

2020 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.

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 cardiothoracic surgeon(s) with experience in treating Marfan and related conditions patients. If the surgeon is a pediatric surgeon, please indicate with a (p) next to their name. If you require more fields, please use the charts after the end of the application. For each cardiothoracic surgeon, provide website link as well as the following surgical statistics:

- a. Number of **composite valve graft (CVG) with aortic root replacement** surgeries in patients **WITH Marfan and related conditions** for one year period, Jan – Dec 2018 and 5-year period 2014-2018 and the number of 30-day mortalities for each time period.
- b. Number of **cardiovascular valve graft** surgeries in patients **WITHOUT** Marfan or related condition (include bicuspid valve surgeries here) during the previous full 12-month period (Jan – Dec 2019) and 5-year period (2015-2019) and the number of 30-day mortalities for each time period.
- c. Number of **valve-sparing root replacement (VSRR)** surgeries in patients **WITH** Marfan or related condition during the previous full 12-month period (Jan – Dec 2019) and 5-year period (2015-2019) and the number of 30-day mortalities for each time period.
- d. Number of **valve-sparing root replacement** surgeries in patients **WITHOUT** Marfan or related condition during the previous full 12-month period (Jan – Dec 2019) and 5-year period (2015-2019) and the number of 30-day mortalities for each time period.
- e. Number of **Florida sleeve aortic root remodeling** surgeries in patients **WITH** Marfan or related condition during the previous full 12-month period (Jan – Dec 2019) and 5-year period (2015-2019) and the number of 30-day mortalities for each time period.
- f. Number of **Florida sleeve aortic root remodeling** surgeries in patients **WITHOUT** Marfan or related conditions during the previous full 12-month period (Jan – Dec 2019) and 5-year period (2015-2019) and the number of 30-day mortalities for each time period.

	Surgeon	CVG for MFS/RC	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
	Surgeon	CVG/Unaffected	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
	Surgeon	VSRR for MFS/RC	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
	Surgeon	VSRR/Unaffected	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
	Surgeon	Florida Sleeve for MFS/RC	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
	Surgeon	Florida Sleeve/Unaffected	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			
Name & Website Link		Jan-Dec 2018			
		Jan 2014 - Dec 2018			

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:

	Surgeon	CVG for MFS/RC	#	30- day mortality	#
Name & Website Link		Jan-Dec 2018			
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