



FD/MAS
ALLIANCE

**2023
Impact
Report**

MISSION & FD/MAS LEADERSHIP TEAM

The FD/MAS Alliance (formerly Fibrous Dysplasia Foundation) is a community-driven 501c3 nonprofit that fosters the development of evidence-based treatments for fibrous dysplasia and McCune-Albright syndrome (FD/MAS). We advance research, provide education and channel the voices of individuals and caregivers with FD/MAS.

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Dear Donors, Friends, and Supporters,

As we gathered our thoughts for this year's annual report, we were filled with gratitude and excitement for the journey we've embarked upon together, as well as the road before us. We are delighted to share the remarkable progress we've made, thanks to your dedicated support. This report covers our fiscal year July 1, 2022 to June 30, 2023. Undoubtedly, we will miss a few things or fail to include something. Please accept our apologies in advance.

Raising Funds for Research: A Milestone Achievement

Over the past nine years, our participation in the Million Dollar Bike Ride has successfully raised over \$1 million to support research initiatives for fibrous dysplasia/McCune-Albright syndrome (FD/MAS). This achievement is a testament to the generosity and dedication of our donors, community members, and collaborators. Read on p. 8 about how our seed grants have played a crucial role in advancing scientific understanding and treatment of FD/MAS and led to greater federal funding that is spurring innovation in the field. Researchers are making tremendous strides in unraveling the mysteries of FD/MAS, and we couldn't have done it without your financial support and belief in our mission.

Launching the Patient Advisory Council (PAC): Amplifying Voices

Our patient-centered focus led us to establish the PAC in fiscal year 2023. (See pp. 6-7 & 12) The PAC is a diverse group of patients whose valuable insights guide our decision-making. By giving a voice to those directly affected by FD/MAS, we ensure that our initiatives are rooted in the real-world experiences and needs of our community.

As the Executive Director and Board President, we want to express our profound gratitude for your continued support. Together, we have achieved remarkable milestones in our journey to combat FD/MAS, and we invite you to take pride in these accomplishments. Your ongoing support is essential to our success, and we look forward to continuing this incredible journey together.

With heartfelt appreciation,



Adrienne McBride
Executive Director
FD/MAS Alliance



Anne Corvelle
Board President
FD/MAS Alliance



PATIENT SPOTLIGHT: MARA WATSON

Mara's battle with FD/MAS

began when she was a toddler, and after a seemingly minor fall she avoided putting any weight whatsoever on her leg and foot. A doctor's appointment revealed a peculiar spot on her fibula that was diagnosed as benign.

Despite multiple bone fractures, she never allowed the pain to dampen her spirits. In the third grade, she snagged her toe on a blanket, which snapped the bone in half. X-ray images showed spots on her bones, and she was diagnosed with fibrous dysplasia. Mara is now a resilient thirteen-year-old who has displayed an indomitable spirit throughout her childhood.

Living in Pullman, WA, a small rural town, the Watsons sought specialized care hours away at a Children's Hospital. The two-hour MRI session was a challenge and revealed tumors in her pelvis, femur, fibula, calcaneus, metatarsals, and toes. It was a relief when the biopsy results confirmed fibrous dysplasia and ruled out cancer on her 10th birthday. Mara received infusions, and surgery



was recommended to place a rod in her femur.

"It felt like I was overreacting, seeking information about a rod placement in her femur that wasn't even fully grown. The doctors didn't actually suggest treatment until I started asking about the merits of prophylactic surgery. We didn't realize how fragile her leg truly was until we were at a family retreat center in the woods before her planned surgery. While doing typical kid activities, her femur broke."

Mara's helicopter rescue was a testament to her composure as she conversed with the EMT, who stabilized her leg and transported her to safety. After surgery, she got around in a wheelchair during middle school and made the best of it by dressing up as Crutchy from "Newsies" for Halloween.

"The FD/MAS Alliance has been an important resource for our family. We support the Alliance because we know that it takes

Continued on page 13

DONOR SPOTLIGHT: KELLY COHEN



A Mother, a Nurse, and a Champion for FD/MAS

Kelly's connection to the FD/MAS community began with the birth of her second child, Liam who entered the world at just 4 pounds and began to lose weight instead of gaining it. Although she no longer works professionally as a nurse, she uses her training, skills, and dedication to advocate for her son and others with FD/MAS. She and her family are also

long-time donors to the FD/MAS Alliance and are dedicated to raising funds to advance our shared mission.

"Today Liam is doing great. I emphasize 'today' because as people who deal with FD/MAS know, his situation can change at the drop of a dime. Every time I think about going back to work something happens and we have to fly out to see specialists. Unless you're living in a few major cities, there's no central place to get care for FD/MAS."

“We knew that research and fundraising were critical and someone needed to get the ball rolling. So, instead of starting something from scratch, we decided to invest in the organization.”

Kelly sees funding the FD/MAS Alliance as an effective organizing presence that amplifies patient voices and pushes for clinical care and scientific progress. Kelly's passion for research and her son's well-being led her to seek out organizations dedicated to the rare disease. At first she thought she would need to start her own organization, but she eventually found the FD/MAS Alliance (then called the Fibrous Dysplasia Foundation).

“We knew that research and fundraising were critical and someone needed to get the ball rolling. So, instead of starting something from scratch, we decided to invest in the organization.”

With a brother who battled Cystic Fibrosis (CF), Kelly believes in the value of research and community support that

Continued on page 13

PATIENT ADVOCACY & EDUCATION

Amplifying the Patient Voice

Recognizing the importance of patient voices in all aspects of education and outreach, in July 2022, the FD/MAS Alliance established its first Patient Advisory Council (PAC). The PAC will guide the stories we tell, the programs we create, the research we pursue, and organizational decision-making.

With the help of our PAC members, the Alliance hopes to improve health outcomes with more patient-centered care, helping healthcare providers to understand better the unique needs and preferences of people living with FD/MAS.

Many of our PAC members also raise funds for the Alliance, share their stories, and connect with donors and medical professionals. We are so grateful. In the future, with your help, we can better integrate the patient voice in improvements for quality care, research prioritization, and clinical trial design.

Thanks to our inaugural Patient Advisory

Committee Members: Brittany Anderson, Andra Andrei, Carmel Shemmesh-Rafalowsky, Nicola Deeley, Bethany Hammond, Shelley Hebert, Genesis Medrano, Sarah Mumper, William Romero, and Olga Sanchez de la Vega.

We seek to increase advocacy and awareness and to help connect newly diagnosed patients with peer support and valuable resources. If you would like to be part of the FD/MAS Alliance Patient Advisory Council, we welcome you to visit our website or email info@fibrousdysplasia.org to receive an application.

Financial Literacy Resources Now Available Online

Patients with FD/MAS often face ongoing, as well as unexpected, medical expenses. Some people with the disease face challenges in gaining and/or maintaining employment due to health issues. Understanding supplemental benefits, health

FD/MAS Patient Priorities

Through a series of community surveys and ongoing meetings, the FD/MAS patient community articulated these priorities. We believe in multi-stakeholder, collaborative and patient-centric progress:

- Projects that feature collaborations across multiple institutions should be encouraged.
- Reagents and research tools, including animal models, must be freely accessible and deposited in a public repository without restriction.
- Clinical, translational, and mechanistic research studies must address any unmet needs in the care of FD/MAS patients and are of the utmost importance.



The Patient Advisory Council met in person at the FD/MAS conference in September 2023.
Left to Right: Nicola Deeley, Sarah Mumper, Tovah Burstein (staff), Brittany Anderson, William Romero

insurance, co-pays, deductibles, and out-of-pocket costs is essential to manage expenses effectively. It's also important for long-term planning and navigating healthcare access.

During the Summer of 2022, the FD/MAS Alliance launched the Financial Literacy 101 & 102 Training with funding from a grant from Global Genes. The two webinars are available on our website and YouTube channel. Topics covered include federal disability benefits, including Supplemental Security Income (SSI), Social Security

Disability Insurance (SSDI), and tips for working while on SSI/SSDI.

A big thank you to Global Genes for their financial literacy grant and to Michael Beloff, CFP, ChSNC Wealth Advisor at Belvedere Wealth Partners, and Caroline Fuchs, CAE, for donating their time, financial and digital strategy expertise to the FD/MAS community for this invaluable resource.

FD/MAS RESEARCH FUNDING: A REMARKABLE YEAR

In 2023, together, we raised \$161,284. Thanks to your contributions, the Alliance will be able to award up to four grants in 2024. The Request for Applications closed in September 2023, and our Scientific Advisory Council will advise and assist the University of Pennsylvania Orphan Disease Center Staff in selecting awardees in early 2024.

The Alliance raises money for seed grants through The Million Dollar Bike Ride (MDBR) hosted by Penn Medicine's Orphan Disease Center. Seed grants are awarded to researchers or research teams to develop and test new ideas or concepts to advance scientific knowledge about fibrous dysplasia and McCune-Albright Syndrome.

These grants play a crucial role in driving innovation, generating preliminary data, demonstrating proof-of-concept, and leveraging larger federal grants. They also serve to stimulate scientific interest in the pursuit of a cure.

In addition to raising funds for the grants, the Alliance has also successfully advocated for the inclusion of FD/MAS research in the Peer Reviewed Medical Research Program (PRMRP) of the Department of Defense for the past four years. This important work has led to a successful FD/MAS grant from the Department of Defense for the first time.

Thanks to Tim Barnicle, grandfather to an FD/MAS patient, and pro bono Strategic Consultant Becky Halkias for volunteering

their expertise. Their guidance has been instrumental in unlocking this opportunity for FD/MAS researchers and has the potential to significantly advance our understanding of this disease.

In 2023, FD/MAS Researchers received more than \$6.7 million in federal funding

- A grant for \$3,346,788 was awarded by the Department of Defense to Yingzi Yang, PhD, and Marc Wein, MD, for a four-year study of fibrous dysplasia (FD).
- An R01 Grant for \$3,360,000 was awarded by the National Institutes of Health (NIH) to: Edward Hsiao, PhD, MD; Fernando Fierro, MD; and Kelly Wentworth, MD, and Richard Nissenson, PhD for a five-year study of FD treatment.

Both sets of grant recipients include previous beneficiaries of MDBR grants, underscoring the Alliance's pivotal role in FD/MAS research.

The past year has been a remarkable one for FD/MAS research, with significant advancements, increased federal support, and a commitment to scientific exploration. The FD/MAS Alliance is steadfast in its pursuit of a cure and improved treatment options for people affected by FD/MAS.

The MDBR announced two \$80,000 FD/MAS research grant awards in 2023:

- Dr. Anne-Marie Heegaard, University of Copenhagen, “Pain and Analgesic Mechanisms in a Mouse Model of Fibrous Dysplasia.”
- Dr. Mara Riminucci, Department of Molecular Medicine, Sapienza University of Rome, “Investigating Key Clinical Aspects of Fibrous Dysplasia of Bone in a Transgenic Mouse Model (EF1a-Gsar201C mice) of the Disease: Pain, Effect of Anti-resorptive Treatments and ‘Rebound’ Phenomenon.”

“Funding from Team FD/MAS and the MDBR is vital. These smaller pilot studies allow researchers to rapidly explore new ideas, facilitate collaborations, and test treatment strategies that have the potential to support better patient care, larger research projects, and breakthroughs in therapy.”

— Edward Hsiao, MD, PhD



Team FD/MAS Million Dollar Bike Ride Awardees who attended our 2023 FD/MAS Community Conference: Facing the Future - Together.
Upper left to right: E. Hsiao, B. Palmisano, A. Heegaard, F. Fierro, J. Charles. Lower left to right: K. Wentworth, M. Riminucci, C. Hoffman, Y. Yang (Missing: J.S. Gutkind)

FD/MAS DONORS: FISCAL YEAR 2023

Thank you to all of our donors whether listed here or not. We would not be here without you. This donor roll call includes those who contributed \$100 or more during our 2023 Fiscal Year (July 1, 2022 - June 30, 2023). If we missed you or made an error, please accept our apologies and let us know.

\$50K+

Justin & Kelly Cohen*

\$25,000–\$50,000

Echo Bay Foundation

\$10,000–\$25,000

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CONFERENCE HIGHLIGHTS



ICFDMAS at the 2023 FD/MAS Community Conference
 Left to right: Martine Dekker- Grootveld, Member; Tovah Burstein, Acting Secretary; Dr. Michael T. Collins, Advisor; Dr. Natasha Appelman-Dijkstra; Director, Adrienne McBride, Director

We spent much of the fiscal year planning for the September 2023 FD/MAS Community Conference. We focused on creating a week-end that could combine patient-centered science and real-world strategies for patients

and families living with fibrous dysplasia and McCune-Albright syndrome (FD/MAS).

The FD/MAS Alliance took pride in hosting the first-ever gathering of the recently incorporated International Consortium for FD/MAS (ICFDMAS). This consortium brings together researchers and patient support groups from 13 countries, and our organization played a crucial role in its formation, serving as a testament to the dedication of the FD/MAS Alliance. One outcome of this meeting will be the revised Best Practice Management Guidelines for fibrous dysplasia/ McCune-Albright syndrome.

FACES OF FD/MAS VIDEO STORYTELLING



Nicola Deeley, FD/MAS Patient, Alliance Board Director, and Patient Advisory Council Member being filmed for the FACES project.

Program Launched

How do you explain a disease that is as complex, varying, and rare as fibrous dysplasia and McCune-Albright syndrome? Through stories, narrative context, and giving the experience a face.

Faces of FD/MAS is an FD/MAS Alliance video project envisioned and guided by our Patient Advisory Council. The project aims to capture the diverse experiences of those in the fibrous dysplasia/McCune-Albright syndrome community. In fiscal year 2023, we identified a videographer and planned to film in person at the FD/MAS Alliance Community Conference in September 2023. Our Patient Advisory Council also helped to guide the selection process to maximize the diversity of experiences represented in our storytelling efforts. We will showcase the series during FD/MAS Global Awareness Week in February 2024.

PATIENT SPOTLIGHT (CONTINUED)



grassroots efforts before we can expect to see significant research advances. Mara has been in so much pain as a result of her fibrous dysplasia. There has to be a better solution for people who struggle with

this disease.” Mara’s tenacity extends to her work ethic at school. Despite facing pain flare-ups and seven days on the couch following infusions, she never misses assignments or deadlines.

“During our family sabbatical in Spain, Mara raised funds for the FD/MAS Alliance by getting sponsors for her eight-mile walk on the Camino de Santiago. This year, she organized ‘Team FDMAS,’ composed of 19 kids and 13 adults who walked seven miles from Moscow, ID, to Pullman, WA. The funds Mara raised benefited both the

FD/MAS Alliance and a brain cancer organization, honoring a family friend battling the disease.

“The FD/MAS Alliance has been an important resource for our family. We support the Alliance because we know that it takes grassroots efforts before we can expect to see significant research advances. Mara has been in so much pain as a result of her fibrous dysplasia. There has to be a better solution for people who struggle with this disease.”

DONOR SPOTLIGHT (CONTINUED)

the FD/MAS Alliance provides. She sees parallels in how the treatment of CF has transformed lives in the past 30 years and has high hopes for FD/MAS.

“With new treatments, CF patients no longer have to suffer in the way they did a few decades ago. That’s what we’re going to do with FD/MAS.”

For those who feel their resources are limited or

feel daunted by the idea of fundraising, she admits that fundraising is hard, but that fundraising connects people with their community and empowers them to help move the needle on research and treatment.

“People want to help, they just don’t know how. Your story and your belief in change for the better hold power. Knowing that

the funds are going to the right place helps people feel good about donating.”

“If the community of people with FD/MAS and their families aren’t bound together to push this train down the tracks, it’s not going to happen. But together, we can bring hope and healing to countless lives.”

ACCOMPLISHMENTS FISCAL YEAR 2023 (JULY 1, 2022 – JUNE 30, 2023)

RESEARCH

- 2023 Million Dollar Bike Ride (MDBR) raises \$161,620 for FD/MAS. Team FD/MAS outperformed all other MDBR teams yet again, demonstrating our remarkable fundraising prowess.
- FD/MAS Researchers awarded more than \$6.7 million in federal funding.
- FD/MAS Patient Registry now has more than 1,000 patients (48 states/43 countries).

See pp. 8-9 for more details about FD/MAS Research

PATIENT ADVOCACY & EDUCATION

- Launched the new Patient Advisory Council (PAC).
- Hosted Financial Literacy 101 & 102 Training with online resources.
- Storytelling Initiative: Faces of FD/MAS video storytelling program launched.

See pp. 6-7 & 12 for more details about Patient Advocacy & Education

ORGANIZATIONAL EFFECTIVENESS

- Planned for “Facing the Future - Together” an FD/MAS Community & Research Conference.
- Active as a founding member and organizer of the inaugural meeting of the newly incorporated International Consortium for FDMAS (ICFDMAS).
- Welcomed new leadership to our Board of Directors, Medical Advisory Council, and Scientific Advisory Council.

FINANCIALS FISCAL YEAR 2023

REVENUE

Individual Contributions	\$143,834
Million Dollar Bike Ride	\$122,476
In-Kind	\$94,291
Grants-Non governmental	\$7,624
Restricted Revenue	\$13,707
Event	\$8,695
Interest	\$133

TOTAL REVENUE **\$390,760**

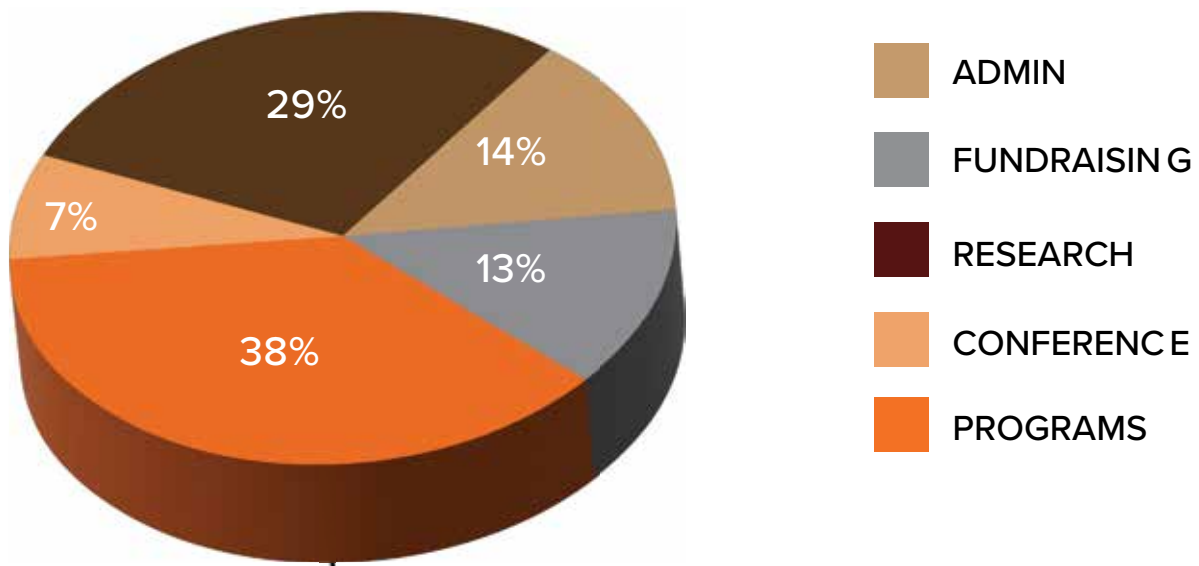
EXPENSES

Administrative	\$64,386
Fundraising and Marketing	\$60,254
Programs	\$177,717
Conference	\$35,156
Research	\$134,684

TOTAL EXPENDITURES **\$472,194**

NOTE: The audited figures do not account for an additional \$52,374 raised by the FD/MAS Alliance for the 2023 Million Dollar Bike Ride. This amount was generated through UPENN matching funds, registration fees, and support from the Association MASFD. In 2023, the FD/MAS Alliance played a crucial role in helping MDBR awardees secure over \$6 million in research funding for FD/MAS. See p. 8 for more details

FY 2023 EXPENSES



MONTHLY DONORS MAKE A DIFFERENCE! JOIN CHARLIE'S ANGELS



Charlie Harles (1946 - 2019) founded the FD/MAS Alliance (formerly known as the Fibrous Dysplasia Foundation) in 2004 and served as its President through 2015. In honor of his ongoing dedication to research, outreach and building a strong patient community, we have named our recurring donor program after him.

Monthly donors are invested in our mission in a deep way, by stretching their gifts throughout the year, making it easy to contribute more in a convenient way. Charlie Harles's Angels also symbolize an army of support that lifts up our community and gives us all strength. If you are not already a monthly donor to the FD/MAS Alliance, please consider joining us and dedicating your monthly gifts in honor of Charlie, a loved one, or someone who inspires you.



FD/MAS Alliance
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