

## 2023 Marfan Foundation Institution Directory Application

- 1. Institution:**
- 2. Official name of clinic servicing patients with Marfan syndrome and related conditions:**
- 3. Clinic address(es):**
- 4. Website:**
- 5. Patient contact information for clinic coordinator/scheduler (name, phone, email):**
- 6. Approximate wait time for new patient clinic appointment:**

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

**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)*

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

**11. General clinic hours per month:**

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

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

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

**15. Is a referral necessary?**

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

**17. Does your site accept Medicaid?**

**18. Age group for services:**

**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:**

**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**

**b. Geneticist**

**c. Genetic Counseling**

**d. Cardiothoracic/Aortic Surgery**

**e. Vascular Surgery**

**f. Scoliosis Surgery**

**g. Foot and Ankle Care**

**h. Pectus Surgery**

**i. Knee Replacement**

**j. Physical Therapy**

**k. Physiatrist**

**l. General Pain**

**m. Headaches/Migraines**

**n. Dural Ectasia**

**o. Hernia and Gastrointestinal Surgery**

**p. High Risk Pregnancy**

**q. Gastrointestinal Medicine**

**r. Glaucoma**

**s. Lens Removal**

**t. Cataract Surgery**

**u. Retinal Surgery**

**v. Nutritionist**

**w. Social Worker**

**x. Pulmonologist**

**y. Neurology**

**z. Allergy**

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

22. Number of patients seen for ongoing management of MFS?
23. Number of patients seen for ongoing management of LDS?
24. Number of patients seen for ongoing management of VEDS?
25. Number of patients seen for ongoing management of EDS (other)?
26. Number of patients seen for ongoing management of FAA?
27. Number of patients seen for ongoing management of Beals?
28. Number of patients seen for ongoing management of Shprintzen-Goldberg?
29. If your center provides data to the [Society for Thoracic Surgeons](#) database, what is your [star rating](#)?

**30. In the chart below, list:**

- a. 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)
- b. 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)
- c. Please attach a letter from your Chief of Surgery validating this data.

|  | Five-year<br>Period (e.g.,<br>1/2019-<br>12/2023) | # of Surgeries<br>for Five-year<br>Period | # of Associated<br>30-day<br>Mortalities | Are these<br>Pediatric or<br>Adult<br>numbers? |
|--|---|---|--|--|
| Total Institutional CTD<br>Aortic Surgeries (CVG,<br>VSARR, Ascending) –<br>REQUIRED |   |   |  |  |
| Total Institutional non-CTD<br>Surgeries (CVG, VSARR,<br>Ascending) –<br>OPTIONAL    |   |   |  |  |



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

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

**33. Date Completed:**