

THE MARFAN FOUNDATION

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GLOBAL VIRTUAL
CONFERENCE

JUNE 15-18, 2026

Marfan | Loeys-Dietz | VEDS | Stickler



The Marfan Foundation’s 2026 Global Virtual Conference brings together a global community of individuals living with Marfan syndrome, Loeyes-Dietz syndrome (LDS), Vascular Ehlers-Danlos syndrome (VEDS), Stickler syndrome, and related conditions, as well as their families, healthcare professionals, and researchers. Over four days, participants will explore the many dimensions of life with these conditions through sessions on medical care, mental health, emerging research, and opportunities to learn, connect, and build community — supporting participants to **Know. Connect. Thrive.**

Attendees may select sessions aligned with their interests and hear from clinical experts, researchers, and community voices.

This event is offered free of charge to the Foundation community. Sessions are scheduled throughout each day to accommodate a range of time zones and availability. Where applicable, recorded workshops will be noted in the [session descriptions](#). A detailed schedule is below. **All times are Eastern Daylight Time (EDT).**

[Adult Programming](#)

[Kids & Teen Programming](#)

[Programa de la conferencia](#)

Adult Programming

Monday, June 15

General Session

12:15 – 12:20 pm Welcome & Conference Overview
Bert Medina; Michael Weamer

12:20 – 12:30 pm 45 Years: The Marfan Foundation

12:30 – 1:30 pm Career-focused Personal Perspectives Panel
Dominga Noe (Moderator)

Connection Opportunity

2:00 – 3:00 pm International Connect

Research Presentations

Choose one session.

4:00 – 5:00 pm Exploring a Novel Biomarker for Thoracic Aortic Aneurysm and Dissection
Bart Loeys, MD, PhD

Type B Dissection in Marfan Syndrome
Nupoor Narula, MD, MSc

Vascular Ehlers-Danlos Syndrome Research Update:
Mechanistic Insights and Potential
Therapeutic Implications
Hal Dietz, MD

Connection Opportunities

7:00 – 8:00 pm

Marfan Connect

LDS Connect

VEDS Connect

Stickler Connect

Marfan Parents
Connect

LDS Parents
Connect

VEDS Parents
Connect

Marfan
Partners/Spouses
Connect

LDS
Partners/Spouses
Connect

VEDS
Partners/Spouses
Connect

Tuesday, June 16

Registry Presentations

Choose one session per timeslot.

12:00 – 12:50 pm An Update on the Montalcino Aortic Consortium: A Patient Registry Improving the Diagnosis and Outcomes for Individuals with Marfan, LDS, and VEDS
Dianna Milewicz, MD, PhD; David Murdock, MD; Siddharth Prakash, MD, PhD

1:00 – 1:50 pm Research Updates from the CLARITY Registry
Christopher Spence, MD

Workshops

Choose one session per timeslot.

3:00 – 3:50 pm Exercise and Physical Activity:
Health, Safety, and New Research
Siddharth Prakash, MD, PhD

Strategies for Managing Chronic
Hypervigilance in VEDS
Melissa Flint, PsyD, FT, CCPT

Diagnosed with Stickler as an Adult?
Now What?
Dana Goodloe, MS, CGC

4:00 – 4:50 pm Eye Issues and Key Management Considerations in
Connective Tissue Conditions
Jefferson Doyle, MD, PhD, MHS, MA(Oxon)

VEDS in Midlife and Beyond: Hormones,
Menopause, and What We Don't Know
Melissa Russo, MD

Bone Health in Marfan and Loey-Dietz Syndromes
Alison Boyce, MD

Replay of Research Presentation (No Live Q&A)

7:00 – 7:50 pm Replay: Type B Dissection in Marfan Syndrome
Nupoor Narula, MD

Wednesday, June 17

Workshops

Choose one session per timeslot.

12:00 – 12:50 pm	Pre- and Post-surgical Mental Health Concerns <i>Melissa Flint, PsyD, FT, CCPT</i> <i>Joaquin Ramos, Jr.</i>	Family Dynamics in the Context of Genetic Aortic Conditions <i>Maya Brown-Zimmerman,</i> <i>MPH, MS, CGC</i> <i>John Aimo</i>	Understanding the Updated LDS Primer for Diagnosis and Management <i>Gretchen MacCarrick, MS, CGC</i> <i>Julie Richer, MD</i>	Managing the Psychological Impact of VEDS in Children and Adolescents <i>Albert Freedman, PhD</i>
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1:00 – 1:50 pm	Healthy Smiles, Airways, and Sleep: Orthodontic and Pulmonary Considerations in Connective Tissue Conditions <i>Sylvia Frazier-Bowers, DDS, PhD</i> <i>Enid Neptune, MD</i>	The Physical and Emotional Aspects of Sexual Health <i>Alan Braverman, MD</i> <i>Kate Jansen, PhD</i>	Understanding Your Loeys-Dietz Subtype and Why It Matters <i>Gretchen MacCarrick, MS, CGC</i> <i>Julie Richer, MD</i>	Understanding Imaging Reports in Plain Language <i>Sanjeev Bhalla, MD</i>
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Ask the Expert/Specialist for All Conditions

Choose one session per timeslot.

6:00 – 6:50 pm	Cardiology <i>Mary Roman, MD</i>	Orthopedics <i>A. Noelle Larson, MD</i>		
7:00 – 7:50 pm	Ophthalmology <i>Rachel Kuchtey, MD, PhD</i>	Gastroenterology <i>Anthony Guerrerio, MD, PhD</i>	Otolaryngology <i>Steven Goudy, MD</i>	Foot & Ankle <i>Adam Bitterman, DO</i>

Thursday, June 18

Ask the Expert/Specialist for All Conditions

Choose one session per timeslot.

1:00 – 1:50 pm

Aging
Reed Pyeritz, MD, PhD

Cardiac Surgery
Duke Cameron, MD

Presentation

3:00 – 3:50 pm

Beyond the Aorta: Understanding Your Vascular System
James Black, MD

Closing Session

4:00 – 4:15 pm

Virtual Conference Reflection
Bert Medina, Michael Weamer

Kids & Teen Programming

Monday, June 15

Teens (Ages 13-18)

7:00 – 8:00 pm Teen Connect

Tuesday, June 16

Teens (Ages 13-18)

12:00 – 12:50 pm Artistic Expression for Teens

Kids (Ages 9-12)

7:00 – 8:00 pm Kids' Scavenger Hunt

Wednesday, June 17

Teens (Ages 13-18)

6:00 – 7:00 pm Ask the Experts

7:00 – 8:00 pm Personal Perspectives: Transitions

Kids (Ages 9-12)

7:00 – 8:00 pm Ask the Experts

Programa de la conferencia

Lunes, 15 de junio

Oportunidad de conexión

7:00 – 8:00 pm Conexiones

Miércoles, 17 de junio

Sesiones

12:00 – 12:50 pm Después del diagnóstico: un plan claro para lo que sigue
Claudia Algaze, MD

1:00 – 1:50 pm Opciones en cirugía aórtica en condiciones del tejido conectivo
Juan Pablo Umana, MD

Pregunta al Experto Para Todas las Condiciones

6:00 – 6:50 pm Pregunta al Experto: Cardiología
Claudia Algaze, MD

Jueves, 18 de junio

Sesiones

1:00 – 1:50 pm Comprendiendo las pruebas genéticas
Laura Muiño Mosquera, MD, PhD

Session Descriptions / Descripciones de las sesiones

Organized Alphabetically by Title

An Update on the Montalcino Aortic Consortium: A Patient Registry Improving the Diagnosis and Outcomes for Individuals with Marfan, LDS, and VEDS

This talk will highlight how the MAC Registry is advancing understanding of aortic disease, including timing for surgery, aortic and arterial events, and outcomes following both elective repair and dissection. It will also explore emerging tools such as facial imaging. In addition, the session will address key cardiac valve issues, including mitral valve disease and bicuspid aortic valve, to provide a more comprehensive view of cardiovascular risk and management.

Ask the Expert – Aging

After a brief overview of key takeaways related to aging with a connective tissue condition, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Cardiac Surgery

After a brief overview of key cardiac surgery takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Cardiology

After a brief overview of key cardiology takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Foot & Ankle

After a brief overview of key foot and ankle takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Gastroenterology

After a brief overview of key gastroenterology takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Ophthalmology

After a brief overview of key ophthalmology takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Orthopedics

After a brief overview of key orthopedics takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Expert - Otolaryngology

After a brief overview of key otolaryngology (ear/nose/throat) takeaways, attendees will have the opportunity to ask questions and gain practical insights for their own care or for their loved ones.

Ask the Experts (Ages 9–12)

Kids have the opportunity to ask healthcare professionals their questions about living with a connective tissue condition.

Ask the Experts (Ages 13–18)

Teens have the opportunity to ask healthcare professionals their questions about living with a connective tissue condition.

Beyond the Aorta: Understanding Your Vascular System

Join Dr. James Black for an in-depth look at the vascular system beyond the aorta. This session will explore how blood vessels throughout the body can be affected, what to watch for, and why understanding your full vasculature is important. People living with Marfan syndrome, Loeys-Dietz syndrome, VEDS, and related conditions will find this session especially helpful in supporting proactive monitoring, care, and informed conversations with their healthcare team.

Bone Health in Marfan and Loeys-Dietz Syndromes

Individuals with Marfan and Loeys-Dietz syndromes may face an increased risk of premature bone loss and fractures, making bone health an important but often overlooked aspect of care. This session will explore why bone density may be affected in these conditions and review current approaches to assessment and screening, including when and how often testing should be done. Practical management strategies will also be discussed.

Comprendiendo las pruebas genéticas

Esta sesión ofrece una visión general sobre cómo entender un informe de pruebas genéticas para personas con Marfan, LDS, VEDS, Stickler y otras condiciones genéticas aórticas y vasculares. Explicaremos los componentes clave de un informe típico, definiremos el vocabulario común y aclararemos cómo se describen las variantes y mutaciones genéticas. Los asistentes aprenderán sobre las diferentes clasificaciones, qué información es importante destacar y cómo interpretar los resultados de manera significativa.

Conexiones

Conozca a otros adultos que viven con el síndrome de Marfan, el síndrome de Ehlers-Danlos vascular (VEDS), el síndrome de Loeys-Dietz, el síndrome de Stickler y otros. Comparta sus experiencias con personas que realmente pueden identificarse con usted.

Después del diagnóstico: Un plan claro para lo que sigue

Un nuevo diagnóstico de una condición del tejido conectivo puede ser mucho para asimilar, pero no tiene que entenderlo todo de una vez. En esta sesión, hablaremos de lo más importante ahora: las prioridades médicas, qué especialistas ver, hábitos diarios y cuándo preocuparse. Queremos ayudarle a enfocarse en lo esencial para que pueda avanzar con claridad y confianza.

Diagnosed with Stickler as an Adult? Now What?

This session will address putting the right care team in place, managing symptoms, emergency planning, aging with Stickler, the role of genetic testing, and more. There will also be time to address your questions.

Exercise and Physical Activity: Health, Safety, and New Research

This session will review the new physical activity recommendations and discuss the implications of recent research findings for individuals planning to stay active. What should you know about exercise, and what should you ask?

Exploring a Novel Biomarker for Thoracic Aortic Aneurysm and Dissection

Thoracic aortic aneurysms often develop without warning, remaining silent until the life-threatening event of dissection occurs. This presentation will discuss how biomarkers may play a crucial role in enabling earlier detection of thoracic aortic aneurysm and improving the prediction of dissection risk. Dr. Loeys will also share the findings of a recent study evaluating the performance of a newly identified biomarker and its potential clinical value.

Eye Issues and Key Management Considerations in Connective Tissue Conditions

This talk will highlight the key features of ocular manifestations in each of the main categories of connective tissue conditions. It will also cover important considerations for managing eye issues specific to connective tissue conditions, including what questions to ask your healthcare professionals. In addition, the speaker will discuss important nuances in the management of common ocular disorders when they are seen in people with connective tissue conditions.

Family Dynamics in the Context of Genetic Aortic Conditions

This session is focused on understanding family dynamics when a genetic aortic condition is present. Specifically, exploring how a diagnosis can shift relationships, and how the ongoing weight of chronic illness affects individuals and families.

Healthy Smiles, Airways, and Sleep: Orthodontic and Pulmonary Considerations in Connective Tissue Conditions

Individuals with Marfan, Loeys Dietz, VEDS, and Stickler syndromes often experience unique craniofacial, dental, and airway features that can influence breathing and sleep. In this joint presentation, Dr. Enid Neptune and Dr. Sylvia Frazier Bowers will discuss how facial growth, orthodontic treatment, and airway health intersect, from childhood through adulthood. The session will highlight common concerns, signs to watch for, and how coordinated care between medical and dental specialists can support both oral health and sleep quality. Practical takeaways will empower patients and families to engage in informed conversations with their healthcare teams.

International Connect

Meet individuals living with connective tissue conditions and their loved ones and share your experiences with those who can truly relate.

LDS Connect

Meet other adults living with 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

Meet other parents/guardians and discuss the unique challenges and joys of parenting younger and older (adult) children living with Loeys-Dietz syndrome.

LDS Partners/Spouses Connect

Meet and share similar experiences with others who are partners, spouses, and significant others of individuals living with Loeys-Dietz syndrome.

Managing the Psychological Impact of VEDS in Children and Adolescents

A VEDS diagnosis affects the whole family — and for children and adolescents, the psychological dimensions can be especially complex. This session will examine the emotional and mental health challenges that young people with VEDS may face at different stages of development, and discuss approaches for supporting them. Parents, caregivers, and clinicians alike will find valuable perspective on how to help children and teens navigate life with VEDS.

Marfan Connect

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

Marfan Parents Connect

Meet other parents/guardians and discuss the unique challenges and joys of parenting younger and older (adult) children living with Marfan syndrome.

Marfan Partners/Spouses Connect

Meet and share similar experiences with others who are partners, spouses, and significant others of individuals living with Marfan syndrome.

Opciones en cirugía aórtica en condiciones del tejido conectivo

Esta sesión explicará las diferentes opciones quirúrgicas para tratar problemas de la aorta en personas con síndrome de Marfan, síndrome de Loeys-Dietz y VEDS. La presentación abordará cuándo puede ser necesaria la cirugía, los distintos tipos de procedimientos disponibles y cómo los médicos eligen el mejor enfoque para cada paciente. También se tratarán aspectos relacionados con la recuperación, el pronóstico a largo plazo y los nuevos avances que están ayudando a mejorar la atención de las personas que viven con estas condiciones.

Personal Perspectives: Transitions (Ages 13–18)

There are many transitions in the teenage years, such as moving from pediatric medical care to adult care or moving from high school to college. During this session, panelists share their own experiences in navigating such transitions.

Pre- and Post-surgical Mental Health Concerns

This session explores the emotional and psychological impact of surgery (planned and emergency), helping participants prepare for and navigate both pre- and post-operative mental health challenges. Topics include managing anxiety before surgery, coping with uncertainty, setting realistic expectations for recovery, and recognizing common post-surgical experiences. Participants will learn practical strategies to support their mental well-being.

Pregunta al Experto: Cardiología

Tras una breve descripción general de los puntos clave en cardiología, los asistentes tendrán la oportunidad de hacer preguntas y obtener información práctica para su propio cuidado o el de sus seres queridos.

Research Update from the CLARITY Registry

The Collaborative for Longitudinal Aortic Research In The Young (CLARITY) is a multicenter registry following the clinical progression, genetic diagnoses, and aortic imaging of patients living with heritable thoracic aortic disorders (HTAD). This network forms a base to help inform ongoing research in these rare conditions. The goals are to assist in risk prediction, medical and surgical intervention planning, and optimize the care of the HTAD community. We are happy to provide an update on our work to date and ongoing projects.

Scavenger Hunt (Kids)

Get ready to have fun! This virtual Scavenger Hunt for kids will have participants searching for unexpected items around their home. Kids will race against the clock and share their discoveries with the group.

Stickler Connect

Meet other individuals living with Stickler syndrome and their family members and share your experiences with those who can truly relate.

Strategies for Managing Chronic Hypervigilance in VEDS

When you live with a condition like VEDS, a heightened state of awareness about your body and your health can become a constant presence. This session will explore what chronic hypervigilance looks like in the context of VEDS, why it develops, and practical strategies for managing it. Attendees will come away with tools and frameworks to help find balance between staying informed and protecting their overall well-being.

Teen Connect (Ages 13–18)

Teen Connect is a session for teenagers aged 13–18 who have been diagnosed with Marfan syndrome, VEDS, Loeys-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.

The Physical and Emotional Aspects of Sexual Health

Living with a connective tissue condition can impact sexual health in a variety of ways. This session will explore the intersection of physical symptoms, such as pain, fatigue, joint instability, and cardiovascular considerations, with the emotional aspects of intimacy, including communication, confidence, and trust. Participants will learn to navigate common concerns, including physical challenges, body image, and anxiety.

Type B Dissection in Marfan Syndrome

In contemporary cohorts of Marfan syndrome, type B dissection is more common than type A dissection. This talk will explore risks and outcomes of type B dissection in Marfan syndrome.

Understanding Imaging Reports in Plain Language

Imaging tests play a key role in diagnosing and managing genetic aortic and vascular conditions—but the reports can feel overwhelming. In this session, we'll break down what each test shows, why your doctor may recommend one over another, how often imaging is typically done, and the most important questions to ask so you can feel informed and confident in your care.

Understanding the Updated LDS Primer for Diagnosis and Management

Join experts for an overview of the updated Loeys-Dietz Syndrome (LDS) Primer for Diagnosis and Management. This session will walk through key updates, what they mean for individuals and families living with LDS, and how the latest guidance can support better care and decision-making. Whether you're newly diagnosed or have been managing LDS for years, you'll gain practical insights to help you better understand your diagnosis and treatment options.

Understanding Your Loeys-Dietz Subtype and Why It Matters

Learn about the different subtypes of Loeys-Dietz Syndrome (LDS) and why knowing your specific subtype is important. This session will explain how subtypes can influence diagnosis, monitoring, and care, and what that means for you or your family. Whether you're newly diagnosed or looking to better understand your condition, you'll leave with practical knowledge to help guide conversations with your care team and feel more confident in managing LDS.

Vascular Ehlers-Danlos Syndrome Research Update: Mechanistic Insights and Potential Therapeutic Implications

This talk will review recent research advances using animal models of Vascular Ehlers-Danlos syndrome (VEDS). This includes application of state-of-the-art research methods to better understand the sequence of events that is initiated by a deficiency of type III collagen and that culminates in impaired tissue integrity and the clinical manifestations of VEDS. We have also used these methods to profile the tissue response to treatments that afford profound protection in VEDS mouse models. We hope to capitalize on this "signature of success" to develop and test new treatments for people with VEDS.

VEDS Connect

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

VEDS in Midlife and Beyond: Hormones, Menopause, and What We Don't Know

Living with VEDS brings unique considerations at every stage of life — and midlife is no exception. This session will explore how hormonal changes, including those associated with menopause, may intersect with VEDS, including what we currently know about the use of hormone supplementation and hormone replacement therapy. Attendees will also learn what the evidence (and gaps in that evidence) can tell us more broadly about VEDS in this life stage. Whether you are navigating these changes yourself or supporting someone who is, this talk will help you think through the right questions to ask your care team.

VEDS Parents Connect

Meet other parents/guardians and discuss the unique challenges and joys of parenting younger and older (adult) children living with VEDS.

VEDS Partners/Spouses Connect

Meet and share similar experiences with others who are partners, spouses, and significant others of individuals living with VEDS.