Rare Genomics Institute

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

Naira Rezende, PhD
VP, Patient Advocacy
- Scientific Advisor at Wilson Sonsini Goodrich & Rosati
- PhD: Cornell

Marisa Dolled-Filhart, PhD
VP, Strategic Alliances
- Principal Scientist at Merck
- PhD: Yale University

Imran Babar, PhD
VP, Scientific Affairs
- Biotechnology Associate with Cowen & Co.
- PhD: Yale

Jonathan Franca-Koh, PhD, MBA
VP, Business Operations
- Project Manager with National Cancer Institute
- PhD: University College in London

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 5th 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.

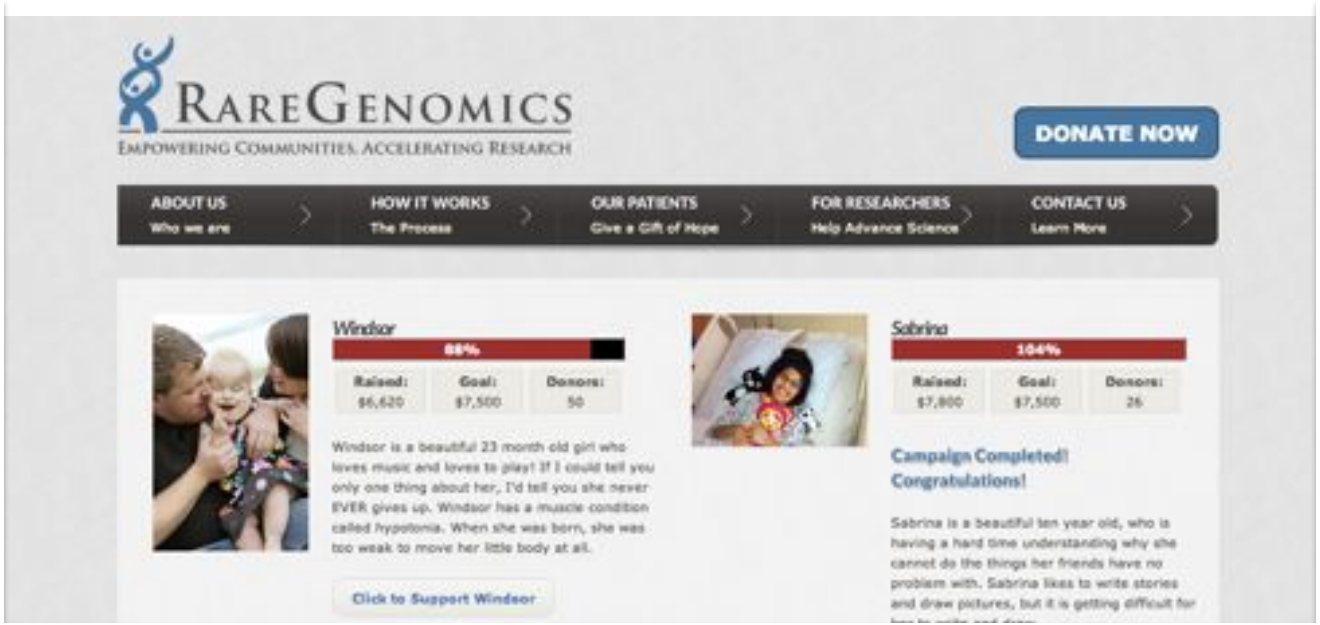
*Current focus is on genomic sequencing. Other “omics” technologies, fibroblast and IPSC creation, model organisms development, drug repositioning screening are under development.

RESEARCH TEAM

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

ACCESS TO CAPITAL

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



A COMPLETE SOLUTION:

Combing 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

THE WALL STREET JOURNAL. TIME

THE HUFFINGTON POST CNN

Bloomberg Businessweek nature

Forbes boingboing TED

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.

Rare Genomics Institute

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contact@raregenomics.org

APPENDIX

MEDIA & PRESS

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

SPONSORS & SUPPORTERS

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