

The VEDS Movement.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. 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. Downloading those documents will allow you to click the hyperlinks within them.

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

Alabama

<u>University of Alabama at Birmingham</u> <u>Children's of Alabama</u>

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

Medical Director:

David H. Liang, MD, PhD*

*Member, The Marfan Foundation Professional Advisory Board Updated February 2024

Contact:

Meg Boeglin, BSN, RN Phone: 949-764-8468

Email: megan.boeglin@hoag.org



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

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

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:

Kally Czapla, RN, Cardiac Genetics Clinic

Coordinator

Phone: 720-777-6498

Email: kally.czapla@childrenscolorado.org

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Colorado continued

University of Colorado

Marfan and Related Aortopathy Clinic 12605 E. 16th Ave

Aurora, CO 80045

Children's appointments are coordinated at Children's Hospital

Medical Director: Amber Khanna, MD

Contact:

Tammy Ben Mansour, RN, BSN

Phone: 720-848-6517 Appointments: 720-848-5300

Email: tammy.benamansour@uchealth.org

Florida

Joe DiMaggio Children's Hospital

Marfan Clinic 1150 N. 35th 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 Xydas, MD

University of Florida Health Heart and Vascular Center

1505 SW Archer Rd Gainesville, FL 32608

Medical Director: Tomas D. Martin, MD

Contact:

Phone: 954-265-3437

Contact:

Luis Mourino, PA-C, MPAS Phone: 305-674-2780 Email: luis.mourino@msmc.com David Agrenot Perez, RN Phone: 305-674-2186

Email: david.agrenotperez@msmc.com

Contact:

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

Georgia

Children's Healthcare of Atlanta (CHOA) Emory University School of Medicine

Cardiology, 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 lannucci, MD

Contact:

Glen lannucci, MD Phone: 404-256-2593

Email: iannuccig@kidsheart.com

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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

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

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 Contact:

Diane Martin 312-227-1551

Contact:

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

Contact:

Rachel Barsella, APP

Email: rbarsella@bsd.uchicago.edu

Phone: 773-702-6169

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

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Email: nicole.jarrett@nortonhealthcare.org



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

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:

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

Nicole Jarrett, Clinic Manager

Phone: 502-588-7450

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

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

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

** Site, The Marfan Foundation Professional Advisory Board

Contact:

Phone: 888-287-1082

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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*

Contact:

Submit an Appointment Request Appointments: 507-538-8124

Genetics Contact:

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

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

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:

Lindsey Holmes Phone: 402-955-4323

Email: lholmes@childrensomaha.org

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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: mkearnev1@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

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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

Duke University Medical Center

Duke Center for Aortic Disease 40 Duke Medicine Circle, Clinic 2F/2G Durham, NC 27710

Second Location:

Adult Genetics/Cardiology 5601 Arringdon Park Dr Morrisville, NC 27560

Medical Director: G. Chad Hughes, MD

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:

Melissa Burkett, NP (adults) Phone: 919-613-4447 Email: melissa.merrill@duke.edu June-Avery Chrismon, RN, BSN, CPN, CNIV

(pediatrics)

Phone: 984-260-5269

Email: pedsheartcenterreferral@dm.duke.edu

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

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:

Amy Shikany, Licensed Genetic Counselor Phone: 513-803-3317

Email:amy.shikany@cchmc.org

Contact:

Roberta Crittenden, Administrative Assistant

Phone: 216-445-7259 Email: critter2@ccf.org

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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

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

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: Staci Kallish, DO

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@pennmedicine.upenn.edu

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Pennsylvania continued

<u>University of Pittsburgh Medical Center (UPMC)</u> 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:

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 Vanderbilt Heart and Vascular Institute 1215 21st Ave S, 5th 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 Soludcyzk

Email: emily.soludczyk@bcm.edu

Phone: 832-822-1723

Appointments: 832-82-HEART (43278)

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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*

<u>University of Texas Southwestern Medical Center,</u> 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

Clinics serve children to age 21

Medical Director: Lynn Mahony, 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

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

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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 Contact:

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

Emily Wannow, RN Phone: 608-890-5700

Email: ewannow@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.

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