



# **FDF's Research Goals**

**Cindi Brandt Levin  
Captain of Team FD  
Board of Directors  
Chair of the Research Committee  
Fibrous Dysplasia Foundation**

# **Find Better Treatments, and Ultimately a Cure for the Patient Community**

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**HOW DO WE TRY ACHIEVE THIS  
MONUMENTAL GOAL WITH FDF'S  
LIMITED RESOURCES?**

# IDENTIFY THE MOST IMPACTFUL RESEARCH

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- **Recruit Scientific Advisory Council comprised of Bone Research All-stars to Review Grants and Help Select Best Projects (including David Burr, Michael Collins)**
- **Survey Patients Identifying Priorities (pain, halting progression/re-growth, and more)**
- **Survey Researchers on Gaps to Progress and What is Needed to Fill these Gaps (robust registry, sharing mouse models, donating bone samples, etc.)**

# CREATE A VILLAGE

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## Bring Together Researchers, Patients, Companies, Universities, Hospitals, Lobbyists and Gov't Agencies

- Work with FD/MAS patient groups Around the Globe to Share and Learn
- Sponsored First International Scientific Conference for FD/MAS in Bethesda and Attended 4 meetings in Europe
- Co-Lead and Assist Dr. Collins for International Alliance of Researchers for 2019 Scientific Conference
- Engage in Federal Advocacy at Government Level to Protect and Increase NIH resources
- Incentivize and Educate Pharma Companies, Hospitals and Universities to Invest in FD/MAS Research and Patient Care

# FUND MORE RESEARCH

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**Strides and Momentum presented by Dr. Collins, Dr. Boyce,  
Dr. Riminucci and Dr. Konradi**

**Getting to The Next Level by Funding Additional Innovative  
Research**

# **Personal Journey to Million Dollar Bike Ride**

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**Daughter Diagnosed with FD in 2007**

**Researched Obsessively**

Limited Treatments, Options, Scientific Research

**Chaired 2014 Patient and Family Conference**

Motivated by Prospects and NEED to Fund Research

**Discovered UPenn Orphan Disease Center Million Dollar Bike Ride (MDBR)**

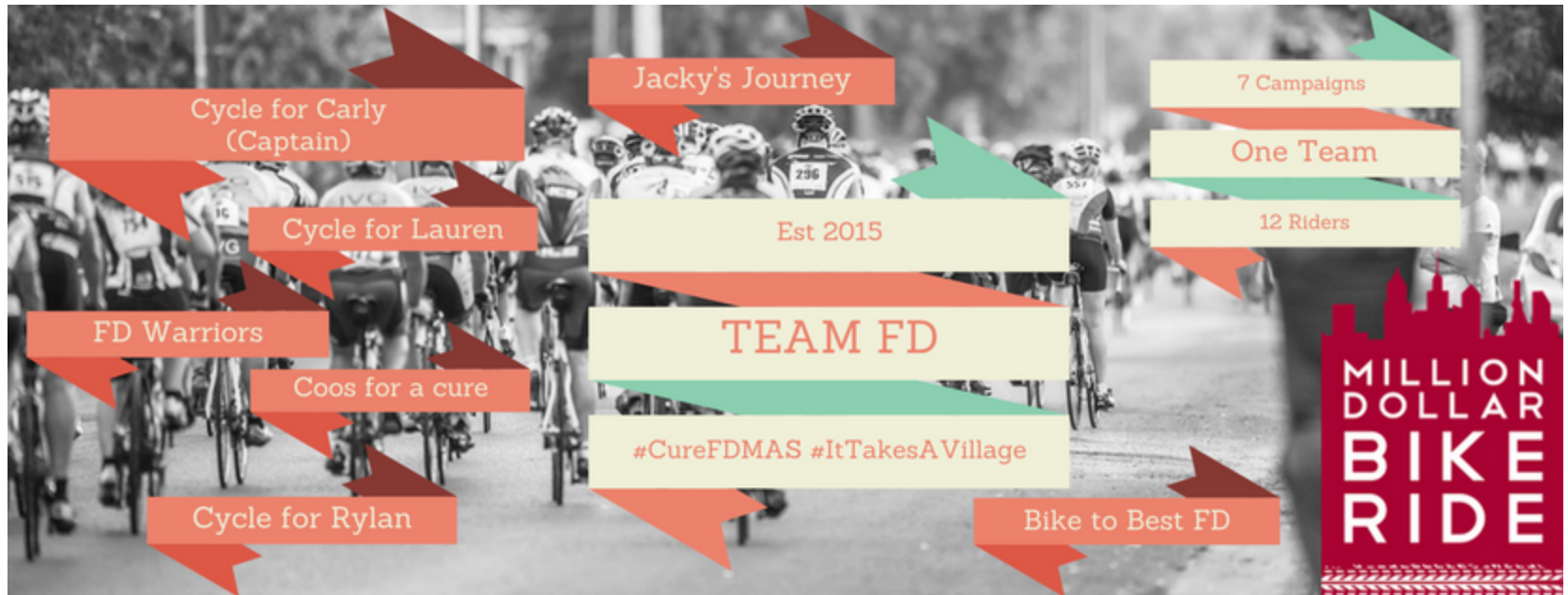
Dollar for Dollar Match up to \$50,000

Raised over \$300,000 for Research Grants 2015, 2016 and 2017

21 Exciting Grant Applications - Only 5 Awarded

MDBR 2018 is CRITICAL- Future Rides Uncertain with New Random Lottery

# Team FD



# Heart of the Village: Patient Community

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**We Can Make it Happen!!**

**#CureFDMAS**





**Thank you!**