

THE EDS MOVEMENT

TheVEDSMovement.org

A Division of The Marfan Foundation

DIRECTORY OF MEDICAL INSTITUTIONS

The Institution Directory provides detailed information about each of the sites to help patients make more informed decisions about the care they receive. The Foundation does not endorse or recommend individual healthcare providers. You are responsible for interviewing and selecting a practitioner. The institutions listed vary greatly in size, staff training, and services offered. We are happy to discuss options with you for your specific situation, if needed. Healthcare provider information is supplied solely by the providers themselves. All information is self-reported and unverified. Clicking on the hyperlinks below will open new documents.

Hospitals listed here, including children's hospitals, accept patients of all ages, unless otherwise noted.

Alabama

[University of Alabama at Birmingham Children's of Alabama](#)

UAB Marfan Syndrome and Related Disorders Clinic
9100 Women & Infants Center
1700 6th Ave S.
Birmingham, AL 35233

Referral necessary

Medical Director:

Walter H. Johnson, Jr., MD
Nathaniel H. Robin, MD

Contact:

Ina Schaffer, Clinical Program Coordinator II
Phone: 205-996-2365
Email: ischaffer@uabmc.edu

Arizona

[Mayo Clinic – Arizona](#)

Comprehensive Aortic Diseases Center
5777 E. Mayo Blvd
Phoenix, AZ 85054

Second Location:

13400 E. Shea Blvd
Scottsdale, AZ 85259

Clinic serves 16 years and older

Medical Director:

David S. Majdalany, MD

Contact:

April Jordan-Kramer
Phone: 480-301-8200
Email: jordan-kramer.april@mayo.edu

California

Hoag Hospital

Hoag Marfan Syndrome and Related Conditions Program
(Located within the Elaine & Robert Matranga Aortic Center)
One Hoag Dr
Newport Beach, CA 92663

Contact:

Meg Boeglin, BSN, RN
Phone: 949-764-8468
Email: megan.boeglin@hoag.org

Medical Director:

David H. Liang, MD, PhD*

*Member, The Marfan Foundation Professional Advisory Board
Updated August 2023

*California continued***Loma Linda University Medical Center**

International Heart Center
11234 Anderson St
Loma Linda, CA 92354

Medical Director:
Padmini Varadarajan, MD

Rady Children's Hospital of San Diego

3020 Children's Way
San Diego, CA 92123

Clinic serves children to age 25

Medical Director:
Paul Grossfeld, MD

Stanford Children's Health

Cardiovascular Connective Tissue Disorders Clinic
1195 West Fremont Ave
Sunnyvale, CA 94087

Clinic serves children to age 22
Referral necessary

Medical Director:
Ronnie Thomas Collins, II, MD

UC San Diego Health

UC San Diego Health Aortopathy & Related Conditions Clinic
9434 Medical Center Drive
La Jolla, CA 92037

Clinic serves adults only

Medical Director:
Laith Alshawabkeh, MD, MSCI

USC Keck Medical Center

1520 San Pablo St, Suite 4300
Los Angeles, CA 90033

Clinic serves adults only

Medical Director:
Sanjeet Patel, MD, PhD

Colorado**Children's Hospital Colorado**

Cardiac Genetics and Aortopathy Clinic
13123 East 16th Ave, B11
Aurora, CO 80045

Medical Director:
Kathryn Chatfield, MD, PhD

Contact:

Stacey Denis, Administrative Assistant
Phone: 909-558-9730
Email: sdenis@llu.edu

Contact:

Jan Hedlun
Phone: 858-966-5855
jhedlun@rchsd.org

Contact:

Samantha Mourrain, Nurse Coordinator
Phone: 650-924-5867
Email: cctd@stanfordchildrens.org

Contact:

Halle Siepman
Phone: 858-246-3271
Email: achd@health.ucsd.edu

Contact:

Jennifer Rios, Genetic Counselor
Appointments: 323-442-5849
Email: jennifer.rios@med.usc.edu

Contact:

Kally Czaplá, RN, Cardiac Genetics Clinic
Coordinator
Phone: 720-777-6498
Email: kally.czaplá@childrenscolorado.org

*Colorado continued***University of Colorado**

Marfan and Related Aorta Disorders Clinic
12605 E. 16th Ave
Aurora, CO 80045

Children's appointments are coordinated at Children's Hospital

Medical Director:
Amber Khanna, MD

Contact:

Tammy Riddell, RN, BSN
Phone: 720-848-6517
Appointments: 720-848-5300
Email: tammy.riddell@uchealth.org

Florida**Joe DiMaggio Children's Hospital**

Marfan Clinic
1150 N. 35th Ave, Suite 490
Hollywood, FL 33021

Medical Directors:
Roman Yusupov, MD

Contact:

Phone: 954-265-4637

Mount Sinai Medical Center

The Aortic Center at Mount Sinai Medical Center
4300 Alton Rd, Suite 2110
Miami Beach, FL 33140

Clinic serves adults only

Medical Director:
Steve Xydas, MD

Contact:

Luis Mourino, PA-C, MPAS
Phone: 305-674-2780
Email: luis.mourino@msmc.com
Lauren Frias, APRN
Phone: 305-674-2780
Email: lauren.frias@msmc.com

University of Florida Health Heart and Vascular Center

1505 SW Archer Rd
Gainesville, FL 32608

Medical Director:
Tomas D. Martin, MD

Contact:

Jordan McBride
Phone: 352-273-5494
Jill Hendrickson
Phone: 352-273-9734

University of Miami

Connective Tissue Disorder Clinic
1601 NW 12th Ave
Miami, FL 33136

Contact:

Phone: 305-243-6583

Georgia**Children's Healthcare of Atlanta****Emory University School of Medicine**

Sibley Heart Center Aorta and Vascular Program
CHOA Center for Advanced Pediatrics (CAP Building)
1400 Tullie Rd NE
Atlanta, GA 30329

Clinic serves children to age 21

Medical Director:
Glen Iannucci, MD

Contact:

Glen Iannucci, MD
Phone: 404-256-2593
Email: iannuccig@kidsheart.com

Illinois

[Ann & Robert H. Lurie Children's Hospital of Chicago](#)

Connective Tissue Disorder Program
225 E. Chicago Ave, Box 21
Chicago, IL 60611

Clinic serves children to age 18

Medical Directors:

Joseph Camarda, MD

Contact:

Diane Martin
312-227-1551

[Northwestern Memorial Hospital](#)

Bluhm Cardiovascular Institute
Marfan Syndrome and Related Disorders Clinic
675 N. St. Clair St., 19-100
Chicago, IL 60611

Clinic serves adults only; children seen at Lurie Children's

Medical Directors:

Marla Mendelson, MD
Chris Malaisrie, MD*
Lisa Wilsbacher, MD

Contact:

Janice Knuckey
Phone: 312-695-0105
Email: jknuckey@nm.org

[University of Chicago-Medicine](#)

Chicago Marfan and Related Connective Tissue Disorder Program
UChicago Medicine Duchossois Center for Advanced Medicine
(DCAM) – Hyde Park
5758 S Maryland Ave
Chicago, IL 60637

Contact:

Rachel Barsella, APP
Email: rbarsella@bsd.uchicago.edu
Phone: 773-702-6169

Alternate Locations:

Comer's Children's Hospital
5741 S Maryland Ave
Chicago, IL 60637

Advocate Children's Hospital
4440 95th St
Oak Lawn, IL 60453

Medical Director:

Michael G. Earing, MD

Indiana

[IU Health \(Indiana University Health\)](#)

Multidisciplinary Aortopathy Clinic (MAC)
Riley Outreach Center at IU Health
Pediatric Cardiology Clinic
575 Riley Hospital Dr, Suite MSA 2
Indianapolis, IN 46201

Serves adults and children

Medical Director:

Ben Landis, MD

Contact:

Stephanie Caine, Scheduler
Phone: 317-944-9337

* Member, The Marfan Foundation Professional Advisory Board

** Site, The Marfan Foundation Professional Advisory Board

Kentucky

University of Louisville / Norton Children's Medical Group

Marfan Syndrome and Connective Tissue Clinic
Novak Center for Children's Health
411 East Chestnut St
Louisville, KY 40202

Clinic serves children to age 18, transitions adults to adult practice

Medical Director:

Lucinda Thurman Wright, MD

Contact:

Nicole Jarrett, Clinic Manager
Phone: 502-588-7450
Email: nicole.jarrett@nortonhealthcare.org

Maryland

Johns Hopkins University

Cardiovascular Connective Tissue Clinic
The Charlotte R. Bloomberg Children's Center
1800 Orleans St, Rm 2201
Baltimore, MD 21287

Medical Director:

Hal C. Dietz, MD*

Contact:

Gretchen MacCarrick, MS, CGC*
Phone: 410-955-3071, Ext 1
Email: goswald1@jhmi.edu

Massachusetts

Boston Children's Hospital

Marfan Syndrome, Connective Tissue, and
Related Disorders Program
Department of Cardiology
300 Longwood Ave
Boston, MA 02115

Medical Directors:

Ronald V. Lacro, MD*
Michael N. Singh, MD

Contact:

Ciara McManus, NP
Email: ciara.mcmanus@cardio.chboston.org
Phone: 617-355-8794

Brigham and Women's Hospital

Marfan Syndrome and Related Connective
Tissue Disorders Clinic
75 Francis St
Boston, MA 02115

Clinic serves adults only

Medical Directors:

Michael N. Singh, MD
Natasha Frank, MD

Contact:

Ciara McManus, NP
Email: ciara.mcmanus@cardio.chboston.org
Phone: 617-355-8794

Michigan

Michigan Medicine Frankel Cardiovascular Center

MI-AORTA at the Michigan Frankel Cardiovascular Center
1500 E. Medical Center Dr, 3rd Floor, Reception C
Ann Arbor, MI 48109

Medical Directors:

Marion Hofmann-Bowman, MD
Clinic serves adults only

Contact:

Phone: 888-287-1082

* Member, The Marfan Foundation Professional Advisory Board

** Site, The Marfan Foundation Professional Advisory Board

Minnesota

Mayo Clinic**

Marfan and Thoracic Aorta Clinic
200 First St SW
Rochester, MN 55905

Medical Directors:

Thais Coutinho, MD
Joseph Dearani, MD

Missouri

Children's Mercy Kansas City

Cardiovascular Genetics Clinic
2401 Gillham Rd
Kansas City, MO 64108
Clinic serves children to age 21

Medical Directors:

Shivarajan M. Amudhavalli, MD (Genetics)
Luisa F. Waitman, MD (Cardiology)

Cardinal Glennon Children's Hospital

Marfan Clinic
1465 S. Grand Blvd
St. Louis, MO 63104
Clinic serves children to age 18

Medical Director:

Chetana Reddy, MD

Barnes-Jewish Hospital / Washington University School of Medicine

Marfan Syndrome and Aortopathy Center
4921 Parkview Place, Suite 8A
St. Louis, MO 63110
Clinic serves adults only

Medical Director:

Alan C. Braverman, MD, FACC*

Nebraska

Children's Hospital and Medical Center and Nebraska Medical Center

Midwest and Omaha Congenital Heart and Aortopathy Clinic
8200 Dodge St
Omaha, NE 68114

Medical Director:

Anji Yetman, MD

Contact:

Caroline Arpin
Phone: 507-284-3758
Email: arpin.caroline@mayo.edu
Appointments: 507-538-8124

Genetics Contact:

Janda Jenkins, MS, CGC
Email: jjenkins@cmh.edu
Caitlin Lawson, MS, CGC
Email: celawson@chm.edu
Office Phone: 816-302-3290
Genetics Appointments: 816-234-3771

Cardiology Contact:

Sarah Bowmaker, BSN, RN
Email: sbowmaker@cmh.edu
Cardiology Appointments: 816-302-3053

Contact:

Pediatric Cardiology Schedulers:
Cheryl Doeschot or Angela Battles
Phone: 314-577-5674
Genetic Counselor:
Katherine Christensen
Phone: 314-268-2700, Ext 3282

Contact:

Dana Gima, RN
Barb Stehman, RN
Cheryl Marshall, Administrative Assistant
Phone: 314-362-1291

Contact:

Lindsey Holmes
Phone: 402-955-4323
Email: lholmes@childrensomaha.org

* Member, The Marfan Foundation Professional Advisory Board

** Site, The Marfan Foundation Professional Advisory Board

New York

Cohen Children's Medical Center of New York Northwell Health

Marfan Syndrome and Related Disorders Center
269-01 76th Ave
New Hyde Park, NY 11042

Clinic serves children through age 18

Medical Directors:

Angela Romano, MD
Joyce Fox, MD

Northwell Health

Center for Marfan Syndrome and Connective Tissue Disorders
300 Community Dr
Manhasset, NY 11030

Clinic serves adults only

Medical Director:

Derek Brinster, MD

Icahn School of Medicine at Mount Sinai

Cardiovascular Genetics Program
Mount Sinai Medical Center

Children's Heart Center (Pediatrics)

1468 Madison Ave (at 100th St)
Annenberg Building, 3rd Floor
New York, NY 10029

Center for Inherited Cardiovascular Disease (Adults)

1190 5th Avenue
Guggenheim Pavilion 1 West
New York, NY 10029

Medical Directors:

Bruce D. Gelb, MD
Amy R. Kontorovich, MD, PhD

New York Presbyterian Hospital Morgan Stanley Children's Hospital Columbia University Irving Medical Center

Pediatric Marfan Clinic
Division of Pediatric Cardiology
3959 Broadway, CHN-2
New York, NY 10032

Clinic serves children through age 18

Medical Directors:

Emile Bacha, MD
Michael DiLorenzo, MD
Alexandra Channing, MD

Contact:

Mary Beth Kearney, RN, MA, CPNP
(Pediatric Cardiology)
Phone: 718-470-7374
Email: mkearney1@northwell.edu
Julie McLaughlin, CGC (Genetics)
Phone: 516-365-3996
Email: jmclaugh@northwell.edu
Appointments: 718-470-7350; Option #3

Contact:

Melissa Chau / Joan O'Connell
Phone: 833-552-6782
Email:
marfanandconnectivetissue@northwell.edu

Contact:

Veronica Fettig, CGC (Clinic Coordinator)
Phone: 212-241-9004
Email: veronica.fettig@mssm.edu
Pediatric Appointment Scheduler
Phone: 844-733-7692
Email: childrensheartscheduling@mssm.edu
Adult Appointment Scheduler
Phone: 212-241-9004
Email: regine.aubourg@mountsinai.org

Contact:

Phone: 844-HRT-DOCS

*New York continued***Weill Cornell Medicine**

Marfan Syndrome and Related Conditions Clinic
525 East 68th St
New York, NY 10065

Medical Directors:

Mary J. Roman, MD*
Richard B. Devereux, MD*

Contact:

Wanda Brown (cardiology)
Phone: 646-962-4733
Email: wobrown@med.cornell.edu
Karmen Baez (cardiothoracic surgery)
Phone: 212-746-5194
Email: kab2026@med.cornell.edu

North Carolina**Sanger Heart and Vascular Institute**
Levine Children's Hospital

Marfan Syndrome and Aortopathy Clinic
1001 Blythe Blvd, Suite 500
Charlotte, NC 28203

Medical Director:

Matthew Lisi, MD
Jorge Alegria, MD

Contact:

Taylor Holmes, RN, Nurse Navigator
Phone: 704-373-1813
Email: taylor.holmes@atriumhealth.org

Ohio**Cincinnati Children's Hospital Medical Center**

Heart Institute - Cardiovascular Genetics Clinic
3333 Burnet Ave, ML 2003
Cincinnati, OH 45229

Medical Director:

Nicole M. Brown, MD
K. Nicole Weaver, MD

Contact:

Amy Shikany, Licensed Genetic Counselor
Phone: 513-803-3317
Email: amy.shikany@cchmc.org

Cleveland Clinic

Aorta Umbrella of Excellence, Marfan and Other Vascular
Connective Tissue Disorder Center
Heart, Vascular and Thoracic Institute
9500 Euclid Ave, Desk J1-5
Cleveland, OH 44195

Medical Director:

Vidyasagar Kalahasti, MD

Contact:

Roberta Crittenden, Administrative Assistant
Phone: 216-445-7259
Email: critter2@ccf.org

* Member, The Marfan Foundation Professional Advisory Board

** Site, The Marfan Foundation Professional Advisory Board

*Ohio continued***Nationwide Children's Hospital**

Cardiovascular Genetics Clinic
700 Children's Drive
Columbus, OH 43205

Clinic serves children to 21 years old; established patients followed at Adult Congenital Heart Disease Clinic

Medical Director:

Jessica Bowman, MD

University Hospitals Case Medical Center

Connective Tissue Disorder Clinic
Center for Human Genetics
11100 Euclid Ave
Lakeside 1500
Cleveland, OH 44106

Medical Director:

Anna Mitchell, MD, PhD

Oregon**Oregon Health and Science University**

Marfan and Related Disorders Clinic (Pediatrics)
Doernbecher Children's Hospital
700 SW Campus Drive
Portland, OR 97239

Adult Congenital Heart Disease Clinic (Adult Aortopathy)
Multidisciplinary Clinic – Vascular Genetic Clinic (Adult Vascular)
Center for Health and Healing, Building 1
3303 S. Bond Ave
Portland, OR 97239

Pennsylvania**Children's Hospital of Philadelphia (CHOP)**

Cardiovascular Connective Tissue Disorders Clinic
Cardiac Center
3401 Civic Center Blvd
Philadelphia, PA 19104

Clinic serves children to age 21

Medical Director:

Stacey Drant, MD

University of Pennsylvania Health System**Perelman Center for Advanced Medicine**

Medical Genetics Clinic
PCAM South Pavilion
3400 Civic Center Blvd
Philadelphia, PA 19104

Medical Director:

Staci Kallish, DO

Contact:

Katherine Myers
Phone: 614-355-6388
Email:
katherine.myers@nationwidechildrens.org
Rachel Gosselin
Phone: 614-722-3296
Email: rachel.gosselin@nationwidechildrens.org

Contact:

Sarah Grimes Hodges, MS, CGC
Phone: 216-844-3936
Email: sarah.grimes@uhhospitals.org

Contact:

Kathryn Holmes, MD, MPH (Pediatric
Aortopathy)
Email: holmesk@ohsu.edu
Hayley Eiden (Adult Cardiology)
Phone: 503-494-1901
Sherene Shalhub, MD, MPH (Aortic Surgery &
Vascular Program)
Email: shalhub@ohsu.edu

Contact:

CHOP Cardiac Referral Center
Phone: 267-426-9600
Fax: 267-426-5139
Email: chopcardiacreferral@chop.edu

Contact:

Megan Lawrence, Clinic Coordinator
Phone: 215-662-4740
Email:
medicalgenetics@penmedicine.upenn.edu

*Pennsylvania continued***University of Pittsburgh Medical Center (UPMC)
Heart and Vascular Institute**

UPMC Center for Thoracic Aortic Disease & UPMC Adult
Congenital Heart Disease Program
UPMC Presbyterian Hospital
200 Lothrop St
Pittsburgh, PA 15213

UPMC Adult Congenital Heart Disease Program
Children's Hospital
4401 Penn Ave
Pittsburgh, PA 15213

Medical Directors:
Ibrahim Sultan, MD
Arvind Hoskoppal, MD, MHS
Rachel Torok, MD

South Carolina**Medical University of South Carolina (MUSC)**

MUSC Marfan Center
MUSC Ashley River Tower
25 Courtenay Dr
Charleston, SC 29425

Medical Director:
Daniel P. Judge, MD

Tennessee**Vanderbilt University Medical Center**

Marfan Syndrome and Aortic Disorders Center
1215 21st Ave S, 5th Floor
Nashville, TN 37232

Clinic serves adults only

Medical Director:
Benjamin Frischhertz, MD

Texas

Texas Children's Hospital
Cardiovascular Genetics Clinic
Genetic Aorta Disorders
6621 Fannin St
Houston, TX 77030

Medical Director:
Shaine A. Morris, MD, MPH*

Contact:

UMPC Center for Thoracic Aortic Disease
Elissa Castor, PAC
Phone: 412-623-2994
Email: aorticcenter@upmc.edu

UPMC Adult Congenital Heart Disease Program
Ashley Draxinger, RN, BSN
Phone: 412-692-3158
Email: achd@upmc.edu

Contact:

MUSC Heart & Vascular Center
Phone: 843-792-1952

Contact:

Lauren Oliver, MSN, ACNP
Phone: 615-322-2318
Email: vanderbiltaorta@vmc.org

Contact:

Taylor Beecroft
Email: txbeecro@texaschildrens.org
Emily Soludczyk
Email: emily.soludczyk@bcm.edu
Phone: 832-822-1723
Appointments: 832-82-HEART (43278)

* Member, The Marfan Foundation Professional Advisory Board

** Site, The Marfan Foundation Professional Advisory Board

*Texas continued***University of Texas Physicians**

Multidisciplinary Aortic and Vascular Disease Clinic
6410 Fannin St, Suite 600
Houston, TX 77030

Medical Director:

Dianna M. Milewicz, MD, PhD*

**University of Texas Southwestern Medical Center,
Children's Health**

Dilated Aorta Caused by Connective Tissue Disorders Program
1935 Medical District
Dallas, TX 75235

Second location:

7601 Preston Rd
Plano, TX 75024

Clinic serves children to age 21

Medical Director:

Lynn Mahony, MD

Utah**University of Utah Health**

Utah Aortopathy Clinic
81 N. Mario Capecchi Dr
Salt Lake City, UT 84106

Medical Director:

Daniel Cox, DO

Washington**University of Washington Medical Center**

Genetic Medicine Clinic
1959 NE Pacific St, Box #357720
Seattle, WA 98195

Clinic serves adults only

Medical Director:

Peter H. Byers, MD*

Wisconsin**Medical College of Wisconsin/Children's Wisconsin**

Marfan and Related Connective Tissue Disorder Program
9000 W. Wisconsin Ave
Milwaukee, WI 53226

Medical Director:

Salil Ginde, MD

Contact:

Main Phone: 713-500-6175
Main Email: cvgenetics@uth.tmc.edu
Isabella Marin, BSN, RN, Coordinator
Phone: 713-500-6854
Email: isabella.c.marin@uth.tmc.edu

Contact:

Erica Granado, Scheduler
Phone: 214-456-0134
Email: erica.granado@childrens.com

Contact:

Louise Jahn, RN
Phone: 801-646-6000
Email: louise.jahn@hsc.utah.edu

Contact:

Debbie Olson, Program Support Supervisor
Email: olsondl@uw.edu

Contact:

Kristen Andersen
Phone: 414-266-7584
Email: kandersen@childrenswi.org
Lindsey Katzmark, APNP
Phone: 414-266-4757
Email: lkatzmark@childrenswi.org

* Member, The Marfan Foundation Professional Advisory Board

** Site, The Marfan Foundation Professional Advisory Board

*Wisconsin continued***University of Wisconsin Hospital and Clinics/UW Health**

Adult Congenital Heart Disease Clinic
600 Highland Ave, Mail Code 4160
Madison, WI 53792

Clinics serve adults and children

Medical Director:

Heather Bartlett, MD

The American Center (2nd location)

4602 Eastpark Blvd
Madison, WI 53718

American Family Children's Health (3rd location)

1675 Highland Ave
Madison, WI 53792

Contact:

Sherri Ruhland, MSN, RN
Phone: 608-890-5700
Fax: 608-265-8887
Email: sruhland@uwhealth.org

Healthcare provider information is supplied solely by the providers themselves and is not checked or warranted by The Marfan Foundation. The Foundation provides contact information for healthcare providers who are known to have seen patients with Marfan syndrome and related conditions. The Foundation does not endorse or recommend individual healthcare providers. You are responsible for interviewing and selecting the practitioner. By requesting healthcare provider resources you understand and agree that the Foundation and its affiliates are not responsible for any providers' services or lack thereof.