



2025 Preliminary Adult Program

The Marfan Foundation, in association with Children's Healthcare of Atlanta, Emory Healthcare, and The Emory Clinic, will host an in-person conference July 10-13, 2025 that provides people living with Marfan syndrome, Loeys-Dietz syndrome (LDS), Vascular Ehlers-Danlos syndrome (VEDS), Stickler syndrome, and related conditions, and their families an opportunity to learn about these conditions from the country's medical experts, hear about the latest research, learn ways to improve their quality of life, and connect with other people who are on the same medical journey.

On Saturday morning, July 12, the General Session will feature a series of expert-led presentations covering the latest information on genetic aortic and vascular conditions, including research, medical therapy, aortic surgery, physical activity, and caring for one's mental health. In the afternoon, attendees can participate in small-group workshops led by experts in Marfan, LDS, VEDS, Stickler, and related conditions. These interactive sessions will provide a more in-depth look at various topics related to diagnosis, treatment, and medical concerns.

On Sunday morning, July 13, small-group workshops will continue, focusing on mental health, quality of life, and peer-to-peer support. These sessions will offer practical coping strategies and hands-on activities that attendees can integrate into their daily routines.

Networking opportunities will be plentiful throughout the weekend, with events like the Creating Connections Luncheon and the special 40th Celebration & Victory Party.

This year's Conference features condition-specific workshops and broader topics relevant to all attendees, including genetics, family planning, exercise and physical activity, and bone and joint health. Conference programming is in English; however, two workshops will be offered in Spanish on Saturday.

Thursday, July 10

7:00 AM – 5:00 PM

Registration and Information

8:00 AM – 4:00 PM

Health Fair Testing Day

Health Fair echocardiograms, eye exams, and lung function testing at Children's Healthcare of Atlanta. Attendance is by appointment only, and an application is required.

Friday, July 11

- 7:00 AM – 5:30 PM Registration and Information
- 8:00 AM – 5:00 PM Health Fair Evaluation Day
Health Fair screenings with experts from various disciplines at Children’s Healthcare of Atlanta. Attendance is by appointment only, and an application is required.
- 5:00 PM – 7:00 PM Condition-specific Mixers
Connect with fellow Conference attendees with the same condition or loved ones affected by it in a relaxed, informal setting. It’s a wonderful opportunity to start building meaningful connections before the Conference officially kicks off. Plus, you can continue the conversation and enjoy the awards dinner together afterward!
- 7:00 PM – 9:00 PM Welcome Dinner & Awards
Enjoy a buffet dinner and celebrate the presentation of the Foundation’s prestigious awards, honoring individuals who have made significant contributions to the Marfan syndrome, VEDS, LDS, and related conditions community. A cash bar is available for drink purchases.

Saturday, July 12

- 7:00 AM – 8:15 AM Continental Breakfast
- 7:00 AM – 5:30 PM Registration and Information
- 8:30 AM – 11:40 AM General Session
- Part 1
- 8:40 Caring for Your Mental Health During the Conference and Beyond
- 9:00 Personal Perspectives Panel
- 9:20 Research Landscape in Genetic Aortic and Vascular Conditions
- 9:40 Q&A + Break
- Part 2
- 10:20 Medical Therapy for Individuals with Connective Tissue Conditions
- 10:40 Aortic Surgery Options for Adults with Connective Tissue Conditions
- 11:00 How to Exercise Safely and Get the Most Out of Physical Activity
- 11:20 Q&A
- 12:00 PM – 1:15 PM Creating Connections Luncheon
Network and engage with other Conference attendees over lunch.

1:30 PM – 5:00 PM

Medically Focused Workshops

Small-group workshops led by experts in Marfan, LDS, VEDS, Stickler, and related conditions provide a more in-depth look at various topics related to your or your loved one's diagnosis or medical concern.

7:30 PM – 10:00 PM

40th Celebration & Victory Party for All Ages

After enjoying a dinner on your own, pop over to the 40th Celebration & Victory Party. This all-ages event promises a night of fun with games, music, dancing, and so much more!

Sunday, July 13

7:00 AM – 8:30 AM

Breakfast

9:00 AM – 12:30 PM

Mental Health and Quality of Life Workshops

Small-group workshops will resume, focusing on mental health, quality of life, and peer-to-peer support. These sessions will offer valuable coping strategies and practical activities that can be incorporated into daily routines at home.

Saturday Workshops

Session 1: 1:30-2:30 PM

Bone and Joint Issues in Adults with Connective Tissue Conditions Learn about bone, hypermobile joint, and ligament issues in people with connective tissue conditions. Discuss how posture, exercise, joint supports, and medication can help.

Cardiac Care for Children Enhance your understanding of heart-related issues in children, including signs and symptoms of heart failure, valve issues, and arrhythmias. Discover effective medications and lifestyle modifications that can help improve and protect your child's heart health.

Coping with Pain This session will address the non-pharmaceutical, psychological/emotional side of coping with pain, including getting ahead of pain prior to surgery.

Genetic Testing to Diagnose Connective Tissue Conditions Learn the limits and benefits of genetic testing and why it is more important than ever for your family.

LDS 101 This session is intended to help the newly diagnosed understand what it means to live with LDS and how to find complete and thoughtful care. It will review the key points of LDS diagnosis and management involving all body systems.

Marfan 101 This session is intended to help the newly diagnosed understand what it means to live with Marfan syndrome and how to find complete and thoughtful care. It will review the key points of Marfan diagnosis and management involving all body systems.

Monitoring Dissections and Aneurysms in VEDS This workshop focuses on managing the elevated risk of dissections and aneurysms (aortic and non-aortic) in VEDS. Participants will learn about early detection, monitoring, and treatment options for these emergency complications.

Post-Dissection Aortic Care in Marfan and LDS Gain a comprehensive understanding of post-dissection care for both aortic and non-aortic arteries. This session will cover the importance of accurate imaging, how to monitor for complications, and when additional interventions may be needed.

Stickler 101 This workshop offers an introduction to Stickler syndrome, focusing on its genetic causes, key symptoms, and potential complications. Attendees will gain an understanding of the condition's impact on vision, hearing, and joint health and strategies for diagnosis, management, and support.

VEDS 101 This session is intended to help the newly diagnosed understand what it means to live with VEDS and how to find complete and thoughtful care. We will review the key points of VEDS diagnosis and management involving all body systems.

Grupo de apoyo Connections Conozca a otros adultos que viven con un diagnóstico de afecciones genéticas aórticas y vasculares, incluyendo 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.

Saturday Workshops

Session 2: 2:45-3:45 PM

Aortic Surgery Options for Adults Explore the benefits and risks of current surgical options for ascending and/or descending aortic surgery. Learn how to evaluate these choices and determine the most appropriate option based on your needs and circumstances for optimal outcomes. Gain a better understanding of the PEARS procedure.

Bright Smiles: Keeping Your Teeth and Gums Healthy Ask questions about dental care and connective tissue conditions. Topics include receding gums, managing high palate/crowded teeth, using expanders and braces, maxillofacial surgery, and the appropriate age to attempt corrections. Learn about when antibiotics are needed during dental care.

Cardiac Care Strategies for Adults Increase your overall understanding of heart-related issues in adults, such as arrhythmias. Learn about medications, lifestyle modifications, and how to help prevent aortic dissection and other emergency situations.

Management Strategies for Early-onset and Severe Forms of Marfan and LDS Explore the cardiovascular, musculoskeletal, craniofacial, and pulmonary challenges faced by children with early-onset and severe forms of Marfan and LDS, along with the latest treatment options available to help manage these conditions.

Managing Dissections and Aneurysms in LDS This workshop focuses on managing dissections and aneurysms in LDS. Participants will learn about early detection, monitoring, and treatment options for these critical complications.

Managing VEDS in Children This session will review the management of VEDS in children, highlighting the benefits and risks of medications, the importance of regular follow-ups, and handling emergencies. Learn strategies to promote a safe yet active lifestyle for children with VEDS.

Medical Approaches to Pain Management Learn about the causes and management of chronic pain.

Medical Trauma This session offers insight into the potential impact that ongoing doctor appointments, medical procedures, surgeries, and emergency situations can have on one's mental health. Learn strategies to manage medical trauma and reduce the distress and anxiety often accompanying it.

Understanding Gastrointestinal Challenges in VEDS Learn about managing constipation and ensuring gastrointestinal health with VEDS to try to avoid serious life-threatening complications. Ask questions about surgical care during intestinal rupture and colostomies.

Vision Care for Children and Adults This workshop focuses on eye care for children and adults, addressing common vision issues such as lens dislocation and retinal detachment. Participants will learn about regular eye screenings, preventive measures, and treatment options to maintain eye health, improve quality of life, and prevent serious complications.

Saturday Workshops

Session 3: 4:00-5:00 PM

Addressing Lung Health in Connective Tissue Conditions Learn about lung complications that can occur in Marfan, LDS, and VEDS and treatment options for the best outcomes.

Aortic Surgery in Children Learn about options for aortic surgery (whether planned or unplanned) in children and teens.

Exercise and Physical Activity 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.

Family Planning, Genetics, and Reproductive Health Learn about medical and non-medical options for planning a family, including prenatal and postnatal genetic testing, preimplantation genetic diagnosis, surrogacy, and adoption.

Hearing Loss and Retinal Detachment in Stickler Syndrome This workshop explores hearing loss and retinal detachment in Stickler syndrome. Discover effective treatments, assistive devices for hearing support, and strategies for managing eye emergencies to preserve optimal vision.

Life After a Dissection Aortic and other dissections can occur when living with a connective tissue condition. Most people are so focused on the physical recovery that they aren't prepared for what happens afterwards from a mental health perspective. This session will address the mental and emotional issues related to life after dissections and tips for coping.

Management of Allergies and Gastrointestinal Issues in LDS Understand the increased prevalence of asthma, food allergies, eczema, and allergic rhinitis in individuals with LDS. Discover effective management strategies including nutrition and medications to alleviate symptoms and prevent serious complications.

Oral Health and VEDS Learn about common oral complications, effective management strategies, and specialized care approaches to improve dental health for individuals with VEDS.

Orthopedic Care for Children with Marfan and LDS This session focuses on managing children's scoliosis and other bone and joint issues, including hypermobility and ligament problems. Meet the experts and discover solutions to positively impact outcomes and reduce pain.

Recognizing and Navigating Emergencies in VEDS Empower yourself with vital knowledge to navigate VEDS-related emergencies confidently. Learn to recognize emergency symptoms, make informed treatment decisions, and communicate effectively with first responders and emergency department staff.

Información general sobre enfermedades del tejido conectivo Esta sesión está diseñada para ayudarle a comprender mejor qué significa vivir con el síndrome de Marfan y condiciones relacionadas, así como a encontrar una atención integral y especializada. También se revisarán los puntos clave del diagnóstico y el manejo de todos los sistemas del cuerpo.

Sunday Workshops

Session 1: 9:00-10:00 AM

Living with a Connective Tissue Condition as You Age (Support Group) Getting older brings its own set of challenges. Meet age 50+ adults living with a connective tissue condition and share your experiences with those who understand.

Living with Loeys-Dietz (Support Group) Meet adults living with a diagnosis of Loeys-Dietz syndrome and share your experiences with others who can truly relate.

Living with Marfan (Support Group) Meet adults living with a diagnosis of Marfan syndrome and share your experiences with others who can truly relate.

Living with Stickler (Support Group) Meet other individuals living with a diagnosis of Stickler syndrome and their family members and share your experiences with those who can truly relate.

Living with VEDS (Support Group) Meet 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.

Mental Health Issues: Recognizing Signs & Getting Help In this session, learn how to recognize mental health warning signs (behaviors, thoughts, etc.) and how to find the right mental health support.

Mindfulness Mindfulness serves as a powerful tool in helping those who live with a chronic condition. Learn about mind-body benefits as well as mindfulness practices that help in reducing stress and coping with adversity.

Parents' Toolbox – Navigating the School System Learn about the best ways to navigate the school system and advocate for your child. This session will help you understand the process of getting the right accommodations, learn tips for partnering with the school nurse and develop effective communication strategies with the teacher and administration.

Teen Perspectives Panel In this session, teens will share their unique perspectives on a variety of topics they hope parents will discuss with their children. There will be a Q&A session at the end of the presentation.

Sunday Workshops

Session 2: 10:15-11:15 AM

Art as Therapy Art therapy can play a powerful role in helping individuals cope with a chronic condition. It can serve as an emotional outlet, provide stress relief and facilitate social interaction. Join this session to learn more about art therapy and how it can improve your overall well-being.

Cooking with a Connective Tissue Condition Do you find cooking to be a challenge because you are fatigued, in pain, and/or have limited mobility? Learn how adapting cooking methods and using helpful kitchen gadgets can make meal preparation more manageable and enjoyable.

Emergency Preparedness: Coping with the Unexpected 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.

Parenting a Child Severely Affected or with Early Onset / Neonatal (Support Group) This support group is for parents/guardians of children who are more severely affected with a connective tissue condition, like early onset Marfan syndrome. Meet other parents/guardians and discuss the unique challenges and joys of parenting a child who has serious health concerns.

Parenting a Child with Loeys-Dietz (Support Group) This support group is for parents/guardians of children (17 years and younger) with Loeys-Dietz syndrome. Meet other parents/guardians and discuss the unique challenges and joys of parenting a child with this condition.

Parenting a Child with Marfan (Support Group) This support group is for parents/guardians of children (17 years and younger) with Marfan syndrome. Meet other parents/guardians and discuss the unique challenges and joys of parenting a child with this condition.

Parenting a Child with VEDS (Support Group) Meet other parents/guardians and discuss the unique challenges and joys of parenting a child with VEDS. This support group is for parents/guardians of children (17 years and younger).

Parenting an Adult Child with a Connective Tissue Condition (Support Group) Meet other parents/guardians and discuss the unique challenges and joys of being the parent/guardian of an adult living with a connective tissue condition. This support group is for parents/guardians of adults (18 years and older).

Practical Considerations as a Young Adult Young adults experience a significant turning point in their lives when they face transitions like work opportunities and independence in living. For young adults who have a connective tissue condition, medical care and workplace accommodations become part of their decision-making process. In this session, learn more about practical considerations for young adults in our community who face these life transitions.

The Emotional Side of Family Planning Family planning is such a personal decision accompanied by a wide range of emotions. This session will explore the thoughts and feelings that so many experience while trying to decide whether and/or when to have children as well as self-care strategies.

Sunday Workshops

Session 3: 11:30 AM-12:30 PM

Advocating for Yourself and Others Advocating for yourself and others living with connective tissue conditions is essential to ensure you receive the proper healthcare, insurance coverage and fair treatment. This session offers practical tips to help you become an effective advocate. Learn how supporting one another and building a community is an important part of advocacy.

Body Image, Self-Acceptance & Relationships Living with a connective tissue condition often means having unique physical characteristics. If you are feeling self-conscious, having a difficult time with relationships, or struggling emotionally, you are not alone. This session will explore body image and strategies for greater self-acceptance.

Fathers/Guardians (Support Group) This support group offers a space to share your experiences with other fathers of children with a connective tissue condition. There are many ways to be a father, so if being a father figure is meaningful to you, you are welcome to join.

Health Insurance & Disability This session is dedicated to navigating the US health insurance landscape. You will be guided through the complexities of the commercial, individual exchanges, Medicaid and Medicare programs, eligibility criteria, and documentation requirements. You will also learn 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.

Mothers/Guardians (Support Group) This support group offers a space to share your thoughts, experiences and feelings with other mothers of children with a connective tissue condition. There are many ways to be a mother figure so if that role is meaningful to you, you are welcome to join.

Music Therapy Enhancing emotional expression, promoting relaxation and stress relief, and alleviating pain are just some of the benefits of music therapy. Join this session to learn more about music therapy and how it can improve your overall well-being.

Partners & Spouses (Support Group) Join this support group to meet and share similar experiences with others who are partners, spouses, and significant others of individuals diagnosed with a connective tissue condition.

Physical Therapy for Connective Tissue Conditions This workshop is led by a physical therapist who personally understands connective tissue conditions. She is excited to share how movement strategies can boost daily function, prevent injury, and improve long-term musculoskeletal health. Learn key exercise principles, tips for finding a knowledgeable physical therapist, and when to try external supports like splints and braces.

Transition to College Transitioning to college with a chronic condition can be overwhelming for both parents and students with a chronic condition. Learn from both parents and students alike about this time of transition and how they are navigating the journey.

Traveling with a Connective Tissue Condition This session focuses on ways to enjoy safe travel away from home, including how to prepare for the trip, essential paperwork, coming up with a plan in case of emergency, and ways to deal with travel obstacles such as pain and fatigue.