

JULY 2025

RESEARCH

WEBINAR



# Town Hall

Featuring  
***Shane DiGiovanna***  
***Greg Landsman,***  
and ***Margot Sosa***



**(EB) RESEARCH PARTNERSHIP**



# Town Hall *Agenda*

1. EBRP Update
2. Meet Your Presenters
3. Shane DiGiovanna's Story
4. Greg Landsman's Journey
5. Shane and Greg: A Conversation on Advocacy
6. Live Q&A Session
7. Thank You & Wrap Up

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# EB Research Partnership *Update*



***Margot Sosa***  
Development Associate  
EB Research Partnership



Our goal is to accelerate treatments and  
***cures for EB***



And pioneer  
a path for the

**400M**

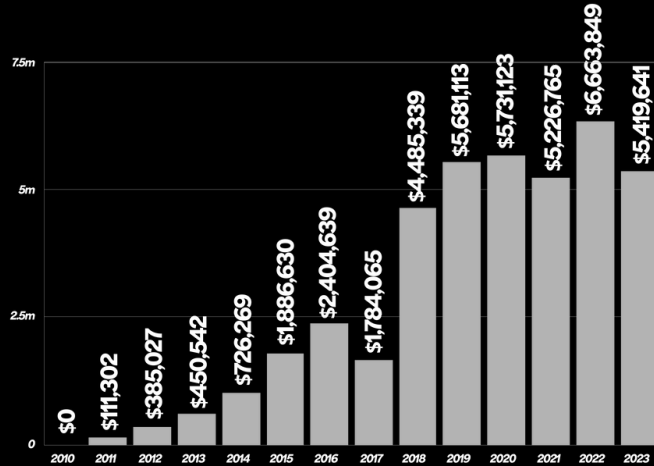
battling ***rare disease***



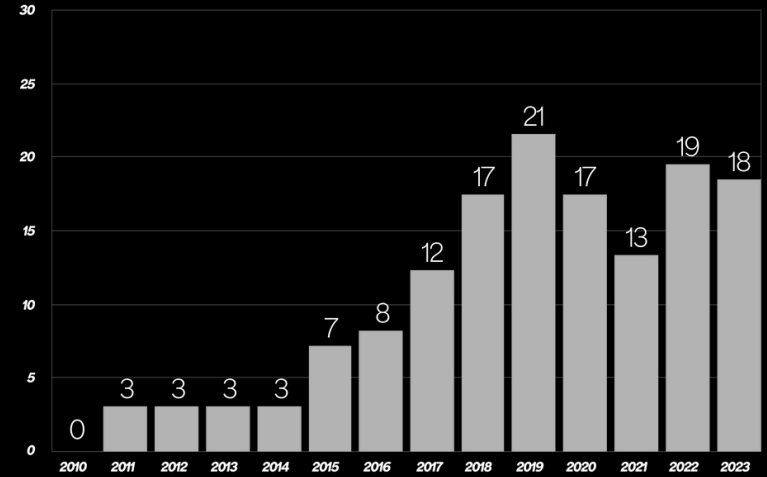


Since our founding, EBRP has  
***Directed over 90% of revenue to research***

**EBRP Research  
Spend**



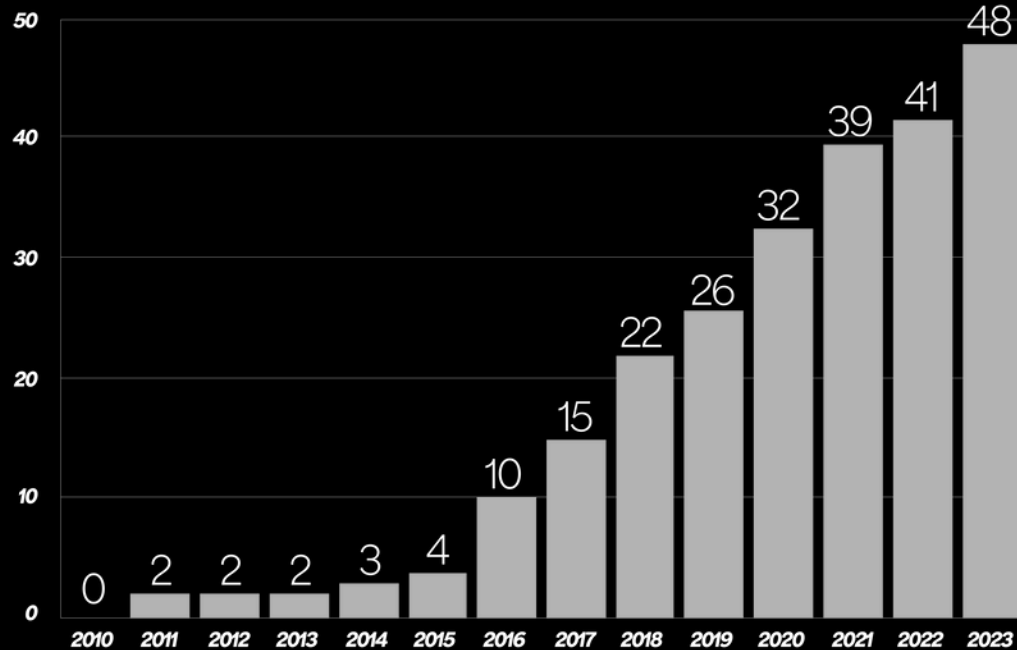
**Projects  
Funded**





# EBRP has directly funded *Over 50% of the active EB clinical trials*

**Active EB**  
Clinical Trials



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# Our *Progress*

3 

FDA Approved  
**Treatments**

160+ 

Innovative  
Projects **Funded**

  
\$70M

Raised for  
**Life-saving** Research

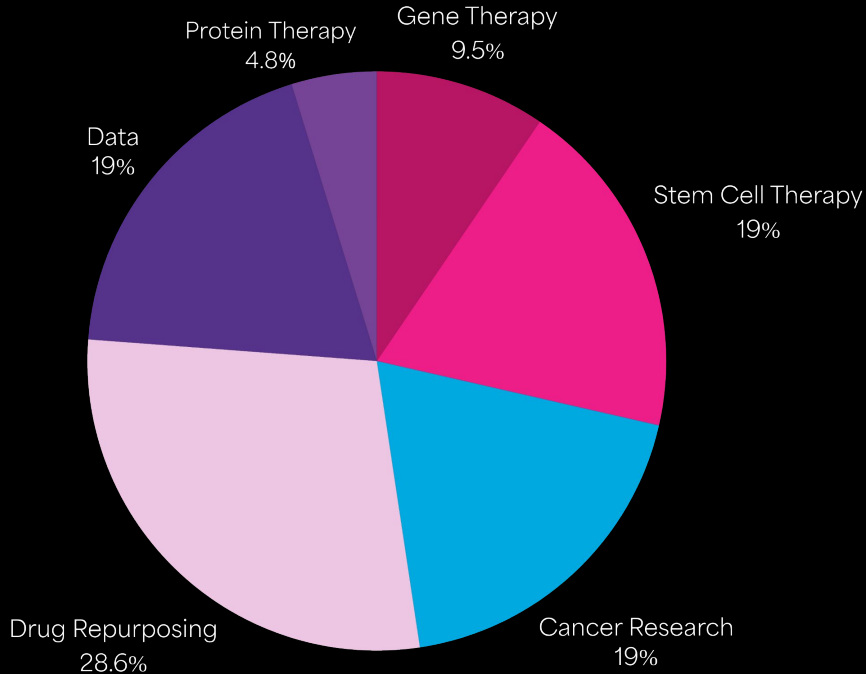
25x 

More Active  
EB **Clinical Trials**

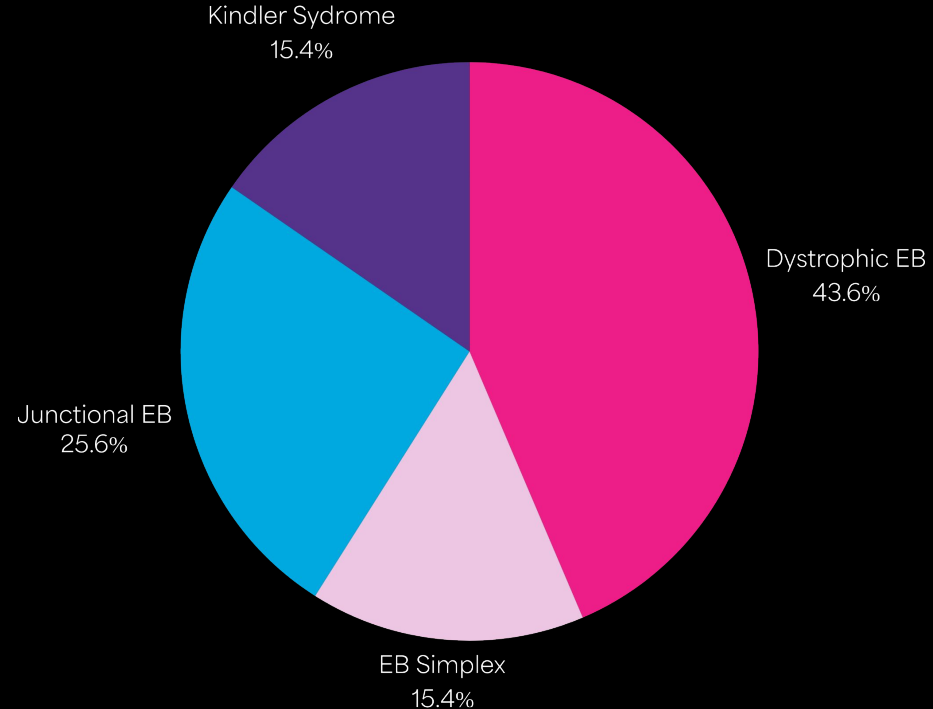


# \$5.6M in *Research Funded in 2024*

## Breakdown of *Techniques*



## Breakdown of *Subtypes*



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# Town Hall *Presenters*



***Margot Sosa***  
Development Associate  
@ EB Research  
Partnership



***Shane DiGiovanna***  
EB Community Member &  
Patient Advocate



***Rep. Greg Landsman***  
U.S. representative from  
Ohio's 1st congressional  
district



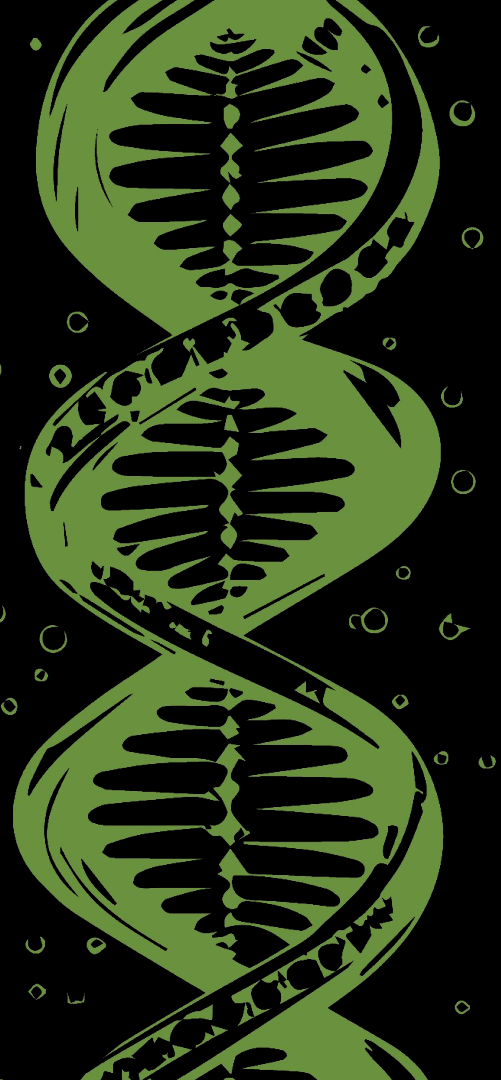
***Shane  
DiGiovanna's  
Story &  
Journey  
With RDEB***





***Rep. Greg  
Landsman's  
Journey &  
Connection  
To the EB  
Community***

***Shane & Greg:  
A Conversation  
on Healthcare  
Policy &  
Advocacy***





# Q&A

***Thank you!***

Please send any follow up questions to:

***info@ebresearch.org***

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# Get *Involved*

*Now - Sept. 4*



**Apply to EBRP's Q3  
2025 Grant Cycle for  
EB research funding**

*August 26*



**Join us at the  
Mariners v Padres game  
for series 2 of the Vedder Cup**

*September 9*



**Join EBRP at the Liberty v  
Mystics game - your ticket  
supports EB research**

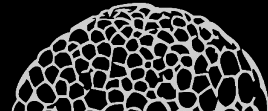
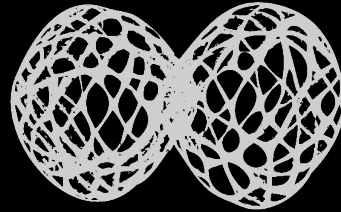
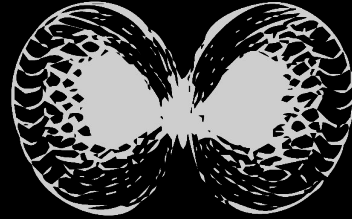
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# *Thank you*



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