

# DIAGNOSIS

HORACE MANN'S MEDICAL JOURNAL

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# Letter From The Editor

# Dear Reader,

I am excited to release the third issue of Diagnosis, Horace Mann's premier medical journal! I am so proud to display the hard work of all of the writers and editors, and hope you enjoy reading this issue!

In this special issue focused on marginalized groups in medicine, you will find articles on the dangers of race-based medical testing, the Guatemala syphilis experiments, healthcare discrimination against transgender people in the US, a variety of doctor profiles (quick reads!), and much more! There also is the second part of a two-part interview with Dr. Chidi Akusobi '08 on how race is utilized in diagnosing patients, the school-to-doctor pipeline, and the importance of confronting systemic racism in the healthcare system. I would like to extend special thanks to all of the writers and editors for all of the time and effort they have dedicated to this issue. I would also like to thank our faculty advisor, Mr. Epstein, for his constant support, guidance, and advice.

Sincerely,

angren

Lauren Ho Editor-in-Chief Volume I, Issue III

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Rising Mortality Rates for African Americans, Asians, and Hispanics

The Dangers of Race-Based Medical Testing Lamia Chowdhury

et me introduce you to Noah. He has just moved to the city and is filling out paperwork at his new doctor's office. He has no trouble answering questions about his personal information until the form asks for his race. He is of Bosnian and Sudanese descent, but there is no multiracial option. Since his African features are far more prominent, he simply checks the box that says Black. Noah doesn't think much more of this because it is a routine question on most questionnaires.

However, it turns out that Noah's selection will play a significant role later on in his life when his doctor suspects that he needs a kidney transplant. In comparison to White people, a disproportionate number of Black people are victims of kidney disease. In fact, a Black person is about three times as likely to experience kidney failure, yet far less likely to receive a transplant.

One important factor that causes this disparity is the method through which doctors determine who qualifies as a candidate for the transplant list in order to receive an organ. The

primary test used to diagnose kidney disease is a measurement of one's estimated glomerular filtration rate (eGFR). To understand what this figure means, it is essential to understand the function of the kidneys. These two bean-shaped organs serve as the body's filtering system; they cleanse the blood of toxins which can be anything from a simple Advil to lots of alcohol. Creatinine, one of these toxins, is easy to quantify through a blood or urine test. This number can be plugged into an equation in order to determine someone's eGFR, a measure of how well their kidneys are functioning.

There are a number of different elements that affect the relationship between creatinine numbers and eGFR, though. Creatinine is produced as a result of repeated wear and tear on one's muscles, so those with a higher muscle mass will naturally have more creatinine in their bloodstream. Because of this, adjustments are made in accordance to gender and age, since women and older adults tend to have less muscle mass. However, in the late twentieth century, a number of scientists con-

cluded that race also plays a factor in creatinine production because of a few studies determining that Black Americans tend to have a higher muscle mass than their White counterparts. As a result, the equation also has been adjusted so that the eGFR of a Black patient is automatically raised by more than 20% to account for the extra muscle mass, which continues to be in the equation today. But, muscle mass of a living human can not directly be measured, only that of a cadaver, or dead person, can. Instead, the conclusion that eGFR should be adjusted based on racial lines was drawn from differences observed in other factors such as body fat, potassium, calcium, and creatinine levels from three small studies of only a few hundred Black and White patients.

Dr. Nwamaka Eneanya MPH, of the Hospital of the University of Pennsylvania argues that race-based kidney disease diagnoses should not be contingent on these studies because of their small scale, and also because race does not exist on the genetic level, according to the Human Genome Project, a scientific

research project that's goal is to identify and map all of the genes in the human genome. Further, she points out that the production of creatinine is influenced by factors other than muscle mass as well, such as diet and medications. Eneanya calls for more and more institutions to take these facts into consideration and question the reliability of race-based testing when it comes to kidney disease.

The example of Noah perfectly displays the issues with taking race into consideration when calculating eGFR. The first problem is that there are no guidelines for determining the eGFR of mixed-race individuals, who, according to the 2010 census, make up about seven percent of the US population. Secondly, since Noah self-identified as Black, he will have to wait longer to get a kidney transplant. This is because a patient is not usually put onto the waitlist until their eGFR reaches about 20, and Noah's eGFR will always be a bit higher than a White patient's as long as race is part of the equation. A recent study suggests that if race was not taken into consideration when calculating eGFR, the condition of approximately one-third of Black patients would be reclassified as a more severe stage of kidney disease, and they would thus be prioritized for treatment options like transplant referrals and dialysis sessions. Evidently, Black patients are not receiving the potentially needed treatment as quickly as they should, which can lead to a lower quality of life and higher risk of death.

Both the American Society of Nephrology (the study of kidneys) and National Kidney Foundation have worked to address this problem. They have created a joint initiative called the Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Diseases, which, through extensive research, analysis, and discussion, has published a report that calls for the implementation of a new mining factor.

By acknowledging existing practices that disproportionately harm one group of people and promote misconceptions based on race and attempting to change them, these societies are challenging the status quo to create a more equitable medical world. It is essential to question older practices in the face of new research (one example being that Black



system for kidney-disease diagnosis which does not consider race a deter-

patients have higher muscle mass when it has been concluded that race does not exist on the genetic level) so that medicine is able to serve all people equally, no matter their race. With more and more technological advances, it is likely that the scientific community will be able to create more just and accurate practices that take into account all people, including those with complicated identities, like our friend Noah.



# Racial Discrimination in the Scientific Community: The Tuskegee Syphilis Experiment Mia Calzolaio

n 1932, a group of physicians under the US Public Health Service (USPHS) initiated an experiment titled "Tuskegee Study of Untreated Syphilis in the Negro Male." The experiment consisted of 600 Black men, 399 of which had latent syphilis, meaning they did not show symptoms of the disease, and the remaining 201 of which did not—the latter acted as a control group. Over the course of 40 years, the USPHS intentionally provided these men with ineffective treatments-even after penicillin was developed as a standard cure—and repeatedly manipulated other health systems to ensure that the test subjects could be observed, unhindered by medicine, until

their deaths. At the time, physicians wanted to survey the impact of untreated syphilis and believed that latent syphilis did not require treatment. According to an article from McGill University, the physicians wished to observe the "natural progression of syphilis within a community that wouldn't seek treatment."

To understand the Tuskegee experiments, it is necessary to understand the medical context of the times. In the early 20th century, a rise in the popularity of social Darwinism led to the fundamentally racist nature of the assumptions that served as the basis for the USPHS's study. At the time, many scientists and physicians believed

that Black people in America were undergoing a degenerative evolutionary process and that emancipation had furthered their mental, moral, and physical degradation. Furthermore, scientists performing biased physical examinations concluded that Black people were the lowest species in the Darwinian hierarchy based on their set of physical characteristics. These anatomical differences centered on the sexual nature of the Black population, specifically Black men's alleged desire for white women. Physicians believed that due to their supposed physical and mental inferiority, Black men had underdeveloped brains but overdeveloped genitalia. Thus, the physicians assumed Black people were prone to venereal diseases, like syphilis, further concluding that Black people could not be convinced to receive treatment for those illnesses. This conclusion provided the physicians with a stronger excuse and reasoning to observe the syphilis of the test subjects in a so-called "natural" environment.

In 1929, the USPHS performed a study in the rural South on the prevalence of syphilis in Black men and the possibility of mass treatment, finding Macon County, Alabama to have the highest syphilis rate amongst the areas surveyed. The study also found that there was a possibility for mass treatmentmercury- and arsenic-based medicines were considered proper care at the time. However, these findings were ignored. In 1932, Dr. Taliaferro Clark decided to renew an experimental study in Macon County, citing its high rate of syphilis as an opportunity for a "study in nature." Essentially, Clark wanted to passively observe the course of syphilis in Black men residing in this area, as he believed that these men would not receive treatment in their lifetime. The initial experiment, coordinated in 1932 by Clark, was supposed to consist of a range of Black men with dormant

syphilis who were observed for six months and had never received treatment. However, after sending Dr. Raymond Vondehler to find subjects, the physicians found they could only gain volunteers under the premise that these patients would receive treatment. Also, the rate of syphilis in Macon County, once projected by the USPHS to be 35%, was in reality near 20%, and a larger number of men had received treatment for syphilis than previously thought, challenging the assumptions once conceived by social Darwinists. When the study officially began, the USPHS did not inform the volunteers that they were participating in an experiment, merely that they were being treated for "bad blood." To maintain both the false pretenses and the subjects' participation, the physicians would give patients ineffective medication, like mercurial ointments or inadequate doses of neoarsphenamine.

In 1933, the USPHS decided to continue the study, despite their initial assumptions about the compliant attitude towards syphilis in Macon County. During this time, physicians believed that autopsies of the men involved in the experiment were the only way to scientifically prove the results of the study;



however, the men were not to be informed that their deaths would be deemed necessary for the study. Vondehler also decided to add a control group of healthy men to the study. If those men ever became syphilitic, they would simply be switched over into the test group, a stark contrast to standard research procedure. To continue the guise of providing treatment, the USPHS hired nurses to provide the men with meals, transportation, and more ineffective medication. When it became difficult to persuade the men to come in for observation, physicians offered to pay for their burial expenses. In 1936, the first paper published about the study concluded that latent syphilis often largely increased the frequency of the development of cardiovascular disease. The study also cited that 16% of the subjects showed no signs of morbidity compared to 61% of the control group. Later articles and statements from physicians regurgitated the same information: dormant or latent syphilis has drastic negative impacts on the life expectancy of Black men. Yet throughout the experiment, subjects never once received treatment directly from the USPHS. Instead, the USPHS proactively worked to ensure that the men would not re-

ceive treatment from anywhere else. In 1934, researchers provided doctors in Macon Country with a list of men in the experiment that were not to be treated. In the early 1940s, the USPHS did the same with the Alabama Health Department. In 1941, when the Army drafted several of the men and asked that they begin antisyphilitic treatment, the USPHS provided the Army with a list of names to be excluded from treatment. In all of these instances, the physicians complied with the manipulations of the USPHS. Even in the early 1950s, when penicillin was accepted as a standard treatment for syphilis, researchers did not provide it. Around 30% of the subjects secured treatment elsewhere on their own, but only 7.5% received an effective dose. An ensuing report in 1955 concluded that the received treatments did not alter the validity of the experiment.

The USPHS repeatedly justified the racial component of the experiment. In a 1965 meeting, the Center for Disease Control determined that race did not affect the study, saying that the subjects were at a point where treatment could not help them and that "they [were] getting better medical care than they would under any other circumstances." In 1969, the CDC again reaffirmed the experiment. It was not until 1972, when accounts of the experiments first appeared in the press, that the Department of Health, Education, and Welfare (HEW) created a panel to investigate and end the experiment. Yet, the injustice did not end there. The panel set out to investigate two main questions: did the subjects provide consent, and should penicillin have been provided when it became widely available as a cure? While the panel examined these

questions, they did not consider a key point of the experiment—the entire trial was based on observing the natural course of the disease, not treating it. In 1973, the panel determined that the trial was "ethically unjustified," a seemingly gross understatement considering that the men involved had never once been informed they were participating in a trial of such nature. The final report stated that the men had not consented but instead volunteered for the experiment when they had been informed that they were receiving free treatment for their syphilis, not that they were participating in an experiment. By the time that the experiment ended, a mere 74 of the 600 test subjects were alive. Among those dead, 128 of the subjects died from syphilis or syphilis-related diseases, and not only that, 40 wives and 19 children of the subjects contracted the disease.

Eventually, the National Association for the Advancement of Colored People filed a lawsuit against the USPHS that was settled for 10 million dollars, which went towards the medical treatments of surviving subjects and infected family members. The US government also established the Tuskegee Health Benefit Program to provide this help. In 1997, President Bill Clinton apologized to eight of the survivors on behalf of the nation. Following these attempts to make amends, the National Bureau of Economic Research published a paper in 2016 that argued that the disclosure of the Tuskegee study in 1972 reduced the life expectancy of Black men at the age of 45 by 1.5 years. However, not only did the study affect life expectancy; it also severely impeded Black people's trust in the US medical system. In retrospect, it is crucial to acknowledge that racism is not only pervasive in social aspects of life and parts of legislative bodies but also largely impacts the medical system in America and the people it serves.







# The Horrific Baltimore Paint Lead Study Charity Chu



he scandal surrounding the Baltimore Lead Paint Study is a perfect example of the ways scientific research can go against morals. The ethics behind research involving human subjects has been debated for a very long time. In a world where people of color have been used for experimentation, including the syphilis experiments during the 1930s and mass sterilization in the 1900s, it is understandable that there would be controversy surrounding the subject. The backlash that was stimulated by the Paint Lead Study, a clinical study conducted in Baltimore by the Kennedy Krieger Institute (KKI) branch of Johns Hopkins Hospital, further cemented widely felt beliefs of the immoral actions conducted by researchers during experimentation with humans.

Lead was used throughout history to increase paint's durability and vibrancy. However, lead is an extremely toxic substance that, when swallowed or inhaled frequently, can have detrimental effects on the human body, especially the brain. Lead poisoning can lead to reduced cognitive functions and behavioral disorders, especially in children suffering from persistent exposure. Even in pregnant mothers, developing babies can be exposed to lead via the transfer of blood from the mother's blood supply into the uterus, which can result in premature birth. Lead can disrupt several processes such as neurotransmitter release, synapse formation, energy production, and message transmission. As the lead inhibits these processes, symptoms such as reduced IQ, learning disabilities, decreased growth, and memory and concentration problems may affect the baby in childhood or adolescence.

Before 1978, a majority of houses in the United States were covered with lead paint. However, once the toxicity of lead became more widely known, the use of lead paint was banned in 1978 nationwide. Baltimore was the first city to address the issue in 1951. The city banned the use of lead paint on new buildings. Despite this, properties with lead paint still remained. These properties were often homes for

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African American families in low-income communities. An estimated 95% of low-income residences in Baltimore had walls painted with lead paint. In houses with lead paint, as the walls begin to decay and the paint begins to crack, lead is subsequently released into the air, which increases the risk of lead indigestion. To combat this, the government began searching for methods of "lead paint abatement," which is a process of permanently eliminating lead-based hazards—a very costly procedure when enforced nationwide. Hoping to find a more inexpensive method, the Kennedy Krieger Institute began the Paint Lead Study.

To compare the effectiveness of various lead abatement techniques, the KKI observed five different groups. From level one to level five, the level of repair and maintenance increased, from minimal repair and maintenance (group one) to greater level of repair and maintenance (group two) to more aggressive repairs (group three) to complete abatement of lead paint (group four) and finally, no

repairs necessary since the house was built after the nationwide ban of lead paint (group five). They studied a total of 100 houses with 20 houses in each group. The KKI recruited families with small children that had already been living in these homes to participate in the study, with a total of 140 children across all groups. The researchers were focused on how much lead accumulated in young children when living in these homes. The families were paid for their participation in the study, which included collecting dust, soil, water, and blood samples. The effectiveness of the different abatement methods was determined by measuring how the children's blood became contaminated with lead while also comparing among the five different groups.

The takeaways of the experiment resulted in the understanding that lead paint quality was more harmful than the concentration of lead in paint due to the increased likelihood of ingesting the paint or dust from decaving lead paint. However, there was a lot of criticism directed at the study. Once the study concluded, many of the African American children who participated in the study were left with neurological disabilities. The results of the study in no way benefited the families besides a small amount of compensation given out during the study. In other medical research studies, the participants would either receive a developing cure to a condition or a placebo which would have no

effect on the participants' health, but in this study, the experiment had detrimental effects on the participants, and the parents of these children felt exploited. The KKI believed that if there were zero risks required in public health research, many problems could not be effectively addressed, resulting in a greater risk of leaving the public in more danger.

Because of the detrimental effects of the study on the participating children, many participants in the study sued the KKI in a class-action lawsuit—a petition in which a large group of people are represented by a select few members-for deliberate exposure and negligence. They argued that the consent form signed by parents did not clearly disclose that their children might accumulate hazardous levels of lead in their blood as a result of participating in the experiment, which led to a range of damage, including damage to the central nervous system and kidneys, to irreversible behavioral problems and, in the most extreme cases, even death. In addition, the parents argued that the KKI knew that the children were suffering from lead poisoning as the researchers were observing the increase of lead concentration in the children's blood. Rather than alerting the parents of this, which could have given the parents time to catch their child's condition before it worsened, the KKI collected and stored the information as data. This negligence led to the families not getting a chance to



treat their children's conditions before the effects of lead poisoning were irreversible.

Throughout a decade-long series of lengthy court battles, the court set out a number of rulings. The first claim said that, under federally regulated and established medical standards, children should not have participated in the measurement of effective lead abatement methods because the study was unethical. Their second claim said that parents could not legally consent to exposing their children to a possible health risk, especially when the trial did not have the best interest of the children in consideration. The court also said that it is up to the researchers to protect child test subjects from harm in nontherapeutic research studies. And in regards to the clarity of the consent forms, the court ruled that, since the KKI did not effectively make the parents aware of the potential harm to their children, the agreement was invalid. The court eventually found the KKI guilty of the claims explained above.

The outcome of this entire study and its aftermath highlights numerous issues today. The families were taken advantage of by an institution that did not respect the lives of the children they were using as guinea pigs. In addition, it also highlights the ongoing health crisis of low-income housing, which disproportionately affects families of color.

# Flesche Picott Susan La



# Susan La Flesche Picotte: The First Native American Female Doctor

vercoming discrimination and adversity due to the fact that she was both a woman and an Omaha Native American, Susan La Flesche Picotte became the first Native American female doctor. When Picotte was a child, a woman in her village died. If the woman had received proper medical care, she would have most likely survived, but the only physician available was a local white doctor who refused to treat the woman. Inspired by the death of this woman who could have been saved if the doctor had not discriminated against her, Picotte became a doctor. She wanted to provide proper medical access to everyone living on her reservation because there were some people, such as this woman, who received negligent care due to racial discrimination.

Picotte attended the Women's Medical College of Pennsylvania and received her degree in 1889. Women, even white women, at this time were considered intellectually inferior to men and received lots of backlash for even applying to medical school. By going against gender norms and gaining a college education, Picotte set a new standard for women across the country. Picotte achieved much success in school;

year early.



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# Mira Bansal

she not only graduated at the top of her class, but she also graduated a

Picotte could have practiced medicine on the East Coast and lived a relatively comfortable lifestyle, however, she instead chose to return to her reservation and help those in need. When she returned as a doctor to her reservation, she worked with a white male counterpart in a government-funded boarding school. So many of the sick patients that came in requested Picotte instead of her colleague that he quit, leaving her as the only doctor within 1,350 square miles. For the next twenty-five years, she attended to over 1,300 people on her own. She would walk to patients' houses for appointments,

sometimes carrying her children with her. Picotte dedicated her life to those patients so that no one would die like the woman from her childhood who died from improper medical care.

In 1913, Picotte fulfilled her life's dream of opening her own hospital, the first one on her reservation. She treated patients without any racial discrimination. Picotte also advocated for the education of proper hygiene and the prohibition of alcohol by leading the charge at rallies in the United States capital. Two years later, in 1915, Picotte died, leaving behind a message that everyone should be allowed access to health care regardless of their gender or race.

ttps://journalstar.com/news/local/govt-and-politics/statue-of-la-flesche-picotte-first-native-doctor-to-f 8cf-580d-5ff9-a468-1b1d86ffca99.html

# The Mother of Modern Medicine

Lamia Chowdhury

he is referred to as the Mother of Modern Medicine, yet so few of us know her name. She is referred to as the Mother of Modern Medicine, yet was not a doctor but rather a patient. She is referred to as the Mother of Modern Medicine, yet was a poor, Black woman who died before the height of the Civil Rights Movement. Her name was Henrietta Lacks, and we owe her a whole lot of thanks for the current understanding of the human body and the development of several therapeutics.

In 1951, Lacks sought treatment for cervical cancer at Baltimore's John Hopkins Hospital, the only clinic that accepted Black patients near her. Little did she know, her doctor, Dr. Howard Jones, had taken a biopsy of her tumor and then stored it in laboratories of the hospital. Medical researchers were astonished by the nature of these cells. Cancerous cell samples had been collected before, but ceased dividing after a couple of days. Lacks, however, did not stop. They are, to this day, dividing, and thus in a sense, immortal. These cells comprise what is known as the first "cell line," a population of cells that grow indefinitely in vitro. An entire generation of cells

is reproduced every 24 hours, and have proven versatile as well as extremely useful for biological research. These cervical cancer cells, named HeLa after the first two letters of Lacks' name, are responsible for a number of the most successful medical breakthroughs in modern history.

One of the first developments that stemmed from HeLa cells is the virtual eradication of polio. In 1936, a polio epidemic spread through the Southeast. Unfortunately, there were extreme racial disparities in the treatment of patients with polio. The well-resourced Warm Springs Foundation in Georgia served as one of the primary treatment locations for white patients. On the other hand, Black patients had little to no access to therapeutics. This resulted in the creation of the Tuskegee Infantile Paralysis Center, dedicated to the treatment of Black people, which eventually led to the success of the polio vaccine.

In order to successfully establish a vaccine, it is essential to run trials. Scientists first chose to test vaccines on Rhesus monkey cells, and analyze the number of antibodies produced in response. However, it soon became evident there was not a large enough supply of Rhesus cells, and thus, researchers resorted to testing on HeLa cells, which proved perfect for the job. The poliovirus easily infected these cells, which allowed scientists to better understand the disease's progression and how a vaccine would affect them. This was the first time that the virus could be grown in a lab on human cells. Tuskegee Uniworld.

In the years following, due to HeLa cells, the scientific community was able to better understand the effect of x-ray radiation on human health, see how space travel may affect astronauts, develop methods to test for Salmonella, and for the first time explore how tuberculosis attacks the body. Countless studies have used these cells, ranging from topics like lactose digestion to mosquito mating, and are cur-



rently playing a large role in the hunt for a cure to Parkinson's. Over 100,000 papers are based in research using HeLa cells, and they have truly changed our understanding of human health. Two of the most important advancements were uncovering the link between the human papillomavirus (HPV) and cervical cancer, which won Dr. Harald Zur Hausen the Nobel Prize in Medicine in 2008, and discovering telomeres, which won Dr. Elizabeth Blackburn, Dr. Carol Greider, and Dr. Jack Szostak the Nobel Prize in Medicine in 2009.

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https://info.umkc.edu/womenc/2017/03/27/henrietta-lacks-and-the-hela-cells/

versity became the first place to have HeLa cells, and now, they are present in labs all around the

In the 1970s, Dr. Harald Zur Hausen found HPV-18 in HeLa cells. HPV is the most common sexually transmitted disease, and 80% of people will acquire it at some point in their life. Hausen hypothesized that the virus had a direct link to cervical cancer. He isolated different strains of HPV and concluded that HPV-16 and HPV-18 increased the risk of developing cervical cancer. Scientists have since deduced that about 92% of cancers are linked to the human papillomavirus. The HPV genome inserts itself into the cell and then produces

a foreign protein that inactivates p53. p53 is a protein in the cell that prevents mutations and tumors from forming. This discovery subsequently led to developing a vaccine for the virus. According to a study published in Lancet by Université Laval, Harvard University and Cancer Council New South Wales, if this vaccine is administered rapidly in 78 developing countries then 62 million deaths could be prevented in the next 100 years. Australia has implemented a strong vaccination and screening effort and is on track to eradicate



cervical cancer soon.

The fact that HeLa cells are immortal is very unusual. For one, they are cancer cells, and as opposed to the usual 46 chromosomes a human cell possesses, these cells have around 80 highly mutated chromosomes. Even so, cancer cells are expected to stop dividing and die eventually. HeLa cells have not, though. Researchers have uncovered that this was because of the telomerase enzyme. In a healthy human cell, telomeres, caps at the tips of all chromosomes, gradually shorten until they can no longer divide any further. However, HeLa cells contain an overactive telomerase enzyme, which means that the telomeres are indefinitely replenished, making the cells immortal. This has dramatically shaped our understanding of aging and

apoptosis (cell death) and won three doctors the 2009 Nobel Prize in Medicine.

While this immortal cell line has been used extensively in biological research and has led to so many important discoveries, there are ethical concerns that come with their usage. In 1951 when Jones had taken a piece of Henrietta Lacks' tumor, it was an unconsented biopsy. Neither she nor her offspring knew that these cells were taken, and they did not realize to what extent they had benefited the medical community. Within a few decades, research using her cells had generated billions of dollars, yet her descendants were living in poverty, many lacking health insurance, never notified of what their foremother had contributed to medicine. It was not until 1971 when, with no explanation, researchers came to collect their blood—two

decades after the establishment of Henrietta's cell line, that they became aware of its existence. In 2010, Rebecca Skloot pub-

lished the New York Times bestseller, The Immortal Life of Henrietta Lacks, which brought attention to the ethics concerning HeLa cells. It was not until 1991 that the Common Rule was established, which dictated that doctors must inform patients if their information will be used for research, and patients will subsequently sign explicit consent forms. This means the law did not require doctors to ask for Henrietta's permission to use her cells in lab research. This leads one to wonder how different the course of medical history may have been if they

did. As a result of Skloot's work, the views of Lacks' children were voiced. The book commemorated Henrietta for the red-nail polish loving mother that she was, and painted her as much more than a biomedical resource. In 2013, the National Institute for Health (NIH) made a deal with her descendants. Now, two members of her family are part of the board to review any application to use HeLa cells, and all researchers must put the names of Lacks' family in their acknowledgments. The family has also been granted reparations by several medical research companies and private donors as well.

The issue of HeLa cells displays how science is never an issue solely isolated in just a lab, but rather extends to a social issue. The cells of Henrietta Lacks were derived without her consent, yet they have led to over a dozen significant scientific developments, and are used for research in labs worldwide. Fortunately, the scientific community has strived to compensate her family for the decades they were left in the darkness. While change is gradual, we must still grapple with who gets credit for innovation and who is left in the shadows. For now, one thing is clear: we all ought to show some gratitude to Henrietta Lacks, the Mother of Modern Medicine.



# **Does Race Exist at the Genetic Level?** Myra Malik



ebates of race and racism have run through American history since its conception. But what is race, biologically? How does the answer to that question reframe our thinking about race?

The typical understanding of race is composed of the "five races": African, European, Asian, Oceania, and Native American. Many legal systems, including the United States', use this classification in legislation. According to popular belief, people within each of these five groups are more genetically similar to those in their group and more distant from those outside of it. However, a 2002 Stanford study found that only 7.4% of alleles were clustered in specific geographic regions. Over 92% of alleles were found in two or more regions, and almost 50% were found in all geographic regions. This evidence demonstrates a fundamental similarity among all people instead of marked genetic differences within socially constructed racial groups.

Since the five-group theory has been proven false, why do certain ethnic groups have different phenotypes, like different skin and hair? How do DNA test kits identify your heritage? The answers lie within race's more biologically useful counterpart, local populations. Studying local populations is important for many reasons, such as investigating specific risks for certain diseases in specific groups of people. For example, people of Sub-Saharan African or Northern European descent are more at risk for cystic fibrosis—a hereditary disease that clogs the lungs.

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Thus, in a medical sense, knowing one's geographic ancestry is much more important than knowing one's race.

While race does not exist biologically, it certainly has real-world effects in both medical and social fields. Although genetic risks for medical conditions are determined by geographic ancestry, treatment and preemptive care is largely based on race. Medical racism has a long and well-documented history in American healthcare. African-Americans are disproportionately affected by hypertension, obesity, and diabetes compared to White Americans. But, it is not due to genetics, as Sub-Saharan Africans experience lower rates of hypertension than both White and African Americans. Rather, factors such as poverty, poor living environ-

ments, and lack of access to healthcare all increase the risks of the aforementioned diseases, and therefore make it more likely for them to be passed on genetically. Another prevalent example of medical racism is the infant mortality rate, which is two times higher in African Americans than in White Americans. However, a 1992 study from the American Journal of Diseases of Children revealed that, at the same military hospital, infant mortality rate lowered significantly for African Americans and became much closer to the rates of White Americans. Additionally, children's skin rash diseases, such as Kawasaki disease, are often misdiagnosed in darker-skinned children as medical textbooks typically only use depictions on light skin. These results support that the main cause of high infant mortality is not genetic or biologically race-based, it is much more dependent on access to healthcare. This holds true even through adulthood, as Black Americans are less likely to be treated for pain than White Americans and receive less pain medication.

Furthermore, race has many implications in society. The racial grouping system in America has gone through many changes, so while someone from Ireland would now be considered as "White," a century ago, "Irish" was considered its own race. Knowing racial groups are merely a social construct and that they are prone to change, what is their usefulness and impact in society? While race has no grounds in biology, its firm place in American law and society has made it a nearly unshakable institution in the country. Therefore, the lived experience of Americans in different racial groups can often have many overlaps. For example, I can relate to other Asian people through shared experiences in American society, but less so through culture or language. Movements like "Stop

Asian Hate" or "Black Lives Matter" are also centered around race, while acknowledging that race divides are unscientific and unfactual. While race continues to draw barriers and perpetuate injustice in American society, one can both acknowledge the lack of basis for race while realizing its effects in the real world.

Abolishing race as a social construct is neither an easy undertaking, nor will it be fast. However, doing so is necessary to highlight the genetic similarity among all people, effectively eliminating any scientific justifications for racism. The first changes must come through education. History classes should teach race as a social construct as opposed to a biological fact. Medical textbooks

### A) Popular conception of genetics and "5 races"



B) Actual genetic variation



https://sitn.hms.harvard.edu/flash/2017/science-genetics-reshaping-race-debate-21st-century/

and training must eliminate teaching false information, such as that Black people are less sensitive or that Asian people are less likely to experience mental illness. As people become more educated on race and its relation to biology, social change against racism will subsequently arrive.

While race has been proven not to exist at the genetic level, geographic ancestry and local populations do affect a person's phenotype and genotype minimally. However, medical racism and societal prejudice still reinforce the idea of race. It is important to recognize that while race is not scientifically real, it produces consequential real-world effects in our society.



# Healthcare Discrimination Against Transgender Individuals in the US Ari Borut

ut of the 1.6 million transgender individuals in the US, nearly one-third of them have been refused medical care due to their identity. A 2015 survey conducted by the National Center for Transgender Equality (NCTE) asked over 27,000 transgender people across the US about their experience with healthcare. The survey reported that a quarter of transgender people do not go to the doctor due to the fear of being harassed or experiencing discrimi-

natory behavior. Similarly, a separate poll conducted by NPR reported that 22% of the transgender people surveyed said they avoided going to doctors in fear of being discriminated against. This theme of associating fear with accessing healthcare is consistent among the trans community, as demonstrated by the polls and statistics that illustrate the health disparities present in the United States.

The NCTE survey found that onethird of the participants reported not getting medical care due to cost

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and that, even with insurance, their hormonal treatments or surgeries may not be covered. Someone who is transgender may want to receive hormone replacement treatments or have a surgical transition but cannot receive these treatments because of the cost and likelihood that insurance will not cover the cost. Of the individuals in the survey, a quarter of them reported being denied coverage for their hormone treatments, and over half of them were denied coverage for transition surgeries. Even though the Affordable Care Act says, "health plans aren't allowed to exclude transition-related care, and healthcare providers are required to treat [patients] with respect and according to [their] gender identity," transgender people are still faced with discrimination.

Transgender individuals, especially transgender women of color, often face difficulty accessing healthcare; they are at a higher risk of developing mental health issues, addictions, and sexually transmitted diseases. 20% of Black transgender women are HIV positive, compared to the general population –with an HIV positivity rate of 3%. Factors such as homelessness and unemployment, which are more common in the trans community due to discrimination, impact their access to healthcare.

For transgender individuals, it is more difficult to receive medical coverage because it is more difficult to get jobs. The unemployment rate for transgender people in the US is three times the unemployment rate of non-transgender people, with 15% of the transgender community reported as unemployed, compared to the 3% unemployment rate for cis-gendered people. Homelessness among transgender people is significantly higher because many transgender individuals leave home at a young age, whether by force or choice. Nearly two-thirds of transgender people do not live in traditional housing or shelters, which has more recently risen to 88%. This high rate of homelessness among transgender people prevents those affected from accessing routine medical care. More recently, transgender youth rights are being targeted by legislatures across the US, limiting their access to treatments and surgeries.

On April 6, 2021, Arkansas passed House Bill 1570, also called the "Save Adolescents From Experimentation Act," which prohibits transgender youth from receiving any hormonal treatment or transition-related surgeries. The Governor of Arkansas, Asa Hutchinson, vetoed this bill, yet the Arkansas House overturned his veto in a vote of 71–24 and Senate vote of 25–8. Hutchinson believed that the bill would be a "vast government overreach," even though he signed bills that targeted transgender individuals in the previous month. In response to the bill's passing, the American Civil Liberties Union stated that they are preparing litigation, their executive director saying that

"[a]ttempting to block trans youth from the care they need simply because of who they are is not only wrong, it's also illegal, and we will be filing a lawsuit to challenge this law in court."

Arkansas is the first state to ban gender-affirming treatments for people under the age of 18, regardless of whether they have their parent's consent to undergo treatments. Prior to passing the bill, Arkansas had passed a bill that gives doctors "the right [not to] participate in non-emergency treatments that violate their conscience." This law would allow doctors to turn away transgender patients due to their own religious or moral beliefs, further adding obstacles for transgender people to face when trying to receive health treatments. As



of April 2021, following Arkansas' passing of House Bill 1570, fourteen other states have introduced similar bills that would restrict trans youths' access to treatments and reassignment surgeries.

Being denied health care can have a severe impact on an individual's mental health. Jami Clare, a transgender woman, described how after she was told that her health insurance would not cover her hormone treatments, she fell into a deep depression and attempted suicide three times. Later on, she and two other transgender people filed against two state agencies and Jami's employer for discriminating against transgender people and explicitly excluding coverage for services to meet their medical needs. Stories like Jami's demonstrate how being denied healthcare can detrimentally impact someone's life and why it is essential that changes within the healthcare system and legislature are made.

Discrimination's presence in the healthcare system against transgender people is severely detrimental to their health and identity. Lawmakers are allowing doctors to use religious exemptions to decide who to treat. Furthermore, some insurance companies will not cover transgender-related treatments. Obstacles like these create an environment in which a transgender person will most likely feel unsafe or that their needs are not considered within the healthcare system. They make something as routine as a doctor's checkup a nerve-racking experience. With an increasing number of states trying to limit youth trans individuals' ability to receive treatments, the future for transgender youths' rights is at risk of being further limited by legislatures.



# Charles Drew: Racial Advocate and Inventor of the Large-scale Bloodbank Elise Kang

espite the challenges of being a Black man in the 20th century, Charles Drew organized the first large-scale blood bank. However, the blood bank was not enough to stop racist policies in his new system.

As a young Black man, Drew had limited options in medical schools. Prominent schools like Harvard University accepted few people of color. More often, aspiring physicians of color attended predominantly Black schools such as Howard University and Meharry Medical College. While Howard University rejected Drew for his lack of college English credits, Harvard accepted him under the condition he delay his enrollment by a year. In order to continue his education as soon as possible, he attended McGill University Faculty of Medicine in Montréal.

At McGill, Drew researched transfusion to treat shock with professor John Beatie. After university, Drew hoped to complete a residency at Mayo Clinic in the US, despite the fact they rarely took Black residents since patients often refused treatment from people of color. He eventually trained at Howard's expanding programs for Black physicians for three years, learning from Allen O'Whipple at New York-Presbyterian Hospital. Ultimately, he earned a doctorate from Colombia in Science in Surgery.

At New York-Presbyterian Hospital, Drew continued to study transfusions, shock, fluid balance, and blood

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preservation. His primary project with John Scudder, a blood transfusion specialist and developer of the Plasma for Britain program during WWII, was an experimental blood bank that they opened at the hospital in 1939. Drew returned to Howard University after his fellowship only to be recalled to New York City in September 1940 for the Blood for Britain Project because they needed blood to treat their soldiers and civilians during the start of World War II (WWII).

In August of 1940, New York-Presbyterian Hospital alongside five other New York hospitals began gathering and sending plasma to Britain. As medical director, Drew implemented standardized procedures and requirements for blood collection, something never done before. At the program's termination in 1941, Drew became assistant director for a national blood banking system sponsored by the National Research Council and the American Red Cross. He invented the "bloodmobile," a breakthrough automobile equipped to collect blood donations. One bloodmobile can collect 100,000 pints of blood, saving 300,000 lives over its lifetime.

Initially, the US military denied blood donations from African-Americans in preparation for WWII. Though biological blood discrepancies between races are nonexistent, social beliefs did not reflect this. The military caved to racial discrimination under political pressure, and later, the policy evolved so that Black people's blood

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was separated from that of whites. Drew challenged these policies for being unscientific and insulting to African Americans, resigning as director.

Drew later became the first African American appointed as an examiner under the American Board of Surgery. He raised standards in Black medical education and fought against the exclusion of Black students in medical societies. He received various awards and honors for his work, including nominations to the International College of Surgeons in 1946 and the American-Soviet Committee on Science. Although Drew passed away on April 1, 1950, his work of resisting racial prejudice and directly aiding thousands in need during WWII continues to help and inspire people today.



# Charles Drew

# Health Disparaties within the LBGTQ+ Community Zahra Motwani

rom discriminatory laws to street harassment to increased rates of youth homelessness, the LGBTQ+ community deals with oppression each day. Similar inequalities are also evident within the healthcare system, and in order to fully understand them, healthcare professionals and the general public need to take social determinants of health into consideration.

Examining statistics on disease and medical conditions is the first step in understanding the LGBTQ+ community's health challenges. As a whole, the LGBTQ+ community has elevated rates of HPV (human papillomavirus) infection, heart disease, substance abuse disorders, and mental illness. 20% of LGBTQ+ adults smoke compared to 15% of straight people, which can cause heart and lung disease. In 2018, gay and bisexual men made up 69% of HIV cases. Social factors also have an impact on health outcomes, as stated by HealthyPeople. gov: "Elderly LGBT individuals face additional barriers to health because of isolation and a lack of

social services and culturally competent providers." Sydney Brodeur McDonald from Veritas Collaborative, a treatment center for eating disorders, offered further explanation for these disparities:

"In comparison to their straight peers, LGBTQ+ individuals experience unique stressors such as bullying, harassment, fear of rejection, internalized homophobia, body image distress, barriers to accessing medical and mental health treatment, and violence."

Obesity is more likely to affect bisexual and lesbian women, and gay and bisexual men are more likely to experience eating disorders than their straight constituents. LGBTQ+ people are more likely to be uninsured due to unemployment and/or denied insurance coverage by their employers due to their identity. Additionally, LGBTQ+ people who do have the means to visit the doctor's office do not go as often as recommended because they fear hostile healthcare officials, which means they may

miss screenings and end up with more severe conditions due to a lack of early intervention. Even if they go to a physician, there is no guarantee that they will receive acceptable care. In a national Center for American Progress survey from 2017 about queer experiences—excluding those of transgender people—at the doctor, 8% of those surveyed reported being refused to be seen by a doctor, 9% said the doctor used abusive language with them, and 7% said that the doctor harassed them. The same survey was conducted with transgender people with similar findings-29% of those surveyed were refused care, 23% were misgendered intentionally, 21% said the doctor used abusive language with them, and 29% said the doctor harassed them. This widespread harassment and medical discrimination leads to increased anxiety in LGBTQ+ people about visiting the doctor and often leads people to hide their identities from their medical providers out of fear.

Even when doctors are not openly homophobic or transphobic,

many healthcare providers are uninformed about LGBTQ+ identities and experiences, which means many patients need to educate their doctors, a detail that straight patients do not have to worry about. Kristen Martinez, a psychotherapist from Pacific NorthWell—a private practice that provides therapydiscussed this challenge: "If you have to teach your health care providers about the lived experience of being trans and/or queer, that is a burden that should not be on your shoulders but often is, on top of accessing care, having resources to pay for care, and more." From this quote, it is clear that going to the doctor is a strenuous situation of potentially harmful interactions for LGBTQ+ people. Viewing the elevated rates of various diseases and conditions through the lens of discriminatory behavior adds nuance to what could otherwise be simply a list of statistics. LGBTQ+ people are not inherently more susceptible to illness; they are disproportionately subjected to discrimination, harassment, and worse treatment, factors that create situations that lead to adverse health outcomes.



However, anti-LGBTQ+ sentiments within the medical system are not limited to individual doctors; there is plenty of systemic prejudice as well. A prime example of systemic homophobia is the strict restriction of blood donations from gay and bisexual men. Until an emergency change due to COVID-19, blood donations from gay men were not allowed at all blood donation sites throughout the nation unless the patient had



stayed celibate for twelve months prior. Despite the fact that HIV/ AIDS can be found in people of all sexual orientations and all blood donations are tested for HIV/AIDS before being administered to a patient, this ban has persisted for decades. The FDA specifically said that they "recommended that blood establishments indefinitely defer male donors who have had sex with another male." Additionally, many people are hesitant to donate blood



because of COVID-19, causing a blood shortage in the United States. Even with the blood shortage, healthy blood is still being turned away. Although the rule was modified in 2020, there is still a required celibacy duration of 3 months for gay and bisexual men that donate blood, regardless of their HIV status, relationship status, or history of behavior because the Center for Disease Control is concerned about HIV/AIDS transmission. Identifying as gay or bisexual is not synonymous with having HIV— risky behavior such as having unprotected sex, having multiple partners without STD testing, and sharing needles when using intravenous drugs are the main contributors to HIV infection.

"Framing the risk of the disease as exclusive to gay and bisexual men is a relic of long-standing discriminatory practices against the LGBTQ+ community and echoes the history of the HIV/AIDS epidemic and the government's lackluster response. "

The HIV/AIDS epidemic swept the country from the 1970s to the 2000s, disproportionately affecting the LGBTQ+ community. The British Academy's data states, "In the USA, by 1995, one in nine

gay men had been diagnosed with AIDS, one in fifteen had died, and 10% of the 1,600,000 men aged 25-44 who identified as gay had died." The lack of serious governmental response was a large part of why the victim count of the epidemic reached such drastic numbers, and the memory of this callous disregard has become a root for medical mistrust within the LGBTQ+ community. HIV was not seen as a pressing public health issue and was regarded as a "gay plague" because it was first discovered in clusters of gay men and more prevalent in the gay male population, people who were not a priority in the eyes of the government. The LGBTQ+ community as well as local activist groups protested for nationwide treatment of HIV, but they were ignored. President Ronald Reagan's administration was known to openly downplay the severity of the situation. When Reagan's press secretary Larry Speakes was asked in a press conference if any action was going to be taken about the epidemic, Speakes and everyone else in the room burst into laughter, as if the thousands of victims of the deadly disease were humorous. Throughout the rest of the conference, Speakes and the other people in the room made many jokes, and Speakes at one point directly stated, "I haven't heard him express concern," referring to President Reagan. In response to this apathy, activist groups like ACT UP (AIDS Coalition To Unleash Power) put significant pressure on the government as well as the pharmaceutical industry to roll out a treatment quicker, staging protests despite arrests and police brutality. Even with these efforts, it was not until 1985 that Reagan began pub-

and it took until 1987 for the first medicine Azidothymidine (AZT) for HIV to be released. Didanosine (ddI) and zalcitabine (ddC), reverse transcriptase inhibitors, were the next treatments to come out for HIV. Using these medicines along with AZT proved to be successful in treating HIV, but this was still not a cure. In 1995, a more effective medication, HAART, a highly active antiretroviral therapy, came out, but it was prohibitively expensive, preventing low-income people from accessing it. Given the disproportionate amount of LGBTQ+ people that live in poverty, this was a dire obstacle. The HIV/AIDS epidemic and response of the US government is an example of systemic discrimination and how various social factors can intersect to create a massive health disparity for a marginalized community. Health disparities in the

LGBTQ+ community do not even begin to scratch the surface of what the community experiences on a day-to-day basis. Additionally, these disparities are not the same for the whole community because experiences vary along the lines of race, class, gender, documentation status, disability, and more. In attempting to understand and alleviate health disparities for the LGBTQ+ community, an intersectional lens is crucial. The LGBTQ+ community should not have to struggle to obtain healthcare when it is the homophobia of many medical professionals and government officials that is barricading them from equality.



licly speaking about the epidemic,





https://en.wikipedia.org/wiki/Carlos\_Finlay

# **Carlos Juan Finlay:** The Man who Saved Millions William Bramwell

arlos Juan Finlay was a Cuban physician and epidemiologist who made groundbreaking discoveries on the nature of yellow fever's transmission. Born in 1833 on his father's coffee plantation in Cuba, Finlay traveled to France and England for school before receiving a medical degree from Jefferson Medical College in Philadelphia in 1855. In Philadelphia, Finlay met physician John Mitchell, an outspoken proponent of Germ Theory, the now well-accepted but then controversial concept that microorganisms caused illness. Finlay would later use Germ Theory to formulate his hypothesis on vellow fever.

Mitchell tried, in vain, to convince Finlay to establish a medical facility for the Hispanic community in New York City, but Finlay instead returned to Cuba. There, Finlay worked with his father for the next twenty years, frequently traveling around South America to treat patients. It was during these trips where Finlay most likely first encountered yellow fever, as the deadly virus had become an epidemic in certain parts of the Caribbean by the mid-19th century.

In 1879, Finlay worked with an American mission sent to Cuba to study the causes of yellow fever. From this work, Finlay and his colleagues concluded that the pestilence's transmission necessitated a vector, an organism that fuels the transmission of a disease among a population. Speaking at the International Sanitary Conference in 1881, by which time Germ Theory had been predominantly accepted by the scientific community,

Finlay convinced the audience that this vector was mosquitoes. To prove his theory, Finlay ran several experiments later that year. He oversaw a colony of Aedes aegypti mosquitoes in captivity and exposed them to yellow fever patients. He then exposed those same mosquitoes to volunteers. Most of these volunteers contracted yellow fever shortly after, validating Finlay's hypothesis. Finlay also found that a single inoculation from a mosquito produced a much more mild version of yellow fever, while also providing immunity from future infections of the disease. However, Finlay's vaccine work was largely discredited at the time, and it would not be until after Finlay's death that his achievements would be fully recognized.

Finlay worked as a doctor in the US army during the Spanish-American War in 1898, during which more soldiers died of yellow fever than in battle. To combat this crisis, Finlay called for the extermination of mosquitoes from army facilities. The success of this policy prompted the US Chief of Health in Cuba to apply it through-

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out other areas in Central America, including Panama and the Caribbean. The scope of yellow fever was greatly reduced, and deaths from the disease plummeted. As a result of both mosquito extermination policies and vaccines, today, yellow fever is very rare in the Americas, though unfortunately it still ravages some areas of Africa. Later in Finlay's life, the President of the newly formed Republic of Cuba, Tomás Palma, proclaimed him Minister of Health in 1902, and the Nobel laureate Ronald Ross nominated him for a Nobel Prize in Medicine in 1905. In 1915, he died peacefully in Havana. Carlos Juan Finlay saved countless lives through his daring scientific experimentation and persevered through adversity in discovering the cause of yellow fever, and his legacy lives on today.

# Inhumanity in the Guatemala **Syphilis Experiments**

# Athena Rem



he Guatemala Syphilis Experiments were blatant violations of human rights and a clear crime against humanity. The experiments (1946–1948) involved approximately 5,500 unconsenting and uninformed Guatemalans and infected 1,300 of them with sexually transmitted disease (STD) bacteria in an attempt to test how well a variety of medicines treat common STDs. Specifically, soldiers in World War II (WWII) used penicillin to treat gonorrhea and syphilis, but it was still unclear how well it worked. Not only were these experiments inhumane, but they also did not produce any of the desired results.

The purpose of the Guatemala Syphilis Experiments was to deal with the crisis of the spread of STDs from prostitutes to soldiers during WWII. The use of penicillin grew in popularity to target the symptoms of common STDs, mainly syphilis, among soldiers. Despite this "quick fix," the users actually knew very little about how the drugs work in treating STDs. This curiosity and confusion prompted scientists to research about treatment, including the range of STDs penicillin could treat, whether or not it actually treats the disease rather than just the symptoms, and how effective it is.

John Cutler sought to answer these questions by starting the Guatemala Syphilis Experiments. Cutler was an American scientist who moved the study to Guatemala to avoid stricter ethics laws in the United States. In these experiments, unconsenting subjects contracted STDs in three ways: using a vaccine-like prick with a needle, taking an oral pill, or engaging in sexual activities with prostitutes carrying the STD. After infection, the experimenters tried various medicines to see how the subjects would react to determine the exact role the drugs play in treating STDs. Throughout the entirety of the experiments, out of the 1,300 infected, at least 83 people died and only 700 received treatment. The details of what happened during the experiment and how many people were infected and treated were unknown until after Cutler's death when medical historian Susan Reverby discovered the files in 2010. The lack of publication of the experiments indicates that the experiment failed to answer any of the questions people had about penicillin as an STD treatment.

The reason this inhumanity ran rampant for over half a century was that it was performed privately until Susan Reverby uncovered the story while searching Cutler's files after his death in 2003. She was shocked by what she found, taking note of the failure to get consent and properly explain to the subjects what their participation would entail, including becoming infected. Little happened regarding the experiments until 2010, when the US government openly released the details of the experiment. This prompted President Obama to issue a public apology

for the lack of consent and a pledge to never let any similar event occur in the future. Secretary of State Hillary Clinton called Guatemalan President Álvaro Colom to explain what had actually happened from 1946 to 1948. A few days later President Obama also called to give a personal apology. While the US government was appropriate in acknowledging this grave error, it took no further action.

In 2012, a lawsuit against the government by the survivors of the experiment resulted in dismissal when the court deemed the case more appropriate for other more political branches of the government. Despite this lack of legal acknowledgment, just one day later, the Department of Health and Human Services issued just under \$2 million for Guatemala to work on STD prevention and conducted a study on the ethics of these experiments. In addition, the Commission for the Study of Bioethical Issues published two studies in September 2011, both of which condemned the US for its lack of ethics in the experiments. Guatemala also conducted its own study, which found racism present throughout the study, and thus the Guatemalan government declared the experiments a crime against humanity. Notably, this report also demanded reimbursement for the victims, however, the US government largely ignored this report. There are very few victims left, yet they still have not received treatment, nor have they and their families received financial compensation.

Unfortunately, this was not the only experiment of its kind. The Guatemala Syphilis Experiments were inspired by the Terre Haute study (1943–1944), which also targeted the containment of STDs, specifically gonorrhea, but ended shortly after it began due to the inability to infect the subjects adequately. Cutler played a role in this study too, as well as in the Tuskegee study of 1932-1972, which targeted 600 African American males to see the impact of untreated syphilis. The Tuskegee study ended with the death of all but



la victims were given nothing. Terre Haute, Tuskegee, and the Guatemala Syphilis Experiments show a trend of racism and inhumanity throughout medical history because they targeted and took advantage of people of color. The Guatemalan experiments demonstrate another atrocity, with lessened government action and a lack of any monetary reparations, in addition to the inhumane treatment of people.

Today, laws and government agencies ensure that medical experiments are conducted in a more ethical manner. Clearly, this standard was not the case during the time of the Guatemala

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of these events. Even though there is some media coverage, victims and their families are still without aid and there have been no consequences for those who let the experiments happen. The unchecked racism and inhumanity of the Guatemala Syphilis Experiments cannot be forgotten.



# Interview with Chidi Akusobi '08

# Interviewed by Lauren Ho

hidi Akusobi was born in Nigeria and grew up in The Bronx, NY. He participated in Prep for Prep and graduated from Horace Mann, Class of 2008. He next attended Yale University where he majored in Biology and graduated Phi Beta Kappa. After Yale, Dr. Akusobi was awarded a Gates-Cambridge scholarship to pursue an MPhil in Biochemistry from the University of Cambridge in 2013. Currently, Chidi is a seventh-year MD-PhD student at Harvard Medical School. He completed his PhD in infectious disease in June 2020 and is currently finishing his MD studies. As a future physician-scientist, Chidi hopes to combine clinical practice, teaching, and conducting pioneer*ing research that contributes to the* better treatment of infectious diseases.

Lauren Ho: You have advocated for a variety of issues, especially those dealing with racial equality and diversity in medicine. As a member of WhiteCoat-4BlackLives, you helped organize the WhiteCoat4BlackLives movement on Harvard Medical School's campus to commemorate Eric Garner and Michael

Brown. Why must health professionals confront police violence and institutionalized racism, and how does institutionalized racism manifest itself in hospitals and medical schools? Dr. Chidi Akusobi: The reason why healthcare professionals must be confronted is because people are disproportionately dying from COVID and other health issues that affect black and brown patients. If you go into healthcare in order to alleviate the suffering of all mankind, and you see that one group is disproportionately suffering, not because of any fault of their own, but because of the systems that society has built to put them in situations that make them sicker, then it's up to us to rectify that injustice. As healthcare professionals who care about improving the human condition, this is on us to step up and say, "This is not right." And we have the tools to improve people's lives in this regard. For me, it's a moral issue. When it comes to how it manifests in a hospital, it manifests in a lot of ways; sometimes it's subtle and implicit, where people aren't actively thinking that they will provide someone subpar care, but just because of how they were acculturated,

they take shortcuts, and they're not fully comprehensive in how they're analyzing a patient. Over time, that can lead to disparities. Sometimes the system can also lead people to have these disparities. For instance, a lot of black and brown patients work as essential workers in jobs in which they cannot sit at home and work on their computers, or they live in places where they have lots of family members because it's cheaper. They cannot keep themselves as safe as white-collar workers, for instance. In that case, you're going to be more exposed to the virus. And then if that's the case, you're going to see more infection, and then more death. So that's a systemic issue. Another issue is housing. Many black and brown people live in neighborhoods that are incredibly dense, places that have lots of public housing. So you see these apartment buildings that have 50 families on one floor, which is a very different COVID risk than an apartment building that has four families on one floor, or the suburbs. The pandemic also has affected genders very differently, as women are more likely to be working in essential jobs, like nurses or teachers or

in supermarkets, and thus have been disproportionately affected by the economic impacts of this pandemic. That's not to say that every physician that sees a black or brown patient or sees a female patient is actively being racist, but that they are working in a system that has placed people in situations that are more dangerous, where they're more exposed to the virus. Sometimes, patients also get worse care because of doctors' implicit biases too, such as where doctors may think that black patients are less likely to feel pain. Doctors also can be less likely to understand a patient's symptoms or what they're saying because of a cultural barrier or language barrier. So this is an area of study that is fascinating, but also has real impacts on people's lives. Thankfully, more and more physicians, young students, and trainees are understanding how this interfaces with their care and their decision-making.

### LH: How is race utilized in medicine?

CA: I love that question because it's something you learn in medical school and have to deal with in medicine all the time. So yes, you do consider [race] when there's epidemiological data for it. There are certain diseases that are more prevalent in certain ethnicities than others. For instance, cystic fibrosis is more common in White populations, Kawasaki disease is more common in Asian and Asian American populations, and sickle cell disease is more common in Black and African American populations. There

are genetic diseases that are more prevalent in certain ethnicities than others. So if a white child comes in and has many cases of pneumonia and mucus in their lungs, you're more likely to test for cystic fibrosis than if it was a child from South America. It's important to have epidemiological data when thinking about these diseases. It's also important for doctors to not automatically assume that one symptom plus a certain race equals a certain disease, because this also happens frequently. Doctors miss diagnosing asthma in an Asian child because they think asthma is only a disease you see in Latino and Black populations from urban areas. The repercussions of having such narrow thinking can actually be devastating, which is why it's important for doctors to have epidemiological data. Those are examples that are very concrete and are based on lots of data, but unfortunately, what also happens in medicine is that some race-based information was built on faulty data or built on biases from decades past that now get propagated over time. For example, there's this myth that black patients' kidney filtration rate is somehow different than white patients'. So because of that, the way that drugs are dosed in black populations with kidney disease in comparison to white people with kidney disease is different, even though there are many studies and papers finding that there is no difference in the kidney function of Black people versus White people. So it's important



human beings are far more alike than they are different. To me, it's only the genetic diseases where we know that there are clear associations with ethnicities. Otherwise, it's very important to be open to diseases being part of any population.

LH: You have a leadership role at the Student National Medical Association, which seeks to encourage minority involvement in the medical field. What barriers are currently in place preventing minorities from getting involved in medicine, and what can healthcare and learning institutions do to take down these

CA: This is something that's near and dear to my heart. There's a lot of work that people are doing to increase the amount of Black and brown scientists in America, and many are focusing on getting people into medical school or other professional schools, but by that time you actually miss so many people who dropped out of the pipeline much earlier. So in order to tackle this problem and actually solve it, you have to be thinking about the pipeline from elementary school all the way to college. Some of the barriers that come up include the lack of role models and representation. If you are

a Black or brown child in America, and you think about what it means to be a scientist and who is a scientist, when you look at popular media, there are not a lot of people that look like you, and you can't be what you can't see. The only reason I felt comfortable going down this path is because when I was a freshman in college, my mentor was an older graduate student, a Black man who had an MD and PhD. And it sounds weird to say, but it clicked in my mind that, "Oh, I can be an MD-PhD." That internal belief that you can do something is huge. Another issue is the way the American education system is set up. If you look at where the majority of Black and brown students are getting educated in America, it's mainly in subpar public schools. If you're not as well prepared for college, especially when it comes to science and math, then you're less likely to do science and math in college. And when you get to college, there's a whole host of reasons that people drop out of the pipeline. Colleges are trying to do a better job of providing mentoring services, first-generation services, programs that provide welcoming spaces. Creating spaces where people feel more welcomed is important. Also, it's important to provide resources to make it easier to go into professions like medicine, which require a big upfront investment. For many, taking another job makes more sense financially. Everything from providing fee waivers to people's applications to better loan programs to entice people to go to graduate schools

to also question the data, because

is good. Finally, by the time you get to professional school, schools are now really good at providing mentors and financial resources to retain students. It's a complex issue, but it goes from elementary school and role models, to providing good schooling, all the way up to retaining people in graduate school.

This is Part 2 of a two-part interview with Dr. Akusobi. Part 1, which discussed Akusobi's background as well as his day-to-day life, among other topics, was released in Issue 2.

# HIV/AIDS Activist Gao Yaojie: Still Fighting Injustice in her 90s

# Zahra Motwani

ao Yaojie, previously a gynecologist, is now a famous AIDS activist who works to spread awareness about and treat HIV/ AIDS. Gao first encountered the HIV epidemic in Zhengzhou, China, in the Henan province. She treated a woman who had HIV in 1996, but at the time did not know the patient had HIV. Gao found that the patient had gotten sick from contaminated blood from a blood transfusion during surgery. She also found that the blood the patient had received came from a blood bank that was distributing blood throughout the area, meaning that hundreds of people were getting infected with HIV.

The epidemic was spreading rapidly, and Gao, through her new AIDS program, worked to educate, prevent, and treat AIDS as a 70-year-old. Additionally, she used her own money from her pension to spread awareness. She went to villages with farmers suffering from HIV and gave them medicine and information about AIDS. Many people believed the epidemic in China was spreading exclusively through sexual activity, but Gao convinced the vice premier, Wu Yi, that blood transfusions were an important factor contributing to the spread.

However, her work was unpopular among many government officials who wanted to ignore the epidemic, and her insistence on the truth was also at odds with the profiteering behavior of health officials, contributing to the backlash against her. Liu Guanxi, the head of the Henan Health Department, wanted farmers to sell their blood because the plasma market was expanding. Blood stations without adequate safety measures were opening, spreading HIV through transfusions. Gao was harassed, stalked, and surveilled because she refused to be silent about this public health crisis. She was also placed on house arrest in her home in Zhengzhou on February 1, 2007 so she would not be able to go to the US and accept the Global Leadership Award for her work. Furthermore, her son was impris-

oned for three years for simply being related to her.

After her husband died in 2006, Gao left China in 2009 so she could write her memoir and several other books about the epidemic in China. Now, Gao is retired from medical practice and lives in America. She uses all her award money to buy and donate her books to continue spreading awareness. She has spoken about AIDS publicly and has said that, "As a doctor, I can only treat at most dozens of patients a daybut as an activist of AIDS prevention, every day I can educate at least hundreds of people so as to save even more lives." Gao Yaojie is honored and respected for her continuous activism and nonstop aid towards those in need, even when her work demanded intense personal sacrifice.





Diagnosis

# jao Yaojie

# The Elderly and COVID-19 Vaccines: Prioritized Yet Vulnerable

# Malcolm Furman

en it comes to vaccine appointments, the most vulnerable face the most struggles and barriers. As COVID-19 vaccines roll out, senior citizens across the country are unable to sign up for vaccine appointments because of complicated appointment websites. Not only are these websites hard to navigate, but appointments are reserved within minutes of becoming available. Reserving an appointment on a complicated website can be difficult, if not impossible, for someone unfamiliar with modern-day technology.

Part of the problem stems from underfunded health departments, said Charles Wallace, an associate professor of computer science at Michigan Technological University. Especially in rural areas, health departments have been scrambling to set up working systems to equitably distribute vaccines, with the elderly being a top priority. Wallace says there is a false sense of accomplishment when it comes to these sites. "We can easily lose sight of how thin people's competencies are," Wallace said. "We put everything on the website and can say, great; we're done. While it is a miracle that vaccines are available about one year after the first COVID-19 case in the US, they do no good if the people who need them most don't have access to them."

According to the US Census Bureau, 9.5 million seniors lack internet access. Elderly adults of color are particularly impacted by this, with more than 25% of Black people, 21% of Hispanic people, and 28% of Native Americans over the age of 65 not having access to the internet. This is substantially higher than the 15.5% of white seniors that don't. These figures further show the inequalities that exist in our society that seep into the healthcare system.

For example, one family in Stevens Point, Wisconsin tried to sign up for vaccinations, but unfortunately, faced difficulties. Alan and Vicki Potter are both 73; Alan has a neuromuscular disorder and Vicki has multiple myeloma. Since they don't have a computer or smartphone, they were unable to schedule an appointment through their state's website. "We're old-school. We've got a landline and that's it. It's very frustrating," Alan said.

Cindy Piotrowski, Director of the Aging & Disability Resource Center of Portage County in Wisconsin, said the disparities and ageism that the elderly face is more pronounced now than ever before. Especially in rural areas where internet access can, at times, not be reliable, navigating a website and scheduling an appointment can be close to impossible. In McComb, Mississippi, 71-year-old



Mary Christian made an appointment online; however, the vaccination location is at least an hour away from her home. Mary has diabetes and lives in a rural area where 77.5% of residents are Black and half of the population lives below the poverty line. Unfortunately, in conjunction with her race and location of residence, Mary's age made the travel to her appointment very difficult.

However, some states have implemented other ways for people to schedule appointments. For example, in Vermont, 12,000 of 26,500 appointments for residents age 75 and up have been made through a new phone-call system. In Minnesota, senior citizens who only have a landline and have registered for a vaccine will be randomly selected for an appointment from a vaccination registry, according to the state Department of Health. In Connecticut, the United Way of Connecticut, a charity devoted to the health needs of its state's citizens, set up a vaccine appointment assistance line for those who are unable to use a computer or website. But still, these alternative methods are not flawless; when vaccines first became available, they were getting massive amounts of calls each day.

AARP, a non-profit organization dedicated to caring for those over the age of 50, outlined steps that lawmakers can take to lessen the burden on senior citizens when making appointments for vaccines. They suggest that states make toll-free 800 numbers that are staffed with qualified representatives, to allow people to schedule appointments, and ensure that all customers can find these numbers and where the sites are located. In the letter, they explained that the demand for vaccines far exceeds the supply. During the week of January 4th, more than one million people went on the appointment website, while only 6,000 appointments were scheduled.

In addition to vaccine appointments, the elderly have been having issues scheduling and doing telehealth and online doctor visits. Again, the people who need these health services most during the pandemic are having the hardest time. Those without internet – who tend to be low income and nonwhite – are less likely to schedule and attend virtual doctor visits, leading to



lapses in their healthcare when they need it most. These are the same people who are left out of other services, such as online grocery shopping. Susan Nash of the Stanford Center on Longevity said that this entire population has been left behind as so many parts of society move online.

The need for speed, efficiency, and safety during the pandemic has disproportionately affected the elderly population. Whether it be in vaccine appointments, wellness visits, or general social services, complex websites and ineffective methods of care have unfortunately failed the senior citizens of America. Everyday people, especially those of color, are struggling and need help in the wake of new vaccine rollouts and developments. But still, the advances that have been made in vaccine distribution, such as walk-in vaccination sites, suggest a brighter future for the country.

# The Lack of Diversity in **Genetic Testing: A Cause** for Misdiagnosis

# Sammi Strasser

enetic testing is a medical tool that helps identify whether one is at high risk for a particular disease. By comparing specific mutations or abnormalities in a sick population's genes to a healthy control group, scientists can reveal whether one is likely to develop the disease later in life. It has been found that certain genetic disorders, as well as specific mutations, are more likely to occur among people whose ancestors come from particular geographic areas. Shared genes passed down through certain ethnic groups could contain mutations, resulting in particular genetic disorders appearing more frequently among them. However, it is essential to remember that these disorders can occur in anyone.

So, when it comes to understanding these mutations and disorders, we must consider these questions: does the lack of diversity in medical research cause misdiagnosis of certain minorities? Is there a lack of diversity in medical research in the first place? The answer is yes. Unfortunately, through multiple studies in genetic research, such as analyzing the mutations linked to hypertrophic cardiomyopathy, the experimental groups whose genetic mutations were analyzed have not been diverse enough to get an accurate result. Certain genes linked to race were determined by researchers to be mutations linked to high-risk diseases. Not only has this caused extreme emotional stress, but it has led to people making decisions not to have children in order to avoid passing genetic diseases down, quitting professional sports to avoid health risks, and losing some of the most important parts of their lives, like hobbies or jobs.

The misdiagnosis of hypertrophic cardiomyopathy (HCM) in African American patients, for example, reveals the prejudice in the world of medical testing. HCM is a thickening of the heart wall that causes abnormal rhythms and sometimes sudden death. As constant intensive activity can trigger arrhythmias, HCM is especially dangerous for athletes, leading to a much higher chance of death. Affecting one in 500 people in the United States, the disease is constantly looked out for by doctors and has been linked to over 1,000 genetic mutations. With genetic testing becoming

an increasingly prominent part of early diagnosis, doctors have used genetic testing to identify whether or not family members of those previously diagnosed have the disease. However, the studies done to identify HCM-linked mutations avoided considering race in their trials. Their inability to consider the significance of race in genetic mutations and possible links to disease caused misdiagnosis.

Researchers around the world have conducted studies to help determine the specific mutations that cause HCM. In the studies most prominently used by doctors worldwide, the researchers compared healthy controls to people with diagnosed HCM. The healthy comparison group was almost entirely White, whereas some of the people in the studies with HCM had African ancestry. This resulted in some gene variants being flagged as





linked to the illness when they were actually a result of racial differences between the groups and nothing to do with HCM. Unfortunately, the lack of diversity in these trials caused misdiagnosis in a large population of African Americans. Dr. Isaac Kohane led the study revealing how the identified mutations in African American people that were said to lead to HCM were actually harmless. He explained that the researchers could have avoided the entire problem by adding even four or five African Americans to the control group which was somewhere between 85-100 people (considerably small). However, by not diversifying their control group, doctors today who have yet to be informed about these incorrect genetic links have continued to misdiagnose African American patients with the mutations linked to the disease, causing both emotional and economic distress among families. In the future, it is crucial to ensure all genetic trials not only consider race when evaluating certain genetic conditions and indications, but also encourage diversity during the trial process to guarantee an outcome that focuses on the individual with the condition.

However, this does not mean that race is not a contributing factor to genetic risk. For example, scientists found that race-specific risk scores were more accurate in determining one's risk for prostate cancer when calculating one's genetic risk score

for a certain disease. In previous genome-wide association studies, scientists identified "more than 100 single nucleotide polymorphisms (SNPs-a type of genetic mutation that occurs in a single nucleotide) associated with prostate cancer." However, these studies were primarily conducted with white men. In this case, the knowledge of links to the disease was limited to one specific race, rather than a split between the experimental and control groups like with HCM. Hence, when Chinese males' genetic risk scores were assessed, these mutations were mostly absent. So, doctors would identify them as less likely to develop prostate cancer when they actually had different mutations that could have led to identification of the same problem. Thus, when these scientists compared a genetic risk score calculated in terms of an East-Asian specific encounter with prostate cancer compared to one that did not take race or geological background into account, they found that a race-specific genetic risk score is more accurate than a non-race-specific genetic risk score for assessing one's risk of developing prostate cancer. Calculating a more accurate genetic risk score helps families organize for potential diseases and understand the risks of passing diseases onto their children. Hence, only SNPs that have been previously confirmed in a specific racial group should be used when calculating genetic risk score concern-

ing a specific population of interest.

In this scenario, race needed to be specified and singled out in analysis to uncover mutations linked to the disease. By doing so there was no concern of race-specific genetic mutations causing misdiagnosis. With HCM, those who analyzed the issues with the research found that a more diverse trial would have avoided the glaring error. So, when considering diversity in genetic trials, the specific diseases and mutations can help determine the types of testing that need to be conducted. The population, specifically whether the location the testing is happening in is more diverse or contains a larger population of one race, is also a large contributing factor to the types of trials. It is most important to acknowledge race in each specific scenario whether concerning a diverse group of trial subjects or one specific group of people, and understand how it could and does affect certain disease-causing genes.



# **Clinical Trials**

or decades, men's health was prioritized over women's health by the government, demonstrated through women's exclusion in clinical studies. Since the 1970s, women have been excluded from clinical trials out of fear that the drugs tested could potentially harm any children they would have in the future. This exclusion created biased results that affected the success of the drugs and treatments being tested once they were out on the market. In the 1970s, very few women worked in medicine and science, and women's healthcare needs were not a priority in the medical research fields. In 1977, after clinical studies on thalidomide-a drug that was supposed to be used to cure morning sickness in pregnant women—caused congenital disabilities in the children of women who took those drugs, the FDA

# Dasha Dolgonos

banned women of child-bearing age from participating in early stages of clinical trials. In the 1970s, drugs like thalidomide did not undergo preclinical testing for reproductive toxicology; instead, the FDA believed women should be excluded from those clinical trials. In addition, it was unknown whether drugs affected women differently than men, and this ban furthered the lack of data to discover the similarities and differences in those effects. Thus, since the ban led to a lack of drug testing on women, drugs were only considered effective on men without knowing how the female body would react. In addition to simply not serving their intended purpose, the drugs also had harmful side effects in women that were not noticeable in men.

The exclusion led many women to fight for their rights to participate in clinical studies, such as for

HIV drugs. Women believed that they should have the right to choose whether they wanted to participate in clinical trials and believed it was unethical for the FDA to decide on their behalf. Furthermore, many argued that the ban not only prevented women from participating in the earliest stages of drug testing, it also made it more difficult for a woman to enter the clinical trial at a later stage. Additionally, even though women with life-threatening diseases were exempt from the ban, they were still excluded in most cases and could not find adequate medication for those diseases.

In 1985, the Public Health Service Task Force recommended doing long-term research on how different factors such as behavior and biology affect women's health. A year later, the National Institutes of Health (NIH) started encouraging research-

ers to include women and other minorities in their trials. In 1988, the FDA recommended that researchers specify and examine the effectiveness and safety of drugs especially within minority groups, such as by examining the results by gender, which was outlined in a Non-Disclosure Agreement.

In 1989, the NIH announced that scientists should include all genders and races in their trials, and any exclusions had to be justified due to ethical or scientific reasoning. However, in 1990, the Government Accountability Office investigated the implementation of these new policies and found that women and minorities were still excluded in actual studies. Even when trials included a diverse group, most results were analyzed together instead of by gender, thus rendering it difficult to examine the differences in reactions between males and females. Finally, in 1993, it became law to require the inclusion of women and minorities in clinical trials.

Today, many more women are included in clinical studies, but there are few studies done as to whether women and men are equally included in those trials. There are no databasWomen are more likely to get sev-

es in the United States that include demographics for all clinical trials combined, so it is almost impossible to see how the inclusion of women is implemented today. Although women's exclusion is now prohibited, past involvement in clinical trials still causes them to be left out of studies or force them to participate in smaller amounts. Many diseases affect men and women differently, so only researching the disease in one gender would create a lack of results for treating the other gender, meaning fewer successful cures for women. eral types of cancers such as breast cancer, and women who smoke are more likely to get lung cancer when compared to men who smoke. Women also show different symptoms for some diseases such as cardiovascular disease and sexually transmitted infections. This means that there is no uniform way to diagnose and treat those types of cancers. If testing were to only be done on men, there would be a medication that might suit them and be expected to help cure cancer in women. Still, since women react differently to the disease, the treatment might not work for them, and those women would not receive



adequate care because of the gender bias in clinical trials.

Additionally, women and men respond differently to the same medications, so having a lack of data on the different reactions means it is harder for women to be treated and properly diagnosed. The inclusion of women in non-gender-specific clinical trials would allow for differences in the treatment. Once the data is analyzed and scientists understand the varied reactions women and men have to medications, drugs can be adjusted to fit both genders' needs. Those differences would help provide adequate care for everyone. Today, the FDA Office of Women's Health (OWH) is conducting studies on and advocating for the inclusion of women in clinical trials. Even with the work the OWH is doing, the exclusion of women in clinical trials historically still affects the clinical studies done today and creates unfair advantages, such as greater access to proper medication and treatments for men in the health care system.





# The Revolutionary Life of Mary Putnam Jacobi **Charity Chu**

orn on August 31, 1842, Mary Putnam Jacobi was one of the most premier woman doctors of her era. Growing up in New York, Jacobi's passion for science set her on the timely path to pursue a career in medicine. She studied at the New York College of Pharmacy and the Female Medical College of Pennsylvania, receiving her MD there in 1864 (the college would go on to be known as the Woman's Medical College of Pennsylvania). However, her eagerness to learn would not end there. After briefly working in Boston at the New England Hospital for Women and Children, Jacobi ventured to Paris to further her medical training at the University of Paris. The many clinics, lectures, and classes she attended at the École Pratique (the Practical School of Advanced Studies) at the University of Paris did not satiate her hunger for knowledge. Subsequently, she sought admission into the École de Médecine (the School of Medicine), a venture unheard of, considering that she was a woman. However, throughout her career, Jacobi never let her gender restrain her. She passionately advocated for co-education, believing that women's colleges did not provide the same level of education that established universities could. She later graduated from the École

her.

at the St. Mark's Hospital.

de Médecine in 1871, after her persistent efforts allowed her to receive a secured directive from the minister of education, which forced the school's faculty to admit

In 1871, Jacobi left Paris and returned to New York. There, she used her vast knowledge of medicine to open her own practice and teach at the Woman's Medical College of New York Infirmary for Women and Children. As a lecturer and a professor, she strove to raise educational standards. Through her strenuous journey to achieve something as simple as knowledge, it was made apparent to Jacobi the lack of quality education available to women aiming to pursue a career in medicine. As a result, she organized and led the Association for the Advancement of Medical Education of Women in 1872, which would go on to be known as the Women's Medical Association of New York City. She went on to accomplish numerous achievements in the years to follow, such as opening a children's dispensary service at the Mount Sinai Hospital, lecturing on diseases at the New York Postgraduate Medical School, opening a children's ward at the New York Infirmary, authoring over 100 medical papers, while simultaneously working as a visiting doctor

On June 10th, 1906, at the age of 63, Jacobi died in New York City. With her many contributions to the literary world of medicine, research, and activism, Mary Putnam Jacobi made an incalculable impression in the world of medicine. During a time where it was commonly believed that medical education would make women ill and that there was no place for them in the medical field, Jacobi worked to disprove these falsehoods and create a space for women as physicians.

## MARY PUTNAM JACOBI



Doctor and Suffragette

# **Rising Mortality Rates for** African Americans, Asians, and Hispanics **Diagnosed** with Melanoma Sophie Rukin



elanoma is a form of skin cancer affecting over 200,000 people in the US per year. The cancer forms in melanin-producing, or pigment-producing cells, known as melanocytes, beginning when these melanocyte cells begin to divide and mutate uncontrollably. While melanoma is not the most common form

of skin cancer, it is one of the most fatal, with an average five-year survival rate of anywhere from 99% to 27% depending on the severity. It is unclear what causes melanoma, but sun exposure, an abundance of moles, fair skin, and family history are all risk factors. Consequently, researchers have found that people with darker skin tones have a lower likelihood of contract-

ing this form of cancer. Statistics show that on average, out of 100,000, 18.4 Caucasians, 2.3 Hispanics, 1.6 Native Americans, 1.0 Asians, and 0.8 African Americans contract melanoma in the United States annually. Yet, despite the lower likelihood of people with darker skin contracting melanoma, the mortality rate for African Americans, Hispanics, and Blacks is much higher

than the mortality rate for Caucasians.

According to a study conducted by oncologist Janice N. Cormier of the University of Texas titled "Ethnic Differences Among Patients With Cutaneous Melanoma," where Surveillance, Epidemiology, and End Result (SEER) data was used to study melanoma survival rates, the researchers found that there was a five-year melanoma survival rate of 89.6% in Caucasians with only a 72.2%-81.1% survival rate in other minority groups. Furthermore, the study showed that minority groups have a much higher chance of disease-specific mortality, with a rate of 3.01 times greater risk, compared to the Caucasian rate of 1.96 times greater risk. Cormier additionally found that Hispanics, Native Americans, African Americans, and Asians were more likely to contract stage IV of the cancer, with a likelihood of 3.6%, 3.4%, 4.2%, and 2.4%, respectively. On a stage-specific, risk-adjusted basis, the study revealed that African Americans have a 1.48 higher mortality rate than Caucasians. The higher mortality rate in minority groups can be attributed to many factors, but the most critical factor is a lack of early diagnosis in minorities with melanoma.

According to a study conducted by Isabell Kolm, a German researcher, "early detection is the most important step to improve prognosis." For minority patients, doctors often detect melanoma in the later stages due to a series of hurdles, one of them being that melanoma in darker-skinned patients is often located on parts of the body that do not have regular UV exposure, such as the palms or the soles of feet, making it harder to detect. There are also less frequent skin checks performed on people of color, either independently or by medical professionals, due to a lack of concern, given it is less likely for darker-skinned people to develop melanoma. Another possible factor could be the social determinants of health created by social, economic, and cultural roadblocks. These roadblocks include a lack of education, inadequate healthcare, and lack of melanoma knowledge. These factors all contribute to a delayed diagnosis, which raises the mortality rate by creating a higher risk of metastasis, which is when cancer spreads to other parts of the body, or advanced stages of cancer where it is much harder to treat. It is necessary that information about melanoma becomes more widely available to both medical professionals and the general population so that the disproportionate mortality rate of melanoma in minorities can be lowered.

Along with the diagnosis, melanoma treatment has shown to have a lower success rate in Black patients in comparison to Caucasians and other races. A study focusing on the success of surgery on melanoma patients led by Karen Kadela Collins found that the 10-year survival rate post-surgery was much lower in African Americans than in Caucasians and other races. The survival rate was 88% for Caucasians, 85% for other races, and only 73% for African Americans. Further research discovered that any African American who had a biopsy, wide excision, or surgery was automatically at a higher risk of post-surgery complications than a White person with the same operation. The research on this is not yet conclusive, and there is no



answer as to why this disparity is occurring. Peoples' lack of education on the issues makes it difficult to solve the higher mortality rates of melanoma in minority groups.

As more research is conducted, it is evident that the healthcare system fails minority groups in protecting, detecting, and treating melanoma while favoring non-minority counterparts. While it may not be easy, action must be taken to ensure that the gaps between different races are closed, which begins at the health level, and more specifically, the health care system taking a stand to fix melanoma racial injustice. Researchers are still working, and hopefully, solutions will begin to appear. The primary concern we face is a lack of education, which we must prioritize in creating change. Both medical employees and the US population as a whole need to become more aware of how to both treat and identify Melanoma, regardless of race or ethnicity. Foundations such as the Melanoma Education Foundation are working hard to help spread awareness and knowledge to the people in our country who need it most. It is each and every person's job to help create more equity in the world of melanoma.

# The Underdiagnosis of Mental **Disorders in Women**

# Miller Harris

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**r** t is always important to know the state of your wellbeing, especially when it comes to your mental health. But what if you were not able to receive a proper diagnosis for a mental disorder? You would then not have access to the necessary accommodations or medications that come with a diagnosis. Unfortunately, there is a group of people who are constantly overlooked when it comes to proper diagnoses of mental disorders: women.

Historically, women's mental illnesses have been dismissed as "hysteria," a term used to describe an exclusively female mental disorder caused simply by the fact that the person was a woman. Although hysteria is no longer diagnosed, some doctors still describe some women's behavior as hysterical when they ask for proper medical assistance. In addition, many modern tests that diagnose mental disorders are tailored to men's symptoms, and women may portray different symptoms than men for the same mental disorder, leading to a lack of diagnosis.

The idea of a female-specific men-

tal disorder has been traced back to ancient Egypt in 1900 BCE, and the causes were thought to be abnormal movements of the uterus. The term "hysteria" originates in ancient Greece, where Hippocrates named the illness after the Greek word for uterus because he, and many others, believed that uteruses caused this disorder. These beliefs had been expanded upon until the 20th century, with many scientists adding on their own hypotheses regarding the causes of hysteria and how it could be cured. One of the most famous of these scientists was Sigmund Freud, who hypothesized that hysteria was an illness that could be obtained by both men and women, but it was innately feminine and caused by trauma. He believed that the reason many women had experienced hysteria was because of their trauma from the realization that they did not have a penis and had been castrated, and he thought hysteria could be remedied by getting married and having sex. Although Freud's theory was wildly

misguided, it shifted the view of hysteria from being a physical ailment of a "wandering womb" to being a psychological one. This shift led to many women being misdiagnosed with hysteria instead of other mental disorders. In the mid-20th century, scientists noticed a decrease in diagnosed cases of hysteria by two-thirds, while also observing an increase in anxiety and depression, alluding to the misdiagnosis of hysteria instead of these mental illnesses.

Currently, mental disorders simply go undiagnosed at a higher rate for women than men. Autism is a prime example of a disorder that is under-diagnosed in women due to the fact that women exhibit symptoms of autism differently than men. The difference is so great that many scientists used to believe that autism was not present in women at all, and when it was, it was caused by too much testosterone in the brain. According to Francesca Happé, Director of the Social, Genetic, and Psychiatry Center at King's College, women are better at masking one's symptoms, and they are able to do such things as maintaining eye contact in a conversation, which could be a difficult feat for others. Be-

cause women are able to mask their symptoms better than men, it makes medical professionals less likely to diagnose autism in women.

Recently, a new study of autism in the United Kingdom using a test tailored to women's symptoms was conducted. Since only men were thought to have autism, the tests are tailored to men's symptoms, and because of the difference in how autism displays itself in men and women, women end up being underdiagnosed because the tests do not recognize women's symptoms. This study found that Asperger's Syndrome, a form of autism without intellectual impairments, is present at a ratio of three men to one woman, while the previous ratio was thought to be ten men to one woman, demonstrating the immense underdiagnosis in the past. In addition, autism is also diagnosed at a younger age for boys than girls; a different study found that 25% of boys with autism are diagnosed before the age of six, while only 8% of girls with autism are diagnosed by that age, and 50% of boys with autism are diagnosed before the age of 11, while 20% of girls with autism are diagnosed by the same age. This difference can be attributed to the difference in how boys and girls display symptoms of autism: boys behave more recklessly while girls are more anxious.

Attention Deficit Hyperactivity Disorder (ADHD) is another mental disorder that displays itself differently in women. Similar to how women with autism do not outwardly show their symptoms, women with ADHD often do not show their symptoms externally, but rather internalize their symptoms. Females who have ADHD will experience more inattentiveness, while males with ADHD will experience more impulsiveness and hyperactivity. Also, there is a social difference in how young boys and girls





with ADHD make friends. One study found that young girls ages six to ten with ADHD have more trouble with interpersonal relationships, such as friendships, than young boys of the same age. Also, women are better at masking their ADHD symptoms when compared to men, which can also lead to difficulties diagnosing women.

There is a need to look at patient history when diagnosing women with ADHD since women who have anxiety or depression in conjunction with ADHD can have their ADHD symptoms overlooked and mistaken for their anxiety or depression symptoms, leading to their ADHD being undiagnosed. Similar to the diagnosis of autism, the ratio of men with ADHD to women with ADHD has changed over the past twenty years. In the 1990s, it was believed that ADHD was nine times more common in men than in women. As of 2020, that number has dropped to only 2.5 times more common in men, although there is no evidence that ADHD is becoming more common in women.

Although the diagnoses of mental disorders have been proportionally low for women, there are strides being made in the scientific community to try and fix this. Happé received £500,000 for further research in gender differences on the autism spectrum. With her research, she has been able to create tests to detect autism specifically in women since the tests are tailored to how autism portrays itself in women.

As research continues, more information about how women display symptoms of various mental disorders comes to light. This allows for tests to be altered and new tests to be created, allowing women to receive a fair and equitable diagnosis of mental disorders.

# David Ho



# **David Ho: Contributions to AIDS Research** and Treatment

avid Ho's influential work to improve treatment of HIV/AIDS was massively influential as the devastating HIV/AIDS epidemic wreaked havoc on the US in the late 1900s. David Ho was born on November 3, 1952 in Taiwan. He immigrated to California when he was 12 and grew up in Los Angeles. After graduating from high school, Ho earned his Bachelor of Science in Biology from California Institute of Technology in 1974. Soon after, Ho attended Harvard Medical School and graduated in 1978, receiving his MD Afterward, he trained at UCLA School of Medicine from 1978 to 1982 and Massachusetts General Hospital from 1982 to 1985 and studied internal medicine and infectious diseases.

Ho has been involved in AIDS research for 20 years and is currently the Director of the Aaron Diamond AIDS Research Center at Columbia University. Ho has both created and improved existing HIV/AIDS treatments since the start of the epidemic at the beginning of the 1980s. Human Immunodeficiency Virus (HIV) is a virus that damages one's immune system. The HIV/AIDS epidemic started in 1981 and has cost over 700,000 lives. Also, there are currently 1.1 million people living with the virus. Ho's groundbreaking findings and discoveries have changed the way that people understand and treat HIV and AIDS patients worldwide. Ho's team at the Aaron Diamond AIDS Research Center has unpacked how HIV replicates in patients which has altered the previous understanding of the illness. Because of this discovery, scientists have created a treatment and therapy process which controls the replication of the virus in patients. Ho continues to learn more and research HIV and AIDS in order to one day put an end to the virus. His innovative and groundbreaking findings and treatments earned him Time



Diagnosis

# Bodhi Lavine

Magazine's Man of the Year in 1996 as well as a United States Presidential Medal in 2001.

In late 2019, as the novel coronavirus started to infect people, Ho and the Aaron Diamond AIDS Research Center applied their extensive knowledge of viral diseases in the fight to quickly develop testing methods, treatments, and a vaccine for COVID-19. Ho's team looked into isolating and using antibodies in order to fight the virus.

Through his attempts to find a cure to HIV/AIDS and now adaptation of old research to fit the needs of a global pandemic, Ho exemplifies the spirit of care and selflessness a medical profession holds. Moving forward, we can expect the same care for humanity as demonstrated in the past through his research. We can look forward to his future findings and discoveries that will positively impact society and help people with infectious diseases worldwide.

# Genetic Diseases that **Disproportionately Affect** Ashkenazi Jews

# Emily Salzhauer

ave you ever wondered why some ethnic groups are more likely to get certain diseases than others? For certain genetic diseases, some are more likely to get it because it is quite literally in their DNA.

Some examples include Tay-Sachs disease, Gaucher disease, and Cystic Fibrosis, all of which affect Ashkenazi Jews at higher rates than any other ethnic group. Because all of the following diseases are recessive genetic disorders, a person will get these diseases when both of their parents are carriers. Ashkenazi Jews are Jewish people whose ancestors come from Eastern Europe as opposed to Sephardic Jews whose ancestors come from the Middle East, Southern Europe, and North Africa. While Judaism is a religion, for Ashkenazi Jews it is also an ethnicity because the Jewish population had a set of genetic variations that distinguished them from the other European populations. Some genetic differences include the genetic markers for the previously mentioned diseases at a higher rate than other groups.

Ashkenazi Jews get these diseases at higher rates because, long ago, the mutations were found in the genes of a few Ashkenazi Jews, so as the population grew, their descendants, other Ashkenazi Jews, are at higher risk for getting or carrying these diseases. This idea of passing down diseases between generations is known as the Founder Effect.

Overall, most genetic diseases affect certain ethnic groups more than others, so for Ashkenazi Jews with a familv history of any of these diseases, it is important to be checked to see if you are a carrier as well.

## **TAY-SACHS DISEASE**

Tay-Sachs disease is a rare disorder that leads to dysfunction and destruction of the central nervous system. It is caused when the body has too little of an enzyme used to break down certain fatty substances; these enzymes are called gangliosides. When they accumulate in the brain in large amounts, it can affect the function of some nerve cells.

For the general population, the rate of carriers for the disease is about one in every 250-300 people, but one in 27 Ashkenazi Jews are carriers for the disease. For reference, 25% of children of carriers will have the disease. Tay-Sachs disease treatment controls the symptoms and prepares for the remainder of the disease, but there is no cure.

Some of the symptoms of Tay-Sachs disease are listlessness, loss of motor skills such as speaking, an exaggerated startle response to sudden sounds, and severely diminished muscle tone, also known as hypotonia. Babies with hypotonia are sometimes described as "floppy" as they cannot do the same exercises or movements as others their age. Another symptom of Tay-Sachs is that many children or infants develop

red spots in the middle layers of their eves and a slow loss of vision and hearing. They also may experience muscle stiffness which leads to restricted movements and eventually paralysis. Some other examples of symptoms for Tay Sachs are dementia and seizures. The most common form of Tay-Sachs begins during infancy and usually becomes fatal during early childhood. Juvenile and adult forms of Tay-Sachs also exist, but they are very rare. Children with the juvenile form of Tay-Sachs, also called the subacute form, will develop symptoms later than the infant form, and they live into late childhood or adolescence. Similarly, those with the adult form of Tay-Sachs will develop symptoms at any point between adolescence and their mid-30s. For all of the forms of Tay-Sachs, the type and severity of symptoms can vary from person to person.

### **GAUCHER DISEASE**

Gaucher disease is another disease that disproportionately affects Ashkenazi Jews. In the general population, about one in 450 people are carriers of Gaucher disease, but one in ten Ashkenazi Jews carry the gene that causes the disease.

Gaucher disease is caused by low levels of glucocerebrosidase, also known as GCase, which is an enzyme that breaks down the fatty chemical glucocerebroside. Gaucher disease happens when fat-laden cells, called Gaucher cells, build up in parts of the body like



the spleen, bone marrow, and liver, leading to inflammation and dysfunction of the organ.

There are three different types of Gaucher disease, and they are categorized by whether or not there is early-onset brain involvement.

Type 1 is the most common type of Gaucher disease in the US and Europe. The symptoms of type 1 include enlargement of the spleen, fatigue, and liver and bone problems. It also does not have as many adverse effects on the brain as types 2 and 3 do. Type 1 Gaucher disease is treatable through enzyme replacement therapy and substrate reduction therapy.

Type 2 is a more rare form of Gaucher disease, and it involves severe abnormalities of the brain stem. Unfortunately, type 2 causes severe and irreversible damage to the brain, and therefore is usually fatal in the first two vears.

Type 3 of Gaucher disease is rare in the US and Europe, but it is the most common form in other parts of the world. Type 3 is not as severe as type 2, but is more severe than type 1. It has the same symptoms as type 1 with some of the neurological problems associated with type 2. Patients with type 3 have a shortened lifespan, but many can live into their 50s with proper treatment.

Cystic Fibrosis (CF) is a genetic disorder that progresses over a patient's lifetime and leads to lung infection and difficulty breathing. It also affects Ashkenazi Jews at a higher rate than any other ethnicity; about one in 31 people in the US are carriers for the disease, while one in 24 Ashkenazi Jews are carriers for CF.

People with CF have a mutation on the cystic fibrosis transmembrane conductance regulator, also called the CFTR gene, which leads to the CFTR protein not functioning as it should. When the protein is dysfunctional, it is unable to move chloride, an ingredient in salt, to the surface of the cell. So without the chloride to bring water to the cell's surface, a thick and sticky mucus forms in many organs.

When the lungs are affected by CF, the thick mucus gets stuck in the airways and can trap germs and bacteria, which leads to infections, inflammation, and eventually respiratory failure. For this reason, limiting exposure to germs is a top priority for patients with CF.

CF symptoms include salty-tasting skin, wheezing, persistent coughing with and without phlegm, frequent lung infections like bronchitis and pneumonia, and poor growth or weight gain despite healthy diets. Because CF is a complicated disease, the

### **CYSTIC FIBROSIS**

type and severity of the symptoms vary from person to person. Also, there are many factors, including age of diagnosis, that will affect the course of the disease and a patient's health.

Treatment plans for most CF patients mostly consist of the same therapies, but critical care teams tailor each plan to best fit their patients' circumstances as well as life and health goals. For example, teens with CF are able to do treatments that do not involve being hooked up to a machine at the hospital so they can attend school and extracurriculars like their peers.

Patients with CF may complete a combination of therapies each day, including airway clearance, inhaled medicines, antibiotics, multivitamins, pancreatic enzyme supplements, CFTR modulators, and special fitness plans. The treatments for CF are very successful and can add years to a patient's life as well as greatly improve their quality of life. In the 1950s, for example, a child diagnosed with CF would rarely live long enough to go to elementary school, but now, thanks to the modern technology and intense treatment that patients undergo, CF patients can live long enough to go to college, have a career, get married and even have children.

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