



The Marfan Foundation's **Global** *Virtual* **Conference**

- ▶ **The Marfan Foundation**
- ▶ **Loeys-Dietz Syndrome Foundation**
- ▶ **The VEDS Movement**

JUNE 17-22, 2024

The Marfan Foundation's Global Virtual Conference connects people living with genetic aortic and vascular conditions, their loved ones, healthcare professionals, and researchers from around the world for a unique event that holistically explores the many facets of life with Marfan, Loeys-Dietz, VEDS, and related conditions. Topics include advancements in medical management, mental health and well-being, the latest research, building community, and much more. A series of live engaging virtual sessions will culminate with a virtual Victory Party celebration.

Attendees can choose sessions based on what's most important to them and hear from medical experts who will be available to answer questions. Condition-specific breakout sessions will create space for community members to connect with one another.

Conference 2024 will span five days, June 17-22. In honor of Juneteenth commemorations, there will be no sessions on June 19. Afternoon and evening sessions will be available to accommodate varying schedules and time zones. Sessions that will be recorded are noted in the [session descriptions](#). A detailed schedule is below. **All times are Eastern Daylight Time (EDT).**

Click on a date to jump to its schedule.

Adult Programming

[Monday, June 17](#) ■ [Tuesday, June 18](#) ■ [Thursday, June 20](#) ■ [Friday, June 21](#) ■ [Saturday, June 22](#)

Children & Teen Programming

[Tuesday, June 18](#)

Adult Programming

Monday, June 17

General Session for All Conditions

6:00 – 6:15 pm Welcome & Conference Overview
Bert Medina; Michael Weamer

6:15 – 6:45 pm [Improving Your Outlook & Making Connections](#)
Melissa Flint, PsyD, FT, CCPT

6:45 – 7:30 pm [Personal Perspectives Panel](#)
Dominick Corso; Jerome Harper; Adriana Rivera; Peter Donato

Support Groups by Condition

8:00 – 9:00 pm	<u>VEDS Connect</u>	<u>Marfan Connect</u>	<u>LDS Connect</u>	<u>Spanish Speakers Connect/Conexiones</u>
	<u>VEDS Parents Connect</u>	<u>Marfan Parents Connect</u>	<u>LDS Parents Connect</u>	
	<u>VEDS Partners/Spouses Connect</u>	<u>Marfan Partners/Spouses Connect</u>	<u>LDS Partners/Spouses Connect</u>	

Tuesday, June 18

Research Presentations by Condition

Choose one per timeslot.

VEDS Track

Marfan Track

LDS Track

2:00 – 2:50 pm

[The France ARCADE Trial Update](#)
Xavier Jeunemaitre, MD, PhD

[Vitamin B₁₂ Analog Cobinamide as a Potential New Treatment for Marfan Syndrome](#)
Gerry Boss, MD

[LDS Research Update](#)
Bart Loeys, MD, PhD
Josephina Meester, PhD

3:00 – 3:50 pm

[US Celiprolol Trial Update](#)
Adrian Quartel, MD

[Investigation of Sleep Disorders and Lung Injury in Marfan Syndrome](#)
Enid Neptune, MD

[Pulmonary Insights from the LDS Natural History & Genetics of Food Allergy & Related Conditions NIH Study](#)
Andrew Lipton, MS, MD, MPH&TM

Workshops by Condition

Choose one per timeslot.

VEDS Track

Marfan Track

LDS Track

5:00 – 5:50 pm

[VEDS Management & Genetics Basics](#)
Shaine Morris, MD, MPH
Ryan Rodarmer, MS

[Insights on Ocular Management for Marfan Syndrome](#)
Rachel Kuchtey, MD, PhD

[Creating a Care Team for LDS](#)
Peter Byers, MD

6:00 – 6:50 pm

[Pulmonary Concerns & Medical Management in VEDS](#)
Enid Neptune, MD

[Scoliosis Management & Surgical Options for Marfan Syndrome](#)
Paul Sponseller, MD

[Navigating GI Management in LDS](#)
Tony Guerrero, MD, PhD

Workshops for All Conditions

Choose one per timeslot.

8:00 – 9:00 pm

[Options for Pain Management](#)
Traci Speed, MD, PhD

[Mental Health Issues: Recognize the Signs & How to Get Help](#)
Karen MountainJohnson, MA, LPCC
Kathy Flynn, RN, PHN

[Advocating for Yourself & Others](#)
Ryan Rodarmer, MS
Kristi Posival

Thursday, June 20

Workshops for All Conditions

Choose one per timeslot.

2:00 – 3:00 pm

<u>Aging with a Connective Tissue Condition</u> <i>Juan Bowen, MD</i>	<u>Family Planning</u> <i>Gretchen MacCarrick, MS, LCGC</i> <i>Jennifer Rios, MS, LCGC</i>
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4:00 – 5:00 pm

<u>Navigating the US Health Insurance Landscape</u> <i>Andrew Toy</i> <i>Kara Toy</i>	<u>Coping with Grief & Loss</u> <i>Melissa Flint, PsyD, FT, CCPT</i> <i>Maya Brown-Zimmerman, MPH</i>
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7:00 – 8:00 pm

<u>Balancing Mental & Physical Health</u> <i>Carole Nowak, NBC-HWC</i>	<u>Understanding & Managing the Impact of Medical Trauma</u> <i>Michelle E. Flaum, LPCC-S, DCMHS</i> <i>Anna Witiuk</i>	<u>Emergency Preparedness & Coping with Crisis</u> <i>Katie Wright</i> <i>Meg Boeglin, BSN, RN</i>
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Friday, June 21

Presentations for All Conditions

1:00 – 1:50 pm [Staying Healthy & Exercising Safely](#)
Siddharth Prakash, MD, PhD

2:00 – 2:50 pm [AI-powered Facial Analysis for Early Diagnosis of Genetic Aortopathies](#)
David Murdock, MD

Replays of Research Presentations from June 18 (No Live Q&A)

Choose one per timeslot.

VEDS Track

Marfan Track

LDS Track

3:00 – 3:50 pm [Replay: The France ARCADE Trial Update](#)
Xavier Jeunemaitre, MD, PhD

[Replay: Vitamin B₁₂ Analog Cobinamide as a Potential New Treatment for Marfan Syndrome](#)
Gerry Boss, MD

[Replay: LDS Research Update](#)
Bart Loeys, MD, PhD
Josephina Meester, PhD

4:00 – 4:50 pm [Replay: US Celiprolol Trial Update](#)
Adrian Quartel, MD
Kim Tharaldsen, MBA

[Replay: Investigation of Sleep Disorders and Lung Injury in Marfan Syndrome](#)
Enid Neptune, MD

[Replay: Pulmonary Insights from the LDS Natural History & Genetics of Food Allergy & Related Conditions NIH Study](#)
Andrew Lipton, MS, MD, MPH&TM

Saturday, June 22

Community Chats for All Conditions

Choose one per timeslot.

10:00 – 11:00 am Choose a breakout: [Creative Expressions](#); [Global Explorers](#); [Wellness & Leisure](#); [Screen & Sound](#)

Closing Celebration for All Conditions

12:00 – 1:00 pm [Global Victory Party](#)

Children & Teen Programming

Tuesday, June 18

Children's Programming

7:00 – 8:00 pm [Kids Connect \(Ages 7-12\)](#)

Teen Programming

7:00 – 9:00 pm [Teen Connect \(Ages 13-18\)](#)

Session Descriptions

Organized Alphabetically by Title

Advocating for Yourself & Others

Living with Marfan syndrome, Loeys-Dietz syndrome, Vascular Ehlers-Danlos syndrome, or other related conditions can be challenging. Not only do these conditions present physical obstacles, but they also can lead to difficulties in securing understanding and necessary accommodations from those who may not be familiar with them. Here, we provide some guidance on how you can become a more effective advocate for yourself and others in similar situations. There will be a Q&A session at the end of the presentation. This session will be recorded.

Aging with a Connective Tissue Condition

Getting older with a connective tissue condition brings its own set of challenges. In addition to aging issues that affect the general population, individuals with Marfan, VEDS, LDS, and related conditions have to deal with progressive issues related to their diagnosis. Learn what you can do to take care of both your physical and mental health as you get older. There will be a Q&A session at the end of the presentation. This session will be recorded.

AI-powered Facial Analysis for Early Diagnosis of Genetic Aortopathies

Aortic dissections are a leading cause of death, especially for individuals with genetic aortopathies. Improved screening methods for these conditions are greatly needed, especially for children, individuals lacking clear syndromic features, and in emergency situations. This session will explore using artificial intelligence (AI) to identify at-risk individuals through facial analysis, with the goal of preventing deaths through early diagnosis. This session will be recorded.

Balancing Mental & Physical Health

This session will explore the importance of balancing both physical and mental health when living with a connective tissue condition. Understandably, the focus tends to be on medical care, and mental health is ignored or avoided despite the impact on physical health. Both are critical to overall well-being, and this session will offer strategies for finding more balance in your life. There will be a Q&A session at the end of the presentation. This session will be recorded.

Community Chats: Creative Expressions

Connect with others who enjoy expressing their creativity, thoughts, and feelings through art, crafts, music, writing, and literature. This casual chat will provide a virtual space for people to share common hobbies and interests and meet others who share their passions. Participants can come and show their projects or share what they're currently listening to or reading.

Community Chats: Global Explorers

This virtual room is all about travel, culture, and cooking. During this casual chat, people will connect with others and share their travel adventures, cultural experiences, and culinary favorites. Participants can learn about new places, people, and dishes from around the world. Join us and share photos, stories, or favorite recipes to exchange.

Community Chats: Screen & Sound

This virtual room is a hub for movie buffs, TV series enthusiasts, and music lovers. During this casual chat, people will connect with others and discuss their favorite films, TV shows, and music. Participants can exchange recommendations, discuss different genres, and explore new and classic entertainment options.

Community Chats: Wellness & Leisure

This virtual room is focused on hobbies and activities that promote relaxation and well-being. This casual chat will provide the opportunity to connect with others and discuss gardening, yoga, meditation, or other activities that help with relaxation. Participants can share tips on how to unwind, their favorite leisure activities, or ways they maintain a balanced and healthy lifestyle.

Coping with Grief & Loss

Loss can be incredibly painful and feel overwhelming. Grief is a normal part of loss – and loss includes the loss of a life or loved one, abilities, the life one thought they would lead, relationships, and so many other things. Learn about the impact of loss and healthy ways to cope. There will be a Q&A session at the end of the presentation. This session will be recorded.

Creating a Care Team for LDS

Learn the importance of creating a care team that includes a local team, a surgical team knowledgeable about genetic aortic and vascular conditions, and multiple specialists who understand your specific circumstances and management needs. This session will be recorded.

Emergency Preparedness & Coping with Crisis

Join this session to improve your preparations for emergencies that may happen with VEDS, Marfan syndrome, LDS, and related conditions. You will learn things to consider and strategies to improve your emergency preparedness toolkit. There will be a Q&A session at the end of the presentation. This session will be recorded.

Family Planning

Choosing whether to have children when living with a connective tissue condition involves several factors, including risk associated with biological children, ethics in genetic selection, and access to adoption or surrogacy. Family planning is such a personal decision, accompanied by a wide range of emotions. This session will explore the options available and address the importance of taking care of yourself throughout the process. There will be a Q&A session at the end of the presentation. This session will be recorded.

The France ARCADE Trial Update

Learn about the Angiotensin II Receptor Blockade in Vascular Ehlers-Danlos Syndrome (ARCADE) trial, a randomized, multicenter, double-blind, placebo-controlled study investigating the addition of an angiotensin blocker (irbesartan) to celiprolol. A replay of this session will be available on Friday, June 21.

Global Victory Party

All participants can put on their favorite Saturday attire and join The Marfan Foundation community around the world to dance, play games, and celebrate the day, in honor or in memory of those affected by Marfan, Vascular Ehlers-Danlos, Loeys-Dietz, and other genetic aortic and vascular conditions. Celebrate, be part of the community, and spread awareness at our Global Victory Party hosted by the Grammy-nominated DJ Willy Wow!

Improving Your Outlook & Making Connections

In this general session, Dr. Melissa Flint will share ways to boost your outlook on life despite the challenges of having a connective tissue condition and the importance of making and maintaining personal connections in your journey. This session will be recorded.

Insights on Ocular Management for Marfan Syndrome

Understanding and managing lens dislocation, myopia, and retinal detachment are crucial for maintaining optimal eye health and overall well-being. Join this session to empower yourself with knowledge and resources to manage your eye health journey with Marfan syndrome effectively. This session will be recorded.

Investigation of Sleep Disorders and Lung Injury in Marfan Syndrome

Learn about the investigation of sleep disorders and lung injury in Marfan Syndrome. A replay of this session will be available on Friday, June 21.

Kids Connect (Ages 7-12)

Kids Connect is for children ages 7-12 with Marfan syndrome, VEDS, Loeys-Dietz syndrome, and related conditions. Kids will get together for a fun-filled virtual Scavenger Hunt and have the opportunity to share what it's like to have a connective tissue condition. Led by our social worker, Kids Connect is designed for participants to have fun and be more connected with others in their age group. This session will be similar to our monthly Kids Club get-togethers, so join us to try it out!

LDS Connect (Support Group)

Meet other adults living with a diagnosis of Loeys-Dietz syndrome and share your experiences with others who can truly relate to what it's like to have the condition.

LDS Parents Connect (Support Group)

This support group is for parents of younger and older (adult) children with Loeys-Dietz syndrome. Meet other parents and discuss the unique challenges and joys of parenting a child with this condition.

LDS Partners/Spouses Connect (Support Group)

This support group is for partners, spouses, and significant others of individuals diagnosed with Loeys-Dietz syndrome to talk with others with similar experiences.

LDS Research Update

An update on new insights from LDS research. A replay of this session will be available on Friday, June 21.

Marfan Connect (Support Group)

Meet other adults living with a diagnosis of Marfan syndrome and share your experiences with others who can truly relate to what it's like to have the condition.

Marfan Parents Connect (Support Group)

This support group is for parents of younger and older (adult) children with Marfan syndrome. Meet other parents and discuss the unique challenges and joys of parenting a child with this condition.

Marfan Partners/Spouses Connect (Support Group)

This support group is for partners, spouses, and significant others of individuals diagnosed with Marfan syndrome to talk with others with similar experiences.

Mental Health Issues: Recognize the Signs & How to Get Help

In this session, Karen MountainJohnson, a licensed professional clinical counselor, and Kathy Flynn, a nurse, will discuss how to recognize the warning signs (behaviors, thoughts, etc.) when experiencing mental health issues and how to find the right mental health support. There will be a Q&A session at the end of the presentation.

Navigating GI Management in LDS

This session will provide attendees with a thorough understanding of the GI manifestations commonly observed in LDS patients and strategies for diagnosis, monitoring, and treatment. This session will be recorded.

Navigating the US Health Insurance Landscape

This session is for individuals with connective tissue conditions dedicated to navigating the US health insurance landscape. Participants will be guided through the complexities of the commercial, individual exchanges, Medicaid, and Medicare programs and discuss eligibility criteria and documentation requirements. We will also discuss how to navigate your benefits as well as get the tests and procedures you need justified through prior authorization and other potential friction points to getting the care you need. This session will be recorded.

Options for Pain Management

Chronic pain can take its toll both physically and mentally, having a significant impact on one's quality of life and overall well-being. Learn strategies for pain relief. There will be a Q&A session at the end of the presentation. This session will be recorded.

Personal Perspectives Panel

Panelists will offer their unique personal perspectives on living with their different connective tissue conditions and share how connections have been an important part of their lives. This session will be recorded.

Pulmonary Concerns & Medical Management in VEDS

Learn about pulmonary challenges associated with this condition and the intricacies of managing pulmonary complications. Acquire invaluable insights and practical strategies for optimizing respiratory health. This session will be recorded.

Pulmonary Insights from the LDS Natural History & Genetics of Food Allergy & Related Conditions NIH Study

Learn about early pulmonary outcome data obtained from the LDS natural history study being conducted at the National Institute for Allergy and Infectious Diseases. A replay of this session will be available on Friday, June 21.

Scoliosis Management & Surgical Options in Marfan Syndrome

Discover essential insights tailored to individuals with Marfan syndrome in this session on spinal issues, including scoliosis and surgical interventions. Learn about the complexities of managing spinal deformities in Marfan syndrome, including guidance on treatment options and how to navigate surgical decisions. This session will be recorded.

Spanish Speakers Connect/Conexiones (Support Group)

Grupo de apoyo virtual para establecer conexiones con otras personas que tienen condiciones del tejido conectivo. (En español).

Staying Healthy & Exercising Safely

Join us for an informative session tailored to individuals with connective tissue conditions, where we'll delve into strategies for maintaining optimal health and exercising safely. Learn expert tips on adapting workouts to accommodate your unique needs while minimizing the risk of exacerbating symptoms. Discover practical lifestyle adjustments and exercises that promote wellness and strength, empowering you to lead an active and fulfilling life despite the challenges of connective tissue conditions. This session will be recorded.

Teen Connect (Ages 13-18)

Teen Connect is a session for teenagers aged 13-18 who have been diagnosed with Marfan syndrome, VEDS, Loays-Dietz syndrome, or related genetic aortic and vascular conditions. This session is aimed at providing an opportunity for social interaction with others who share the same diagnosis. Our Teen Program leaders, staff member Dominga Noe and volunteer leader Peter Donato, will lead this session. It will include open conversations and connections on various appropriate topics. Please note that this session is not designed to offer therapy or counseling but rather an opportunity to speak on the highs and lows of living with chronic conditions as a teenager and be more connected with others in the same age group.

Understanding and Managing the Impact of Medical Trauma

Learn about the potential impact the ongoing doctor appointments, medical procedures, surgeries, and emergency situations can have on the mental health of individuals with genetic aortic and vascular conditions and strategies to address these sometimes traumatic experiences. There will be a Q&A session at the end of the presentation. This session will be recorded.

US Celiprolol Trial Update

Learn about a phase 3 clinical trial investigating the efficacy and safety of celiprolol for individuals with VEDS being conducted by Zevra Therapeutics (formerly Acer Therapeutics). A replay of this session will be available on Friday, June 21.

VEDS Connect (Support Group)

Meet other adults living with a diagnosis of VEDS and share your experiences with others who can truly relate. This support group is for those with a confirmed diagnosis of VEDS.

VEDS Management & Genetics Basics

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

VEDS Parents Connect (Support Group)

Meet other parents and discuss the unique challenges and joys of parenting a child with this condition. This support group is for parents of younger and older (adult) children with VEDS.

VEDS Partners/Spouses Connect (Support Group)

This support group is for partners, spouses, and significant others of individuals diagnosed with VEDS to talk with others with similar experiences.

Vitamin B₁₂ Analog Cobinamide as a Potential New Treatment for Marfan Syndrome

Learn about research that shows that a Vitamin B₁₂ derivative (cobinamide), when given to a Marfan mouse, prevented pathological changes in the aorta and reduced aortic dilation. A replay of this session will be available on Friday, June 21.