

# **ByteBlood: The DNA Privacy and Biotech Scandal**

*Thomas Jefferson Model United Nations Conference*

TechMUN XXXII



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High School Double Delegate Crisis Committee

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Committee Director: Dilnaaz Talwar

Thomas Jefferson High School for Science and Technology

April 11th-12th, 2025

Esteemed Delegates,

Welcome to the ByteBlood: The DNA Privacy and Biotech Scandal committee at TechMUN XXVI. It is our pleasure to be your co-chairs and director for this crisis committee! As crisis delegates ourselves, we have experienced the stress and craziness, but learned to love it with all our hearts.

With regards to this committee, we want it to be an enjoyable experience for everyone.

We will be looking for delegates who bring unique, new ideas to the table and understand the importance of being a diplomatic delegate. We are very excited to hear your debates and discussions about the two pressing issues we face related to privacy and DNA using your particular stance to back up your opinions and solutions.

In regards to the types of delegates we're looking for, we want individuals who can bring creativity to the table and make a real impact, both in their speeches and behind the scenes in the backroom. Leadership matters, but we're more interested in leaders who can inspire collaboration and bring fresh ideas. This conference is your chance to think outside the box and come up with innovative directives that can shape the direction of the committee. Don't be afraid to take calculated risks and explore new approaches. Lastly, no forms of harassment, bullying, or plagiarism will be tolerated.

All in all, as your co-chairs and director, we hope to make the committee exciting and something memorable to always hold onto. We are beyond ecstatic to meet you in April! If you have any questions don't hesitate to contact us at [bytebloodtechmun2025@gmail.com](mailto:bytebloodtechmun2025@gmail.com).

Best regards,

**Dilnaaz Talwar, Rishika Singh, and Akul Dixit**

ByteBlood: The DNA Privacy and Biotech Scandal

## **Topic 1: DNA Black Markets: The Rise of Genetic Trafficking**

### ***Background:***

In the modern era of genetic advancements, DNA has become an invaluable commodity.

While legal genetic research has led to breakthroughs in medicine, forensic science, and ancestry tracing, a darker market has emerged beneath the surface—one that thrives on the illegal trade of genetic material. The rise of genetic trafficking, or DNA black markets, is an alarming phenomenon where biological samples, including blood, saliva, and even entire genomes, are bought and sold without proper consent or oversight.

These black markets operate in various ways. Some involve the theft of genetic material from medical institutions and biobanks, where DNA samples are collected for research but later misused. Others involve the illegal acquisition of high-profile individuals' genetic data for exploitation, including unauthorized cloning attempts, medical fraud, or targeted bioweapon development. In some cases, individuals in vulnerable populations, such as indigenous communities or impoverished groups, are coerced or tricked into providing their DNA for commercial gain. This unregulated trade raises ethical, legal, and security concerns, as it poses risks to personal privacy, public health, and global biosecurity.

### ***Current Situation:***

The market for genetic material has grown alongside advancements in genomic sequencing and biotechnology. Direct-to-consumer DNA testing companies, such as 23andMe and AncestryDNA, have normalized the collection and storage of genetic data, yet concerns about privacy persist. The recent surge in cybercrime has made it easier for hackers to steal genetic information, creating a lucrative underground economy where DNA is sold for research,

medical fraud, or even corporate espionage. Additionally, high-profile legal cases have emerged where individuals discovered their genetic material had been used without consent for drug development or forensic investigations.

The international community has struggled to regulate this growing crisis. While some nations have stringent genetic privacy laws, others lack clear legislation, allowing traffickers to exploit loopholes. Organizations such as the World Health Organization and the United Nations have begun discussing potential global frameworks, but enforcement remains a challenge. As DNA becomes an increasingly valuable resource, black market operations continue to evolve, forcing policymakers to address the legal and ethical dilemmas surrounding the commodification of human genetics.

### ***Possible Solutions:***

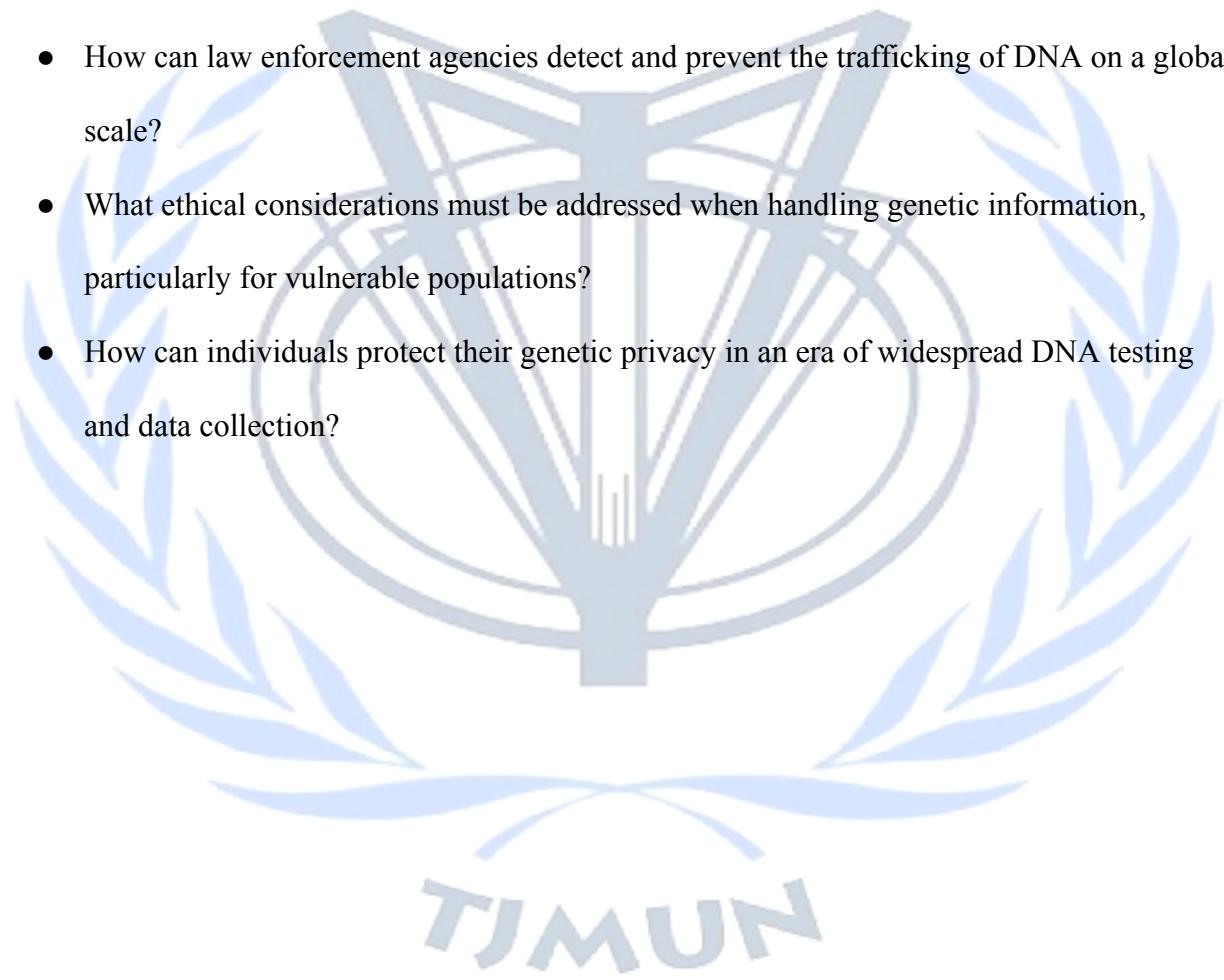
Combating the rise of DNA black markets requires a multi-faceted approach that includes legal, technological, and ethical considerations. One potential strategy involves strengthening global regulations surrounding genetic data collection and storage, ensuring that DNA samples are not misused or sold without consent. Implementing stricter cybersecurity measures within DNA testing companies and biobanks can also prevent unauthorized access to genetic data.

On a broader scale, international cooperation is essential to combat the illegal trade of genetic material. Countries must work together to establish a unified legal framework that criminalizes genetic trafficking and enforces penalties against offenders. Additionally, raising public awareness about the risks associated with sharing genetic information can help individuals make informed decisions about their DNA data. Finally, investing in ethical genetic research and

responsible data-sharing practices can ensure that the benefits of genomics are not overshadowed by exploitation and illicit activities.

***Questions to Consider:***

- What legal frameworks should be established to regulate the use and trade of genetic material?
- How can law enforcement agencies detect and prevent the trafficking of DNA on a global scale?
- What ethical considerations must be addressed when handling genetic information, particularly for vulnerable populations?
- How can individuals protect their genetic privacy in an era of widespread DNA testing and data collection?



## **Topic 2: The Billionaire Gene: Should DNA Be Patentable?**

### ***Background:***

As biotechnology advances, the question of DNA patentability has become one of the most controversial debates in science, law, and ethics. The ability to sequence and manipulate genes has led to groundbreaking medical treatments, but it has also sparked corporate battles over the ownership of genetic material. Historically, biotechnology companies have sought patents on specific genes associated with diseases, such as the BRCA1 and BRCA2 genes linked to breast cancer. By securing patents, these companies gain exclusive rights to research, develop, and commercialize treatments based on these genetic discoveries.

Proponents of DNA patenting argue that granting intellectual property rights incentivizes research and innovation. Without the promise of financial return, many companies may lack the motivation to invest in expensive genetic research. Patents also allow for structured commercialization, ensuring that new treatments are developed under regulated conditions. However, critics argue that patenting genetic material restricts access to life-saving treatments and creates monopolies over natural biological components. When companies hold exclusive rights to specific genes, they can control who can research, test, or develop therapies related to those genes, ultimately raising ethical concerns about the privatization of human biology.

### ***Current Situation:***

The debate over DNA patenting has led to significant legal battles worldwide. In 2013, the U.S. Supreme Court ruled in *Association for Molecular Pathology v. Myriad Genetics* that naturally occurring human genes cannot be patented. The decision marked a turning point,

preventing companies from owning exclusive rights to genetic sequences. However, the ruling still allows for the patenting of synthetically modified genes or DNA sequences altered in a laboratory.

Despite legal restrictions, biotech companies continue to seek innovative ways to secure intellectual property over genetic discoveries. Some firms have shifted their focus to patenting methods of using genetic information, such as diagnostic tests and gene-editing techniques like CRISPR. This shift has reignited ethical debates, as many fear that allowing patents on genetic manipulation technologies could lead to further commercialization of human DNA. Additionally, disparities in global patent laws have created inconsistencies, where some countries still allow patents on naturally occurring genes, creating potential loopholes for corporate exploitation.

### ***Possible Solutions:***

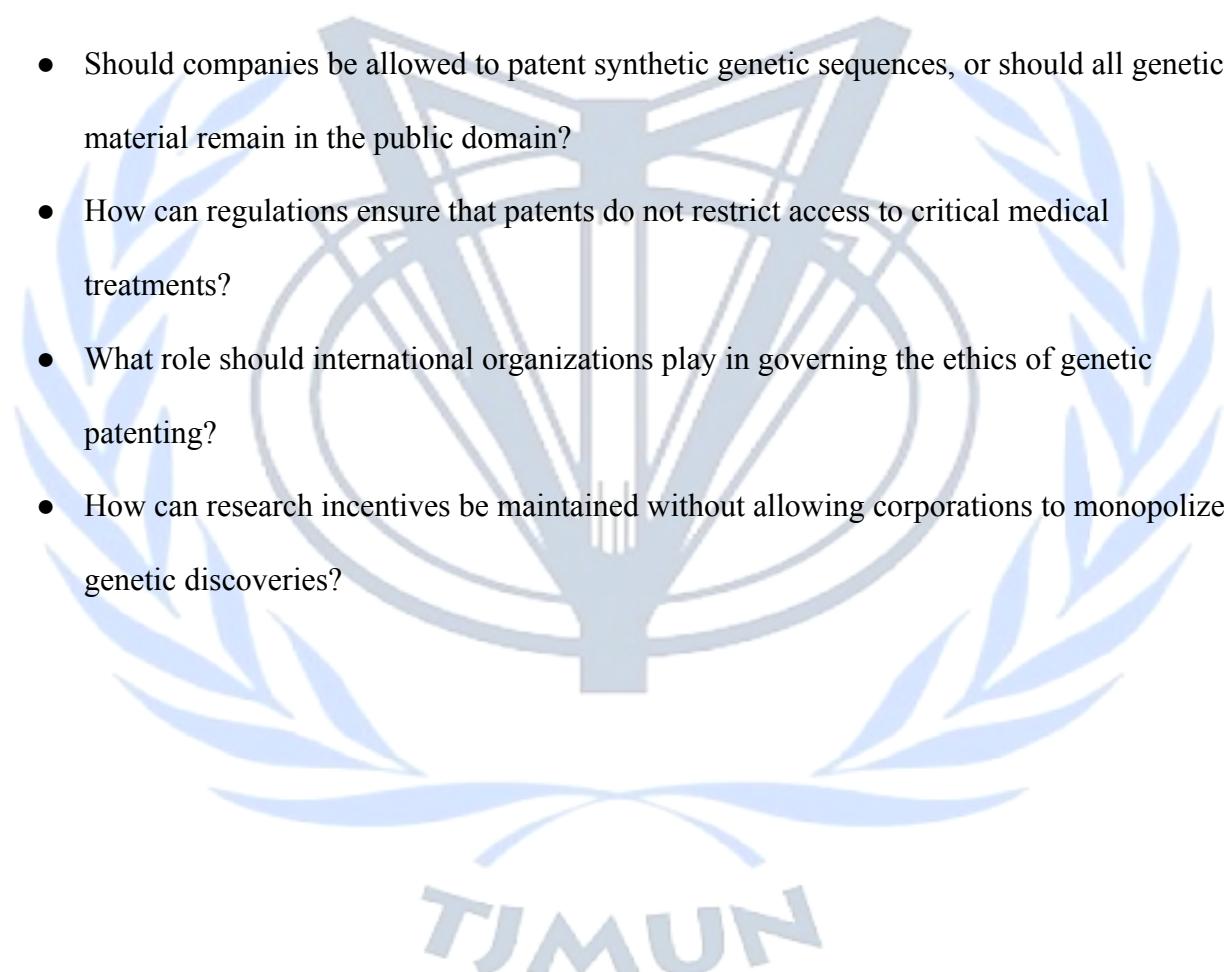
The question of whether DNA should be patentable requires balancing scientific progress with ethical responsibility. One approach is to establish clearer international guidelines that prevent monopolization while still encouraging innovation. Governments could enforce stricter regulations that differentiate between naturally occurring genetic sequences and genuinely novel, synthetic genetic developments.

Another solution involves promoting open-source genetic research, where discoveries are shared within the scientific community rather than controlled by private entities. Publicly funded research initiatives could help reduce corporate dominance in genetic science while ensuring broader access to medical advancements. Additionally, strengthening ethical review boards and oversight committees can prevent the misuse of genetic patents and ensure that research aligns with humanitarian goals.

Ultimately, the resolution of this issue will shape the future of medicine, genetics, and biotechnology. Whether DNA remains a shared human resource or becomes an exclusive corporate asset will depend on how policymakers, scientists, and the public navigate the complex intersection of ethics, law, and innovation.

***Questions to Consider:***

- Should companies be allowed to patent synthetic genetic sequences, or should all genetic material remain in the public domain?
- How can regulations ensure that patents do not restrict access to critical medical treatments?
- What role should international organizations play in governing the ethics of genetic patenting?
- How can research incentives be maintained without allowing corporations to monopolize genetic discoveries?

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## **23andMe**

23andMe is a direct-to-consumer genetic testing company that allows customers to learn about their ancestry and health risks based on their DNA. The company was at the center of a massive data breach in 2023, exposing sensitive genetic and personal data of millions of users. The breach raised significant concerns about data privacy and the security of genetic information in the biotech industry. The scandal has led to lawsuits, public backlash, and regulatory scrutiny.

## **AncestryDNA**

AncestryDNA is a key competitor to 23andMe in the genetic testing industry, offering services to trace ancestry and genetic health risks. Although it hasn't faced a breach as significant as 23andMe's, it shares similar concerns over data privacy. As the company collects vast amounts of personal genetic information, it has come under scrutiny regarding how it handles, stores, and shares genetic data with third parties, including law enforcement. The 23andMe breach has sparked further concerns about the security of AncestryDNA's practices.

## **MyHeritage**

MyHeritage provides genetic testing services for genealogy research and family connections, similar to 23andMe. The company suffered a data breach in 2018, compromising user information, though it did not include genetic data at that time. Despite this, it has contributed to the growing debate over the risks of storing genetic data online. With the rise in DNA testing, MyHeritage is increasingly under pressure to implement robust data protection measures.

## **Illumina**

Illumina is a leading biotechnology company specializing in genetic sequencing technology, which is widely used by consumer genetic testing companies like 23andMe and AncestryDNA. Although Illumina doesn't directly handle consumer data, its technology is integral to the industry. The 23andMe scandal raised questions about whether companies like Illumina are doing enough to ensure the security of genetic data that passes through their systems. The company's involvement in the genetic testing ecosystem makes it a key player in discussions about data protection and security.

## **CNN (Cable News Network)**

CNN is a major news outlet that has been covering the 23andMe scandal extensively, providing a platform for experts, consumer advocacy groups, and legal professionals to discuss the implications of the data breach. As a global news organization, CNN plays a critical role in shaping public awareness of the risks involved in genetic data privacy. Their reporting on issues such as government surveillance, corporate responsibility, and consumer rights has made them a major influence in the discourse around DNA privacy. CNN's coverage is instrumental in holding both biotech companies and regulators accountable.

## **Guardant Health**

Guardant Health is a company focused on developing blood-based diagnostic tests using next-generation sequencing (NGS) technology to detect cancer. As a leader in genomic testing, Guardant Health has seen increased scrutiny regarding data privacy and the potential for sensitive genetic information to be misused. While not a direct competitor to 23andMe, it operates in the broader genomics space, contributing to discussions on how genetic data should be protected in the biotech sector.

## **Helix**

Helix is a personal genomics company that provides DNA testing services for health and wellness. It partners with other companies to offer genetic insights but has faced criticisms about its data-sharing practices and the potential for data misuse. The company came under increased scrutiny after the 23andMe scandal, with consumer advocacy groups raising concerns over how it secures and handles sensitive genetic information. Helix's practices will likely be under closer examination as more people become aware of privacy risks in DNA testing.

## **Veritas Genetics**

Veritas Genetics offers whole genome sequencing services to consumers, which provides a deeper analysis of an individual's DNA than traditional testing services like 23andMe. The company has focused on using genomic data for personalized healthcare, but concerns about its data security practices are growing, particularly in light of the 23andMe scandal. Veritas is now part of the broader conversation on how to balance personalized medicine with robust data protection measures for consumers.

## **Quest Diagnostics**

Quest Diagnostics, one of the largest providers of diagnostic testing, has ventured into genetic testing services, including partnerships with companies like 23andMe. As the demand for genetic testing grows, Quest faces increasing pressure to ensure the privacy and security of customer data. The 23andMe breach has added urgency to these concerns, as any mishandling of genetic information could lead to significant legal and financial consequences for companies like Quest.

## **Labcorp**

Labcorp is another major player in the genetic testing field, offering services that range from ancestry testing to health-related genetic analysis. Like Quest Diagnostics, Labcorp faces the challenge of ensuring that sensitive genetic data remains secure. With growing consumer concerns about privacy, Labcorp must navigate the fine line between offering cutting-edge genetic testing services and safeguarding user data from potential breaches.

## **Genetic Alliance**

Genetic Alliance is a nonprofit organization that works on the promotion of genetic research while advocating for the privacy and ethical treatment of genetic data. It is dedicated to creating more stringent guidelines for how genetic information is collected and shared. The organization has been vocal in the aftermath of the 23andMe breach, calling for more oversight and regulations to protect individuals' genetic privacy in the biotech industry.

### **BGI Group**

BGI Group is a leading global genomics company based in China, specializing in DNA sequencing and data analysis. It provides similar services to 23andMe and has been involved in several international projects concerning genomic research. BGI's involvement in genomic data collection raises privacy concerns, especially in light of the 23andMe scandal, as some fear that such data could be used for surveillance or inappropriately shared with governments or third parties.

### **DNA Diagnostics Center**

DNA Diagnostics Center is a private laboratory offering DNA testing for paternity, ancestry, and health information. As a player in the genetic testing field, the company faces growing concerns regarding how it protects consumer data. The rise of consumer interest in genetic testing has led to increased scrutiny of companies like DNA Diagnostics Center regarding the security of genetic and personal information.

### **PathAI**

PathAI is an AI-powered company that uses artificial intelligence to improve the accuracy of pathology diagnoses, including cancer detection. Although PathAI doesn't focus on consumer genetic testing, its role in the healthcare and biotechnology industry brings it into the broader conversation about the handling and security of medical data, including genomic data. As the use of AI in medicine grows, the company's data security practices are increasingly relevant to ongoing debates over genetic privacy.

### **Amazon Web Services (AWS)**

AWS provides cloud computing services to many companies, including those in the genetic testing space, offering the infrastructure for storing and processing genetic data. The use of cloud services for storing sensitive genetic information raises concerns about data security and privacy. After the 23andMe breach, AWS faces growing pressure to ensure that companies utilizing its services implement adequate security measures to protect consumer data.

### **IBM Watson Health**

IBM Watson Health leverages artificial intelligence and data analytics to help healthcare providers make data-driven decisions, including in genomics. IBM has faced scrutiny over the use of health-related data, particularly regarding consent and privacy. As a technology company in the healthcare sector, it is part of the broader conversation on how AI, healthcare, and genetic data should be handled securely.

### **Invitae**

Invitae offers a variety of genetic testing services, primarily focused on health risks, genetic disorders, and carrier status. The company has been part of growing discussions about the ethical concerns surrounding genetic data, especially after high-profile breaches like the one at 23andMe. As consumer interest in genetic testing increases, Invitae is under increasing pressure to adopt more stringent data security and privacy measures.

### **Sequoia Capital (23andMe Investors)**

Venture capital firms like Sequoia Capital and Google Ventures have invested heavily in 23andMe. These investors have a significant stake in how the company handles data breaches and consumer privacy. Their involvement brings attention to the intersection of tech investments, corporate governance, and consumer data protection in the biotech space.

### **Consumer Reports**

Consumer Reports is an independent nonprofit organization that advocates for consumer rights and provides detailed reviews of products and services, including genetic testing companies like 23andMe. After the 23andMe data breach, Consumer Reports examined the company's practices, particularly focusing on privacy policies and the potential risks of using DNA testing services. Their evaluations and reports influence public opinion, pushing for more transparency and consumer protections in the biotech industry. Consumer Reports plays a crucial role in holding companies accountable for their handling of personal data.

### **Genetic Literacy Project**

The Genetic Literacy Project is an independent organization that aims to provide accurate, science-based information on genetics, biotechnology, and public policy. It often covers controversies related to genetic data privacy, including the risks associated with consumer DNA testing services like 23andMe. In the wake of the 23andMe breach, the organization has contributed to discussions about ethical concerns, corporate accountability, and the potential for genetic discrimination. Its work helps shape public and industry perspectives on genetic privacy and security.

### **American Civil Liberties Union (ACLU)**

The ACLU is a prominent organization that advocates for privacy rights and civil liberties, including the protection of genetic information. The ACLU has been a vocal critic of how companies like 23andMe handle consumer data and has called for stronger privacy protections in the genetic testing sector. Its influence is vital in shaping public and legislative reactions to the growing concerns over genetic privacy.

### **Electronic Frontier Foundation (EFF)**

The Electronic Frontier Foundation (EFF) is a nonprofit organization that advocates for digital privacy, civil liberties, and consumer data protection. EFF has been vocal about the risks posed by genetic data collection, warning about potential misuse by corporations, insurers, and governments. Following the 23andMe breach, the organization has pushed for stronger regulations and encryption practices to safeguard sensitive DNA data. EFF's work is crucial in shaping legal and policy debates surrounding data security in the biotech industry.

### **The Wellcome Trust**

The Wellcome Trust is a global charitable foundation that funds health-related research, including genomic studies. The Trust advocates for ethical research practices and has raised concerns about how genetic data is shared and stored. Its work has helped inform policies around genetic privacy, making it an important player in the ongoing discussions spurred by the 23andMe breach.

### **CRISPR Therapeutics**

CRISPR Therapeutics focuses on gene editing technology, which has the potential to revolutionize medical treatments but also raises privacy concerns regarding genetic data. The company's work on gene therapy makes it a key player in the biotech space, with an increasing focus on data protection as genetic data becomes more valuable. The broader implications of gene editing and privacy are increasingly intertwined with the controversies sparked by 23andMe.

### **Privacy International**

Privacy International is an advocacy group focused on protecting individual privacy rights worldwide. It has been involved in the growing discussion about how consumer genetic data is handled by biotech companies. Privacy International has pushed for stricter laws and regulations to protect consumers from the misuse of genetic data, making it an important organization in the context of the 23andMe scandal.