



Gendia Foundation Newsletter

Providing Financial Support for Genetic Testing

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The Foundation : Our Vision and Mission

The Gendia Foundation is a nonprofit organization dedicated to raising funds to help subsidize the cost of genetic testing for individuals without the financial resources to afford these testing services.

The Gendia Foundation also offers general information on genetics, genetic diseases, genetic testing and support for affected individuals and families.

Why the Foundation ?

Several decades of intensive research on the genetic causes of human diseases have resulted in over 2.000 tests offered to diagnose genetic diseases. Unfortunately, there are huge differences with respect to accessibility, price and quality of the genetic testing. The spectrum of genetic diseases tested varies from several hundreds in countries with a well-developed service system to only a few in most countries of the world.

A major bottleneck in genetic testing is the cost, which are often unaffordable when not reimbursed by insurance companies. This makes genetic testing unaffordable to many people.

To meet this challenge Gendia has developed the Gendia Foundation, that pays for free testing of those that do not have the financial means.

How does the Foundation Provide Services ?

A. Operations:

The way the foundation operates is depicted below :

All medical doctors (MDs) throughout the world can propose genetic tests to be supported by the Foundation.

To do so they must submit a [standardised request](#) to the Foundation that will ask the [National Representative](#) of the home country of the patient whether such proposal is acceptable. If no national representative is available for the country in question, the executive committee of the Foundation will select an appropriate national representative.

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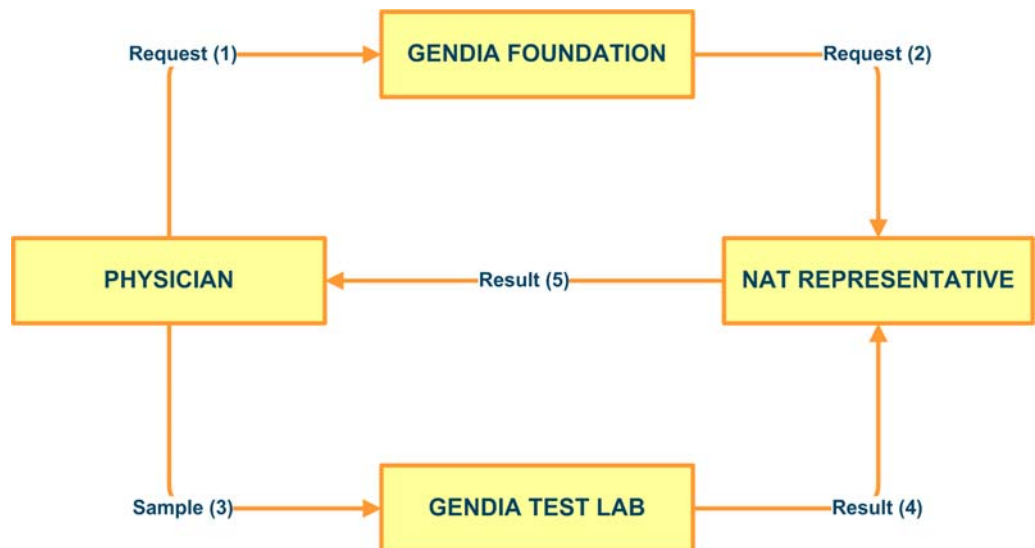
Monica Troncoso
(Chile)

Qi Ming
(China)

Alejandro Giraldo
(Colombia)

If the proposal for testing is accepted by the national representative, the latter will submit the proposal to the executive committee of the Foundation who will then make a final decision based upon the financial possibilities of the Foundation.

The Medical doctor of the patient will be informed by the foundation when testing is accepted, and can then submit a sample from the patient to Gendia for free testing. The results will be communicated by Gendia to the medical doctor of the patient.



B. Costs:

The costs of the genetic tests and sending of the samples will be paid by the foundation, and the patient nor the referring clinician or lab will receive a bill. There will be no cost at all for the patient or referring MD/laboratory.

C. Quality control:

The quality of genetic testing will be guaranteed by the GENDIA network that works with only internationally recognised labs. All the GENDIA labs in the US are accredited by the US quality control system (CLIA) and most of the European labs are accredited by the European system (ISO 17025), or are in advanced stage to receive such accreditation.

D. Confidentiality:

There will be maximum confidentiality and privacy concerning the genetic tests. Results will only be sent to the patient or his/her physician or referring lab. Insurance companies evidently have no access to the results or names of patients tested.

Also the foundation has no access to the test results.

Samples are only studied for the test asked by the patient or physician, and kept only in the test lab. Also the results will be kept in the test lab.

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(Lithuania)

Maria Arenas-Sordo
(Mexico)

Genetic News from SAB Members

In the next edition of the Newsletter SAB members from different countries will discuss their experience with genetic diagnosis in their respective country.

Genetic Stories from around the world

We would all love to hear about your experiences with obtaining your genetic diagnosis.

Write us your story to be published in the next newsletter (please use Email : info@gendia-foundation.net).

Geneticist Answers to Your Questions

Here is your chance to ask questions about genetic disease.

Our professional geneticists will address your questions.

Please note that we cannot diagnose or recommend treatment in this column.

(please use Email : info@gendia-foundation.net).

How can I make a donation ?

You may help the foundation by making a Donation.

(please go the website www.gendia-foundation.net and click on: [Donations](#))

How can I help the Foundation ?

The Gendia Foundation is currently seeking individuals interested in helping develop fundraising campaigns.

(please go the website www.gendia-foundation.net and click on: [Support the Foundation](#))

Helpful Websites

GENDIA (<http://www.gendia.net>)

Website of GENDIA, an international network of genetic labs, offering more than 1.000 different genetic tests.

Martijn Breuning
(Netherlands)

Lars Engebretsen
(Norway)

Qasim Ayub
(Pakistan)

Ricardo Fujita
(Peru)

Bogdan Kaluzewski
(Poland)

Purita Tavares
(Portugal)

Michaela Mataringa
(Romania)

Evgeny Ginter
(Russia)

Brian Meyer
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Borut Peterlin
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Munro Marx
(South Africa)

Pilar Madero Barrajon
(Spain)

Vajira Dissanayake
(Sri Lanka)

Magnus Nordenskjold
(Sweden)

Roland Spiegel
(Switzerland)

Abdelmoula Nouha
Bouayed
(Tunisia)

Serdar Ceylaner
(Turkey)

Sherri Bale
(USA)

Luong Le Dinh
(Vietnam)

GENETESTS

(<http://www.geneclinics.org>)

Website with information on genetic diseases, genetic tests, and labs (mainly US) offering these tests.

GENETIC INTEREST GROUP (GIG)

(<http://www.pharmaco-gendia.net>)

Website of GIG, a national alliance of organizations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders to promote awareness and understanding of genetic disorders.

GENETIC ALLIANCE

(<http://www.geneticalliance.org>)

Website of the Genetic Alliance, an international coalition comprised of more than 600 advocacy, research and healthcare organizations represent individuals with genetic conditions. The site contains information on hereditary diseases, patient support groups, terminology in the genetics, and hot topics in genetics.

NORD

(<http://www.rarediseases.org>)

Website of the National Organization of Rare disorders with information on hereditary diseases, patient support groups, terminology in the genetics.

ORPHANET

(<http://www.orpha.net>)

The Orphanet website includes information on rare (orphan) diseases and medications, with and a directory or services on specialized outpatient clinics, clinical laboratories, research activities and support groups.

MEDLINE PLUS

(<http://www.nlm.nih.gov/medlineplus/geneticdisorders.html>)

Website of the American National Library of Medicine with information on hereditary diseases, genetic tests, prenatal diagnosis, genetic terminology, illustrations, and information on patient support groups.

GENETICS EDUCATION CENTER

(<http://www.kumc.edu/gec/>)

Website of the University of Kansas with information on genetic terminology, drawings, hereditary diseases, genetic tests, patient support groups, the Human Genome project, art in genetics, books and brochures.

TALKING GLOSSERY OR GENETIC TERM

(<http://www.genome.gov/glossery.cfm>)

Website with explanation of the terminology used in genetics with a lot of illustrations.

OMIM

(<http://www.ncbi.nlm.nih.gov/omim/>)

The website of ONLINE MENDELIAN INHERITANCE IN MAN, the bible of geneticists, with much information on genetic diseases and disease genes.

PUBMED

(<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed>)

Contact

Gendia Foundation

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Website : www.Gendia-Foundation.net

Website with systematic filing of almost all medical scientific publications, classified according to author or subject.

YOUR GENES YOUR HEALTH

(<http://www.ygyh.org>)

Website with attractively presented information on a number of genetic syndromes such as cystic fibrosis, fragile X syndrome, hemophilia, polycystic kidney disease, Marfan syndrome, neurofibromatosis, Alzheimer disease, phenylketonuria, hemochromatosis, sickle cell anemia, thalassemia, Tay-Sachs disease and Down syndrome.

Calendar of Conferences & Events

1. European Society of Human Genetics (ESHG) meeting : May 6-9, Amsterdam, The Netherlands
2. 11th International Congress of Human Genetics (ICHG): Aug 6-10, Brisbane, Australia
3. American Society of Human Genetics (ASHG) meeting : Oct 9-13, New Orleans, USA