Fibromuscular Dysplasia Society of America
2022 Annual Report

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

Fibromuscular Dysplasia Society of America
2022 Annual Report

Dear Friends and Members of the FMDSA,

As we reflect on the past year, I am thrilled to share with you the highlights and accomplishments of the Fibromuscular Dysplasia Society of America (FMDSA) in our annual report. This document encapsulates the collective efforts and achievements of our organization in advancing our mission to support, educate, and advocate for individuals affected by fibromuscular dysplasia (FMD).

Throughout the year, FMDSA continued to raise awareness about FMD through various channels, including social media campaigns, webinars, and educational materials. We reached a broader audience and provided valuable information to both patients and healthcare professionals, empowering them with knowledge about FMD diagnosis, treatment options, and management strategies.

FMDSA remains committed to supporting research endeavors aimed at better understanding FMD and improving patient outcomes. We actively collaborated with researchers, clinicians, and other stakeholders to advocate for increased funding and attention towards FMD research. Our advocacy efforts have helped elevate FMD on the healthcare agenda, paving the way for advancements in diagnosis, treatment, and support services.

FMDSA continued to foster a strong sense of community and support for individuals living with FMD and their families. Our online support groups provide a platform for members to connect, share experiences, and offer mutual support. Additionally, our online resources and volunteer support help remained accessible to those in need, offering guidance and assistance whenever required.

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.

As stewards of FMDSA's resources, we have remained dedicated to ensuring financial sustainability and transparency. In 2022 we received the GuideStar 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.

In conclusion, the past year has been marked by significant achievements and milestones for FMDSA. None of this would have been possible without the unwavering support and dedication of our members, volunteers, donors, and partners. We are excited about the opportunities that lie ahead and remain steadfast in our commitment to serving the FMD community.

Bradley Daar, FMDSA President

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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 that are still involved in the organization today. We owe our success to the countless number of volunteers, board members, patients, researchers and donors that have supported the organization over the last 19 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 and 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 which 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 with the goal of increasing 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 (MCORRP) 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 3,750 patients! Due to the pandemic data entry and publications slowed but we are getting back on track. This year we added our **first International registry center. The Ottawa hospital in Ontario, Canada is our newest center and with this addition the name of the registry was changed to the North American registry for Fibromuscular Dysplasia. To date 3758 patients have participated in the registry.**

MCORRP
MICHIGAN CARDIOVASCULAR OUTCOMES
RESEARCH AND REPORTING PROGRAM

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FMD Awareness/ Education and Support

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, perform data collection, analyses, and data entry. They also have the opportunity to conduct their own research. Over the years many students have chosen to research FMD which helps us to better understand the disease and its relationship to SCAD.

Health Design Podcast

Pam Mace, Executive Director, was interviewed by Dr. Jiwa Moyez from Victoria, Australia. Dr. Moyez is the Editor- in- Chief of the Journal of Health Design. He is also an associate dean and professor of Health Innovation at the Melbourne Clinical School. Dr, Moyez is also a practicing general practitioner in Melbourne, Australia. His podcasts are shared within the medical community, and they are publicly available worldwide.

Go Red for Women – Akron, Ohio

Board Member, Christi Eberhardt shared her story of survival from sudden cardiac arrest and a spontaneous coronary artery dissection which ultimately led to her being diagnosed with FMD. This is always a very well attended event and great opportunity to raise awareness.

Neuroscience Expo, Louisville, Kentucky

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

National Organization for Rare Disorders (NORD), Cleveland, Ohio

Executive director, Pam Mace was invited to present at the Living Rare, Living Stronger Patient and Family Forum in Cleveland, Ohio. Pam had the opportunity to share her medical journey and discuss rare disease onset and diagnosis in adulthood. She also discussed patient registries and the importance of research.

Pediatric Renovascular Sympossium, Ann Arbor, Michigan

This symposium draws pediatric experts worldwide and Pam Mace had the opportunity to participate and raise awareness of FMD and the FMDSA.

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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. The Marathon usually held in May each year was postponed until October due to the pandemic and government restrictions placed on gatherings.

Elfus Sports Management First 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. Pam Mace attended and had the opportunity to discuss what FMD is and share information about FMDSA and research.

Zoom Meetings/Webinars offered in 2022

- Jan 18th “Headache Management and the FMD Patient” Dr. Heather Gornik (University Hospital in Cleveland) and Pam Mace along with guest speaker Deborah Reed, MD from University Hospital in Cleveland.
- March 18th “Overview on FMD” Executive Director Pam Mace along with Dr, Bryan Wells from Emory Healthcare in Atlanta, Georgia.
- April 19th University Hospital “Recent Medical Literature Review” with Dr. Heather Gornik
- July 12th University Hospital with Dr. Heather Gornik “Guest speaker Emma Greenwood from Whooshers.com. An update on pulsatile tinnitus.
- October 18th “Renal FMD and Kidney Health”. Dr. Heather Gornik, Pam Mace and guest speaker Aparna Padiyar, MD

FMDSA Website

Many hours were spent this year updating and adding materials to our website at FMDSA.org.
A wealth of knowledge pertaining to Fibromuscular Dysplasia, including up to date research articles in the Research Network Section, can be found on our website. 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 can all be found on our YouTube Channel, along with other educational videos. They are offered for free.

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Awards
Medical advisory Board Member, Dr. Heather Gornik named the Inaugural John B. Lally Family Master Clinician in FMD and Vascular Care. Funding received from this position will create a biorepository of blood and urine samples to catalyze FMD research.

Executive Director, Pam Mace and Medical Advisory Board Chair, Dr. Jeffrey Olin were both nominated as Global Genes " Champions of Hope"

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.

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FINANCIAL INFORMATION PREPARED FROM FINANCIAL STATEMENTS

Statement of Financial Positions

Deember 31, 2021 and 2022

	2021	2022
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	$ 199,366	$ 175,125
Total Assets	$ 199,366	$ 175,125
LIABILITIES AND NETASSETS		
CURRENT LIABILITIES		
Accounts payable	$ 6,433	$ 2,634
Total Current Liabilities	$ 6,433	$2,634
NET ASSETS WITHOUT DONOR RESTRICTIONS	192,933	172,491
Total Liabilities and Net Assets	199,366	175,125

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	2021	2022
SUPPORT AND REVENUE		
Contributions and grants	188,698	142,236
PPP Loan Forgiveness	13,900	0
Total Public Support	**$ 202,598**	**$ 142,236**
Other revenue:		
Investment Income	22	11
Total support and revenue without restrictions	**202,620**	**142,247**
EXPENSES		
Program services	114,737	135,639
Fundraising	19,490	14,849
General and administration	23,519	12,201
Total expenses	**157,746**	**162,689**
Change in assets without donor restrictions	44,874	20,442
Net assets without donor restrictions at beginning of year	148,059	192,933
Net assets	**192,933**	**172,491**

Statement of Functional Expenses
For the Year Ended December 31, 2021

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	Program Services	**Fundraising**	**General and Administrative**	**Total**
Patient Registry	50,000			50,000
Fundraising Fees	0	2,002	0	2,002
Accounting and Legal	0	0	4,953	4,953
Salaries and Payroll Taxes	51,473	10,286	8,112	69,851
Supplies	$119	285	1,638	2,042
Telecommunications	0	0	941	941
Information Technology	$ 3,259	2,815	151	6,225
Insurance	0	0	2,310	2,310
Postage and Mailing Services	22	288	0	310
Printing and copying	305	160	0	465
Facility and Equipment Expenses	0	0	4,720	4,720
Travel and Meetings	9,257	0	95	9,352
Miscellaneous	200	0	370	570
Website	0	654	0	654
Advertising	122	0	229	351
Business Registration Fees	0	3,000	0	3,000
	$ 114,737	**$ 19,490**	**$ 23,519**	**$ 157,746**

For the Year Ended December 31, 2022

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	Program Services	Fundraising	General and Administrative	Total
Patient Registry	50,000	0	0	50,000
Fundraising Fees	0	4,805	0	4,805
Accounting and Legal	0	0	5,746	5,746
Contracted services	0	0	0	0
Salaries and Payroll Taxes	69,342	3,109	4,688	77,139
Supplies	1,273	44	69	1,386
Telecommunications	752	34	54	840
Information Technology	2,218	3,101	105	5,424
Insurance	1,575	66	960	2,601
Postage and Mailing Services	502	146	23	671
Printing and copying	171	8	12	191
Facility and Equipment Expenses	3,607	461	231	4,299
Travel and Meetings	4,778	468	0	5,246
Miscellaneous	200	139	313	652
Business Registration Fees	0	2,458	0	2,458
Website		10		10
Advertising	1,221	0	0	1,221
	$ 135,639	**$ 14,849**	**$ 12,201**	**$ 162,689**

2022 EXECUTIVE DIRECTOR AND BOARD OF DIRECTORS

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Pamela Mace, **RN**
Executive Director
FMD patient

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

Rosie Miklavcic, RN
Treasurer

Directors-At-Large
Virginia Edleman – Secretary -retired 2022
Lisa foster – retired 2022
Claudia Klime -retired 2022
Rochelle DesRochers
Christi Eberhardt

New Board Members in 2022
Cathlin Jamison
Jezette Vicedor
Allision Gaines

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Medical Advisory Board

Jeffrey W. Olin, DO, FACP, FACC
Board Chairman
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
UH Cleveland Medical Center
Cleveland, Ohio

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
Handleman Research Professor of Vascular
Surgery
University of Michigan Health System

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

Michael R. Jaff, DO, FACC, FAH
Associate Professor of Medicine, Harvard Medical School. Medical Director, Vascular Center-Vascular Diagnostic Laboratory-Vascular Ultrasound Core Laboratory

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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
Ethics Investigator, Global Ethics & Compliance Office
Dell Technologies

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FMD

The US Registry for Fibromuscular Dysplasia

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 (Bruce Gray, 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 (Esther Kim, MD)
18. Ottawa Hospital, Ontario, Canada (Dr. Swapnil Hiremath)