



All pieces in this collection are compelled to bring a sense of humanity back to biomedical research. Heavily referencing the Tuskegee Syphilis Study, each piece has been carefully crafted to promote a conversation about discriminatory design within the medical field. All materials were sourced from small, family owned farms and mills, bringing a direct connection to the conception of each piece.





Often recognized in modern bioethics as a symbol to abide by, “sankofa” is derived from three words that can be traced back to the Akan tribe in Ghana. The word literally translates to “it is not taboo to fetch what is at risk of being left behind” and is represented by a bird with its feet firmly planted forward and head arching back. For Akan, the bird symbolized the importance of planning for the future, however the Tuskegee Bioethics Center utilizes the bird as a recognition for the troubled past of discriminatory science within the research field. While the United States has had a particularly long and excruciating history of discrimination and racism, it can not only be seen in the physical and verbal abuse those of color have experienced. Through the study of past medical research, one can notice the Caucasian bias many of the research plans took. The study of the past is an important factor in developments of the future, as the world cannot look past the discrimination of history without formally recognizing it. As technology is advancing at an alarmingly rapid rate, researchers must consider their role in the discrimination of others and how certain decisions can negatively impact communities.

In 1932, a scientific study was administered to 623 African American men participated in Tuskegee Study of Untreated Syphilis in the Negro Male held by the United States Public Health services, in the Tuskegee and Macon County, Alabama. Researchers were hoping to study the development of syphilis in the African-American male in order to find a remedy for the greater population. At the start of the trial, there was no known cure for syphilis. However, researchers simply told participants that they were being treated for “bad blood” which was identified as several ailments, including anemia, fatigue and syphilis. When penicillin became available as a cure for syphilis, between 1932-1947 dozens of participants and family members died because of the untold rules of the study. Without proper information on their medical conditions, the men participating in the trial were left with a questionable situation of ethics. On July 25, 1972 Jean Heller of the Associated Press broke the news of the 40 year syphilis study that jeopardized minority lives. This set into motion a series of actions initiated by U.S. federal agencies. “While the panel concluded that the men participated in the study freely, agreeing to the examinations and treatments, there was evidence that scientific research protocol routinely applied to human subjects was either ignored or deeply flawed to ensure the safety and well-being of the men involved.”¹ In October of 1972, the panel concluded that the study was “ethically unjustified” and declared the end of the study. One year later, a class-action lawsuit is filed on behalf of the men in the study, their wives, children, and families. Part of the suit settlement promised that the U.S. government would provide a range of free services to the survivors of the study and their families. In 1997 President Clinton issued an official apology to the families of men involved in the Tuskegee Syphilis Study, followed by the opening the Tuskegee University National Center for Bioethics in Research and Health Care in 1999.²

¹ Riggins R. Earl Jr, PhD, “Sankofan Socio-Ethical Reflections: The Tuskegee University National Bioethics Center’s Decade of Operation, 1999-2009,” *Journal of Health Care for the Poor and Underserved* 21, no. 3 (08, 2010): 6-20.

² Riggins R. Earl Jr, PhD

Following its inception the organization quickly coined their symbol “Sankofa” and outlined their envisioned objectives for the foundation:

- 1) To promote racial and ethnic diversity in the field of bioethics and in public debates about bioethical issues.
- 2) To conduct research and publish scholarship on bioethics and underserved populations.¹

This establishment of principles led the need for multiple fields to join together. “The looking back dimension, critical reflection on the past, of the Sankofan principle requires that social ethicists be dialogical partners with bioethicist.”² The Tuskegee Syphilis Study not only inspired the dialogue about the discriminatory design of medical practices, but also involved social factors that affect can affect the functioning of a community.

The Tuskegee Syphilis Study exemplifies a long and gruesome journey to bioethical science, however this was not the only occurrence of discriminatory practices within the field of medical research. Simultaneous to the events in Tuskegee, Henrietta Lacks arrives and eventually passes away at the Johns Hopkins Hospital in 1951. According to medical records, Mrs. Lacks was undergoing radium treatments for her cervical cancer. A researcher at the hospital, Dr. George Grey, had been researching cells collected from patients with cervical cancer, however all the samples seemed to die rapidly in his lab. Upon receiving cells from Henrietta Lacks, Dr. Grey noticed that her cells were largely resilient and doubled every 20 to 24 hours. These cells would later become known as the infamous “HeLa” cells, named after the first two letters of her first and last names. Over the years her cells were used to study the effects of toxins, drugs, hormones, and viruses on the growth of cancer cells. Her cells also played a crucial role in the development of the polio vaccine.³ While Henrietta ended up passing away on August 8, 1951, leaving her cells to live forever. In the following years of her death, HeLa cells had been part of essential research and played roles in thousands of patents. It was not until the 1970’s that descendants and relatives of the Lacks family learned about the globalization of Henrietta’s cells. The realization of the profit generated by their mother’s cells reasonably upset the Lacks family, and they took action to protect their mother’s cells from further distribution. Today, the use of HeLa cells is still present, however it is a much more rigorous and expensive process to obtain access to these prized cells.⁴

It is interesting to note that both the Tuskegee Syphilis Study and the Henrietta Lacks case occurred within the same time period as the birth of the eugenics movement during World War II in Germany. Eugenics, the set of beliefs and practices that aim at improving the genetic quality of the human population, previously found itself rooted in America. In 1907, Indiana passed the first eugenics-based compulsory sterilization law in the world, forcing people to undergo sterilization for the sake of improving the American genetic traits. The ties between eugenics and racism coursed through the medical community, and simultaneously taught the public to think lesser of someone who does not exemplify the “ideal American.” Following the American eugenics movement, World War II Nazi Germany was heavily influenced by the ideals of famous eugenicists in America.⁵

These movements held strong feelings towards racism in America and Germany, outlining an ideal genetic appeal, and being seen as unworthy if a child’s genetics did not match these ideals. This prejudice grew to be second nature, representing those of minorities as objects not human beings. Reflecting back on the period of slavery in America, scientists sought out African American bodies to dissect and learn from because doctor’s viewed African Americans as non-human.¹ Both the eugenics movement and the cases concerning bioethics stemmed from societal class systems that viewed certain people to be superior to others.

While eugenics is not a major movement in the present day, there still exists a certain bias towards upper classes within medical research. Not only can the effects of cases like the Tuskegee Syphilis Study and Henrietta Lacks be seen in these marginalized communities, but as science progresses rapidly, it begs the question as to who will reap the benefits from these advancements. Recently, the use of CRISPR technology has been used in terms of genetic modification within human babies and fetuses. This new use of genetic engineering allows parents to predict and change certain traits within their children. It is argued to be a positive development for the medical community, preventing illnesses and diseases that could be life changing for future children. However, how far can this technology go? In November of 2018, Dr. He Jianku, a Chinese scientist, announced that he had successfully used CRISPR technology to engineer embryos and implant them within a mother.² Following this announcement to the world “scientists and ethicists condemned the experiment as unethical and unsafe, fearing that it could inspire rogue or frivolous attempts to create permanent genetic changes using unproven and unregulated methods.”³ Not only was this practice unethical, but the speculation of where this technology could take the human race concerned many.

CRISPR technology had been used to modify crops previously, however the ethics and possibilities of use on human embryos brought many arguments in terms of the future of the human race and the world as it stands. On January 30, 2018, months ahead of Dr. He Jianku’s Earth-shattering announcement, Victor Tangermann published an article for the online journal Futurism. The piece was simply titled, “A CRISPR Future: Five Ways Gene Editing Will Transform Our World.” A rather hopeful title, the article began to list the multitude of ways CRISPR might be able to help the global population, concluding its tagline with “What can’t CRISPR do?” Highlighting the research of the Oregon Health and Science University in 2017, Tangermann expanded on embryonic genetic corrections to possibly eradicate hypertrophic cardiomyopathy.⁴ While the success of this study may seem to be a positive expansion of the medical field, one must note the ability to apply this technology to other genetic traits. The term “designer babies” is one that has been used recently in terms of gene editing at the embryonic stage. Many believe this technology could give humans the ability to “play god” in terms of evolution and natural selection, bringing to light social inequalities that stem from economic imbalance. The implications of interfering on such terms questions the human involvement in the natural world, and the authority man believes to hold over nature as a whole.

1 Riggins R. Earl Jr, PhD.

2 Riggins R. Earl Jr, PhD.

3 DeNeen L. Brown, “Can the ‘Immortal Cells’ of Henrietta Lacks Sue for Their Own Rights?” The Washington Post, June 25, 2018, Accessed May 05, 2019. https://www.washingtonpost.com/news/retropolis/wp/2018/06/25/can-the-immortal-cells-of-henrietta-lacks-sue-for-their-own-rights/?utm_term=.f9b9dd016f68.

4 DeNeen L. Brown

5 Robert A. Wilson, *The Eugenic Mind Project*, Cambridge, MA: MIT Press, 2018.

1 Robert A. Wilson

2 Pam Belluck, “Gene-Edited Babies: What a Chinese Scientist Told an American Mentor,” The New York Times, April 14, 2019, Accessed May 05, 2019, <https://www.nytimes.com/2019/04/14/health/gene-editing-babies.html>.

3 Pam Belluck

4 Victor Tangermann, “A CRISPR Future: Five Ways Gene Editing Will Transform Our World,” Futurism, January 09, 2019, Accessed May 05, 2019, <https://futurism.com/crispr-genetic-engineering-change-world>.

Lorraine Daston's *The Moral Authority of Nature* outlines the involvement of man on the natural world, zooming in deeper to human interaction in Londa Schiebinger's piece "Human Experimentation in the Eighteenth Century: Natural Boundaries and Valid Testing." Previous to the boom of slavery within the New World, there had been a consensus within physicians that there was a "certain unity of humanity, an interchangeability of bodies."¹ As the slave trade started to boom there began to be a shift in the perception of skin color between the thirteenth and sixteenth centuries. By the eighteenth century, there had been a shifted ideology that skin color implied that certain bodies did not properly represent humankind. This brought an influx of grave robbers, targeting slave graves in order to attain bodies to experiment on. Some physicians even went as far as killing slaves for the sake of experimentation. However, this discrimination within the medical field extended beyond the physicality of skin tone. "William Withering, known for developing digitalis, discussed openly the practice of using the poor to test dosages of his new cure before prescribing it for his paying patients."² The interest in using the impoverished for experimentation did not lie in any differences within their bodies, but their availability. Withering believed he was equally compensating those who participated in his experimentation, by offering them one hour of his free medical advice per day. However, while these patients were receiving medical attention, Withering would often abstain from prescribing relief to these patients until he was able to obtain personal gain from these experimentations.

The Tuskegee Syphilis Study, while almost two centuries after Withering, contained many similarities to Withering's ideology. The men participating in this trial were not fully informed of the extents of the study, and were simply told they were being treated for illness. As uniformed participants the Tuskegee men were being taken advantage of on a biological level. Unaware of their possession of the syphilis virus, the virus began to spread throughout their families and their communities. It was not until 1943, that penicillin was discovered as the cure for syphilis, yet the unaware men participating in the trial, were not granted this cure, as researchers wanted to continue to pursue their study. For years the United States Public Health Services, chose to perform the same type of "charity research" that Withering justified during his studies. They believed that they were giving an equal exchange to these men and their families, by giving them the ability to visit hospitals and obtain medical services, yet there was still knowledge that was being withheld from them, simply because of their economic status. This lack of transparency has permeated the medical industry from the era of slave trade, up to the modern day. As researchers begin to progress further and further within medicine and technology, there is much to be questioned behind their research methods.

While much of scientific research seems to be done to benefit the general good of society, much of this research often contains underlying bias. Whether that is by individual background or research funding, the inherent bias of the human being is almost always present in research developments. Three specific case studies exemplify these biases: Crye Precision, a private sector company that makes military uniforms and gear, Ronald Koder, a biophysicist at City College of New York City working on the synthesis of artificial blood, and finally Final Frontier Design, a private sector design firm contract to make space suit components.

¹ Lorraine Daston, *The Moral Authority of Nature*, Chicago: University of Chicago Press, 2010.

² Lorraine Daston

Crye Precision is a design firm based in the Brooklyn Navy Yard in New York City. Upon entering their facility, one can get a sense at the size of their operation. Having recently moved into a former boat repair building, the entire warehouse-type space has been gutted and filled with state of the art technology. The entryway is filled with a small forest of trees, sprouting from a rugged path of gravel. Moving past this luscious entrance are rows and rows of inventory, each bin containing a particular clothing or accessory piece Crye Precision has designed specifically for the military. The company's claim to fame is stated clearly on the about page of their website: "Crye Precision designs and manufactures truly innovative equipment for America's fighting forces."¹ Crye Precision claims that their efforts and research go directly towards America's military, yet upon my visit to their facility, I witnessed many other developments. While there is a true Americana feeling to the concealed carry clothing that they are developing, and the specific camouflage the company has coined, I found myself walking among a display for a design pitch for the United Arab Emirates. Since the United States government does not directly produce their military supplies directly under government license, they outsource to Crye Precision. The Brooklyn based company operates as a private sector design firm, contracting work wherever necessary. Much of their funding does come from the United States Government, however their research and finding does not belong directly to the United States. The developments of the company are open to the customer willing to pay the higher price, making developments in military technology accessible to just about any country. While it is produced and researched on United States soil, Crye Precision has the ability to contract to any country.

Ronald Koder is a PhD recipient in biophysics from the Johns Hopkins University, who's work follows a similar storyline to that of Crye Precision. On February 25, 2019, Ronald spoke at the Theresa Lang Community and Student Center, educating a group of biodesign students on the mechanisms of biosynthetic modification as well as his work in biosynthesis. As a postdoctoral fellow in biophysics at the University of Pennsylvania School of Medicine, he worked on the design and optimization of artificial oxygen transport proteins. He furthered this research recently, designing solar biofuels, enzymatic chemotherapies, and artificial blood. During his discussion in February, Ronald emphasized the reason he entered into the field of synthetic biology. His inherent goal within the industry was, and still is, to positively impact the human race through his scientific research and developments. However, upon a magnified look to his career within the field, the bias held in much of his research is weighted. For example, his research to develop artificial blood could be beneficial to the medical field as a whole, but the primary funding for this project comes from the United States Department of Defense. Their main goal with this research is to be able to keep soldiers out on the field longer after being injured. Ronald's research promotes thoughts that patients suffering from illnesses all over the world could be given a new lease on life, but the initial bias is from a military point of view.

these suits is rarely done for those of different ethnicities, weights, builds, and heights, leaving a gap in knowledge for this demographic.

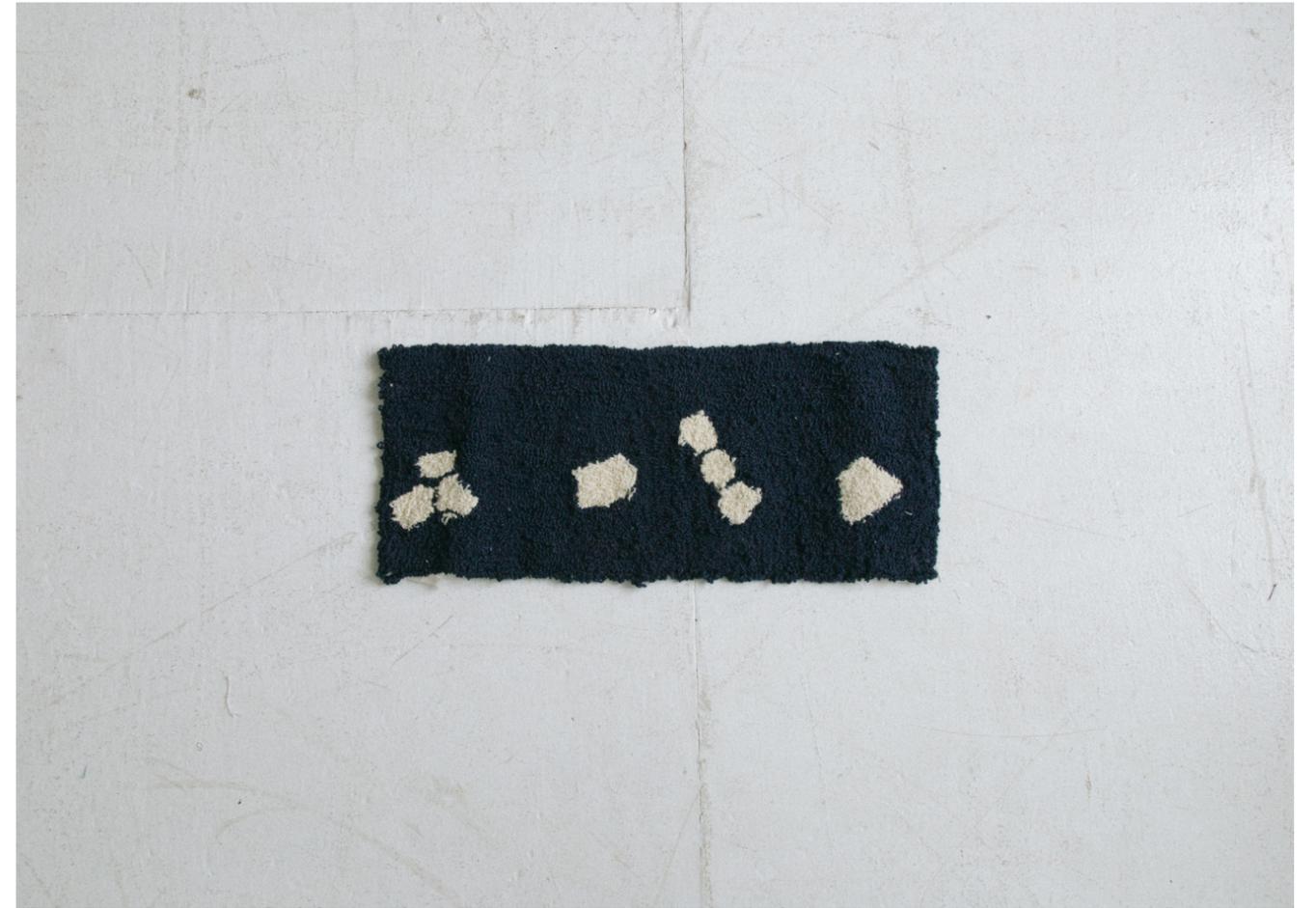
¹ "About." Crye Precision. Accessed March 31, 2019. <https://www.cryeprecision.com/About>.

Funding for research is often very difficult to acquire, so it makes sense that limited research can be performed with limited funding. However, assuming that all scientific research should be taken as unbiased fact is often incorrect. There is often a subliminal motive within the roots of a research plan, and as spectators from outside of the industry, we must constantly be questioning the motives of the scientists we put much of our trust into. Sankofan ethics suggest gazing upon past tragedies, such as the Tuskegee Syphilis Study and Henrietta Lacks, to question how the system can be formatted to create a more just and equal society for all humans and animals to live in. When designing, whether that be in medical research or within the art world, we must always investigate the implications of each decision within the process and how it can affect those that surround the situation.





Algorithmic Patterning derived from Tuskegee Syphilis Study statistics. Rug tufted using regionally sourced yarn.



Manipulated tonal studies of "Freedom" by Richie Havens, a piece referenced in "Freedom: The Never Ending Struggle
Reflections on the Keynote Address of Dr. Lucius Outlaw,
'Evolving Spheres of Ethics'" by Edward Francis Gabriele, MDiv, DMin. Rug tufted using regionally sourced yarn.









Creative Direction
Christina Wong

Aparrel
Christina Wong

Photography
Leoder Sanchez

Model
Josue Caraballo

C. Wong

@CHRISTINAWHITNEYWONG