

# THE EDS MOVEMENT

[TheVEDSMovement.org](http://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 6<sup>th</sup> 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](mailto: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](mailto: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

*Medical Director:*

David H. Liang, MD, PhD\*

**Contact:**

Meg Boeglin, BSN, RN  
Phone: 949-764-8468  
Email: [megan.boeglin@hoag.org](mailto:megan.boeglin@hoag.org)

\*Member, The Marfan Foundation Professional Advisory Board

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*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 Alshwabkeh, 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 16<sup>th</sup> 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

**Florida**

**Joe DiMaggio Children's Hospital**

Marfan Clinic  
1150 N. 35<sup>th</sup> Ave, Suite 490  
Hollywood, FL 33021

*Medical Directors:*  
Roman Yusupov, MD

**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 Xydias, MD

**University of Florida Health Heart and Vascular Center**

1505 SW Archer Rd  
Gainesville, FL 32608

*Medical Director:*  
Tomas D. Martin, MD

**University of Miami**

Connective Tissue Disorder Clinic  
1601 NW 12<sup>th</sup> Ave  
Miami, FL 33136

*Medical Director:*  
Irman Forghani, MD

**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:**

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

**Contact:**

Phone: 954-265-4637

**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

**Contact:**

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

**Contact:**

Phone: 305-243-6583

**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

### [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:**

Diane Martin  
312-227-1551

**Contact:**

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

## 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

## 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, 3<sup>rd</sup> Floor, Reception C  
Ann Arbor, MI 48109

*Medical Directors:*  
Marion Hofmann-Bowman, MD  
*Clinic serves adults only*

### **Contact:**

Phone: 888-287-1082

## Minnesota

### **Mayo Clinic**

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

*Medical Directors:*  
Juan Bowen, MD\*  
Joseph Dearani, MD

### **Contact:**

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

## 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

### 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

## New York

### **Cohen Children's Medical Center of New York Northwell Health**

Marfan Syndrome and Related Disorders Center  
269-01 76<sup>th</sup> Ave  
New Hyde Park, NY 11042  
*Clinic serves children through age 18*

*Medical Directors:*  
Angela Romano, MD  
Joyce Fox, MD

#### **Contact:**

Janda Jenkins, MS, CGC  
Email: jljenkins@cmh.edu  
Caitlin Lawson, MS, CGC  
Email: celawson@chm.edu

Office Phone: 816-302-3290  
Clinic Appointments: 816-234-3771

#### **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

#### **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

*New York continued*

**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 100<sup>th</sup> St)  
Annenberg Building, 3<sup>rd</sup> Floor  
New York, NY 10029

Center for Inherited Cardiovascular Disease (Adults)  
1190 5<sup>th</sup> 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

**Weill Cornell Medicine**

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

*Medical Directors:*  
Mary J. Roman, MD\*  
Richard B. Devereux, MD\*

**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

**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:**

Lubna Al Allaf, Administrative Assistant  
Phone: 216-445-7259  
Email: alallal@ccf.org

### 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

**Contact:**

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

### **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

**Contact:**

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



## 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

### **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

## 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:*  
Theodore Drivas, MD, PhD\*

### 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

### **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:  
megan.lawrence@pennteam.upenn.edu

### **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

## 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

**Contact:**

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

## Tennessee

### Vanderbilt University Medical Center

Marfan Syndrome and Aortic Disorders Center  
1215 21st Ave S, 5<sup>th</sup> Floor  
Nashville, TN 37232  
*Clinic serves adults only*

*Medical Director:*  
Benjamin Frischhertz, MD

**Contact:**

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

## 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:**

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

### 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\*

**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

### 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

**Contact:**

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

## Utah

### University of Utah Health

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

*Medical Director:*  
Daniel Cox, DO

**Contact:**

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

## 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\*

**Contact:**

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

## 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:**

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

### 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

**Contact:**

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

### **The American Center (2<sup>nd</sup> location)**

4602 Eastpark Blvd  
Madison, WI 53718

### **American Family Children's Health (3<sup>rd</sup> location)**

1675 Highland Ave  
Madison, WI 53792

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.