



Rare
Genomics
Institute



Your dedication

helped Robert get a diagnosis in 6 months after fourteen years of searching and is helping Maya and her dad find answers to her disease.

What We Do



We help...

families access the resources they need to identify, diagnose, treat, and hopefully find a cure for rare diseases.



We partner...

with doctors, research institutes, and laboratories to complete DNA sequencing for patients.



We supply...

a personal team of scientific experts dedicated to interpreting sequenced results, and a pro-bono consulting team of world-leading physicians and researchers in rare diseases.



We raise...

money to help patients and families fight their disease and evaluate the viability of genetic sequencing.



We advance...

scientific discovery. Through Our Rare Reference initiative we share our research and findings with the global scientific and medical communities.



We connect...

rare disease communities through Rareshare.org, a social network for patients, families, healthcare professionals and others affected by rare diseases.

Rare Genomics Institute (RG) is an international non-profit that provides access to cutting edge research technologies, physicians, and scientists to the estimated 350 million children and adults affected by a rare or unknown disease.

Get Involved today! Visit raregenomics.org for more information!

Our Results

15-20%

Our genome analysis improves diagnosis rates by 15-20%

75X

For each 1 dollar given we can provide \$75.00 of support and research. We multiply your donation 75X

8

We have discovered 8 unique gene mutations, that is 2 a year

1 MONTH

1 month from application to referral, diagnosis in less than a year (industry average is 7 1/2 years)

475

Kids given hope for a proper treatment 475



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Get involved as a...

DONOR

Visit our website and give a tax-deductible gift. Becoming a monthly contributor at just \$10.00 a month enables us to provide a child the support they need to find a cure.

VOLUNTEER

RG has a strong culture of volunteerism that drives our mission. We are always looking for professionals to join the fight against rare diseases.

PARTNER

Some challenges require significant support. Helping kids and advancing genomic science is what we do and you can help us deliver those new programs to patients around the globe.

About Our Founder

Cheng-Ho Jimmy Lin, MD, PhD, MHS, is Founder & President of Rare Genomics Institute, the world's first platform to enable any community to leverage cutting-edge biotechnology to advance understanding of any rare disease. Partnering with top medical institutions, Rare Genomics helps custom design personalized research projects for rare diseases. Dr. Lin is also the Chief Scientific Officer, Oncology at Natera. Prior to this, he led the computational analysis of the first ever exome sequencing studies of cancer at Johns Hopkins and the Director of Clinical Genomics at the Genetics Branch of the National Institute of Health/National Cancer Institute (NIH/NCI), where he leads a team to create a clinical genomics program within the intramural program. He has numerous publications in Science, Nature, Cell, Nature Genetics, and Nature Biotechnology, and has been featured in Forbes, Bloomberg, Wall Street Journal, New York Times, Washington Post, BBC, TIME, and the Huffington Post. He is a 2012 TED Fellow and 2016 Senior TED Fellow.



"Instead of laying in bed at night **wondering** what our son has and if he's going to worsen over time, we now know that he will likely live a long life." says Harrison's mother, Susan.

"We **can now make plans** for our family's future...something we never felt comfortable doing without a diagnosis." Susan Snow (Mother of Harrison)

Get Involved today!
Visit
raregenomics.org
for more
information!

www.raregenomics.org
contact@raregenomics.org
844-448-7273

2657 Annapolis Road, Suite G, #105
Hanover, MD 21076

