



# Rare Genomics Institute

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Empowering communities. Accelerating cures.

<http://raregenomics.org>

# OUR TEAM



**Jimmy Lin, MD, PhD, MHS  
President**

- Faculty, Washington University in St. Louis
- MD/PhD: Johns Hopkins



**Imran Babar, PhD  
VP, Scientific Affairs**

- Biotechnology Associate with Cowen & Co.
- PhD: Yale



**Naira Rezende, PhD  
VP, Patient Advocacy**

- Scientific Advisor at Wilson Sonsini Goodrich & Rosati
- PhD: Cornell



**Jonathan Franca-Koh, PhD, MBA  
VP, Business Operations**

- Project Manager with National Cancer Institute
- PhD: University College in London



**Marisa Dolled-Filhart, PhD  
VP, Strategic Alliances**

- Principal Scientist at Merck
- PhD: Yale University



**Meisha Bynoe, PhD  
Director, Marketing**

- Associate at McKinsey & Company.
- PhD: Yale

# THE PROBLEM:

There are more than **7,000** rare diseases – affecting more than **300 million** people globally.\*



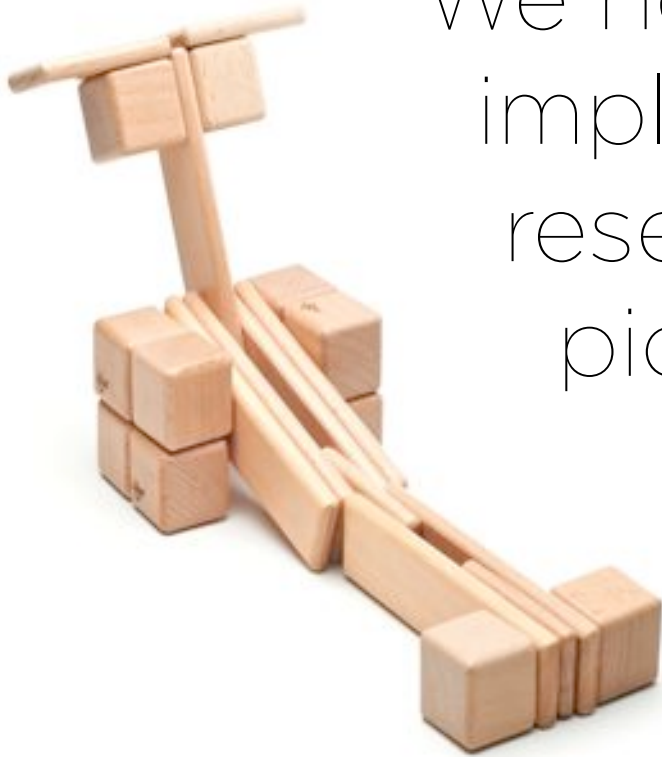
\*3 in 4 are children. 3 in 10 don't survive past their 5<sup>th</sup> birthday.

The current **top-down model** for biomedical research is **not** designed to address so many diseases. As a result, **less than 5%** of rare diseases have any type of therapy.



# OUR SOLUTION:

We help families design and implement **one-of-a-kind** research programs. We are pioneering a new paradigm for **bottom-up, patient-driven** research.



# WE PROVIDE:



# STUDY DESIGN

Our team of scientists and clinicians custom design research projects personalized to each patient and each rare disease.



\*Current focus is on genomic sequencing. Other “omics” technologies, fibroblast and iPSC creation, model organisms development, drug repositioning screening are under development.

# RESEARCH TEAM

We partner with top medical centers, who perform the research experiments.

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# ACCESS TO CAPITAL

We provide access to grants and a crowd-funding platform to raise funds online.

The screenshot displays the Rare Genomics website. At the top left is the logo for Rare Genomics, featuring a stylized blue figure and the text "RARE GENOMICS" with the tagline "EMPOWERING COMMUNITIES. ACCELERATING RESEARCH." To the right is a blue "DONATE NOW" button. Below the logo is a navigation bar with five items: "ABOUT US" (Who we are), "HOW IT WORKS" (The Process), "OUR PATIENTS" (Give a Gift of Hope), "FOR RESEARCHERS" (Help Advance Science), and "CONTACT US" (Learn More). The main content area features two campaign cards. The first card is for "Windsor", showing a 68% progress bar, a raised amount of \$6,620, a goal of \$7,500, and 50 donors. The second card is for "Sabrina", showing a 104% progress bar, a raised amount of \$7,800, a goal of \$7,500, and 26 donors. Below the Sabrina card, it says "Campaign Completed! Congratulations!" and provides a brief description of her condition.

**RARE GENOMICS**  
EMPOWERING COMMUNITIES. ACCELERATING RESEARCH

[DONATE NOW](#)

[ABOUT US](#) > [HOW IT WORKS](#) > [OUR PATIENTS](#) > [FOR RESEARCHERS](#) > [CONTACT US](#) >

Who we are > The Process > Give a Gift of Hope > Help Advance Science > Learn More >

**Windsor**

68%

Raised:	Goal:	Donors:
\$6,620	\$7,500	50

Windsor is a beautiful 23 month old girl who loves music and loves to play! If I could tell you only one thing about her, I'd tell you she never EVER gives up. Windsor has a muscle condition called hypotonia. When she was born, she was too weak to move her little body at all.

[Click to Support Windsor](#)

**Sabrina**

104%

Raised:	Goal:	Donors:
\$7,800	\$7,500	26

**Campaign Completed!**  
**Congratulations!**

Sabrina is a beautiful ten year old, who is having a hard time understanding why she cannot do the things her friends have no problem with. Sabrina likes to write stories and draw pictures, but it is getting difficult for

# A COMPLETE SOLUTION:

Combining all these elements,  
we **create** research projects  
that would otherwise  
not exist – **tailored** for  
each individual and  
each rare disease.



# A RESEARCH PROJECT, JUST FOR ...



DAVID



RIVER



GRAM



SABRINA

# RESEARCH PROJECTS, AS UNIQUE AS ...



WINDSOR



MAYA



ROBERT



SELAH

# PILOT YEAR STATISTICS:

Number of research sites: **18**

Number of researchers: **54**

Global expansion:

Singapore, Malaysia,  
Israel, Spain, Australia  
and the UK.



# PILOT YEAR STATISTICS:

Number of applications: >200

Projects under way: 19

Number completed: 3

Number of large-scale  
campaigns: 2

Total raised: >\$700,000



# OUR FIRST SUCCESS STORY!



World's first crowdfunded genome sequencing project uncovers 4-year-old's unknown genetic disease

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THE WALL STREET JOURNAL.

TIME

THE HUFFINGTON POST

THE INTERNET NEWSPAPER · NEWS BLOGS VIDEO COMMUNITY

CNN

Bloomberg  
Businessweek

nature

Forbes

boingsboings  
A Division of Business Week

TED  
IDEAS WORTH SPREADING

Mashable

npr

BBC

# OUR DREAM:

**Every child** has the **hope** of living a happy healthy life.

**Every disease** will be on its way to a **cure**.

No matter how rare.







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[contact@raregenomics.org](mailto:contact@raregenomics.org)

# **APPENDIX**

# MEDIA & PRESS

Our work has been featured and mentioned in over 90 articles and media appearances.

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**THE WALL STREET JOURNAL.**

**THE HUFFINGTON POST**  
BREAKING NEWS AND OPINION

**The Washington Post**

*the Atlantic*

**Xconomy**

**TIME**

**SCIENTIFIC AMERICAN™**

**THE  SUN**

**boingboing**  
A Directory of Wonderful Things 

**BBC**

**Bloomberg Businessweek**

**Bio·IT World**

**nature**

**TED**

**npr**

**Forbes**

**Mashable**

**TORONTO STAR**

**CNN**

# SPONSORS & SUPPORTERS

We are thankful for the more than 40 companies and organizations that make this possible.

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