freezer for 24 hours or until dry ice can be obtained. At present, the most convenient place is Dairyland, Opelika. Secure 4-lbs. of dry ice to pack specimen; take it to the bus station, Tuskegee, for the 9:00 a.m. bus. Send package C. O. D. Call 404-633-3311 Extension 3345 and tell them to meet the 3:30 p.m. bus for the package. (Call Dairyland to see if they have the ice. If not, when will they have it. There is a possibility that you have to go over and get it.)
- 5. The Pathologist prepares the report and sends it to the Atlanta office.
- 6. Prepare the bills for the autopsy and present to Mr. L. A. Rabb, John A. Andrew Hospital, Tuskegee Institute, who will have checks drawn on the Milbank Fund at Tuskegee Institute to:

Wife - Mrs. Mary Doe----- \$100.00 Pathologist----- 125.00 Undertaker----- 25.00 Total----- \$250.00

Mail to Pathologist check with a blank receipt to be signed and sent to the Atlanta office.

Wife and Undertaker's checks are delivered personally and receipts are sent to the Atlanta office.

ERL 8/1970 NOTE: A COPY OF THIS MATERIAL WAS GIVEN TO MRS. KENNEBRE

# NOTES

# Abbreviations Used for Archives After First Citation

MMF-NYC Minutes of the Board of Directors Meetings, Milbank Memorial Fund Office,New York, NYMMF-Yale Milbank Memorial Fund Papers, Yale University Archives, New Haven, CT

Parran Papers Thomas Parran Papers, University of Pittsburgh Archives, Pittsburgh, PA

NA-DC U.S. PHS Division of Venereal Diseases, Record Group 90 (1918-1936), Tuskegee Syphilis Study Papers, National Archives, Washington, DC

NA-GA CDC Venereal Disease Division Records, Tuskegee Syphilis Study Administrative Records, RG 442, National Archives Southeast Region, Morrow, GA

<sup>1</sup> According to Fund board member Robert Harvey, who has researched this history, John Kingsbury wrote this quote for Elizabeth Milbank Anderson. Bob Harvey to Susan M. Reverby, email, January 6, 2022. See also Robert Eldon Harvey, "Case Studies of a Social Network: The Folks, Kingsbury and Anderson Network and Its Role in Public Health and Social Reform in New York City during the Progressive Era," Master's Integrative Project, History and Ethics of Public Health, Department of Sociomedical Sciences, Mailman School of Public Health, Columbia University, May 2007. I am grateful to Bob Harvey for making this available to me and for his edit suggestions and corrections on a previous draft.

- <sup>2</sup> H.S. Cumming to the Milbank Memorial Fund, November 29, 1935, Box 9, Folder 1936, CDC Venereal Disease Division Records, Tuskegee Syphilis Study Administrative Records, RG 442, National Archives Southeast Region, Morrow, GA (hereafter NA-GA).
- <sup>3</sup> John A. Kingsbury, letter from John A. Kingsbury to Albert G. Milbank, February 13, 1919, John A. Kingsbury Papers, Library of Congress, Part II, Box 23, cited in Daniel M. Fox, "The Significance of the Milbank Memorial Fund for Policy: An Assessment at Its Centennial," *The Milbank Quarterly* 84 (March 2006): 8. While Kingsbury was no longer with the Fund when the monies were given out for the Study and the language of "economy and efficiency" came out of the Progressive movement of the 1910s, the concept of applying a business/scientific model to research in public health practices was the hallmark of the Fund's operations for many years. For more on efficiency and scientific management in health and medicine in the early 20th century, see David Rosner, *A Once Charitable Enterprise* (New York: Cambridge University Press, 1982); Susan M. Reverby, "Stealing the Golden Eggs: Ernest Amory Codman and the Science and Management of Medicine," *Bulletin of the History of Medicine* 55 (Summer 1981): 156-171.

<sup>4</sup> Clyde W. Kiser, *The Milbank Memorial Fund* (New York: Milbank Memorial Fund, 1975), p. 17.

- <sup>5</sup> Bob Harvey supplied this dollar amount to me based on his research into the Fund's history. Bob Harvey to Susan M. Reverby, email, January 6, 2022.
- <sup>6</sup> Fox, "The Significance of the Milbank Memorial Fund for Policy," p. 10.
- <sup>7</sup> Examples of the press releases and summaries are in the Milbank Memorial Fund Papers, Yale University Archives, New Haven, CT (hereafter MMF-Yale).
- <sup>8</sup> Allan M. Brandt and Martha Gardner, "Antagonism and Accommodation: Interpreting the Relationship between Public Health and Medicine in the United States during the 20th Century," *American Journal of Public Health* 90, no. 5 (May 2000): 707-715.
- <sup>9</sup> Ibid., p. 711.
- <sup>10</sup> Seth Koven and Sonya Michel, eds., *Mothers of a New World: Maternalist Politics and the Origins of Welfare States* (New York: Routledge, 1983).
- <sup>11</sup> "If the health official's job depends on partisan politics, of course his situation is well nigh hopeless." Joseph Earle Moore, "The Public Health Officer and the Control of Syphilis," American Journal of Public Health 25 (January 1935): 35. See also Susan Reverby, "Introduction," The East Harlem Health Center Demonstration: An Anthology of Pamphlets (New York: Garland Publishing, 1985), pp. vii-xi.
- <sup>12</sup> John Duffy, "The American Medical Profession and Public Health: From Support to Ambivalence," Bulletin of the History of Medicine 53 (Spring 1979): 19. See also Amy L. Fairchild, David Rosner, James Colgrove, Ronald Bayer, and Linda P. Fried, "The Exodus of Public Health: What History Can Tell Us about the Future," American Journal of Public Health 100 (January 2010): 54-63.
- <sup>13</sup> Kiser, Milbank Memorial Fund; Fox, "The Significance of the Milbank Memorial Fund for Policy"; Patricia D'Antonio, Nursing with a Message: Public Health Demonstration Projects in New York City (New Brunswick, NJ: Rutgers University Press, 2017); C.-E. A. Winslow, Health on the Farm and in the Village (New York: Macmillan, 1931).
- <sup>14</sup> "Distinguished Service," The Survey, May 1935, p. 144, clipping in Box 25, Red Folder, MMF-Yale.
- <sup>15</sup> The minutes of the Technical Board are held in the Fund Papers at Yale. Members were paid \$1,000 per annum in 1930. According to Kingsbury, in the years up to 1935 the Technical Board met monthly except for the summer; see Minutes of the Technical Board, April 18, 1935, Box 14, Folder 124, MMF-Yale. On the functions of the Technical Board, see John Kingsbury to Doctor Parran, December 5, 1930, Box 7, Folder 22, Thomas Parran Papers, University of Pittsburgh Archives, Pittsburgh, PA (hereafter Parran Papers).

- <sup>16</sup> Cumming served on the Advisory Board in the 1920s and 1930s, and Welch served on the Technical Board from 1922 till his death in 1934. Welch is memorialized in the famous John Singer Sargent painting "The Four Doctors," which still hangs in the Welch Medical Library Great Hall at Johns Hopkins. The membership list is in Kiser, *The Milbank Memorial Fund*, pp. 26–27.
- <sup>17</sup> Welch is quoted by Kingsbury in Minutes of the Technical Board, April 18, 1935, Box 14, Folder 124, p. 5, MMF-Yale.
- <sup>18</sup> Elizabeth Toon, "Selling the Public on Health: The Commonwealth and Milbank Health Demonstrations and the Meaning of Community Health," in *Philanthropic Foundations: New Scholarship, New Possibilities*, ed. Ellen C. Lagemann (Bloomington: Indiana University Press, 1999), p. 125; Fox, "The Significance of the Milbank Memorial Fund for Policy."
- <sup>19</sup> In the immediate post–World War II period, one of the pieces of advertising created by organized medicine to fight another effort for national health insurance involved the use of a 19th-century English painting by Luke Fildes. Showing a doctor caring for a dying girl in a dimly lit Victorian workers' cottage as her distraught parents look on, the painting was copied by the millions and prominently displayed in doctors' offices across the country. "Keep politics," the tag line said, "out of this picture." See John Harley Warner, "The Doctor in Early Cold War America," The Lancet 381, no. 9876 (2013): 1452–1453.
- <sup>20</sup> Thomas Parran to Miss Roche, October 16, 1935, Box 1, Folder 3, Parran Papers.
- <sup>21</sup> Daniel M. Fox traces much of this controversy in his "The Significance of the Milbank Memorial Fund for Policy," especially pp. 13-17. For example, see John A. Kingsbury, Secretary of the Fund, to The Honorable Franklin D. Roosevelt, November 24, 1933, Box 40, Folder 4, of Kingsbury Papers in Box 25, Red Folder, MMF-Yale. Kingsbury was trying to get the president to pay attention to an article he had written outlining a national health plan in *The Milbank Quarterly*. Kingsbury knew Roosevelt well from his years in New York, and many of Roosevelt's letters to him began as "Dear John"; see Susan Gross Solomon, "The Perils of Unconstrained Enthusiasm: John Kingsbury, Soviet Public Health, and 1930s America," in *Comrades in Health*, ed. Anne Emanuelle-Birn and Theodore Brown (New Brunswick, NJ: Rutgers University Press, 2013), p. 47.
- <sup>22</sup> Thomas B. Gore, "A Forgotten Landmark Medical Study from 1932 by the Committee on the Cost of Medical Care," *Baylor University Medical Center Proceedings* 26 (April 2013): 142-143; The Committee on the Costs of Medical Care, *Medical Care for the American People* (Chicago: University of Chicago Press, 1932).
- <sup>23</sup> Milbank Memorial Fund, Annual Report for 1933 (New York: Milbank Memorial Fund, 1934), pp. 20–21, and quoted in Kiser, The Milbank Memorial Fund, pp. 53–54. I.S. Falk's papers are in the Yale University archives, and a collection of Edgar Sydenstricker's essays can be found in Richard V. Kasius, ed., The Challenge of Facts: Selected Public Health Papers of Edgar Sydenstricker (New York: Prodist for the Milbank Memorial Fund, 1974).

- <sup>24</sup> Jaap Kooijman, "Soon or Later On: Franklin D. Roosevelt and National Health Insurance, 1933-1945," Presidential Studies Quarterly 29 (June 1999): 338. Harry Hopkins, Roosevelt's point person on social security and later his Commerce Secretary, had been mentored by the Fund's John Kingsbury in the 1910s; *ibid.*, p. 337. See also Daniel M. Fox, *Health Policies, Health Politics: The British and American Experience*, 1911-1965 (Princeton, NJ: Princeton University Press, 1986), pp. 70-94.
- <sup>25</sup> In October 1934, Edgar Sydenstricker assured the Fund's Board of Directors "that he had received assurances from the American Medical Association of their full cooperation in the study and that he on his part was bringing in experts in the field of medicine, public health hospitals and dentistry to assist him." Milbank Memorial Fund Board of Directors Minutes, October 26, 1934, p. 461, Milbank Memorial Fund Office, New York, NY (hereafter MMF-NYC). See Daniel M. Fox, "Foundations and Health: Innovation, Marginalization, and Relevance since 1900," in *American Foundations: Roles and Contribution*, ed. Helmut K. Anheier and David C. Hammack (Washington, DC: Brookings Institution Press, 2010), pp. 128-131; for a general history of what happened to health insurance in the 1930s and 1940s, see Daniel S. Hirshfield, *The Lost Reform: The Campaign for Compulsory Health Insurance in the United States from 1931-1943* (Cambridge, MA: Harvard University Press, 1970), and for the longer time period, see Jonathan Engel, *Doctors and Reformers: Discussion and Debate over Health Policy, 1925-1950* (Columbia: University of South Carolina Press, 2002), and Beatrix Hoffman, *Health Care for Some: Rights and Rationing in the United States since* 1950(Chicago: University of Chicago Press, 2012).
- <sup>26</sup> John Kingsbury to Sir Arthur Newsholme, April 24, 1935, Box 40, Folder I, Kingsbury Papers in Box 25, Red Folder, MMF-Yale. On Kingsbury's early life and its difficulties, see Arnold S. Rosenberg, "The Rise of John Adams Kingsbury," *The Pacific Northwest Quarterly* 63 (April 1972): 55–62.
- <sup>27</sup> Sir Arthur Newsholme and John Adams Kingsbury, *Red Medicine: Socialized Health in Soviet Russia* (Garden City, NY: Doubleday, Doran & Co., 1933). The book is dedicated to the memory of Lady (Sara) Newsholme and "Dr. William Henry Welch, the Nestor of the Medical Profession in America, who first suggested the investigation which is concluded by this volume." (Nestor was the wise King of Pylos in Homer's *Odyssey*, an Argonaut who fought the centaurs.) See also Solomon, "The Perils of Unconstrained Enthusiasm," pp. 45-84.
- <sup>28</sup> "Mr. Kingsbury Explains," New York Herald Tribune, May 19, 1935, Kingsbury Papers, Library of Congress, clipping in Box 41, Folder 2, copied to Box 25, Red Folder, MMF-Yale. An article appeared in that newspaper on April 20, 1935, claiming that Kingsbury "had for several years expressed approval of socialized medicine as practice in Russia and has advocated the adoption of a similar health insurance plan in the United States." Kingsbury to Mrs. Reid, April 20, 1935, Box 25, Red Folder, *ibid.*; see also Kingsbury to Radin, p. 5, *ibid.*

- <sup>29</sup> Kingsbury, "Dear Friends," p. 1, July 19, 1935, p. 4, Kingsbury Papers, Box 41, Folder 2, in Box 25, Red Folder, MMF-Yale.
- <sup>30</sup> John Kingsbury to Dear Radin, March 12, 1935, p. 1, Box 40, Folder 8, Kingsbury Papers in Box 25, Red Folder, MMF-Yale. Kingsbury claimed in this letter that Milbank's Princeton friends and his doctor had even been after him. "History," Borden, https://www.bordendairy.com/press-room/history/ (accessed November 14, 2021); and Joe B. Frantz, Gail Borden: Dairyman to a Nation (Whitefish, MT: Literary Licensing, LLC, 2011).
- <sup>31</sup> Kingsbury to Dear Radin, p. 4.
- <sup>32</sup> Ibid. Just before Kingsbury was let go, "Auerbacher conferred with representatives of the Wayne County Medical Society on April 3, 1935, relative to the problem of Mr. Kingsbury, et. al." See "Now They Understand," clipping from *Detroit Medical News*, April 29, 1935, Box 3, Folder 12, Parran Papers.
- <sup>33</sup> Minutes of the Meeting of the Board of Directors of the Milbank Memorial Fund, October 26, 1934, p. 4, MMF-NYC. The minutes were signed by John Kingsbury as the Fund's secretary.
- <sup>34</sup> For an analysis of the importance of these social networks, see Harvey, "Case Studies of a Social Network." Harvey focuses on the Progressive era, but many of those ties forged in the 1910s continued into the 1930s.

<sup>35</sup> Ibid., p. 5.

- <sup>36</sup> Fox, Health Policies, Health Politics, pp. 70-94. Frances Perkins, foreword to Edwin E. Witte, The Development of the Social Security Act (Madison: University of Wisconsin Press, 1963), p. viii.
- <sup>37</sup> Kingsbury to Radin, March 12, 1935, p. 3; Kingsbury to Willian Hard, February 15, 1935, Kingsbury Papers, Box 40, Folder 8, in Box 22, Folder 79, MMF-Yale; Kingsbury, "Memorandum for Mr. Milbank from Mr. Kingsbury Reviewing the Fund's Efforts to Secure Cooperation with the Medical Profession," March 1, 1935, Box 13, Folder 124, Parran Papers.
- <sup>38</sup> Albert G. Milbank, "The Relationship of the Milbank Memorial Fund to the Field of Health and the Medical Profession," address before the Annual Conference of Secretaries of the County Medical Societies of Indiana, Indianapolis, Indiana, January 27, 1935, Group 845, Series I, Box 22, Folder 79, MMF-Yale; press release, January 28, 1935, *ibid.*; *Milbank Memorial Fund Quarterly* 13 (April 1935): 99-121.
- <sup>39</sup> "Harmony Is Urged in Health Field," *New York Times*, March 29, 1935, p. 19.
- <sup>40</sup> John Kingsbury to Lillian Wald, April 29, 1935, Box 25, Red Folder, MMF-Yale.
- <sup>41</sup> Fox, "The Significance of the Milbank Memorial Fund for Policy," p. 17.

- <sup>42</sup> Albert G. Milbank to John Kingsbury, April 12, 1935; John Kingsbury to Mr. Milbank, April 18, 1935, Kingsbury Papers, Box 40, Folder 9, copied to Box 25, Red Folder, MMF-Yale; Minutes of the Annual Meeting of the Milbank Memorial Fund, April 19, 1935, Milbank Memorial Fund Board of Directors Minutes, p. 6, MMF-NYC.
- <sup>43</sup> Kingsbury to Radin, March 12, 1935, p. 2. This explanation of their differences would become Kingsbury's mantra in the ensuing months.
- <sup>44</sup> The Fund, "Press Release," April 20, 1935, Box 29, Red Folder, MMF-Yale. Although Kingsbury was duly worried about how he would support his family, he did land on his feet. He would go to work for Harry Hopkins in Washington, published the book *Health in Handcuffs* with an attack on the AMA, and went on to chair the National Council of American-Soviet Friendship, which came under investigation by the House Un-American Activities Committee as a "subversive organization"; see Solomon, "The Perils of Unconstrained Enthusiasm," pp. 58-59. Kingsbury's years as a health policy power broker, however, ended when he was fired. He died in 1956, 21 years after he left the Fund.
- <sup>45</sup> John Kingsbury to Doctor Galdston, April 24, 1935, Box 25, Red Folder, MMF-Yale. In response, Galdston protested he was not the source of the rumors; April 29, 1935, *ibid.*
- <sup>46</sup> Paul Kellogg to John A. Kingsbury, telegram, April 20, 1935, *ibid.* For a sympathetic and radical analysis from Kingsbury's viewpoint, see James Rorty, "The Attack on Group Medicine," *The Nation* 143 (July 4, 1936): 15–17.
- <sup>47</sup> John Kingsbury, "Mr. Kingsbury Explains," *New York Herald Tribune*, May 19, 1935, clipping, Box 25, Red Folder, MMF-Yale.
- <sup>48</sup> See Allan M. Brandt, No Magic Bullet (New York: Oxford University Press, 1985); John Parascandola, Sex, Sin, and Science: A History of Syphilis in America (Westport, CT: Praeger, 2008).
- <sup>49</sup> "Internal Medicine as a Vocation," in Aequanimitas, with Other Addresses to Medical Students, Nurses, and Practitioners of Medicine (Philadelphia: Blakiston Company, 1904), p. 131.
- <sup>50</sup> Thomas Parran, "The Next Plague to Go," *The Survey Graphic* 25 (July 1936): 405-411; Moore, "The Public Health Officer and the Control of Syphilis," p. 31. Moore believed syphilis as a cause of death was very undercounted, with deaths "masquerading under more polite but less definite names," p. 32.
- <sup>51</sup> Moore, "The Public Health Officer and the Control of Syphilis," p. 33.
- <sup>52</sup> Brandt, No Magic Bullet, p. 122. By 1936, the Julius Rosenwald Fund's Michael Davis told Parran he used the word "syphilis" on a CBS radio show and "one of the officers of the Columbia Broadcasting System called up to express regret that the word had been used instead of 'social diseases,' but entered no formal protest." Michael D. Davis to Dear Tom, March 10, 1936, Box 1, Folder 3, Parran Papers.

- <sup>53</sup> Parran was only off the Technical Board for a year between 1933 and 1934; see Kiser, The Milbank Memorial Fund, p. 159.
- <sup>54</sup> Parascandola, Sex, Sin, and Science; Brandt, No Magic Bullet; James H. Jones, Bad Blood (New York: Free Press, 1981); Susan M. Reverby, Examining Tuskegee: The Infamous Syphilis Study and Its Legacy (Chapel Hill: University of North Carolina Press, 2009).
- <sup>55</sup> For more on Moore and syphilis research, see Reverby, *Examining Tuskegee*, pp. 137 and 151, and "Normal Exposure' and Inoculation Syphilis: A PHS 'Tuskegee' Doctor in Guatemala, 1946–1948," *Journal of Policy History* 23 (January 2011): 6–28.
- <sup>56</sup> Joseph Earle Moore to Thomas Parran, December 11, 1934, Box 13, Folder 124, Parran Papers. On Moore's importance to his peers, see A.J.K., "Obituary Joseph Earle Moore," *British Journal of Venereal Diseases* 34 (March 1958): 58–59.
- <sup>57</sup> R. H. Kampmeier, "The Tuskegee Study of Untreated Syphilis," Southern Medical Journal 65 (1972): 1251, and reprinted in Susan M. Reverby, ed., Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study (Chapel Hill: University of North Carolina Press, 2000), p. 200.
- <sup>58</sup> Trygve Gjestland, The Oslo Study of Untreated Syphilis (Oslo: Akademisk Forlag, 1955).
- <sup>59</sup> Brandt, No Magic Bullet, p. 131; see also Reverby, Examining Tuskegee, pp. 24-28. For a contemporary understanding of syphilis treatment, see Joseph Earle Moore, The Modern Treatment of Syphilis (Springfield, IL: Charles C. Thomas, 1933). The book went through multiple editions over the next two decades.
- <sup>60</sup> Christopher Crenner, "The Tuskegee Syphilis Study and the Scientific Concept of Racial Nervous Resistance," *Journal of the History of Medicine and Allied Sciences* 67 (April 2012): 244–280.
- <sup>61</sup> Raymond A. Vonderlehr, "A Comparison of Treated and Untreated Syphilis," *John A. Andrew Clinical Society Annual Bulletin* 1-5 (Tuskegee, AL: Tuskegee Institute, 1938), p. 1.
- <sup>62</sup> Paul S. Carley and O.C. Wenger, "The Prevalence of Syphilis in Apparently Healthy Negroes in Mississippi," *Journal of the American Medical Association* 94 (June 4, 1930): 1826-1829. Wenger, who worked for the PHS, would go on to play a major role in the Study in Tuskegee.
- <sup>63</sup> Fox, "The Significance of the Milbank Memorial Fund for Policy," p. 17.
- <sup>64</sup> See the Fund, "Memorandum Concerning the Development of the Program of the Milbank Memorial Fund since 1931," November 24, 1934, p. 4, Box 14, Folder 126, Parran Papers.
- <sup>65</sup> John Kingsbury to Joseph Earle Moore, March 21, 1935, and Joseph Earle Moore to Thomas Parran, March 29, 1935, Box 3, Folder 23, Parran Papers.

- <sup>66</sup> Milbank Memorial Fund Board of Directors Minutes, June 21 and October 18, 1935. Minutes Books, MMF-NYC.
- <sup>67</sup> Thomas Parran to John A. Kingsbury, January 12, 1931, Box 2, Folder 12, Parran Papers; Thomas Parran, "Unsolved Problems in Syphilis," American Journal of Tropical Medicine 10 (November 1930): 441-449; see also Harry Marks, "Notes from the Underground," in *Grand Rounds: One Hundred Years of Internal Medicine*, ed. Russell C. Maulitz and Diana E. Long (Philadelphia: University of Pennsylvania Press, 1988), pp. 297-338. Much of these difficulties with the Cooperative Clinical Group Study can be traced through Parran's correspondence in his papers. They also demonstrate his willingness to push for projects on the Fund's Technical Board, especially when they could be linked to a public health department; see, for example, Thomas Parran to Earle, October 11, 1936, and Catherine A. Doran to Dr. Parran, July 25, 1936, Box 13, Folder 124, Parran Papers.
- <sup>68</sup> Edgar Sydenstricker to Thomas Parran, April 3, 1931, Box 23, and Lida J. Usilton to Edgar Sydenstricker, April 6, 1931, Box 23, Folder 221, Parran Papers. On the "bone cuts," see Thomas Parran to Taliaferro Clark, December 5, 1932, Box 2, Folder 22, Parran Papers.
- <sup>69</sup> Edgar Sydenstricker to Thomas Parran, December 29, 1933, Box 12, Folder 124, Parran Papers. Thirteen months earlier, Taliaferro Clark had raised the possibility of asking for money from the Fund since he was facing drastic cuts to his Venereal Disease Division budget within the PHS; see Taliaferro Clark to Thomas Parran, April 21, 1932, Box 23, Folder 221, Parran Papers.
- <sup>70</sup> Sydenstricker to Parran, December 29, 1933, Box 12, Folder 124, Parran Papers. For such a discussion, see Minutes of the Fund Technical Board, April 18, 1935, p. 2, Box 14, Folder 125, Parran Papers.
- <sup>71</sup> Edgar Sydenstricker to Thomas Parran, November 21, 1935, Box 13, Folder 125, Parran Papers.
- <sup>72</sup> Minutes of the Technical Board, February 18, 1932, p. 3, Box 14, Folder 124, Parran Papers.
- <sup>73</sup> Special Meeting on Venereal Disease, January 24, 1935, Box 14, Folder 124, Parran Papers. The New York City venereal disease issue was also taken up by the Technical Board at their meetings in December 1934 and April 1935; see Technical Board Minutes, December 6, 1934, pp. 3-4, and April 18, 1935, pp. 2-4, Parran Papers.
- <sup>74</sup> MMF Board of Directors Minutes, May 17, 1935, p. 7, MMF-NYC.
- <sup>75</sup> Edgar Sydenstricker to Parran, April 11, 1934, Box 13, Folder 124, Parran Papers.
- <sup>76</sup> Ralph E. Wheeler to Dr. Parran, October 28, 1935, Parran Papers.
- <sup>77</sup> Technical Board Minutes, November 14, 1935, pp. 2-3, Parran Papers.

- <sup>78</sup> Technical Board Minutes, May 16, 1935, pp. 2-3, Parran Papers.
- <sup>79</sup> Thomas Parran, Shadow on the Land: Syphilis (New York: The American Social Hygiene Association in cooperation with Reynal and Hitchcock, 1937). The book was in its third printing by 1939. On the Fund money for the book, see MMF Board of Directors Minutes, December 18, 1936, MMF-NYC.
- <sup>80</sup> Fox, "The Significance of the Milbank Memorial Fund for Policy."
- <sup>81</sup> See John Parascandola, "From MCWA to CDC: Origins of the Centers for Disease Control and Prevention," *Public Health Reports* 111 (November-December 1996): 549-551, and Elizabeth W. Etheridge, *Sentinel for Health: A History of the Centers for Disease Control* (Berkeley: University of California Press, 1992).
- <sup>82</sup> Ralph C. Williams, The United States Public Health Service, 1798-1950 (Washington, DC: The Commissioned Officers Association of the U.S. Public Health Service, 1951); Fitzhugh Mullan, Plagues and Politics: The Story of the U.S. Public Health Service (New York: Basic Books, 1989).
- <sup>83</sup> Hugh S. Cumming Sr., Memoirs of General Hugh S. Cumming, Sr., Special Collections, University of Virginia Library, Charlottesville, VA, UVA microfilm. Cumming noted proudly that his wife, Lucy Booth Cumming, was a member of the United Daughters of the Confederacy, p. 23; Paul A. Lombardo and Gregory M. Dorr, "Eugenics, Medical Education, and the Public Health Service: Another Perspective on the Tuskegee Syphilis Study," Bulletin of the History of Medicine 80 (Summer 2006): 291-316.
- <sup>84</sup> Clyde Frost, "Report Concerning Medical Conditions," p. 5, Box 556, Folder 10, Rosenwald Fund Papers, Fisk University, and quoted in Reverby, *Examining Tuskegee*, p. 34. The words "susceptible to kindness" were given to the fictional Nurse Evers by David Feldshuh in his play/HBO film *Miss Evers' Boys* about the Study, but they were written by Frost. Both the video and a pamphlet prepared by Cornell University, where Feldshuh taught, for discussion of the play are called "Susceptible to Kindness."
- <sup>85</sup> Telegram from Michael M. Davis to Dr. Thomas Parran Jr., May 18, 1931, Box 1, Folder 3, Parran Papers; Thomas Parran, "Syphilis Control among Rural Negroes: Report of an Investigation Made for the Julius Rosenwald Fund in Six Southern Counties Where the Fund Has Supported Syphilis Control Projects," typescript, 1932, Box 30, Folder 335, Parran Papers; Charles Johnson, *Shadow of the Plantation* (Chicago: University of Chicago Press, 1934). The interviews that Johnson did for the book are in the Rosenwald Fund Papers in the archives at Fisk University in Nashville, TN. There were also tensions between Parran and Clark over who was the right person to analyze the Rosenwald Fund work in the South; see Thomas Parran to Taliaferro Clark, October 21, 1931, Box 17, Folder 167, Parran Papers.

- <sup>86</sup> Taliaferro Clark, The Control of Syphilis in Southern Rural Areas (Chicago: Julius Rosenwald Fund, 1932). "Not a single physician was found who voiced opposition to the work or its continuation," Clark reported in the typescript ("Report of Syphilis in the South") of what would become the book, p. 1, Box 17, Folder 160, Parran Papers. For more analysis of the Rosenwald Study, see Jones, Bad Blood, pp. 61-90.
- <sup>87</sup> Thomas Parran, "Results of Rosenwald Demonstrations in the Treatment of Syphilis," typescript, March 27, 1935, Box 17, Folder 160, Parran Papers; Michael M. Davis to Thomas Parran, July 22, 1936, discusses the possibilities of setting up a health clinic in Tuskegee, but there is no mention in the letter of the Study, which would have been in its fourth year then (Box 1, Folder 3, Parran Papers).
- <sup>88</sup> Taliaferro Clark to Dr. Parran, May 25, 1931, James A. Crabtree to Dr. Parran, September 25, 1931, Michael Davis to Dr. Parran, November 9, 1931, Box 1, Folder 3, Parran Papers.
- <sup>89</sup> Parran, Results of Rosenwald Demonstrations, p. 2.

90 Ibid.

- <sup>91</sup> Michael M. Davis to Dr. Moore, June 4, 1936, Box 1, Folder 3, Parran Papers. Davis was kept on, however, to continue other health work; see Edwin R. Embree and Julia Waxman, Investment in People: The Story of the Julius Rosenwald Fund (New York: Harper, 1949), and Julius Rosenwald Fund, Julius Rosenwald Fund: Eight Years' Work in Medical Economics, 1929-1936 (Chicago: Julius Rosenwald Fund, 1937).
- <sup>92</sup> Allen Hornblum, "The Secret Story of How a Revered Future Surgeon General Inspired the Tuskegee Syphilis Study," The Daily Beast, August 20, 2017, https://www.thedailybeast.com/the-secret-story-of-how-a-revered-future-surgeon-general-inspired-thetuskegee-syphilis-study (accessed November 21, 2021); both Jones (Bad Blood) and Reverby (Examining Tuskegee) made the case for Clark and Cumming.
- <sup>93</sup> Thomas Parran, "Macon County, General Observations Concerning the Syphilis Control Demonstrations," typescript, January 15, 1932, p. 4, Box 17, Folder 164, Parran Papers.
- <sup>94</sup> Taliaferro Clark to J.N. Baker, August 29, 1932, U.S. PHS Division of Venereal Diseases, Record Group 90 (1918-1936), Box 239, Folder 1, Macon County, National Archives, Washington, DC (hereafter NA-DC), and reprinted in Reverby, *Tuskegee's Truths*, pp. 73-74. There do not appear to be any letters on this between Parran and Clark in the archival papers they left behind.
- <sup>95</sup> My analysis of some of the medical records suggest that not everyone in the Study was actually in latency; see Reverby, *Examining Tuskegee*, p. 260. Furthermore, when the Study ended, CDC Director David Sencer made the decision to treat any of the men's wives and children who were positive for syphilis, without doing any contact tracing as to how they became infected. For how the numbers of family members infected were

then reported over the years, see Carol Kaesuk Yoon, "Families Emerge as Silent Victims of Tuskegee Syphilis Experiments," *New York Times*, May 12, 1997, pp. A1 and A12, and reprinted in Reverby, *Tuskegee's Truths*, pp. 457-460. When she was questioned by the CDC in 1974, Nurse Rivers Laurie claimed the women *had* been treated but that records had been "destroyed by the Macon County Health Department"; Public Health Advisor, For the Record, Telephone Conversation with Mrs. Eunice Louie (typo) regarding treatment of infected spouses and children of Tuskegee Study participants, June 26, 1974, Box 5, Folder 1974-75, NA-GA.

- <sup>96</sup> Eugene H. Dibble Jr., to R.R. Moton, September 17, 1932, R.R. Moton Papers, General Correspondence, Box 180, Folder 1516, Public Health Service, Tuskegee University Archives, Tuskegee, Alabama, and reprinted in Reverby, *Tuskegee's Truths*, pp. 75-76.
- <sup>97</sup> H.S. Cumming to Dr. R.R. Moton, September 20, 1932, *ibid.*, p. 77.
- <sup>98</sup> Dibble died in 1968 before the Study was exposed, and therefore was never interviewed on his views. From his papers left behind at Tuskegee University, I tried to re-create his thinking; see Reverby, *Examining Tuskegee*, pp. 152-166.
- <sup>99</sup> See Jones, *Bad Blood*, and Reverby, *Examining Tuskegee*, on how the Study unfolded. On the amount of treatment given at first, see Austin V. Deibert to R.A. Vonderlehr, November 26, 1938, Box 7, Folder 1938, NA-GA, and reprinted in Reverby, *Tuskegee's Truths*, pp. 89-90.
- <sup>100</sup> Raymond A. Vonderlehr to O.C. Wenger, July 18, 1933, U.S. PHS Division of Venereal Diseases, Record Group 90 (1918-1936), Box 239, Folder 2, Macon County, NA-DC, and reprinted in Reverby, *Tuskegee's Truths*, pp. 83-84.
- <sup>101</sup> Box 5, Folder Correspondence, NA-GA, and reprinted in Reverby, *Tuskegee's Truths*, pp. 84–86, quote on p. 85.
- <sup>102</sup> Susan Lederer, "The Tuskegee Syphilis Study in the Context of American Medical Research," in Reverby, *Tuskegee's Truths*, p. 267.
- <sup>103</sup> On the arguments with the American Heart Association, see Jones, *Bad Blood*, p. 139. On Moore as the intellectual father of the Study as it unfolded, see Reverby, *Examining Tuskegee*, pp. 49, 58–59, 138, 249.
- <sup>104</sup> On the importance of the autopsy, see Lester S. King and Marjorie C. Meehan, "A History of the Autopsy: A Review," American Journal of Pathology 73 (November 1973): 514-544; Michael Sappol, A Traffic in Dead Bodies: Anatomy and Embodied Social Identity in Nineteenth-Century America (Princeton, NJ: Princeton University Press, 2002).
- <sup>105</sup> Raymond Vonderlehr to Dr. B.W. Booth, Shorter, AL, April 18, 1934; Vonderlehr to Doctor G.C. Yancey, March 26, 1934, Box 239, Folder 4, NA-DC.
- <sup>106</sup> Hugh S. Cumming to R.R. Moton, July 27, 1933, Box 239, Folder 4, NA-DC.

- <sup>107</sup> Rivers remains one of the most controversial and enigmatic figures in the Study. For differing views on her, see Reverby, *Tuskegee's Truths*, pp. 321–398; Jones, *Bad Blood*, pp. 151–170; and Reverby, *Examining Tuskegee*, pp. 167–186.
- <sup>108</sup> Vonderlehr asked Moore at Hopkins to arrange for extra training for Peters with the white staff at Hopkins; Raymond Vonderlehr to Joseph Earle Moore, January 27, 1934, Box 239, Folder 4, NA-DC. Moore promised Vonderlehr: "We shall be very glad to have the Negro roentgenologist come to the Johns Hopkins Department of Pathology for a week to observe the methods employed"; Moore to Vonderlehr, February 28, 1934, *ibid.* Peters was also the senior author on the article on the autopsy results; see Jesse J. Peters et al., "Untreated Syphilis in the Male Negro: Pathologic Findings in Syphilitic and Nonsyphilitic Patients," *Journal of Chronic Diseases* 1(1955): 127-148. Moore commented on the paper, and it went through many edits by the PHS staff and Moore.

<sup>109</sup> Taliaferro Clark to Eugene Dibble, November 23, 1933, Box 239, Folder 3, NA-DC.

- <sup>110</sup> Jones, *Bad Blood*, pp. 132-150, provides the details on how this was set up.
- <sup>111</sup> Lederer, "The Tuskegee Syphilis Study in the Context of American Medical Research," p. 268.
- <sup>112</sup> Eugene H. Dibble to Raymond Vonderlehr, January 5, 1934, Box 239, Folder 4, NA- DC.
- <sup>113</sup> Murray Smith to R.A. Vonderlehr, April 23, 1941, Box 3, Folder Alabama Untreated Syphilis Misc. Rough Drafts, 1936, NA-GA. Smith was made a "consultant" to the PHS to keep him involved, and he wrote to his superiors there on PHS stationery.
- <sup>114</sup> See Karla FC Holloway, Passed On: African American Mourning Stories (Durham, NC: Duke University Press, 2002), and Suzanne E. Smith, To Serve the Living: Funeral Directors and the African American Way of Death (Cambridge, MA: Harvard University Press, 2010).
- <sup>115</sup> Author interview with Mr. Herman Shaw, Tallassee, Alabama, January 17, 1997.
- <sup>116</sup> Mary Stuart, Box 526, Folder 5, Rosenwald Fund Papers, Fisk University Archives, and quoted in Reverby, *Examining Tuskegee*, p. 277, n. 153.
- <sup>117</sup> Jones, Bad Blood, p. 135.
- <sup>118</sup> H.S. Cumming to the Milbank Memorial Fund, November 29, 1935, Box 9, Folder 1936, NA-GA.
- <sup>119</sup> Jones, Bad Blood, p. 153. His citation reads: "Rivers to Vonderlehr, January 3, 1934, Records of the USPHS, Venereal Disease Division, Record Group 90, National Archives, Washington National Record Center, Suitland, Maryland" (p. 266). These records have been moved to the National Archives in Washington, DC. I did not have the time to examine them again, and this letter was not in my notes when I did the initial research in the early 1990s.

- <sup>120</sup> Discussion with Laura Stark on the history of payment to subjects/controls by the federal government, December 11, 2021. Stark has written extensively on the history of institutional review boards and the use of subjects in medical research by the federal government.
- <sup>121</sup> Raymond Vonderlehr to Michael Davis, October 30, 1933, Box 4, NA-DC.
- <sup>122</sup> H.S. Cumming to Michael M. Davis, October 4, 1934, Box 9, Folder 1935, NA-GA; Jones, Bad Blood, p. 154.
- <sup>123</sup> CPI Inflation Calculator, "Why a Dollar Today Is Worth Only 5% of a Dollar in 1932," https://www.in2013dollars.com/us/inflation/1932 (accessed December 16, 2021).
- <sup>124</sup> "Memorandum Concerning the Development of the Program of the Milbank Memorial Fund since 1931," 1934, Box 14, Folder 126, Parran Papers.
- <sup>125</sup> Cumming to the Milbank Memorial Fund, November 29, 1935, Box 9, Folder 1934, NA-GA.
- <sup>126</sup> The clearest statement is in the Fund's Board of Directors Abstract of Appeal for 1936; see Appendix 2.
- <sup>127</sup> A. J. Aselmeyer from the PHS's division of Venereal Diseases told Austin Deibert, the PHS officer then working on the Study in Tuskegee, "to prepare a tentative draft of a letter to the Milbank Memorial Fund requesting continued financial support...." The letter would then be signed, Deibert was told, by the Surgeon General. A. J. Aselmeyer to Austin V. Deibert, September 25, 1939, Box 9, Folder 1939, NA-GA.
- <sup>128</sup> Thomas Parran to Catherine A. Doran, October 19, 1939, Box 9, Folder 1939, NA-GA.
- <sup>129</sup> Parascandola, "From MCWA to CDC," p. 551.
- <sup>130</sup> The letters among the PHS, the Tuskegee Institute, and the Fund are scattered within the boxes in the Study records in NA-GA.
- <sup>131</sup> Raymond Vonderlehr to Lloyd Isaacs, May 8, 1937, Box 1. Folder 1937, NA-GA.
- <sup>132</sup> Catherine A. Doran to Dr. Vonderlehr, October 22, 1940, Box 9, Folder 1963, NA-GA. Vonderlehr's request is in Vonderlehr to Doran, October 18, 1940, *ibid*. Please note that some of the letters were clearly not in chronological order and were in the wrong folders in the archives; for example, a letter from 1940 was in the 1963 folder. When I accessed these boxes 20 years ago, they were more in order. I suspect too many researchers have not been careful in returning the papers to the proper folders.
- <sup>133</sup> Catherine A. Doran to Dr. Bauer, January 7, 1952, and Theodore J. Bauer to Catherine A. Doran, January 11, 1952, Box 9, Folder General 1952, NA-GA.
- <sup>134</sup> J. Jerome Peters to R.A. Vonderlehr, October 19, 1937, Box 1, Folder 1937, NA-GA.

- <sup>135</sup> Raymond Vonderlehr to C.A. Walwyn, Medical Director, Tuskegee Institute, October 28, 1937; see also Vonderlehr to R.D. Lillie (NIH), November 6, 1937, NA-GA.
- <sup>136</sup> C.A. Walwyn to Raymond Vonderlehr, December 27, 1937, NA-GA.
- <sup>137</sup> Murray Smith to R.A. Vonderlehr, August 19, 1937, NA-GA.
- <sup>138</sup> Eunice Rivers Laurie to Anne Yobs, July 8, 1965, Box 9, Folder 1964, NA-GA.
- <sup>139</sup> Eunice Rivers Laurie to Dr. Yobbs [sic], July 25, 1965; William J. Brown, VD Branch Chief, to H.K. Logan, Business Manager, Tuskegee Institute, October 1, 1965, Box 9, Folder 1965, NA-GA. Similarly, the PHS asked the Fund to send \$50.00 to family members who had agreed to the autopsies that did not happen because notifications of the deaths came too late. See William J. Brown to Dr. Alexander Robertson, March 13, 1969, Box 9, Folder 1969, NA-GA.
- <sup>140</sup> See, for example, Lloyd Isaacs, Treasurer, Tuskegee Institute, to R.A. Vonderlehr, April 23, 1940, and Murray Smith to R.A. Vonderlehr, April 11, 1940, and R.A. Vonderlehr to Murray Smith, December 30, 1940, Box 3, Folder Alabama Untreated Syphilis Misc. Rough Drafts, 1936, NA-GA; Fred D. Gray, *The Tuskegee Syphilis Study* (Montgomery: New South Books, 1998), p. 56. It was the county health officer Murray Smith who asked that the families be given a bit more money than just to cover burial expenses; see Murray Smith to R.A. Vonderlehr, April 11, 1940, and Lloyd Isaacs to R. A. Vonderlehr, April 23, 1940, Box 3, Folder 1936. Smith also thought the Institute was being slow in getting out the checks to the undertakers and was worried the health department might lose the undertakers' cooperation. He wanted the checks to be sent to the health department, not the Institute, for disbursal, but this did not happen. See Murray Smith to R.A. Vonderlehr, November 27, 1941, and Austin V. Deibert to R.A. Vonderlehr, September 21, 1942, Box 3, Folder 1936, NA-GA.
- <sup>141</sup> J.D. Millar to Harold K. Logan, July 28, 1972, and John Baugh to Luther H. Foster, November 16, 1972, Box 1, Folder 1972, NA-GA.
- <sup>142</sup> "Milbank Memorial Fund Grants, Fellowships and Other Appropriations in 1957-58," Box 113, Folder 1609, Parran Papers.
- <sup>143</sup> Allan Brandt makes this argument, with no footnote to back it up, in his "Racism and Research: The Case of the Tuskegee Syphilis Experiment," *The Hastings Center* Report 8 (December 1978): 21-29, and reprinted in Reverby, *Tuskegee's Truths*, pp. 15-33. Both Jones and I continued this argument, with some reference to African American burial concerns.

- <sup>144</sup> I compiled the number of autopsies from the men's medical records at NA-GA nearly 20 years ago. My numbers of autopsies are higher than those compiled by the CDC. Without going back to those records, which I did not have the time to do, I cannot explain the difference in my numbers versus the CDC's 1971 number. Since the CDC's numbers comport more closely to the data in the Fund records, I am going to suggest these may be more accurate.
- <sup>145</sup> Murray Smith to R.A. Vonderlehr, November 16, 1937, Box 1, Folder 1937, NA-GA.
- <sup>146</sup> Joseph R. Heller to Catherine A. Doran, December 4, 1947, Box 9, Folder 1947, NA-GA.
- <sup>147</sup> Eunice V. Rivers, Stanley H. Schuman, Lloyd Simpson, and Sidney Olansky, "Twenty Years of Followup Experience in a Long-Range Medical Study," *Public Health Reports* 68 (1953): 391-395, and reprinted in Reverby, *Tuskegee's Truths*, pp. 125–131, quote on p. 129.
- <sup>148</sup> William J. Brown to Alexander Robertson, November 5, 1968, Box 9, Folder 1968, NA-GA.
- <sup>149</sup> "Minutes of the Ad Hoc Committee Meeting to Examine Data from the Tuskegee Study and Offer Advice on Continuance of This Study, CDC," February 6, 1969, Box 9, Folder 1963, p. 6, NA-GA, reprinted in Reverby, *Tuskegee's Truths*, pp. 463-472.
- <sup>150</sup> John C. Cutler to Dr. Bauer, November 20, 1952, Box 1, Folder 1952, NA-GA.
- <sup>151</sup> Heller to Doran, December 4, 1947, Box 9, Folder 1947 General, NA-GA.
- <sup>152</sup> John C. Cutler to Dr. Bauer, July 22, 1952, Box 1, Folder 1952, NA-GA.
- <sup>153</sup> Stanley H. Schuman to John Cutler, October 13, 1952, Box 1, Folder 1952, NA-GA.
- <sup>154</sup> John C. Cutler to Dr. C.A. Smith, January 5, 1956, Box 9, Folder 1956, NA-GA.
- <sup>155</sup> Alexander Robertson to William J. Brown, December 10, 1964, Box 9, Folder 1964, NA-GA.
- <sup>156</sup> R.A. Vonderlehr to Eunice V. Rivers, October 16, 1937, Box 1, Folder 1937, NA-GA. On the number of controls who became syphilitic, see Reverby, *Examining Tuskegee*, p. 258.
- <sup>157</sup> See Reverby, *Examining Tuskegee*, pp. 178-184. Private conversations between the author and James H. Jones, 2007-2008.
- <sup>158</sup> Reverby, Examining Tuskegee, pp. 120–129.
- <sup>159</sup> Charles J. McDonald, "The Contribution of the Tuskegee Study to Medical Knowledge," Journal of the National Medical Association 66 (1974): 1-7, reprinted in Reverby, Tuskegee's Truths, pp. 202–212. Benjamin Roy makes a more tendentious argument that the Study was used as part of the PHS's efforts to calibrate the TPI serologic test for syphilis; see "The Tuskegee Syphilis Experiment: Biotechnology and the Administra-

tive State," *Journal of the National Medical Association* 87 (1995): 56-67, and reprinted in Reverby, *Tuskegee's Truths*, pp. 299-317.

- <sup>160</sup> On the history of the goals and accomplishments of the Fund at the time of its centennial, see Fox, "The Significance of the Milbank Memorial Fund for Policy."
- <sup>161</sup> Thomas Parran to Catherine A. Doran, Assistant Secretary, Milbank Memorial Fund, November 4, 1943, Box 7, Folder 1941, NA-GA.
- <sup>162</sup> J.K. Shafter, Lida J. Usilton, and Geraldine A. Gleeson, "Untreated Syphilis in the Male Negro: A Prospective Study of the Effect on Life Expectancy," *Milbank Memorial Fund Quarterly* 32 (September 1954): 262-274. In the introduction to this issue of the *Quarterly*, the technical staff editor [unnamed] wrote: "The long-term effects of untreated syphilis in Negro males have been investigated by the United States Public Health Service by the method of continuous follow-up of cases over a period of twenty years. This longitudinal, prospective study has afforded unusual data on the natural history of syphilis and on survival of chronic cases." See "In this Issue," *ibid.*, p. 245.
- <sup>163</sup> Reverby, Examining Tuskegee, pp. 73-85.
- <sup>164</sup> Martha Solomon [Watson], "The Rhetoric of Dehumanization: An Analysis of Medical Reports of the Tuskegee Syphilis Project," Western Journal of Speech Communication 49 (1985): 233–247, and reprinted in Reverby, Tuskegee's Truths, pp. 251–275, quote on p. 252.
- <sup>165</sup> The PHS found a pathologist who would do the autopsies for \$75. The Fund was asked then to pay \$150 for each one; William J. Brown to Alexander Robertson, December 15, 1965, Box 3, Folder 1936, NA-GA.
- <sup>166</sup> William J. Brown to Alexander Robertson, August 18, 1965; Robertson to Brown, August 24, 1965; Brown to Robertson, September 9, 1965, Box 3, Folder 1936, NA-GA.
- <sup>167</sup> Robertson to Brown, September 15, 1965; Robertson to Brown, December 9, 1965 (contains quote); Brown to Robertson, December 15, 1965, NA-GA.
- <sup>168</sup> John S. Baugh to All Members of the Technical Board, January 13, 1969, Box 5, Folder 90, George A. Silver Papers, Group No. 1002, Series No. 1, Yale University Archives, New Haven, CT. I am grateful to Kaleigh Larsen, a Yale undergraduate, who retrieved this for me when I could not go to the major Yale archives to find this.
- <sup>169</sup> George A. Silver, "The Infamous Tuskegee Syphilis Study," letter to the editor, American Journal of Public Health 78 (1988): 1500, and reprinted in Reverby, Tuskegee's Truths, p. 507. See also John C. Cutler and R.C. Arnold, "Venereal Disease Control by Health Departments in the Past: Lessons for the Present," *ibid.*, pp. 495–506, and John C. Cutler, "Dr. Cutler's Response," *ibid.*, p. 508.

- <sup>170</sup> Susan L. Smith, "Neither Victim nor Villain: Eunice Rivers and Public Health Work," *Journal of Women's History* 8 (1996): 95-113, and reprinted in Reverby, *Tuskegee's Truths*, pp. 348-364, quote on p. 355.
- <sup>171</sup> See Susan M. Reverby, "Normal Exposure' and Inoculation Syphilis: A PHS 'Tuskegee' Doctor in Guatemala, 1946-48," *Journal of Policy History* 23 (Winter 2011): 6-28.
- <sup>172</sup> L.E. Burney to Division of Venereal Diseases, NIH, Attention Surgeon Ralph D. Lillie, June 10, 1937. Burney writes: "Attached hereto is autopsy report on [name redacted], control case in the Untreated Syphilis Study in the Negro in Macon County." Box 1, Folder 1937, NA-GA. R.A. Vonderlehr told the county health officer that Burney had been sent in January 1937 to Macon County. "I hope it will be possible for you to give him your usual extremely helpful advice. Doctor Burney has little experience in the far South and I have recommended that he go to you whenever he needs suggestions." R.A. Vonderlehr to Murray Smith, January 5, 1937, *ibid*. Dan Fox called Burney a PHS lifer; author interview with Dan Fox, New York, NY, July 21, 2021.
- <sup>173</sup> Milbank Memorial Fund, "Leaders of the Milbank Memorial Fund since 1905," https://www.milbank.org/about/history/leaders-of-the-milbank-memorial-fundsince-1905/ (accessed December 19, 2021).
- <sup>174</sup> Henry K. Beecher, "Ethics and Clinical Research," New England Journal of Medicine 274 (June 16, 1966): 1354–1360; Lara Freidenfelds, "Recruiting Allies for Reform: Henry Knowles Beecher's 'Ethics and Clinical Research," International Anesthesiology Clinics 45 (February 2007): 79–103. When the listed experiments were decoded later, the Study in Tuskegee was not one of the research studies that Beecher had covered and criticized.
- <sup>175</sup> Minutes of the Technical Board, October 11, 1966, Box 6, MMF Papers.
- <sup>176</sup> Minutes of the Technical Board, October 11, 1977, December 10, 1968, March 10, 1970, October 19, 1971, MMF Papers.
- <sup>177</sup> "Minutes of the Ad Hoc Committee Meeting to Examine Data from the Tuskegee Study and Offer Advice on Continuance of this Study," CDC, February 6, 1969, Box 9, Folder 1963, NA-GA.
- <sup>178</sup> Kiser, *The Milbank Memorial Fund*. Kiser never mentions the Study, and the book was published three years after its public exposure.

<sup>179</sup> Frank H. Musselman, Frank W. Notestein, L.E. Burney, and Clyde V. Kiser, "Remarks at Dinner Honoring Clyde V. Kiser," *Milbank Memorial Fund Quarterly* 49 (October 1971): 239-247; "Demographic Destinies: Interview with Clyde V. Kiser, Population Association of America President in 1952-53," https://higherlogicdownload.s3.amazonaws.com/POP-ULATIONASSOCIATION/3e04a602-09fe-49d8-93e4-1dd0069a7f14/UploadedImages/ Past\_President\_Interviews/16\_Clyde\_Kiser.pdf (accessed December 5, 2021).

<sup>180</sup> Jones, *Bad Blood*, p. 193.

<sup>181</sup> Reverby, Examining Tuskegee, p. 80.

- <sup>182</sup> For discussion of the 1969 meeting, see Reverby, *Examining Tuskegee*, pp. 79–82, and Jones, *Bad Blood*, pp. 193–199.
- <sup>183</sup> Author interview with David J. Sencer, Atlanta, GA, January 12, 2007.
- <sup>184</sup> Clyde Kiser to Alexander Robertson, February 20, 1969, "Trip to National Communicable Disease Center, Atlanta, Georgia to attend Conference on Future of the Tuskegee Study of Untreated Syphilis," Box 20, Folder 3, MMF-Yale.
- <sup>185</sup> Eunice V. Rivers to R.A. Vonderlehr, October 11, 1937, Box 1, Folder 1937, NA-GA. For more on what Rivers did or knew about the treatment clinics in the 1930s, see Reverby, Examining Tuskegee, p. 96.
- <sup>186</sup> Anne R. Yobs to David J. Sencer, July 28, 1970, Box 9, Folder 1970s, NA-GA.
- <sup>187</sup> James B. Lucas, Assistant Chief, VD Branch, to William J. Brown, Chief, VD Branch, September 10, 1970, Box 9, Folder 1970, NA-GA. See also Arnold L. Schroeter to Chief, VD Branch, August 5, 1970, Box 1, Folder 1945, NA-GA. On the importance of Joseph Lawton Smith, see R. Michael Siatkowski, "In Memoriam: Joseph Lawton Smith MD (1929-2011)," Archives of Ophthalmology 129 (July 2011): 175. The numbers in the various reports are not the same. In his letter to Robertson at the Fund about the 1969 meeting, Kiser said there were 89 surviving participants, of whom "53 were in the syphilitic group and 36 in the control group"; Kiser to Robertson, February 20, 1969, Box 20, Folder 3, MMF-Yale.
- <sup>188</sup> Jean Heller, "Syphilis Victims in U.S. Study Went Untreated for 40 Years," New York Times, July 26, 1972, and reprinted in Reverby, Tuskegee's Truths, pp. 116-118.
- <sup>189</sup> U.S. Congress, Senate Subcommittee on Health of the Committee on Labor and Public Welfare, *Quality of Health Care—Human Experimentation*, 93rd Cong., 1st Sess. (Washington, DC: Government Printing Office, 1973). David Sencer, Fred Gray, and four men from the Study gave testimony.
- <sup>190</sup> Board of Directors Minutes, October 17, 1972, p. 1618, MMF-NYC.
- <sup>191</sup> Ibid., March 20, 1973, p. 1649.
- <sup>192</sup> Author interview with Charlie Pollard, Notasulga, Alabama, January 13, 1995.

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- <sup>193</sup> Gray, The Tuskegee Syphilis Study, pp. 80-99; Reverby, Examining Tuskegee, pp. 86-108. Gray is a bit defensive about not suing Nurse Rivers, but he saw her as a "victim just like the men" as he would say repeatedly. He also never sued the Tuskegee Institute, for which at the time he served as chief counsel. His legal instincts clearly told him that making this a case of racism, without the complicated addition of Black personnel or institutions, would make his case stronger.
- <sup>194</sup> Pollard v. U.S. et al., Civil Action No. 4126-N, U.S. District Court, Middle District of Alabama, Northern Division, Amendment to Complaint, September 1, 1973, p. 4, Box 20, Folder 3, MMF-Yale.
- <sup>195</sup> Pollard v. U.S. et al., Affidavit for Service, October 17, 1973, MMF-Yale. Gray tells his side of events in the lawsuit in *The Tuskegee Syphilis Study*, pp. 80-99.
- <sup>196</sup> Andrew J. Connick to John S. Baugh, MMF, April 11, 1974, Box 20, Folder 4, MMF-Yale.
- <sup>197</sup> Oakley Melton, lawyer, Montgomery, Alabama, to Andrew J. Connick, Attorney at Law, New York, November 26, 1973, Box 20, Folder 4, MMF-Yale.
- <sup>198</sup> John S. Baugh to Andrew J. Connick, October 15, 1973, MMF-Yale.
- <sup>199</sup> Fred D. Gray to Susan M. Reverby, email, October 10, 2021.
- <sup>200</sup> Kiser, The Milbank Memorial Fund.
- <sup>201</sup> Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel (Washington, DC: U.S. Department of Health, Education, and Welfare, Public Health Service, 1973), pp. 23-24, and reprinted in Reverby, Tuskegee's Truths, p. 177.
- <sup>202</sup> U.S. Government, Department of Health, Education, and Welfare, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report* (Washington, DC: U.S. Government Printing Office, September 30, 1978).
- <sup>203</sup> It was followed by Fred Gray's 1998 The Tuskegee Syphilis Study (which has no footnotes) and my edited book, Tuskegee's Truths (2000), and then my monograph, Examining Tuskegee (2009). Numerous articles and reviews exist as well. My book also mentioned the Fund's role, but primarily relied on Jones's evidence for it. I spent more pages on the previous Rosenwald Study and the research done by sociologist Charles Johnson in Macon County.
- <sup>204</sup> The link was first made by Stephen Thomas and Sandra Crouse Quinn, "The Tuskegee Syphilis Study, 1932–1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community," American Journal of Public Health 81 (1991): 1498–1505, and reprinted in Reverby, Tuskegee's Truths, pp. 404–417. More studies after this article have suggested its limitations and a more sophisticated analysis of the effect of the

Study; see Ralph Katz and Rueben Warren, eds., The Search for the Legacy of the USPHS Syphilis Study at Tuskegee: Reflective Essays Based upon Findings from the Tuskegee Legacy Project (Lexington, MA: Lexington Books, 2011).

- <sup>205</sup> Author interview with David Feldshuh, Ithaca, NY, June 5, 1992; David Feldshuh and Walter Bernstein, *Miss Evers' Boys*, DVD, directed by Joseph Sargent (New York: HBO, February 22, 1997).
- <sup>206</sup> Don Byron, Tuskegee Experiments, Elecktra Nonesuch 79260-2, 1991, and author interview with Don Byron, Somerville, MA, April 20, 1993.
- <sup>207</sup> Saturday Night Live, NBC, hosted by Hugh Laurie, season 32, episode 4, October 28, 2006.
- <sup>208</sup> See Reverby, Examining Tuskegee, pp. 187-226.
- <sup>209</sup> "The Tuskegee Study," Primetime Live, ABC, February 6, 1992. Olansky was even more skewered for his moral stigmatism when writer Tom Junod profiled him after the Primetime Live story aired; see "Deadly Medicine," Gentleman's Quarterly (1993): 164–171, 231–234, and reprinted in Reverby, Tuskegee's Truths, pp. 509–524.
- <sup>210</sup> *The Secret of Bad Blood*, VHS (London: a Diverse Production for Channel 4, in association with the Arts and Entertainment Network, 1992).
- <sup>211</sup> "The Deadly Deception," *Nova*, DVD, PBS, directed by Denisce Dilanni (Boston: WGBH Education Foundation Films for the Humanities and Sciences, 1993).
- <sup>212</sup> The Secret of Bad Blood and "The Deadly Deception."
- <sup>213</sup> For more on Cutler and his thinking, see Susan M. Reverby, "Enemy of the People/Enemy of the State: Two Great(Iy) Infamous Doctors, Passions, and the Judgment of History," *Bulletin of the History of Medicine* 88 (Fall 2014): 403-430.
- <sup>214</sup> In my interview with Dan Fox, he said the idea for the film came from him. But ABC reporter George Strait told me it was his idea. Author interview with Dan Fox; author interview with George Strait, February 6, 2007.
- <sup>215</sup> D.M. Fox to the board, "President's Report: Controversies New, Resumed and Old," April 30, 1992, p. 3. I am grateful to Dan Fox and Kathleen Andersen for finding this.
- <sup>216</sup> Draft Minutes, MMF Board of Directors meeting, May 1992. I am grateful to Kathleen Andersen for finding this in the Fund records in New York.
- <sup>217</sup> Minutes, MMF Board of Directors meeting, May 1992, MMF-NY.
- <sup>218</sup> Draft Minutes, MMF Board of Directors meeting, May 1992.
- <sup>219</sup> Author interview with Dan Fox; Reverby, *Examining Tuskegee*, pp. 216–220.

<sup>220</sup> Reverby, Examining Tuskegee, pp. 216-226.

- <sup>221</sup> The Milbank Quarterly 83 (December 2005). A number of the reprinted articles were in the Quarterly and others were online; see https://onlinelibrary.wiley.com/ toc/14680009/2005/83/4 (accessed December 19, 2021). See also Fox, "The Significance of the Milbank Memorial Fund for Policy."
- <sup>222</sup> Chris Koller to Susan M. Reverby, email, December 24, 2021.
- <sup>223</sup> Evelynn M. Hammonds and Susan M. Reverby, "Taking a Medical History: COVID, 'Mistrust,' and Racism," *The Mudsill* 1 (April 15, 2021), https://themudsill.substack.com/p/ the-mudsill-vol-1-no-7 (accessed December 19, 2021).
- <sup>224</sup> Koller to Reverby, email.
- <sup>225</sup> Reverby, Examining Tuskegee, pp. 82-83; Harrison Smith, "Bill Jenkins, Epidemiologist Who Tried to End Tuskegee Syphilis Study, Dies at 73," Washington Post, February 27, 2019, https://www.washingtonpost.com/local/obituaries/bill-jenkins-epidemiologistwho-tried-to-end-tuskegee-syphilis-study-dies-at-73/2019/02/27/2319e142-3aa2-11e9a06c-3ec8ed509d15\_story.html (accessed December 18, 2021).
- <sup>226</sup> Koller to Reverby, email.
- <sup>227</sup> There is a debate in the historical and bioethics literature on the nature of informed consent with a large debate on when it starts and what counts. See, for example, Martin Pernick, "The Patient's Role in Medical Decision-Making: A Social History of Informed Consent in Medical Therapy," in *Making Health Care Decisions* (Washington, DC: U.S. Government Printing Office, 1982), pp. 1-35; Ruth Faden, Tom L. Beauchamp, and Nancy M.P. King, A History and Theory of Informed Consent (New York: Oxford University Press, 2002).
- <sup>228</sup> George H. Ramsey, "Shadow on the Land—Syphilis," The Milbank Memorial Fund Quarterly 16 (January 1938): 108-110.
- <sup>229</sup> Number calculated from the list in Kiser, The Milbank Memorial Fund, pp. 154-157.
- <sup>230</sup> When the story of the Study broke in 1972, Danny Williams, then the head of the Tuskegee University archives, did not show, or did not know about, all the records in his archive that he then showed to the Institute leadership. For years, the university would say in public settings that they had not known what had happened. I witnessed this time and time again when I was there. Furthermore as noted in the text here, lawyer Fred Gray sued neither Nurse Rivers nor Tuskegee University. Author discussions with Danny Williams, Tuskegee, Alabama, January 24, 1993, and discussions over the years with Cynthia Wilson, then assistant archivist, Tuskegee University.

- <sup>231</sup> U.S. Government, Department of Defense, "Crisis Communication Strategies, Analysis, Case Study: The Johnson and Johnson Tylenol Crisis," https://www.ou.edu/deptcomm/ dodjcc/groups/02C2/Johnson%20&%20Johnson.htm (accessed December 18, 2021).
- <sup>232</sup> Truth and Reconciliation Commission of South Africa, *Report*, 5 volumes (London: Palgrave Macmillan, 1998); Desmond Tutu, *No Future without Forgiveness* (New York: Doubleday, 1999); Facing History & Ourselves, "Truth and Reconciliation," https:// www.facinghistory.org/stolen-lives-indigenous-peoples-canada-and-indian-residential-schools/historical-background/truth-and-reconciliation (accessed December 19, 2021); Center for Justice & Reconciliation, "Restorative Justice," http://restorativejustice.org/ (accessed December 19, 2021).
- <sup>233</sup> Donald G. McNeil Jr. "U.S. Apologizes for Syphilis Tests in Guatemala," New York Times, October 1, 2010, https://www.nytimes.com/2010/10/02/health/research/02infect.html (accessed December 20, 2021). See also Reverby, "Normal Exposure' and Inoculation Syphilis."
- <sup>234</sup> American Medical Association, "The History of African Americans and Organized Medicine," https://www.ama-assn.org/about/ama-history/history-african-americans-and-organized-medicine (accessed December 19, 2021). For a similar concern about the rewriting and acknowledging the colonialism and racism of nursing history, see "Beyond Florence," Nursing Clio, https://nursingclio.org/topics/beyond-florence/ (accessed December 19, 2021); on Sims, see P.R. Lockhart, "New York Just Removed a Statue of a Surgeon Who Experimented on Enslaved Women," Vox, April 18, 2018, https://www.vox.com/identities/2018/4/18/17254234/j-marion-sims-experiments-slaves-women-gynecology-statue-removal (accessed December 20, 2021). On Parran, see numerous articles in the Sexually Transmitted Diseases journal (April 2013) and "Parran Hall Name Disappears After Board of Trustees Agrees with Chancellor's Recommendation," University of Pittsburgh University Times 50 (July 12, 2018), https:// www.utimes.pitt.edu/news/parran-hall-name (accessed December 20, 2021). I served as a consultant to both the American Sexually Transmitted Diseases Association and the dean of the University of Pittsburgh School of Public Health on this issue.
- <sup>235</sup> Ta-Nehisi Coates, "The Case for Reparations," *The Atlantic*, June 2014, https:// www.theatlantic.com/magazine/archive/2014/06/the-case-for-reparations/361631/ (accessed December 20, 2021); NPR, "How Slavery Shaped America's Oldest and Most Elite Colleges," September 17, 2013, https://www.npr.org/sections/codeswitch/2013/09/17/223420533/how-slavery-shaped-americas-oldestand-most-elite-colleges (accessed December 20, 2021).
- <sup>236</sup> Adam Serwer, "The Fight over the 1619 Project Is Not about the Facts," *The Atlantic*, December 23, 2019, https://www.theatlantic.com/ideas/archive/2019/12/historians-clash-1619-project/604093/ (accessed December 20, 2021); Lauren Michele Jackson, "The 1619 Project and the Demands of Public History," *The New Yorker*, December 6, 2021, https://www.newyorker.com/books/under-review/the-1619-project-and-the-demands-of-public-history (accessed December 20, 2021).

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