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

How do we try achieve this monumental goal with FDF’s limited resources?
IDENTIFY THE MOST IMPACTFUL RESEARCH

• 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

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

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

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
Heart of the Village: Patient Community

We Can Make it Happen!!

#CureFDMAS
Thank you!