



EB RESEARCH
PARTNERSHIP



Everyone
by Smart**Cities**Council



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CEO

EB Research Partnership

[@MichaelPHund](#) [@EBresearch](#)

WWW.EBRESEARCH.ORG

RARE DISEASE STATS

350 Million+

People suffer from a rare disease globally

7,000

Types of rare diseases

1 in 10

People are affected by a rare disease

RARE DISEASES

Impact more people than cancer and AIDS combined

1 of 2

Patients diagnosed with a rare disease is a child

3 of 10

Children with a rare disease won't live to see their 5th birthday

8 in 10

Rare diseases are caused by a faulty gene

8 Years

Average time it takes for rare disease patients to receive an accurate diagnosis

1 in 2

Rare diseases do not have a Foundation or Research Support Group

95%

Of rare disease lack an FDA approved treatment



95%

**Of rare disease lack an
FDA approved treatment**









OUR MODEL

THE VENTURE INTO CURES MODEL

SHARE. COLLABORATE. CURE.

We have reached the threshold of a far more promising future for children born with EB. Leading researchers believe that both life-changing treatments and a cure are within reach. To realize our vision of a world without EB, we're building a research model based on three core pillars.



DATA PLATFORM

The largest gathering of EB data imaginable, including clinical, genomic, and patient data underlying the disease.



RESEARCH NETWORK

An open and fluid collaboration consortium that brings together the often siloed academic, medical, and patient communities.

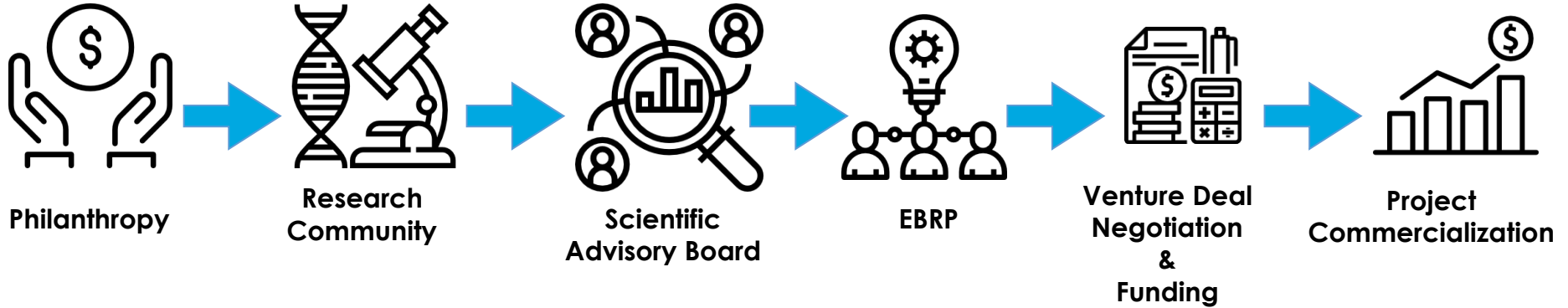


IMPACT PORTFOLIO

Direct investment in the most promising projects, including disease controlling, changing, and curing therapies.



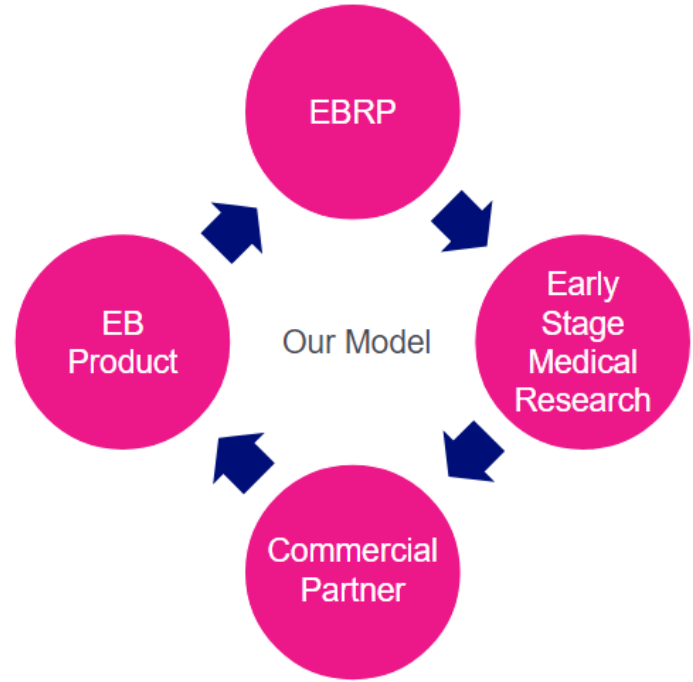
THE KEY: VENTURE PHILANTHROPY



**Return on investment directed
back into more research funding
until a cure is found**



VENTURE PHILANTHROPY LIFE CYCLE- LOOK FAMILIAR?



EBRP IMPACT



120

Projects funded
since 2011

20x

The amount of
clinical trials (2-40)

4

Phase III clinical trials

1,200%

Increase in clinical
trials

20

Countries funded

51x

The amount of
annual research
funded

450%

Increase in annual
revenue

8

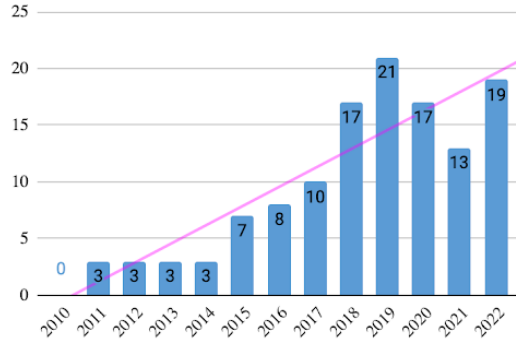
Companies formed

Public equity
Private equity
Milestone payments
Guaranteed ROI

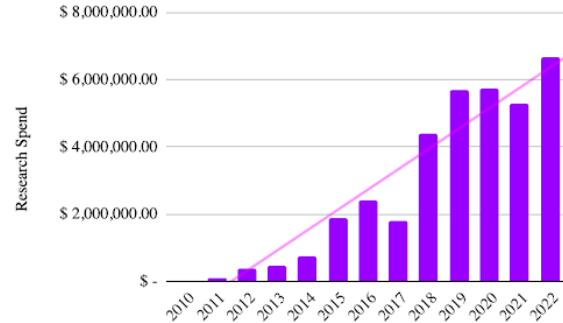
Deal structures used

EBRP IMPACT

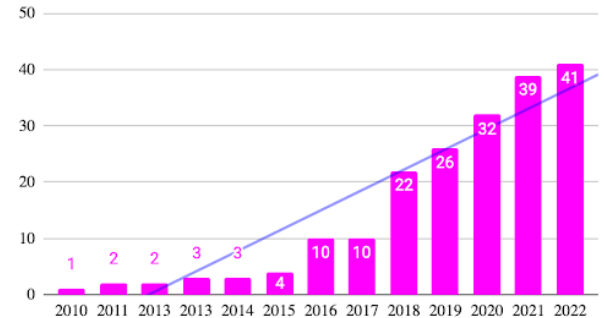
EBRP Research Funded # of Projects



EBRP Research Funded \$ Spend



EB Clinical Trials





50M

DOLLARS RAISED
FOR RESEARCH



120

PROJECTS
FUNDED



20X

MORE ACTIVE EB
CLINICAL TRIALS

EBRP IMPACT



CLINICAL RESEARCH CONSORTIUM INFRASTRUCTURE





Stanford
MEDICINE



GeneDThe GeneD logo, featuring the word "GeneD" in a teal, sans-serif font, followed by a stylized DNA double helix icon in red and teal.





Clinical Data

1. GeneDX Genetics
2. Existing Biobanks, Datasets, & Studies
3. Community Cell Bank



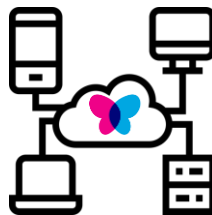
Ecosystem Data

1. ClinicalTrials.gov
2. PubMed
3. Hospital/ Clinic Network



Patient Reported Data

1. Longitudinal Surveys
2. Patient control of data sharing/ preferences
3. Connection to patients, researchers, clinicians



Clinical Research Consortium

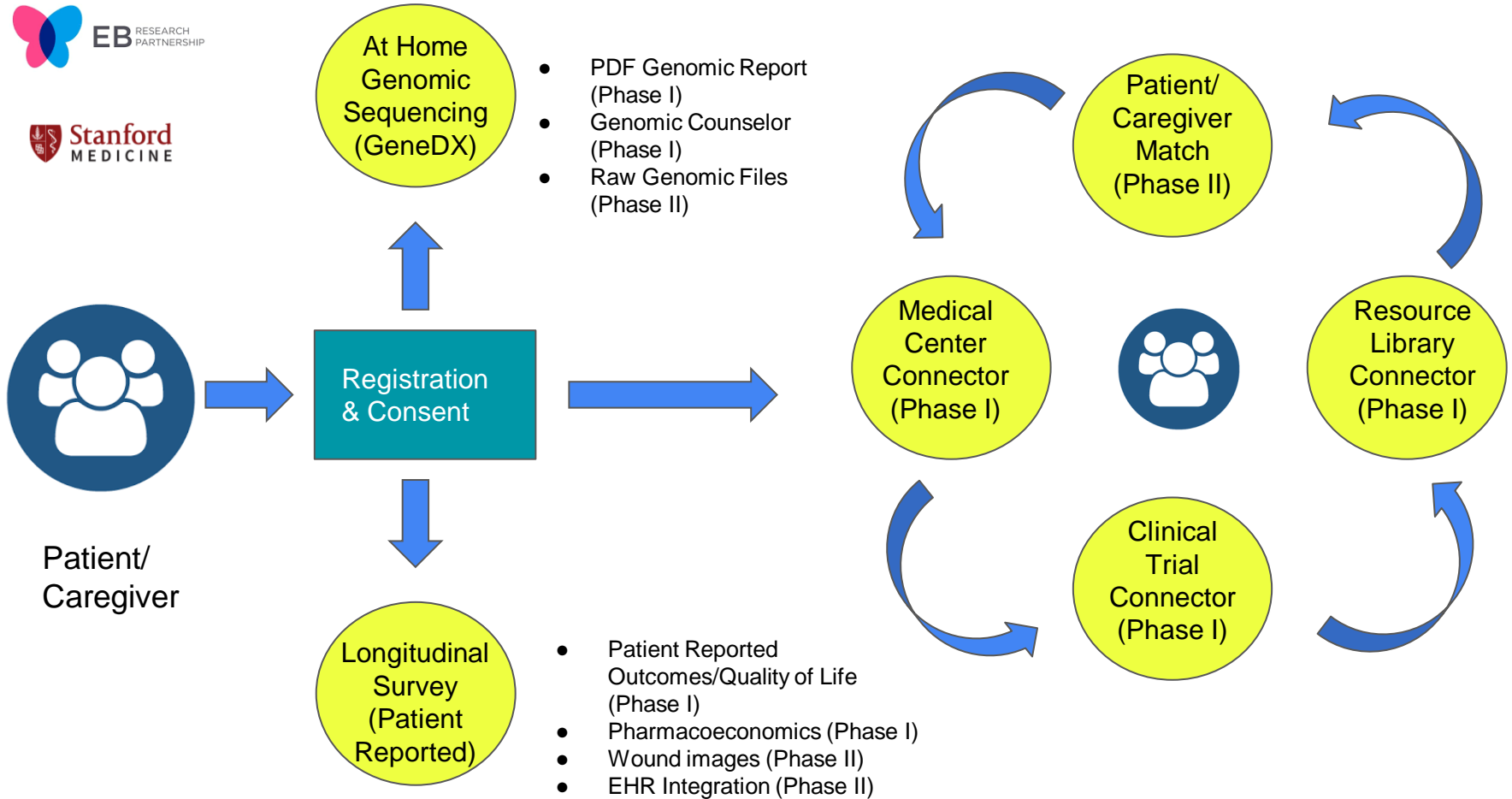


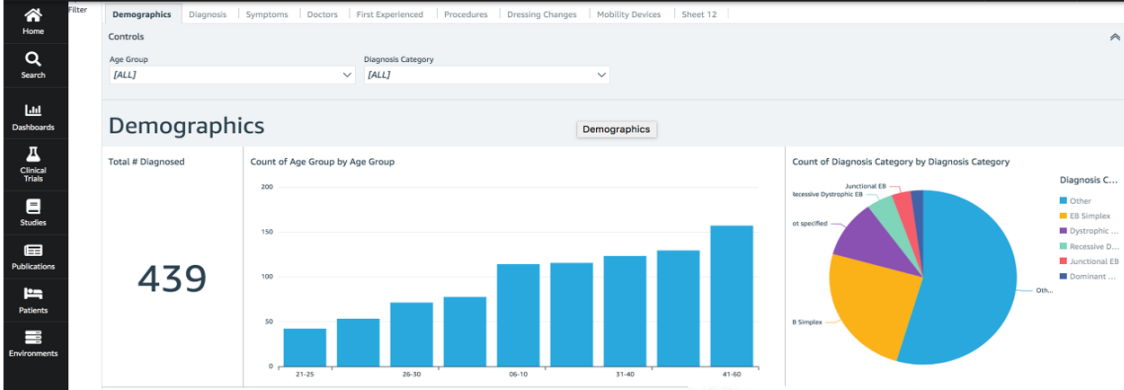
Industry

- Biotech/ Pharma
- FDA
- Tech



Patients & Families





Undo Redo Reset

Filter: Clinical Trials | Sheet 2

Clinical Trials

Start by selecting a location from the map. Clinical trials from that location will appear in the table below. Conditions may also be filtered by selecting a box from the tree map. Condition filters currently do not affect the map.

Locations

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Conditions

Epidermolysis Bullosa 12	Recessive Dystrophic Epid... 7	Epidermolysis Bullos... 5	Junctional Epid... 4				
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- Home
- Search
- Dashboards
- Clinical Trials
- Studies
- Publications
- Patients
- Environments

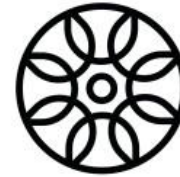
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