

2023 Marfan Foundation Institution Directory Application

1. Institution:

UC San Diego Health

2. Official name of clinic servicing patients with Marfan syndrome and related conditions:

UC San Diego Health Aortopathy and Related Conditions Clinic

3. Clinic address(es):

9434 Medical Center Drive
La Jolla, CA
92037

4. Website:

health.ucsd.edu/ACHD

5. Patient contact information for clinic coordinator/scheduler (name, phone,email):

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

6. Approximate wait time for new patient clinic appointment:

4 weeks standard
2 weeks urgent

7. Name of medical director and link to their bio:

Laith Alshawabkeh MD, MSCI, FACC
<https://profiles.ucsd.edu/laith.alshawabkeh>

8. Clinic best characterized as:

- ☒ a. Marfan and Related Conditions Clinic
- ☐ b. Aortic Center
- ☐ c. Connective Tissue Center
- ☐ d. Medical Genetics Group
- ☐ e. Cardio/Genetics Group
- ☐ f. Other:

9. Clinic service description: *(Limit 10 sentences)*

The Aortopathy and Related Conditions Clinic at UC San Diego Health is part of the accredited comprehensive adult congenital heart disease program. The clinic offers comprehensive, multidisciplinary care for patients with genetic and other aortopathies. The multidisciplinary team consists of physicians with dedicated training and board certification in adult congenital heart disease, surgeons with expertise in both pediatric and adult aortopathies, a genetic counselor, coordinated care with ophthalmology, orthopedics, high-risk obstetrics, a dedicated nurse and a coordinator, as well as access to a social worker. The clinic offers advanced imaging including cutting-edge 4D Flow MRI, congenital echocardiography, and a comprehensive surgical and transcatheter capabilities.

10. Is your center part of a tertiary care hospital?

Yes

11. General clinic hours per month:

160

12. Marfan and related conditions clinic hours per month, if available:

8

13. Number of years the clinic has served patients with Marfan and related conditions:

6

14. Number of years medical director has served patients with Marfan and related conditions:

7

15. Is a referral necessary?

No

16. If you participate in telemedicine, which states can you service, and what is the procedure for patients to sign up?

Provide telemedicine service for patients in state of California.
Patients need to register with UC San Diego Health and request a visit with Aortopathy Clinic or ACHD Clinic.

17. Does your site accept Medicaid?

Yes

18. Age group for services:

18 years & older (14+ in unique circumstances necessitating adult care)

19. For Pediatric Only centers, if children are formally transitioned to an adult facility with an existing collaboration for care, please list the institution's name and website:

N/A

20. List the name and corresponding email link for the following multidisciplinary physicians at the clinic or institution referred to. These physicians should have an established relationship/agreement with the clinic director to provide service. If there is more than one physician in a specific area, please provide all names and email links where agreements to service Marfan patients have been established. Please note if physician services adults or pediatrics.

a. Cardiologist

1. Laith Alshawabkeh, MD, MSCI, FACC
2. Matthew Carazo, MD, FACC

b. Geneticist

Kristen Wigby, MD

c. Genetic Counseling

Lauren Korty

d. Cardiothoracic/Aortic Surgery

Michael M. Madani, MD
Eugene Golts, MD
Victor Pretorius, MBChB
<https://health.ucsd.edu/specialties/thoracic-surgery/pages/default.aspx>

e. Vascular Surgery

Mahmoud Malas
<https://health.ucsd.edu/specialties/surgery/pages/vascular-endovascular.aspx>

f. Scoliosis Surgery

Joseph Osorio, MD, PhD
<https://health.ucsd.edu/specialties/neuro/specialty-programs/spine-center/pages/default.aspx>

g. Foot and Ankle Care

1. David Dalstrom, MD

2. Ian Foran, MD

<https://health.ucsd.edu/specialties/orthopedics/foot-ankle/Pages/default.aspx>

h. Pectus Surgery

Joshua Boys, MD

<https://health.ucsd.edu/specialties/thoracic-surgery/pages/default.aspx>

i. Knee Replacement

Catherine Robertson, MD

<https://health.ucsd.edu/specialties/orthopedics/joint-replacement/Pages/knee.aspx>

j. Physical Therapy

Sports Physical Therapy and Rehabilitation Center

<https://health.ucsd.edu/specialties/rehabilitation/pages/default.aspx>

k. Physiatrist

Sports Physical Therapy and Rehabilitation Center

<https://health.ucsd.edu/specialties/orthopedics/pages/physical-medicine.aspx>

l. General Pain

Sports Physical Therapy and Rehabilitation Center at UC San Diego Health

<https://health.ucsd.edu/specialties/rehabilitation/pages/default.aspx>

<https://health.ucsd.edu/specialties/pain-management/Pages/default.aspx>

m. Headaches/Migraines

Headache and Migraine Center at UC San Diego Health

<https://health.ucsd.edu/specialties/neuro/specialty-programs/pages/headache.aspx>

n. Dural Ectasia

Neurological Spine Care Center

<https://health.ucsd.edu/specialties/neuro/specialty-programs/spine-center/pages/default.aspx>

o. Hernia and Gastrointestinal Surgery

Minimally Invasive and Robotic Surgery Center at UC San Diego Health
<https://health.ucsd.edu/specialties/surgery/mis/pages/default.aspx>

p. High Risk Pregnancy

High Risk Obstetrics at UC San Diego Health
<https://health.ucsd.edu/specialties/pregnancy-birth/prenatal/maternal-fetal-medicine/pages/default.aspx>

q. Gastrointestinal Medicine

Irine Vodkin, MD
<https://health.ucsd.edu/specialties/gastro/pages/default.aspx>

r. Glaucoma

Jolene Rudell, MD, PhD
<https://shileyeye.ucsd.edu/specialties/glaucoma>

s. Lens Removal

Jolene Rudell, MD, PhD

t. Cataract Surgery

Jolene Rudell, MD, PhD
<https://shileyeye.ucsd.edu/eye-conditions/cataracts>

u. Retinal Surgery

Jolene Rudell, MD, PhD
<https://shileyeye.ucsd.edu/specialties/retina-vitreous>

v. Nutritionist

UC San Diego Health Weight Management Program
<https://health.ucsd.edu/specialties/surgery/bariatric/non-surgical/Pages/default.aspx>

w. Social Worker

Nicole Keaton, MSW

x. Pulmonologist

Jeremy Orr, MD

<https://health.ucsd.edu/specialties/pulmonary/pages/default.aspx>

y. Neurology

Neurology and Neurosurgical Center at UC San Diego Health

<https://health.ucsd.edu/specialties/neuro/Pages/default.aspx>

z. Allergy

Marc Riedl, MD

<https://health.ucsd.edu/specialties/allergy/pages/default.aspx>

21. If your clinic has an emergency protocol for patients with Marfan syndrome and related conditions, briefly describe:

If a patient with Marfan or related aortopathies presents to the emergency room with an emergency aortic condition, the emergency room consults with the on-call adult congenital heart disease cardiologist and surgeon to promptly evaluate the patient and determine needs for emergency surgery.

22. Number of patients seen for ongoing management of MFS? 70
23. Number of patients seen for ongoing management of LDS? 15
24. Number of patients seen for ongoing management of VEDS? 10
25. Number of patients seen for ongoing management of EDS (other)? 30
26. Number of patients seen for ongoing management of FAA? 20
27. Number of patients seen for ongoing management of Beals? 0
28. Number of patients seen for ongoing management of Shprintzen-Goldberg? 1

29. If your center provides data to the [Society for Thoracic Surgeons](#) database, what is your [star rating](#)?

2-3 Stars

30. In the chart below, list:

- The total institutional number of aortic root/ascending aortic root procedures (CVG, VSARR, and ascending aorta), ONLY in patients with the following CTDs (MFS, LDS, vEDS, ACTA2, SMAD3, MYLK, or PRKG1) for a five-year period with associated 30-day mortality. If you are a pediatric site, please provide pediatric numbers. Indicate on the chart whether these are pediatric or adult numbers. (REQUIRED)
- The total institutional number of CVG, VSARR, and ascending aorta surgeries for patients without CTD for a five-year period with the associated 30-day mortality. Please indicate whether these are pediatric or adult numbers. (OPTIONAL)
- Please attach a letter from your Chief of Surgery validating this data.

	Five-year Period (e.g., 1/2018-12/2022)	# of Surgeries for Five-year Period	# of Associated 30-day Mortalities	Are these Pediatric or Adult numbers?
Total Institutional CTD Aortic Surgeries (CVG, VSARR, Ascending) – REQUIRED	1/2018-12/31/2022	65	1	Adult
Total Institutional non-CTD Surgeries (CVG, VSARR, Ascending) – OPTIONAL	1/2018-12/31/2022	98	1	Adult

31. List past significant involvement with Foundation activities, including dates.

Planned for future

32. List participation in collaborative research studies or trials involving Marfan and related conditions patients.

TBD

33. Date Completed:

3/3/23