

Fibromuscular Dysplasia Society of America 2023 Annual Report



**Happy 20th Anniversary to FMDSA!
FMDSA continues to grow far beyond our original
hopes and dreams.**

FMDSA 26777 Lorain Rd, Suite 311, North Olmsted, Ohio 44070

Fibromuscular Dysplasia Society of America

2023 Annual Report

Dear Members, Partners, and Supporters,

Wow, we've come a long way! We are celebrating two decades of progress for the Fibromuscular Dysplasia Society of America! Our commitment to advancing research, supporting patients, and raising awareness is stronger than ever. We have made notable strides in understanding FMD and advocating for those affected. We are proud to share our achievements and express our deep gratitude to everyone who has contributed to our mission. Your support has been invaluable and integral to our success.

In 2023, we hosted our first in-person Annual Meeting since 2019. This was a highlight for many patients and an opportunity for FMD researchers to gather for the first time since the pandemic began. Once again, our sponsors were here for us!

Throughout the year, FMDSA continued its efforts to raise awareness about FMD through various channels, including a press release, social media campaigns, webinars, and educational materials. These initiatives successfully reached a wider audience, providing valuable information to patients and healthcare professionals alike. By enhancing understanding of FMD diagnosis, treatment options, and management strategies, we empowered individuals with crucial knowledge.

FMDSA recognizes the importance of collaboration in achieving our goals. Over the past year, we forged partnerships with other organizations, healthcare institutions, and advocacy groups, amplifying our collective impact and strengthening our advocacy efforts. These collaborations have facilitated the exchange of knowledge, resources, and expertise, ultimately benefiting the FMD community. Our advocacy efforts have helped elevate FMD on the healthcare agenda, paving the way for advancements in diagnosis, treatment, and support services.

In addition to advocacy, FMDSA continued to cultivate a supportive community for individuals living with FMD and their families. Our online support group and social media platforms served as a way for members to connect, share experiences, and provide mutual support. Moreover, our accessible online resources and volunteer support ensured guidance and assistance whenever needed.

As stewards of FMDSA's resources, we have remained dedicated to ensuring financial transparency. In 2023, we received the GuideStar Platinum Seal of Transparency. Our financial practices have enabled us to maximize the impact of every dollar invested in our programs and initiatives. We are committed to upholding the highest standards of accountability and transparency, providing our members with confidence in how their contributions are utilized.

Sincerely,

Bradley Daar,
FMDSA President

Fibromuscular Dysplasia Society of America

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On March 11, 2003, around a kitchen table, several Fibromuscular Dysplasia (FMD) patients, family, and friends gathered to officially form The Fibromuscular Dysplasia Society of America, Inc. (FMDSA). Dr. Jeffrey Olin and Executive Director Pamela Mace are two of the original members who are still involved in the organization today. We owe our success to the countless number of volunteers, board members, patients, researchers, and donors who have supported the organization over the last 20 years.

Our growth since the founding of FMDSA has given our organization a worldwide presence and helped us to create awareness on a scale we never imagined. We have educated patients and healthcare providers globally. Our efforts have increased awareness, education, collaboration, and research, which has led to a better understanding of the disease and resulted in proper diagnosis and better treatment of patients with FMD. One of our proudest accomplishments to date has been the establishment of the United States Registry for Fibromuscular Dysplasia (which is solely funded by FMDSA and our patient community), along with inspiring the establishment of FMD Clinics throughout the United States.

By uniting physicians with an interest in FMD throughout the world, we assisted in the development of the International FMD Research Network. May 2014 was the first International FMD Research Symposium. The Network team has since hosted meetings globally, harmonized definitions, and identified research priorities. They have already identified multiple genes involved in FMD and they are attempting to address the many issues specific to FMD and FMD-related diseases.

Awareness, Education, and Research Since 2003

The Fibromuscular Dysplasia Society of America, Inc. was founded on March 11, 2003, and received tax-exempt status on October 7, 2003. FMDSA is a Delaware nonprofit corporation that is classified by the IRS as exempt under IRC Section 501(c)(3) and as a "public charity" under IRC Section 509. Donations from individuals and corporations are tax-deductible to the extent permitted by law.

The Fibromuscular Dysplasia Society of America is a public health charity working towards better diagnosis and treatment of Fibromuscular Dysplasia (FMD). We do this by building awareness of FMD, funding research activities, providing patient support, and educating patients and the healthcare community.

FMDSA has become the recognized leader in the support of Fibromuscular Dysplasia (FMD) awareness, education and research. We will continue to achieve our goals by successfully raising money for the purpose of awarding FMD research grants, building awareness programs, and educating the public and medical communities about FMD.

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FMD Patient Registry

Fibromuscular dysplasia (FMD) is a non-atherosclerotic, non-inflammatory vascular disease that most commonly affects the renal and internal carotid arteries but has been described in almost every arterial bed in the body. It may be entirely asymptomatic and discovered incidentally or it may present with a variety of symptoms.

The prevalence and natural history of FMD is not known. Since FMD may involve many different organ systems, a number of different specialists may see patients with FMD. Patients often have a difficult time finding physicians who have experience in treating patients with fibromuscular dysplasia. These individuals all tell a similar story: it took too long for my condition to be diagnosed; physicians do not know very much about this condition; health care providers do not know how to treat patients with FMD; there is no research being conducted on FMD. This lack of medical knowledge leads to unclear therapies as well as a tremendous amount of anxiety on the part of the patient and their family members.

In 2007, the Fibromuscular Dysplasia Society of America (FMDSA) began a data registry to increase understanding of the disease and its treatment. The specific goals of this registry are to identify patient characteristics associated with FMD, potential markers of the disease, and commonly used imaging and treatment modalities. Michigan Clinical Outcomes Research and Reporting Program (MCOORP) is the coordinating center for the FMD Registry. Beginning initially with 7 sites, the first patient was entered into the online database at the beginning of 2009.

The United States Registry for Fibromuscular Dysplasia continues to grow yearly and has grown to be the largest FMD database in the world, with well over 4,100 patients! Not a day goes by that a newly diagnosed patient does not contact us. There are currently 20 active participating sites, and Atrium Health in North Carolina and Texas Heart Institute joined the registry this year.



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FMD Awareness/ Education and Support

Vancouver SCAD Conference

Pam Mace, executive director, participated in the conference and spoke on Living with Fibromuscular Dysplasia. Pam and Dr. Ester Kim led the patient session, during which patients had the opportunity to ask questions.

University of Michigan

Pamela Mace, Executive Director, presented FMD and SCAD to a group of undergraduate and graduate medical students participating in the MCORRP Summer Internship Program. The students have the opportunity to shadow physicians, collect data, analyze data, enter data, and conduct their own research. Over the years, many students have chosen to research FMD, which helps us better understand the disease and its relationship to SCAD.

Neuroscience Expo, Louisville, Kentucky

Board Member Rosie Miklavcic and patient members of FMDSA attended the expo with the goal of sharing their stories, raising awareness, and educating as many medical professionals as possible. The event was well attended, and they accomplished their goals.

Women's Health Month

FMDSA Board Member Christi Eberhardt was featured Nationally on the American Heart Association's website "Stories From The Heart." Christi shared her story of going into cardiac arrest at the age of 29 and then 12 years later suffering a SCAD heart attack, which led to her FMD diagnosis.

Cleveland Marathon

The FMDSA once again participated in the Cleveland Marathon as an official charity. We had a team of runners and also a group of volunteers working at the expo and marathon finish line. Our participation gave us the opportunity to fundraise and raise awareness for FMD.

Elfus Sports Management 2nd Inaugural Charity Golf Tournament, Carlsbad, California

The event was hosted by Brian Elfus, whose wife was diagnosed with FMD. FMDSA was one of two benefiting charities, and FMDSA received a check for \$10,000.

The Fibromuscular Dysplasia (FMD) and Arterial Dissection Virtual Support Group hosted by Dr. Heather Gornik. Pam Mace and University Hospital

- Four University Hospital Zoom support group meetings were held during 2023. Topics included "Headache Management and the FMD Patient" and "Women's Health and Menopause."

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- **Support Group and Social Media:** Expanded our network of social media and online Inspire support group.
- **Patient Support Requests:** Our volunteers assisted and provided information to over 1,000 individuals through calls, emails, and messenger social media platforms.
- **Educational Resources:** Updated and distributed educational materials, including brochures and a comprehensive patient toolbox guide.
- **FMD Awareness Month:** Successfully ran a nationwide campaign during May, increasing public awareness through social media, events, and media coverage. New this year were landmark lightings throughout the United States and Canada. Some of the landmarks that participated in our awareness campaign included The Rock and Roll Hall of Fame, Niagara Falls, The Mid-Hudson Bridge, The Wells Fargo Building, Zakim and Longfellow Bridges, and the Terminal Tower in Cleveland, Ohio.



FMDSA Website

Our website contains a wealth of knowledge about Fibromuscular Dysplasia, including up-to-date research articles in the Research Network Section. We also offer a robust section of materials under “Patient Support.”

FMDSA – YouTube Channel

Presentations from our virtual meeting have been made available to patients and the public worldwide. The videos, along with other educational videos, can all be found on our YouTube Channel. They are offered for free.

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Awards

Pamela Mace, executive director, and DR. Jeffrey Olin, Chair of the medical advisory board, were both nominated for the Global Genes 2023 Champions of Hope Award for the Rare Champion in Advocacy.

Research/ Education and Support Worldwide

The FMDSA has a worldwide presence and offers support to patients globally. We continue to identify volunteers and resources for patients around the world. Currently, three board members reside outside of the United States. Board member Cathlin Jamison oversees the European Association FMD-BE. She works closely with Prof. Alexandre Persu; together, they have worked to develop resources for patients in at least eight languages. Rochelle Desrochers and Jezette Vicedor reside in Canada, where many of our patients live. Outside of the United States the majority of patients contacting us are from Canada.

Community Grant

FMDSA received a \$2,000 community grant from Walmart to use towards awareness and education.

2023 Faces of FMD



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Photo gallery from highlights of 2023

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**Our Financial information can be found on our website or by contacting
us at admin@fmdsa.org**

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2022 EXECUTIVE DIRECTOR AND BOARD OF DIRECTORS



Pamela Mace, RN
Executive Director
FMD patient



Dr. Bradley Daar, DDS
President
brad.daar@fmdsa.org

Rosie Miklavcic, RN
Treasurer

Directors-At-Large

Rochelle DesRochers

Cathlin Jamison

Jezette Vicedor

Allision Gaines

Christy Eberhardt -term expired mid-2023

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Medical Advisory Board



Jeffrey W. Olin, DO, FACP, FACC
Board Chair
Professor of Medicine
Director, Vascular Medicine
Zena and Michael A. Wiener
Cardiovascular Institute
Mount Sinai School of Medicine
New York, New York



Heather L. Gornik, MD
Co-Chair, Vascular Center at the
Harrington Heart and Vascular
Institute



Kevin E. Meyers, MD
Pediatric Nephrologist
Assistant Professor of Pediatrics
The Children's Hospital of
Philadelphia and University of
Pennsylvania
Philadelphia, Pennsylvania



Santhi K. Ganesh, M.D.
Assistant Professor of Medicine
Division of Cardiovascular Medicine
University of Michigan Health System



James C. Stanley, MD
Professor of Surgery - Retired
Handleman Research Professor of Vascular
Surgery
University of Michigan Health System

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Medical Advisory Board – Continued



Alan H. Matsumoto, M.D., FACR, FSIR
FAHA Chair and Theodore E. Keats Professor of
Radiology
Department of Radiology and Medical Imaging
University of Virginia Health System

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ADVISORY COUNCIL

Kim A. Eagle, MD

Albion Walter Hewlett Professor of Internal Medicine
Chief of Clinical Cardiovascular Medicine
Director and Education Lead, Cardiovascular Center
Ann Arbor, Michigan

Robert D. Kubic, MBA

Chief Operating Officer
Honigman Miller Schwartz and Cohn LLP
Detroit, Michigan

Kay Tanner, JD

Former FMDSA Board Member
Retired- Ethics Investigator, Global Ethics & Compliance Office
Dell Technologies

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Participating Centers and Principal Investigator

1. Baptist Health South Florida, Miami, FL (Barry Katzen, MD)
2. Children's Hospital of Philadelphia, Philadelphia, PA (Kevin Meyers, MD)
3. The Cleveland Clinic Foundation, Cleveland, Ohio (Natalia Fendrikova Mahlay, MD)
4. Emory University, Atlanta, GA (Bryan Wells, MD)
5. Massachusetts General Hospital, Boston, MA, USA (Ido Weinberg, MD, MSc)
6. Mount Sinai School of Medicine, New York, New York (Jeffrey Olin, MD)
7. Northshore Cardiovascular Institute, Skokie, IL, USA (Kambiz Zorriasateyn, MD)
8. North Central Heart Institute, Sioux Falls, South Dakota (Michael Bacharach, MD)
9. Prisma Health, Greenville, South Carolina USA (Andrew Dicks, MD)
10. Seattle Children's Hospital, Seattle, Washington (Susan Halbach, MD)
11. Stanford Medicine, Stanford, CA (Eri Fukaya, MD)
12. University Hospitals Cleveland Medical Center, Cleveland, OH (Heather Gornik, MD)
13. University of Colorado, Aurora, CO (Kevin Rogers, MD)
14. University of Kansas, Kansas City, KS (Kamal Gupta, MD)
15. University of Michigan Health System, Ann Arbor, Michigan (James Froehlich, MD)
16. University of Virginia (UVA), Charlottesville, VA (Aditya Sharma, MD)
17. Vanderbilt University, Nashville, TN (Aaron Aday, MD)
18. Ottawa Hospital, Ontario, Canada (Dr. Swapnil Hiremath)
19. Sanger Heart & Vascular Institute, Atrium Health, Charlotte, NC (Ester Kim, MD)
20. The Texas Heart Institute, Houston, Texas (Stephanie Coulter, MD)