

Criteria for Development of A Marfan Clinic as Recommended by The National Marfan Foundation

The diagnosis, evaluation and management of the Marfan syndrome and related disorders require health practitioners from multiple disciplines with specialized knowledge, skills and experience in heritable disorders of connective tissue. Patients and families are best served in clinics with demonstrated interest and expertise in this field.

The National Marfan Foundation believes that many academic medical centers can provide exceptional diagnostic and management services. In order to develop the expertise and commitment necessary for a clinic specializing in the Marfan syndrome, investigators are encouraged to follow the criteria listed below:

1. The clinic should offer coordinated, multidisciplinary evaluation and management of Marfan syndrome and related disorders. Although extensive clinical experience with Marfan syndrome is not necessary for all of the specialists the cardiologist, the cardiovascular surgeon, the medical geneticist, the ophthalmologist, the orthopedist and the genetic counselor should be knowledgeable about Marfan syndrome and related conditions, their variable manifestations, the utility of molecular genetic testing, and the current management options. Moreover, specialists should be available in a number of other fields, including but not limited to thoracic surgery, radiological imaging, echocardiography, obstetrics and gynecology, pain management and social work. Clinics should also provide access to ancillary services such as lab services, physical therapy, occupational therapy, rehabilitation, psychiatry to name a few. When a patient requires specialty care not available at the clinic, referral to appropriate consultants must be arranged.
2. The clinic should be directed by a health professional, typically a physician, who has a demonstrated interest and expertise in some aspect of the Marfan syndrome as evidenced by extensive clinical and administrative experience. Although the precise area of medical specialty is not of primary importance, the physician must be willing to assume administrative responsibilities for the clinic, and should be given appropriate authority by the medical institution in which the clinic exists.
3. A clinic should have a coordinator, who may be a genetic counselor, nurse, nurse practitioner, social worker, or secretary. This coordinator should perform the following important functions:
 - a. Facilitate scheduling of all appointments, with particular regard to patients who find it difficult to make multiple trips to a clinic.
 - b. Educate the patient or family in detail and in advance about their upcoming visit, explain billing and insurance issues, and determine which medical records and imaging studies that need to be brought by the patient to the visit or forwarded in advance.
 - c. Ensure that the patient follows through on the scheduled appointments.
 - d. Conduct an exit interview/counseling session and make sure no unanswered questions remain.

- e. Ensure that both family and referring physician or agency receive correspondence summarizing the visit.
 - f. For diagnosis and management of patients with financial or insurance hardships, the coordinator should assist patients and families in obtaining appropriate and adequate insurance or funding from other sources to cover the costs of multidisciplinary care. Consideration should be given to innovative approaches to billing and collection within institutional guidelines, such as: a sliding fee scale based on income; a single all-encompassing clinic charge; use of clinical research center funds if clinical investigation is being performed; or, charge reductions when more than one family member is evaluated on the same day.
4. Ideally, the clinic should diagnose and manage Marfan syndrome and related conditions across the ranges from prenatal through adult age. The transition from medical management in childhood to adulthood is especially important and a clear plan must be in place for all patients.
 5. The clinic should conduct at least a monthly outpatient clinic.
 6. The clinic should offer patients and their physicians educational materials and resources developed by the National Marfan Foundation through its Professional Advisory Board.
 7. The health professionals of a clinic are encouraged to utilize the staff at the National Marfan Foundation and Professional Advisory Board for advice about diagnosis and management.
 8. The clinical staff should be willing to act as an educational resource for the medical profession, the National Marfan Foundation, the media, and the lay public. To the extent feasible, the clinic should work with local chapters of the Foundation to promote activities aimed at increasing public and professional awareness and knowledge of about Marfan syndrome and related disorders.
 9. Although the primary functions of the clinic are patient evaluation, treatment, counseling, and education, the professional staff should be willing to advance understanding of Marfan syndrome and related disorders through basic, clinical and translational investigations. While independently designed and conducted studies are encouraged, cooperation in collaborative investigations with the National Marfan Foundation through its Professional Advisory Board in collaborative investigation is encouraged.