

NVN Program Activity Outline: **Public Awareness Flyer Distribution**

Objective(s):

- To raise awareness of MFS among the general population by posting flyers on public bulleting boards that encourage people with substantial Marfan features to seek information/evaluation

Procedure:

- Select a project coordinator within your Network Group. This person will be responsible for organization, implementation, and follow-up of project activities.
- Select the person that will be the contact person listed on the flyer (may or may not be the same as project coordinator).
 - This person should be well-spoken, skilled at providing basic information on Marfan syndrome in a non-threatening, supportive, and clear manner. Before this person is finally selected, a brief telephone orientation is required with Jennifer Buffone, NMF Director of Support Services.
 - Instead of a local person, you may have the NMF Information Resource Center toll-free number and email address listed on the flyer
- Contact Kathy Jeffers at the NMF to have a flyer with local contact information produced. The flyer will be emailed to you to print on your computer. If you are not able to print the copies needed, the NMF will print and send them to you.
- Compile a list of potential community bulletin board locations. These include, but are not limited to:
 - Churches, temples, synagogues, etc.
 - Schools, universities, community colleges
 - Supermarkets, shopping malls, and other retail outlets
 - Community centers, YMCAs, health clubs
 - Anyplace else that has community boards—be creative
- Assign locations to Network Group members to avoid duplication of efforts, and establish a “due date” for completion of the initial posting. We suggest one month.
- Set up a schedule for the person responsible for each location to check back on the status of the flyer:
 - Is it still there? If so, how many tabs have been removed?
 - If not, ask if it can be reposted. (Some places may only allow items to be posted for a limited length of time.)
- The project coordinator should track the following information on the attached chart:
 - Location- Where was the flyer posted?
 - Person responsible- Who will make the contact?

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- Date posted- When did it happen?
 - Date for follow up- When will you check back?
 - Date follow up completed- When was it done?
 - Notes- What was the outcome? How many tabs have been taken? Was new flyer needed/posted?
- If a local contact's name is on the flyer, s/he should also track inquiries on the attached telephone contact log.
 - Date- When did the caller first contact you?
 - Name of caller- Did they share their name with you?
 - Nature of inquiry- What is their reason for calling?
 - Source- How did they find out about you?
 - Action taken- For example: Did you refer them to the NMF? Did you encourage them to discuss with their physician? Did you notify them upcoming Network Group activities?
 - Share results with the group and send status reports to Jonathan Martin at the NMF to let us know how it's going. We need to hear about your successes and challenges.

If you have questions, please feel free to contact us:

Toll free: (800) 8-MARFAN

Kathy Jeffers, Coordinator of Member Services
Extension 11
kjeffers@marfan.org

Jonathan Martin, Director of Education and Public Awareness
Extension 16
jmartin@marfan.org

Jennifer Buffone, Director of Support and Volunteer Development
Extension 22
jbuffone@marfan.org

Telephone/Email Contact Log Sheet:

Date submitted: _____

Date	Caller or Sender's Name/Address/Phone/Email	Nature of Inquiry	How did they find you?	Action Taken

Network Group: _____
(if applicable)

Telephone Contact: _____ Phone: _____ Email: _____

(return a copy of completed forms to Jonathan Martin)

Do you or someone you know have several of the features listed below?

- Tall, thin body type
- Long arms and legs
- Curvature of the spine
- Long, thin fingers
- Unexplained stretch marks on the skin
- Chest bone that sticks out or is sunken in
- Flexible joints
- Flat feet
- Crowded teeth
- Severe nearsightedness

Other features that are hidden include:

- Heart murmur or mitral valve prolapse
- Aortic aneurysm (enlargement of the large artery carrying blood away from the heart)
- Dislocated lense of the eye
- Sudden collapse of the lung

If so, you may want to be checked for a condition called Marfan syndrome.



National Marfan Foundation

**For more information, contact
National Marfan Foundation
Phone: (800) 8-MARFAN, ext. 26
Email: InfoOutFly@marfan.org**

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