

## NMF Clinical Council Charter

- 1) Mission: The NMF Clinical Council should focus on diagnosis and clinical care and promote best practices to enhance patient care among physicians caring for those with Marfan syndrome.
  - a) The long term goal would be not only to include all physicians in specialties related to Marfan syndrome and but also allied health professionals such as but not limited to genetic counselors, nurse geneticists, clinical nurse practitioners, dentists and physical therapists. These allied health professionals will be added to the council incrementally.
  
- 2) Criteria for Participation
  - a) Must be a physician active in the care of patients with Marfan syndrome.
  - b) NMF Professional Membership dues
  
- 3) Application Procedure
  - a) Application form
  - b) Yearly renewal through NMF dues
  
- 4) Benefits of Participation
  - a) Benefits For Physicians
    - i) Provide a venue for new ideas and allow physicians to have a voice at the NMF about issues concerning Marfan management and care.
    - ii) Provide a source of networking and practice development through development of clinical guidelines and best practices
    - iii) Provide an option to participate in NMF annual conference clinical council meeting (must provide own transportation and registration fees).
    - iv) Provide an opportunity to participate in conference clinic on a first come, first serve basis depending on the number of slots available.
    - v) Provide an opportunity for awareness of facilities to patients and an opportunity to participate in local and national events and media, and promote a direct relationship to chapters and local support groups.
    - vi) Provide a network for electronic updates and web based seminars.
  
  - b) Benefits For NMF
    - i) Develop a network of physicians to further promote the mission of the NMF through medical education and public awareness utilizing NMF key messages, support to chapters and network groups, and to promote the importance of patients participating in research studies and clinical trials.
    - ii) Provide an opportunity to develop a network of knowledgeable physicians to be used as speakers for local and national events and media.
    - iii) Serve as advocates for the Foundation to the local community by actively supporting and publicizing the Foundation's activities, projects and events

- 5) Reporting Structure:
  - a) NMF to appoint first two co-chairs to help organize group and also to develop agendas with the NMF.
  - b) Co-chairs can be invited to participate in NMF Professional Advisory Board meetings.
  
- 6) Council Member Responsibilities:
  - a) Be active participants in council by participating in teleconference calls, in-person meetings, prioritizing issues and responding to tasks.
  - b) Stay up-to-date in research and clinical trial opportunities to inform patients, be spokespeople for both national and local events and media, participate with local groups where present.
  - c) Inform patients of the all the services of the National Marfan Foundation and the resources available.
  - d) Participate in NMF fundraising events when possible.
  
- 7) Charge or Tasks to Council
  - a) Develop agenda of priority issues to enhance and advance access to quality care and management in Marfan syndrome. Agenda items can come from NMF Board, staff, PAB and clinical council members.
  - b) Develop methods to enhance care by other physicians by establishing best practices among clinics and physicians, and broaden the number of health care providers with expertise of diagnosis and management of Marfan syndrome and related disorders.