

25th Annual Conference on Marfan Syndrome and Related Disorders
Psychosocial Workshops
Sunday, August 9, 2009

8:30 – 9:45	10-11:15	11:30 -12:45
A4 Coping with Marfan Syndrome	A5 Coping with Marfan Syndrome	A6 Coping with Related Disorders
B4 Communicating with Your Doctors	B5 Coping with Loeys-Dietz Syndrome	B6 Developing Your Emergency Plan
C4 Communicating with Your Child's School	C5 Facing Cardiovascular Surgery (guided imagery)	C6 Transitioning to Adult Care
D4 Preparing Your Child for Surgery	D5 Support Group for Parents of Teens	D6 Support Group for Mothers
E4 Support Group for Couples	E5 Support Group for Unaffected Spouses and Significant Others	E6 Support Group for Fathers
F4 Non-Operative Management for Musculoskeletal Issues	F5 Facing Orthopedic Surgery	F6 Support Group for Young Adults (20s and 30s)
G4 Becoming an NMF Volunteer	G5 Fundraising for the NMF	G6 Should You Participate in a Research Study?
H4 Medical Insurance/Disability Issues?	H5 Options for Home INR Monitoring	H6 Pilates and Connective Tissue Disorders
I4 Positive Effects of Massage and Physical Therapy for Marfan Syndrome	I5 Gentle Chair Yoga	I6 Open

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Session #4 8:30 – 9:45

Session #5 10:00-11:15

Session #6 11:30-12:45

Becoming an NMF Volunteer – G4

Interested in becoming a volunteer? This workshop is for you. There are many ways to get involved. The NMF Manager of Volunteer Development will discuss one time and ongoing volunteer opportunities that exist through the NMF.

Communicating with Your Child’s School – C4

Parents will offer their insights about how to help school personnel, especially school nurses, and students understand Marfan syndrome. There will also be a discussion on IEPs (Individualized Education Plans) and 504s. What is a 504 regulation, how does it differ from an IEP, is one better for your situation? Understanding these parts of the federal law will help you advocate with the school for your child’s special needs.

Communicating with Your Doctors – B4

Learn tips for effective communication to make the most of your doctor visits from doctors. Communication is a two way street.

Coping with Marfan Syndrome – A4, A5

This workshop will provide an open forum to share experiences and concerns about living with a chronic medical condition. Hear tips from others and learn about practical approaches to manage daily life, as well as stress and depression.

Coping with Loeys-Dietz Syndrome – B5

This workshop will provide an open forum to share experiences and concerns about living with Loeys-Dietz syndrome. Hear tips from others and learn about practical approaches to manage daily life, as well as stress and depression.

Coping with Related Disorders – A6

This workshop will provide an open forum to share experiences and concerns when the diagnosis is not Marfan syndrome, but a “related disorder.” Hear tips from others and learn about practical approaches to manage daily life, as well as stress and depression.

Developing Your Emergency Plan – B6

When an emergency arises, there is no time to pull together all the medical information the doctors will need to provide appropriate care. This workshop tells you how to plan ahead to maximize a successful outcome.

Facing Cardiovascular Surgery – C5

Veterans of aortic surgery will share experiences and answer questions to help minimize stress and fear for those who are facing surgery in the future.

Facing Orthopedic Surgery – F5

Veterans of multiple orthopedic surgeries will offer insights for creating a positive outlook and managing hospitalization, recovery, and rehabilitation. If you have had or are facing orthopedic surgery, bring your questions and concerns so that they may be addressed.

Fundraising for the NMF – G5

Learn how to organize a successful local fundraising event for the NMF. NMF staff will provide key pointers and answer questions from workshop attendees.

Gentle Chair Yoga – I5

Appropriate for people of all ages and fitness levels. Learn seated yoga exercises that can be practiced anywhere and by everyone, including people with limited mobility.

Medical Insurance and Disability Issues – H4

Learn your rights and responsibilities related to medical insurance coverage and disability. This workshop addresses questions such as how to approach your doctor and your insurance carrier for out-of-network care, how to challenge denial of service, who is eligible for disability, how one might increase chances for a successful application, and how to appeal a decision.

Non-Operative Management for Musculoskeletal Issues – F4

This workshop will focus on conservative measures to assist in managing common musculoskeletal conditions associated with Marfan syndrome. An overview of common musculoskeletal conditions, exercise recommendations, activity modification, signs of overuse, indications for seeking medical advice, and bracing will be discussed.

Options for Home INR Monitoring – H5

People who take a blood thinner such as coumadin need to closely check their blood. A nurse from the Mayo Clinic will discuss how to use a home monitor, how to decide if you should try a home monitor and how to get the monitor if it is right for you.

Pilates and Connective Tissue Disorders – H6

Pilates is one of the most popular exercise systems in the country. Find out how this unique form of physical fitness can strengthen the core and enhance balance and coordination through simple mat exercises.

Positive Effects of Massage and Physical Therapy for Marfan Syndrome – I4

A discussion about how a combination of soft tissue manipulation, physical therapy and stretching helped one person affected with Marfan syndrome reduce joint pain and improve flexibility, balance, gait and posture.

Preparing Your Child for Surgery – D4

Parents of children who have undergone surgery will share their experiences and will present some ways they've learned to help their children be prepared and will answer your questions about this topic.

Should You Participate in a Research Study? – G6

This workshop will be an open discussion. Topics will include: benefits of participating in a study, ethics, safety, expectations and experience regarding participation in clinical research.

Support Group for Couples – E4

This workshop is for the affected person and their spouse or significant other to attend together. Discussion will center on how Marfan syndrome and related disorders have an effect on each person's daily life and also on the relationship.

Support Group for Fathers of Affected Children – E6

Please note: *Participation is limited to Fathers*

Share your role and concerns with other fathers of children with Marfan syndrome and related disorders in this professionally facilitated forum. In preparation for your discussion, you may wish to identify and think about in advance, one or two topics of particular concern to present to the group.

Support Group for Mothers of Affected Children – D6

Please note: *Participation is limited to Mothers*

Share your role and concerns with other mothers of children with Marfan syndrome and related disorders in this professionally facilitated forum. In preparation for your discussion, you may wish to identify and think about in advance, one or two topics of particular concern to present to the group.

Support Group for Parents of Affected Teens – D5

Please note: *Participation is limited to parents or guardians*

Share your concerns with other parents of teens with Marfan syndrome and related disorders. In preparation for your discussion, you may wish to identify and think about in advance, one or two topics of particular concern to present to the group.

Support Group for Unaffected Spouses and Significant Others – E5

Often the primary focus of concern is on the person who has Marfan syndrome or a related disorder. This workshop provides an opportunity for those who provide love and support to an affected person to discuss their own needs and concerns.

Support Group for Young Adults (20's and 30's) – F6

Share with other young adults, life experiences, questions and concerns related to health management, career, dating, sex life, physical activities, and living an independent, fulfilling life.

Transitioning to Adult Care – C6

Transitioning from pediatric to adult care can be overwhelming. Often this means finding and building relationships with new doctors as well as young adults being responsible for their own care for the first time. This workshop is geared towards young adults transitioning into adult care as well as their care givers.