

STARTING A MARFAN SYNDROME ORGANIZATION

1. Probably the first thing you need to do is find other affected persons in your country and ask if they would be interested in helping you form a Marfan syndrome group or organization.

- Ask in the clinic or doctor's office where you or your family are treated for MFS if you can post a notice that you want to start a group.
- Ask if the clinic will help in other ways to find and notify other affected persons of your interest in starting a group.
- There are e-mail lists available in many of the IFMSO organizations.

Please check the websites on www.marfanworld.org.

- Go on-line with the Marfan-list (www.marfan-list.org) and ask for List members who are from your country.
- Give permission to the IFMSO by contacting the membership secretary to give your name, address and email to other persons from your country who are known to the IFMSO.

2. Decide with other interested persons what your needs are and decide the order in which you will address the needs. At the first, just connecting with, and perhaps meeting, other affected persons will be helpful. It is likely you will want to have information in your own language and a list of doctors in your country who have experience with MFS or who are willing to learn about Marfan syndrome.

3. Try and find doctors and allied professionals who will advise your group regarding medical information and who may help with translating medical information into your language.

4. Set up a website. You may want to review other IFMSO website (www.marfanworld.org) for ideas. In the beginning the site may simply help bring other affected persons together and help with determining what the group most needs to do. Later you may want to post information about MFS in your own language.

5. Find out if there are any laws in your country that govern how you organize or regulate NGO's (Non-Governmental Organizations). There are certain papers that must be filed with the governments in order to comply with the law.

6. Consult with Marfan organizations in other countries. Ask them how they got started and how they manage their projects. Many of these organizations are small and are run by volunteers such as you. You can find these organizations on the website of the International Organization of Marfan Syndrome Organizations (IFMSO) www.marfanworld.org

7. Consider joining IFMSO. Information on how to join is available on the IFMSO website www.marfanworld.org

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