2021 Marfan Foundation Institution Directory Application

1. Institution:

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

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. Medical Director name, bio link & states where tele-medicine can be practiced.

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: (Open text box)

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 been serving patients with Marfan and related conditions?

14. Number of years medical director has been serving Marfan and related conditions patients?

15. Is a referral necessary?

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

16. Does your site accept Medicaid?

17. Age group for services:

18. 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:

19. List the name and corresponding e-mail 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 e-mail 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

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

21. Number of patients seen for on-going management of MFS?
22. Number of patients seen for on-going management of LDS?
23. Number of patients seen for on-going management of vEDS?
24. Number of patients seen for on-going management of EDS (other)?
25. Number of patients seen for on-going management of FAA?
26. Number of patients seen for on-going management of Beals?
27. Number of patients seen for on-going management of Shprintzen-Goldberg?
28. If your center provides data to the Society for Thoracic Surgeons database what is your star rating?

29. 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, SMAD 3, MYLK, or PRKG1) for a 5-year period with associated 30-day mortality. If you are 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 5-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.

		# of Surgeries for 5 year period	*5-Year Period (ex 1/17-12/21)*	*# of associated 30 day mortalities*	*Are these Pediatric or Adult numbers:*
(Required)	*Total Institutional CTD (CVG,VSARR and Ascending) Aortic Surgeries*				
(Optional)	*Total Institutional (CVG, VSARR and Ascending) Aortic Surgeries (not CTD)*				

30. List past significant involvement with Foundation activities with dates.

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

32. Date Completed: