

DIRECTORY OF MEDICAL INSTITUTIONS

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

Alabama

Children's of Alabama at University of Alabama-Birmingham

UAB Marfan Syndrome and Related Disorders Clinic 1700 6th Avenue South, Suite 9100 Birmingham, AL 35233

Medical Director: Walter Johnson, MD Nathaniel Robin, MD

Arkansas

Arkansas Children's Hospital

The Multidisciplinary Connective Tissue Clinic 1 Children's Way Little Rock, AR 72202

Medical Director:

R. Thomas Collins II, MD

California

Reagan/UCLA Medical Center

Ahmanson/UCLA Adult Congenital Heart Disease Center 100 Medical Plaza, Suite 630 Los Angeles, CA 90095 Center serves adults only

Medical Director: Jamil Aboulhosn, MD

Mattel Children's Hospital at UCLA

UCLA Pediatric Marfan Clinic 200 Medical Plaza Suite 330 Los Angeles, CA 90095 Clinic serves children to age 21

Medical Director: Gregory Perens, MD

Contact:

Ina Schaffer, Admin Office Specialist II, for appointments

Phone: 205-996-2365 Fallon Brewer CGC Phone: 205-934-5384

Contact:

Beth Martin, RN Phone: 501-364-2088 Email: eamartin@uams.edu

Contact:

Jennifer Doliner, RN, BSN Phone: 310-794-5636

Email: jdolinerr@mednet.ucla.edu

Appointments: Register at UCLA Medical Center 310-825-9011 and then call Jennifer Doliner

Contact:

Gregory Perens, MD Phone: 310-267-7667

Email: gperens@mednet.ucla.edu Appointments: 310-267-7667



California continued

Cedars-Sinai Medical Center

Cedars-Sinai Heart Institute Cardiogenetics Program 127 S. San Vicente Blvd. Suite A3600 Los Angeles, CA 90048

Medical Director: Robert J. Siegel, MD

Loma Linda University Medical Center

International Heart Center 11234 Anderson Street Loma Linda, CA 92354 Center serves adults only

*Medical Director:*Padmini Varadarajan, MD

Loma Linda Children's Hospital

11234 Anderson Street, Suite 1617 Loma Linda, CA 92354 Serves children to age 18

Medical Director: Matthew Bock, MD

Stanford University Medical Center

Stanford Marfan Syndrome & Aortic Center 300 Pasteur Drive Room H2157 Stanford, CA 94305

Medical Director: David H. Liang, MD, PhD*

Colorado

Children's Hospital Colorado

Cardiac Genetics Clinic 13123 East 16th Avenue B100 Aurora, CO 80045

Medical Director: Kathryn Chatfield, MD, PhD

Contact:

Daria Ma MS LCGC Phone: 424-315-2358 Email: Daria.Ma@cshs.org Appointments: 310-423-2726

Contact:

Stacey Denis, Administrative Assistant

Phone: 909-558-9730 Email: sdenisllu.edu

Contact:

Diana Sanchez, RN Phone: 909-558-4207 Email: dsanchez@llu.edu

Contact:

Sunny Pellone, Center Coordinator

Phone: 650-725-8246

Email: spellone@stanfordmed.org

Mitchel Pariani, MS, LCGC Phone: 650.498.0675

Email: mpariani@stanfordhealthcare.org

Contact:

Shari Borcherding, Staff Assistant

Phone: 720-777-2944

Email: shari.borcherding@childrenscolorado.org



Colorado continued

University of Colorado-Anschutz Medical Campus

Marfan and Related Aorta Disorders Clinic Anschutz Inpatient Pavilion 12605 E. 16th Avenue Aurora, CO 80045 Children's' appointments are coordinated at Children's Hospital

Medical Director: Amber Khanna, MD

Florida

Joe DiMaggio Children's Hospital

Marfan and Related Disorders Clinic 1150 N. 35th Avenue, Suite 490 Hollywood, FL 33021

Medical Directors: Roman Yusupov, MD Kak-Chen Chan, MD

Georgia

Emory St. Joseph's Hospital

Emory Aortic Center 5665 Peachtree Dunwoody Road, Suite 200 Atlanta, GA 30342 Center serves adults only

Medical Director: Edward Chen, MD

Children's Healthcare of Atlanta

Sibley Heart Center Cardiology Aortic and Vascular Diseases Program 5455 Meridian Mark Road, Suite 530 Atlanta, GA 30342 Clinic serves children to age 21

Medical Director: Denver Sallee, MD

Contact:

Michelle Pierce, RN, BSN Phone: 720-848-6517

Email: Michelle.Pierce@uchealth.org

Contact:

Michelle Yen, MSN, RN Phone: 954-265-4637 Email: myen@mhs.net Appointments: Sandra Cherisol Phone: 954-265-4637

Contact:

Phone: 404-778-3484

Contact:

Leslie Bishop, CPNP Phone: 404-256-2593

Email: bishopl@kidsheart.com



Illinois

Ann & Robert H. Lurie Children's Hospital of Chicago

The Connective Tissue Disorder Clinic 225 E. Chicago Avenue, Box 59 Chicago, IL 60613 Clinic serves children to age 26

Medical Directors:
Joseph Camarda, MD (Cardiology)
Mindy Li, MD (Genetics)

Northwestern Medicine

Marfan & Related Disorders Clinic 201 E. Huron Street Galter 19 Floor Chicago, IL 60611 Clinic serves adults only

Medical Directors: S. Chris Malaisrie, MD Marla Mendelson, MD

University of Chicago Medicine

The Marfan Syndrome Center 5841 South Maryland Avenue Room C104 (Section of Pediatric Cardiology) Chicago, IL 60637

Medical Directors: Darrel Waggoner, MD

Indiana

Peyton Manning Children's Hospital at St. Vincent

Connective Tissue Disorders Clinic 8402 Harcourt Road, Suite 300 Indianapolis, IN 46260

Medical Director: Luis F. Escobar, MD

Indiana University School of Medicine

Marfan Syndrome Clinic Department of Medical and Molecular Genetics IB130 975 W. Walnut Street Indianapolis, IN 46202-5215

An echocardiogram and an ophthalmology evaluation prior to appointments are helpful.

*Medical Director:*David D. Weaver, MD

Contact:

Elizabeth S. Cappella, MSN, APN, CPNP

Phone: 312-227-4641

Email: ECappella@luriechildrens.org

Appointments: 312-227-6120

Contact:

Amy Pastalaniec, MSN, APN, CNP Phone: 312-695-5893

Email: aochs@nmh.org

Contact:

Mary Ann Carter, Clinic Coordinator

Phone: 773-834-9110

Email: mcarter1@bsd.uchicago.edu

Contact:

Megan Tucker, MS, LGC Phone: 317-338-5288

Email: mxtucker@stvincent.org

Contact:

Kenya Alexander, Specialist Phone: 317-948-0695 Email: kenalexa@iu.edu



Kentucky

University of Louisville

Marfan Syndrome and Connective Tissue Disease Clinic 601 South Floyd Street, Suite 602 Louisville, KY 40202 Clinic serves children to age 21

Medical Director: Lucinda Wright, MD

Maryland

Johns Hopkins University

Cardiovascular Connective Tissue Clinic 600 N. Wolfe Street Blalock 1008 Baltimore, MD 21287

Medical Director: Hal C. Dietz, MD*

Massachusetts

Boston Children's Hospital

Marfan Syndrome, Connective Tissue, and Related Disorders Program Department of Cardiology 300 Longwood Avenue 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 Street Boston, MA 02115 Clinic serves adults ages 18 and over only

Medical Directors: Michael N. Singh, MD Natasha Frank, MD

Contact:

Julia Campbell, Scheduling Coordinator

Phone: 502-585-4802 ext 234 Email: julia.campbell@ulp.org

Contact:

Gretchen MacCarrick, MS, CGC

Phone: 410-955-0316 Email: goswald1@jhmi.edu

Appointments: 410-955-3071, Option 1

Contact:

Martha King, RN Phone: 617-355-8794

Email: Martha.King@cardio.chboston.org Allyson Galle, administrative assistant

Phone: 617-355-8794

Email: Allyson.Galle@cardio.chboston.org Appointments: 617-355-8794, Allyson Galle

Contact:

Allyson Galle, Administrative Assistant

Phone: 617-355-8794



Michigan

University of Michigan Medical Center

University of Michigan Aortic and Genetic Syndrome Center 5143 Cardiovascular Center Drive 1500 E. Medical Center Drive Ann Arbor, MI 48109

Medical Directors:

Anna M. Booher, MD Himanshu J. Patel, MD

Minnesota

Mayo Clinic

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

Medical Directors: Juan Bowen, MD Joseph Dearani, MD

Missouri

Children's Mercy Kansas City

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

Medical Director: Robert Ardinger, MD

Geneticists:

Holly Ardinger, MD Shivarajan M. Amudhavalli, MD

Washington University School of Medicine, Barnes-Jewish Hospital

Marfan Syndrome Clinic and Center for Genetically Triggered Aortic Diseases 4921 Parkview Place, Suite 8A St. Louis, MO 63110 Clinic serves people 16 and older

Medical Director:

Alan C. Braverman, MD, FACC*

Geneticist:

Marcia Willing, MD

Contact:

Mary Passow RN, BSN Diane Salata, RN Phone: 888-287-1082

Contact:

Caroline Arpin Phone: 507-284-3758

Email: arpin.caroline@mayo.edu Appointments: 507-538-8124

Contact:

Janda Jenkins MS, CGC Email: jljenkins@cmh.edu Lauren Grote, MS, CGC Email: lgrote@cmh.edu Phone: 816-234-3290

Contact:

Dana Gima, RN, BSN Barb Stehman, RN, BSN

Phone: 314-362-1291 or 888-210-8375

^{*} Member, The Marfan Foundation Professional Advisory Board



Missouri continued

St. Louis Children's Hospital

1 Children's Place St. Louis, MO 63110

Geneticist:

Marcia Willing, MD

SSM Cardinal Glennon Children's Medical Center

SLU Care

Marfan Syndrome and Familial Aortopathy Clinic 1465 South Grand Blvd.

St. Louis, MO 63104

Clinic serves children to age 21

Medical Director:

Angela Sharkey, MD

Nebraska

Children's Hospital and Medical Center and Nebraska Medical Center

MOCHA-Midwest & Omaha Congenital Heart & Aortopathy Clinic

8200 Dodge Street

Omaha NE 68114

Medical Director:

Anji Yetman, MD

New Jersey

Rutgers Robert Wood Johnson Medical School

Rutgers Robert Wood Johnson Aortic Clinic

1 Robert Wood Johnson Place

New Brunswick, NJ 08901

Medical Director:

Leonard Y. Lee, MD

New York

Icahn School of Medicine at Mount Sinai

Cardiovascular Genetics Program

1468 Madison Avenue

Annenberg Building 3rd Floor

Division of Pediatric Cardiology

New York, NY 10029

Medical Director:

Bruce D. Gelb, MD

Contact:

Phone: 314-454-6095

Contact:

Beth Eller, RN

Phone: 314-577-5674

Email: elizabeth_eller@ssmhc.com

Contact:

Lindsay Holmes

Phone: 402-955-4323

Email: lholmes@childrensomaha.org

Contact:

Joan Zenuch

Phone: 732-235-7806

Email: joan.zenuch@rwjms.rutgers.edu

Contact:

Meghan Mac Neal, MS, CGC, MPH

Phone: 212-241-6012

Email: Meghan.MacNeal@mssm.edu

Appointments:

scheduler at 212-241-8592 or

the genetic counselor at 212-241-6012



New York continued

NewYork-Presbyterian Hospital/ Columbia University Medical Center

ColumbiaDoctors Midtown 51 West 51st Street, Suite 330 New York, NY 10019

Milstein Hospital Buildling, 7-435 177 Fort Washington Avenue New York, NY 10032 Clinic serves adults only

Medical Directors: David Engel, MD Hiroo Takayama, MD

NewYork-Presbyterian Hospital/ Weill Cornell Medical College

Division of Cardiology 520 East 70th Street, Starr 4 New York, NY 10021

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

Division of Human Genetics 505 East 70th Street, Helmsley Tower, 3rd Fl. New York, NY 10021

*Medical Director:*Christopher Cunniff, MD - Pediatric

New York University-Langone Medical Center

NYULMC Aortic Disease Center 530 First Avenue, Suite 9V New York, NY 10016

*Medical Director:*Aubrey C. Galloway, MD

Cohen Children's Medical Center of New York Northwell Health

Marfan Syndrome and Related Disorders Center 269-01 76th Avenue New Hyde Park, NY 11042 Center serves children through age 18

Medical Directors:

Angela Romano, MD (Pediatric Cardiologist)

Joyce Fox, MD (Medical Geneticist)

Contact:

Regina Delgado Phone: 212-326-8949

Email: rd2244@cumc.columbia.edu

Contact:

Phone: 646-962-4733

Contact:

Phone: 646-962-2205

Contact:

Aubrey C. Galloway, MD Phone: 212-263-7185

Email: aubrey.galloway@nyumc.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

^{*} Member, The Marfan Foundation Professional Advisory Board



New York continued

Winthrop University Hospital

Winthrop Aortic Institute 120 Mineola Boulevard, Suite 500 Mineola, NY 11501

Medical Director:

George Gubernikoff, MD

North Carolina

Duke University Medical Center

Duke Marfan/Connective Tissue Disease Clinic 2301 Erwin Road Durham, NC 27710

Medical Directors:

Stephanie B. Wechsler, MD (Cardiology and Genetics) Marie T. McDonald, MD (Genetics)

Ohio

Cincinnati Children's Hospital Medical Center

Cardiovascular Genetics Clinic 3333 Burnet Avenue Cincinnati. OH 45229

Medical Director:

Peace Madueme, MD

Cleveland Clinic

Marfan and Connective Tissue Diseases Clinic 9500 Euclid Avenue, J4-1 Cleveland, OH 44195

Medical Director:

Vidyasagar Kalahasti, MD

Nationwide Children's Hospital

Cardiogenetics/Marfan Screening 700 Children's Drive Columbus, OH 43205

Medical Director: Kim McBride, MD Contact:

Diane Onorato

Phone: 516-663-2046

Email: donorato@winthrop.org

Contact:

Jennifer Coker, BSN Phone: 919-668-2196

Email: jennifer.coker@duke.edu

Contact:

Amy Shikany, MS, CGC Phone: 513-803-3317

Email: amy.shikany@cchmc.org

Contact:

Beverly Olenik, Secretary Phone: 216-445-=7259 Email: olenikb@ccf.org

Contact:

Sara Fitzgerald-Butt Phone: 614-722-1429

Email: Sara.Fitzgerald-Butt@nationwidechildrens.org



Ohio continued

University Hospitals Case Medical Center

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

Medical Director:

Anna Mitchell, MD, PhD

Pennsylvania

Children's Hospital of Philadelphia

Connective Tissue Clinic 34th and Civic Center Boulevard Philadelphia, PA 19104 Clinic serves children to 18 years old

Medical Director: Paige Kaplan, MD

Perelman Center for Advanced Medicine University of Pennsylvania Health System

Medical Genetics Clinic PCAM South Pavillion 3400 Civic Center Boulevard Philadelphia, PA 19104

Medical Director:

Reed E. Pyeritz, MD, PhD*

Tennessee

Vanderbilt University Medical Center

The Vanderbilt Marfan Syndrome and Aortic Disorders Center 1215 21st Ave South Medical Center East, 5th Floor Nashville, TN 37232

*Medical Director:*Joshua Beckman, MD

Contact:

Sarah Grimes Hodges, MS, CGC

Phone: 216-844-3936

Email: sarah.grimes@uhhospitals.org

Contact:

Appointments: 215-590-3376

Contact:

Kara M. Welsh, Clinic Coordinator

Phone: 215-662-4740

Email: kara.welsh@uphs.upenn.edu

Contact:

Rita Williams, RN Phone: 615-936-4987

Email: rita.williams@Vanderbilt.Edu



Texas

Texas Children's Hospital

Cardiovascular Genetics Clinic Genetic Aorta Disorders 6621 Fannin Street Houston, TX 77030

Medical Director:

Shaine A. Morris, MD, MPH

University of Texas Medical Branch-Galvaston

UTMB Marfan Clinic 1005 Harborside Drive, 5th Floor Galveston, TX 77555

*Medical Director:*Abe DeAnda Jr., MD

University of Texas Physicians

Medical Genetics and Multidisciplinary Aortic and Vascular Disease Clinic 6410 Fannin Street, Suite 600 Houston, TX 77030

Medical Director:

Dianna M. Milewicz, MD, PhD*

University of Texas Southwestern Medical Center, Children's Health

Cardiovascular Genetics at Children's Health 1935 Medical District Dallas, TX 75235

Medical Director: Lynn Mahony, MD

Contact:

Andi Lewis, CGC Phone: 832-822-1723 Email: amlewis@bcm.edu

Appointments: 832-82-HEART (43278)

Contact:

Abe DeAnda Jr., MD Phone: 409-772-1203

Email: abdeanda@utmb.edu

Contact:

Stephanie Wallace, MS, CGC Phone: 713-500-7072

Email: Stephanie.E.Wallace@uth.tmc.edu

Contact:

Erica Granado

Phone: 214-456-0134

Email: erica.granado@childrenshealth.com



Utah

Primary Children's Outpatient Services/ Intermountain MedicalCenter and University of Utah Hospital

Marfan syndrome and Aortopathy Center 81 Mario Capecchi Drive Salt Lake City, UT 84113

Medical Director: Arvind Hoskoppal, MD

Washington

Seattle Children's Hospital

Cardiac Genetics 4800 Sandpoint Way NE Seattle, WA 98105

Center serves children to age 21

Medical Director: Mark Lewin, MD

University of Washington Medical Center

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

Medical Director:
Peter H. Byers, MD*
Clinic serves adults only

Wisconsin

Medical College of Wisconsin

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

Medical Director: Michael Earing, MD

Contact:

Louise Jahn, RN Phone: 801-213-7632

Email: louise.jahn@hsc.utah.edu

Nancy M. Veit, FNP BC Phone: 801-213-7628

Email: nancy.veit@hsc.utah.edu

Appointments:

Primary Children's Outpatient Services: 801-213-3599 (adults and children)

Intermountain Medical Center: 801-507-4000

(adults only)

University of Utah Hospital: 801-585-7676

(adults only)

(request Marfan appointment—patients can be seen

at any of these three locations)

Contact:

Dawn Earl, ARNP, APNG, MSN, RN

Phone: 206-987-2015

Email: dawn.earl@seattlechildrens.org

Appointments: 206-987-2015

Contact:

Debbie Olson, Program Support Supervisor

Phone: 206-598-4030 Email: olsondl@uw.edu

Contact:

Lindsey Katzmark, APNP Phone: 414-266-4757 Email: Ikatzmark@chw.org Appointments: 414-266-6784



PROFESSIONAL ADVISORY BOARD

Our Professional Advisory Board is comprised of the country's leading experts on Marfan syndrome and related connective tissue disorders. They provide us with medical oversight to our programs and services and advise us on research opportunities and priorities. These doctors see patients at the hospital where they are affiliated. Following is a list of our Professional Advisory Board members, their medical specialties, and their institutions. To make an appointment with any of them, please contact the clinic coordinator at their hospital.

Heidi M. Connolly, MD, FACC, Chair Mayo Clinic (Minnesota) Specialty: Cardiology

Juan Bowen MD Mayo Clinic, Rochester (Minnesota) Specialty: Internal Medicine/Geriatric Medicine

Alan C. Braverman, MD Washington University School of Medicine (Missouri) Specialty: Cardiology

Peter H. Byers, MD University of Washington School of Medicine Specialty: Genetics

Duke Cameron, MD Johns Hopkins Hospital (Maryland) Specialty: Cardiac Surgery

Joseph S. Coselli, MD Baylor College of Medicine and St. Luke's Episcopal Hospital (Texas)

Specialty: Cardiac Surgery

Jessica G. Davis, MD NewYork Presbyterian Hospital-Weill Cornell Medical Center

Specialty: Genetics

Richard B. Devereux, MD New York Presbyterian Hospital-Weill Cornell Medical Center Specialty: Cardiology

Hal Dietz. MD Johns Hopkins University School of Medicine (Maryland) Specialty: Genetics/Cardiology

Sylvia A. Frazier-Bowers, DDS, PhD University of North Carolina at Chapel Hill Specialty: Orthodontics

Children's Hospital Boston

Ronald V. Lacro, MD

Specialty: Genetics/Pediatric Cardiology

David Liang, MD, PhD Stanford University School of Medicine (California) Specialty: Cardiology

Irene H. Maumenee, MD University of Illinois Eye and Ear Infirmary Specialty: Ophthalmology

Dianna M. Milewicz, MD, PhD University of Texas Medical School at Houston Specialty: Genetics

D. Craig Miller, MD Stanford University School of Medicine (California) Specialty: Cardiac Surgery

Enid R. Neptune Johns Hopkins University School of Medicine (Maryland) Specialty: Pulmonology

Reed E. Pyeritz, MD, PhD University of Pennsylvania Perelman School of Medicine Specialty: Genetics

Mary J. Roman, MD NewYork Presbyterian Hospital-Weill Cornell Medical Center Specialty: Cardiology

Lynn Y. Sakai, PhD Shriners Hospital and Oregon Health & Science University Specialty: Research (does not see patients)

Paul D. Sponseller, MD Johns Hopkins Hospital (Maryland) Specialty: Orthopedics

Disclaimer: The Marfan Foundation does not certify, recommend or warrant the quality of care provided by any of the institutions listed on this directory. This listing is a directory and not a referral service.

The Marfan Foundation (the Foundation) is a health advocacy organization and does not provide medical advice or treatment. We are not a healthcare provider. It is important to realize that information provided by the Foundation is not meant as a replacement for proper care from a doctor, therapist, etc. Information provided by the Foundation is not a substitute for medical treatment or psychological care. It is vital that you talk with your healthcare providers regarding the diagnosis and treatment of Marfan syndrome and related disorders and your symptoms/features. Minors should consult with a parent/legal guardian when considering treatment and providers.

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 disorders. 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.