

# ANBI

## Policy plan of Human Genome Foundation

Fiscaal nr/ RSIN: 857659066

Kamer van koophandel: 68944098

### Activities (SBI): 94996 – Additional ideology organisations

**Doelstelling:** Creëren van draagvlak en bewustzijn over het zelfbeschikkingsrecht over DNA; zorgen voor ultieme zelfbeschikking voor iedere persoon op aarde over diens genetisch DNA; het werkstelligen van het voornoemde zelfbeschikkingsrecht nationaal en internationaal erkend wordt door overheden en regulerende organen van de Verenigde Naties; het verrichten en bevorderen van alle verdere handelingen, die met het vorenstaande in de ruimste zin verband houden en daartoe bevorderlijk kunnen zijn.

**Bestuur:** Susanne Baars (voorzitter) & Martijn de Bie (secretaris), vacature uitstaand voor 3e bestuurder.

**Beloning:** Onbezoldigd

**Contact persoon:** Susanne Baars - s.baars@humangenomefoundation.org

### Invulling voorwaarden voor stichting de Human Genome Foundation zijn:

1. 90% eis: De stichting richt zich op het opkomen voor zelfbeschikking over genetische data en de mogelijkheid om deze data te delen met onderzoekers wereldwijd.
2. Geen winstoogmerk: De stichting is een stichting en heeft geen winstoogmerk winst te maken, louter het nastreven van haar missie: Het bieden van zelfbeschikking over genetische data en de mogelijkheid om deze data te delen met onderzoekers wereldwijd. Door het vergroten van awareness, educatie en het bevorderen van nieuwe technologieën en wetenschap om dit toekomst perspectief te creëren.
3. Integriteitseisen: de de bestuurders van de stichting zijn mevrouw Baars, de heer de Bie. De bestuurders zijn niet betrokken geweest bij het aanzetten tot haat of het gebruik van geweld en hier ook nooit voor veroordeeld. Op dit moment staat een vacature uit voor een derde bestuurder.
4. Gescheiden vermogen: het bestuur bestaat uit twee leden. De gelden worden beheerd via de rekening bij de ABN AMRO bank te Amsterdam en vormen geen onderdeel van het vermogen van de bestuurders. Gezamenlijk zijn zij bevoegd. (Artikel 3.3 van de statuten)
5. Eigen vermogen beperkt: De stichting zal niet meer vermogen aanhouden dan nodig is voor de ontwikkeling van het concept en de stichting.
6. Beloning voor bestuurders: de bestuurders van de stichting werken onbezoldigd en zonder vorm van onkosten vergoeding.
7. Actueel Beleidsplan: zie bijgevoegd plan
8. Redelijke verhouding tussen kosten en bestedingen: De beheerskosten zullen bestaan uit de kosten nodig voor het organiseren van de Global Campagne, hackathons, handelsmissies in het buitenland en alsmede verder het ontwikkelen en faciliteren van de uitrol. Het doel van de stichting is deze kosten zo laag mogelijk te houden en meer dan redelijk in verhouding.
9. Opheffing: Conform artikel 16.6 van de statuten : "Een eventueel batig saldo van de ontbonden Stichting wordt besteed ten behoeve van een algemeen nut beogende instelling met een soortgelijke doelstelling als de doelstelling van de Stichting of van een buitenlandse instelling die uitsluitend of nagenoeg uitsluitend het algemeen nut beoogt en die een soortgelijke doelstelling

als de doelstelling van de Stichting heeft”

10. Administratie: De stichting voert een degelijke administratie welke jaarlijks zal worden gecontroleerd door accountancy kantoor VDB Advocaten Notarissen en WVDB Adviseurs Accountants.

11. Publiceren van gegevens: De stichting heeft alle benodigde gegevens gepubliceerd op haar website: [www.humangenomefoundation.org](http://www.humangenomefoundation.org)

## **Policy plan Human Genome Foundation**

### **Mission**

Our groundbreaking mission is to provide people self-ownership over their genomic data to solve the world's most deadliest diseases. Using the collective power of knowledge from our unique genomes to unlock the potential to find new and better solutions. With the aim to prevent unnecessary disease suffering and to solve the world's deadliest diseases in both developed and developing countries and hence make health sustainable for all. Because together we can empower the transition towards a sustainable future.

### **Providing self-ownership over genomic data to every human**

Making genomic knowledge accessible for every human being on this planet by providing people the key to unlock the secrets of their genome. By placing genomic data inside our own hands, we can take control over our health and that of our children. We can start taking care of future generations, our future planet. Using our DNA to protect ourselves against diseases by taking early preventive measures. To obtain better and faster diagnoses and receive the right medicine. And to contribute to finding new insights to tackle the world's deadliest diseases.

### **Providing access to genomic knowledge, you can save a person's life**

While our DNA is important to protect our live, it is even more valuable when shared. Scientists need millions of genomes to find new disease patterns, disease markers for new and better medicine and personalised food. Fundamentally, by sharing our genome we can help others. As our genome might carry the information to unlock the secrets of the genome of, for example, a little boy or girl on the other side of our planet, who is waiting for a medical breakthrough to survive. By gaining access to our DNA, we can start sharing our data with scientists around the world and actively participate in research. This way every human can become a research partner. And together we can accelerate scientific breakthroughs much faster. Taking part of something that is bigger than ourselves. Together, we can all solve a small part of the puzzle to unravel insights to solve all kind of diseases and save millions of lives.

### **Solving the world's most deadliest diseases**

Genomics has the potential to prevent against terrible diseases and fasten new scientific breakthroughs with unknown speed in a way that we have never imagined before. Our DNA tells us everything about us; about how to prevent disease, better personalised medication, personalised treatment, personalised food. It provides us the means to prevent against the world's deadliest diseases such as cancer, malaria, rare genetic diseases, heart diseases, diabetes and even HIV. However this is only the tip of the iceberg as currently most people do not even have access to their DNA. Using next generation DNA sequencing and technology we can change this and accelerate the transition of sustainable health. So that we each can make use of the abundance of available knowledge inside our DNA to stay fit and health.

### **A global approach is needed**

A global approach is needed to unlock the unknown potential of our unique life code, our genome. To unlock this potential, we first need to create awareness and provide people the opportunity to obtain their own DNA. We need awareness, we need to reach out to people, we need empowerment. We need the power of the crowd to shape our future. By create a change in

perception among people this campaign helps people around the world realize what their unique blueprint can mean for them, their children, their loved ones and neighbors. Making people realize how their unique genome can save someone's else live by making them ambassadors of their own life code.

### **Declaration of Self-Ownership over Genomic Data**

To achieve our grand vision, our dream, and to stand up for our rights we have written the Declaration of Self-Ownership over Genomic data. As we believe that ultimate access to genetic knowledge can be achieved by providing access to genomic data to humans.

This way, data can be freed from fragmented silo's and become accessible by people, experts and scientist around the world. People have always access to their data and the ability to share data with research. Based on consent of the person, data can be shared with trusted research institutes globally and so does knowledge.

### **Creating a global social movement**

Using genomics to prevent against diseases! We fight to solve the world's most deadliest diseases by enabling access to our DNA. By creating ambassadors of our own unique genetic blueprint Creating a social movement of motivated global shapers around the world. By increasing awareness about this topic and involving the crowd.

### **Become ambassador of your unique blueprint**

Using next-generation technology and our mobile phone to enable people to safely own, store and share their digital genome with scientists around the world. Creating awareness to accelerate the transition towards a healthier planet

By enabling people to become ambassador of their own unique blueprint by having access to their digital YOU we can create a cognitive shift in awareness and thinking about the essence of our DNA. In our fight for a better world, the conflicts that divide people and institutes become less important and the need to create a more fair and sustainable society with the united will to protect ourselves, our children and next generations will become obvious and imperative. Human Genome Campaign 2018

To initiate this movement, we will make every human ambassador of his/her own unique genetic blueprint. We will launch our global awareness campaign in summer 2018. Using a ultra modern Genomics Van to tour through different continents and along sport and entertainment festivals. A special Van to enable people to become ambassadors of their own unique blueprint and the ability to cure the world's most deadliest diseases. Such as Rare genetic diseases, Muscle diseases, Blood & Heart diseases, Cancer and Alzheimer.

### **Establishing 3 principles:**

- 1) Contribute to the United Nations Sustainable Development Action Goals to improve health and foster global partnerships
- 2) Provide people their own genomic data inside their own hand (self-ownership)
- 3) Acceleratescienceonaglobalscale(freedomofscience)

## **About us**

Being grown and raised in a medical family specialized in genetics, Susanne Baars (Founder) has experienced first-hand that there is more knowledge to prevent terrible diseases than what we use in practice. Being a scientific genomics researchers and ethicist she knows what needs to be changed in field – being aware of the ethical complexity of the theme. Having lost their son due to a genetic disease which could have been prevented if they would have had the key to unlock the secrets of Mathieu's unique lifecode, Martijn de Bie (Patient advocate) embraced this initiative immediately. Together with a fantastic team, ambassadors, donation givers, companies, world governments, activists and volunteers we are working day and night to overcome these global challenges. Read our story (bottom)

## **Directory Board**

The Human Genome Foundation directory board consists of 2 members. Susanne Baars (President and chair) and Martijn de Bie (Treasurer). They do not receive any salary for their activities.

## **Board of the Future**

In 2017 the Human Genome Foundation has appointed a Board of the Future. Consisting of world leading experts, leaders and influencers from various fields. They do not receive any salary for their activities. The directory board is independent and has an independent chair.

## **Ambassadors / Partners**

The foundation has extraordinary ambassadors and active supporters from all kind of fields within society. Each of them has a unique story why they support our cause, why they believe in the world changing mission and how they can strengthen the movement. Next year we will continue searching for global ambassadors to extend our reach.

## **Fundraising**

The foundation is raising funds through moneygivers who believe in the mission. This includes both individual people, NGO's, governments and social responsible organisations. The money raised will be collected within the network of the directory board of the Human Genome Foundation. Once the campaign has been launched, we expect that fundraising will be easier. This will be a continuous process.

## **Management of Funds**

The capital of the Human Genome Foundation will be managed by the directory board of the Human Genome Foundation. The administration will be performed by an external office. The finances will be validated once a year by an accountancy office.

## **ACCOUNTABILITY**

The majority of Human Genome's revenue comes from private donors and companies. Human Genome strives to report transparently on our successes and failures in all aspects of our programming, finances, and operations to communicate openly to our constituency.

## **Spending of the Capital**

The capital will be spent for operation cost related to all activities related to the mission. In practical terms this means that we need to finance the global campaign, a genomics van and cost related to public actions to make people ambassador of their own unique genetic blueprint. We need financing to arrange stakeholder meetings and engagement with leaders from governments worldwide to spread the vision, increase awareness and mobilize society towards our goal. This also includes operational costs, costs to hire employees, food and travel costs. But also practical costs such as accountancy, the website (as activation means) and bank costs.

## **Low costs policy**

The Human Genome Foundation is focused on minimalizing costs as much as possible. So that most of the funding will be spent on making a meaningful change in the world, for those who most need it. Read more about financing (bottom). Hence the Human Genome Foundation conducts a low-cost policy. Overhead such as ICT, mobile phones and office furniture is 100% sponsored. Salaries of the directory board and team members are below the guidelines of the Foundation of Fundraising institutions (VFI). Because of this as much donation gifts can be given.

## **Transparency**

The Human Genome Foundation is open. Transparent in communication and results from all our activities. We do not have a hidden agenda. We are shaping the future, serving a higher goal.

## **Human Genome Global**

Human Genome Global is the worldwide net of independent organizations, research and knowledge institutes who supporting our cause.

## **Code of Conduct**

Everyone committed to our cause and the organization management needs to comply to the Code of Conduct. The Code of Conduct consists of ethical norms & values to safeguard the integrity of the mission. You can read more about the Code of Conduct here (bottom)

## **Social Policy**

The Human Genome Foundation believes that publishing information about policy and all projects will increase the value of its existence. The Human Genome Foundation is a social impact driven Foundation with complete transparency of all its activities. Because of this we publish 'open data' (bottom to publishing activity data). By publishing this data we can spread knowledge with the world and learn from each other.

## **Period**

This policy plan is focused on 2017 – until the end of 2018. The directory board will review the policy plan for the year after based on achieved results and resources available