

25th Annual Conference on Marfan Syndrome and Related Disorders
Medical Workshops/CME
Saturday, August 8, 2009

2:00-3:00	3:15-4:15	4:30-5:30
A1 Cardiac Concerns	A2 Post Dissection Cardiac Concerns	A3 Cardiac Concerns
B1 Aortic Surgery- Options	B2 Vascular Surgery Aneurysms Affecting Vessels other than the Ascending Aorta	B3 Aortic Surgery in Children and Teens
C1 Pediatric Issues	C2 Dental Issues	C3 Pediatric Cardiac Issues
D1 Pectus Management	D2 Orthopedic Issues	D3 Pediatric Orthopedic Issues
E1 Podiatric Issues	E2 Pre-conception, Pregnancy and Postpartum Cardiovascular Management and Related Issues	E3 Non-surgical Approaches to Dural Ectasia and BackPain
F1 Ocular Issues- General	F2 Ocular Corrections and Visual Rehabilitations	F3
G1 Genetic Testing limits/benefits	G2 Pulmonary Issues	G3 Planning a Family: Preimplantation Genetics, Genetic Diagnosis, Adoption
H1 Loeys-Dietz Syndrome Introduction	H2 Loeys-Dietz Syndrome: Vascular Surgery in LDS	H3
I1 Pain Management Adults/Pediatrics	I2 Growing Older with MFS	I3 Cardiac Imaging: Understanding Your Imaging Studies & Z-score
J1 Marfan 101	J2 Radiology	J3 Complementary Medicine
K1 Exercise and Staying Fit	K2 Related Disorders	K3 Sleep Apnea

25th Annual Conference on Marfan Syndrome and Related Disorders
Medical Workshops
Saturday, August 8, 2009

Saturday, August 8, 2009 - Afternoon Workshops

Session #1 2:00 - 3:00

Session #2 3:15 - 4:15

Session #3 4:30 – 5:30

Aortic Surgery Options- B1

Learn more about the advantages and disadvantages of the current options for ascending and/or descending aortic surgery, and how to decide which option is best for you.

Aortic Surgery in Children and Teens- B3

Learn about the special considerations and options for aortic surgery in children and teens.

Cardiac Concerns- A1 and A3

Increase your understanding of adult cardiac concerns including drug therapies, arrhythmias, lifestyle modification, how best to prevent aortic dissections and avoid emergency situations.

Cardiac Imaging: Understanding Your Imaging Studies and Z-score- I3

Addresses the many questions related to how the aorta can be imaged (studied). Topics include advantages and disadvantages of various imaging modalities, and how to interpret your Z-score.

This workshop will focus on cardiovascular imaging. Individuals should consider the various orthopedic workshops for skeletal imaging questions.

Complementary Medicine J3

Increase your understanding of alternative treatment options that can improve well being and are performed in conjunction with standard medical care (such as acupuncture).

Dental Issues- C2

A dentist will answer questions about dental care in patients with Marfan syndrome. Included will be management of high palates/crowded teeth, use of expanders and braces, maxio-facial surgery, and the appropriate age(s) to attempt corrections.

Exercise and Staying Fit- K1

Exercise is important for physical and psychological well-being. Insight and suggestions on how to have beneficial and safe physical activity at home and at work will be provided.

Genetic Testing Limits and Benefits- G1

The benefits and limitations of genetic testing for Marfan syndrome and related disorders such as Loeys-Dietz syndrome will be provided.

Growing Older with Marfan Syndrome- I2

As persons with the Marfan syndrome are expected to live nearly normal life expectancy, new and challenging issues arise in the “aging” Marfan population. Come share your questions and concerns while learning how general principles of self-care also apply to those with Marfan syndrome.

Loeys-Dietz Syndrome - Introduction- H1

The differences between Marfan and LDS, and LDS-specific diagnosis and management, including cardiovascular, gastrointestinal, cranial issues, will be addressed.

Loeys-Dietz Syndrome – Vascular Surgery in Loeys-Dietz Syndrome– H2

Special considerations for LDS patients concerning vascular surgery. Cardiovascular surgery as well as aneurysms throughout the body will be addressed. **This workshop will focus on Loeys-Dietz Syndrome specifically. Other attendees should consider Workshop B2.**

Marfan 101- J1

The key points of Marfan management involving all body systems will be reviewed. This session is designed to help the newly diagnosed to understand the big picture and obtain complete and thoughtful Marfan care.

Non-Surgical Approaches to Dural Ectasia and Back Pain - E3

Learn about dural ectasia, associated back and leg pain, and how it can be managed.

Ocular Issues-General F1

Learn about the eye problems associated with Marfan syndrome and various options for treatment. Questions about both children and adults will be addressed.

Ocular Corrections and Visual Rehabilitations- F2

“Low vision” describes a visual impairment that hinders a person’s ability to perform every day tasks, despite the use of eyeglasses, contact lenses, medical or surgical therapy. Learn what visual aids can help you best utilize your remaining vision to its fullest potential.

Orthopedic Issues- D2

Increase your overall understanding of adult orthopedic issues including scoliosis, pain management, dural ectasia, as well as foot issues. In depth workshops are offered on many of these specific topics, including pediatric orthopedic issues, for those who wish more detailed information.

Pain Management Adults/Pediatrics- I1

The management of chronic pain in adults with Marfan syndrome will be discussed (dural ectasia, podiatric, back, etc.)

Pectus Management- D1

The methods of both pigeon chest (pectus carinatum) and funnel chest (pectus excavatum) repair will be reviewed, including who might benefit and at what age the surgery can be done.

Pediatric Cardiac Issues- C3

The cardiac management of children will be reviewed. Topics will include medical therapy, when to start, which medication and what dose to use. In addition, exercise guidelines and timing of aortic surgery will be reviewed.

Pediatric Issues- C1

This will be a general overview of the medical management of Marfan syndrome in children. This session should help you identify questions you can ask your doctor(s) about medical care specific to your child. **This workshop will emphasize non-cardiac issues since there is a workshop devoted to pediatric cardiac concerns.**

Pediatric Orthopedic Issues- D3

This workshop will address orthopedic issues faced by children. After a brief overview, the facilitator will take questions about specific concerns for your child's care.

Planning a Family: Preimplantation Genetics, Genetic Diagnosis, Adoption- G3

This workshop will explore your options in planning a family, including prenatal and postnatal genetic testing, preimplantation genetic diagnosis, surrogacy, and adoption.

Podiatric Issues- E1

This workshop will focus on the surgical and non-surgical care of Marfan feet.

Post Dissection Cardiac Concerns- A2

This workshop will address the special issues of heart and aortic care one should follow after an aortic dissection.

Pre-conception, Pregnancy and Postpartum Cardiovascular Management and Related Issues- E2

The management of the heart and aorta before, during, and following pregnancy will be reviewed.

Pulmonary Issues- G2

Ongoing research is revealing new information about the lungs and Marfan syndrome. Learn how this information might help explain lung problems and affect the care of the lungs in persons with Marfan syndrome.

Radiology – J2

This workshop will address the radiology procedures (x-ray, CT, and MRI) commonly used in individuals affected by Marfan syndrome including primarily aortic imaging options but also joint and bone imaging.

Related Disorders- K2

This workshop will address related disorders. Issues covered include differential diagnosis and management of various related disorders. **Loeys-Dietz will not be discussed as there is a special extended session for this disorder.**

Sleep Apnea – K3

This workshop will address the diagnosis and management of sleep apnea and similar sleep disorders. These disorders may affect individuals with Marfan syndrome and can affect blood pressure, as well as heart rhythm and function.

Vascular Surgery Aneurysms affecting vessels other than the Ascending Aorta-B2

This workshop focuses on reviewing anatomy, surveillance and surgical management for aneurysms **affecting vessels other than** the ascending and descending thoracic aorta.