



## 2023 PRELIMINARY ADULT PROGRAM

On both Saturday and Sunday, July 15 and 16, adult attendees will hear the latest information on diagnosis, treatment, and research during the General Session and participate in small-group workshops led by aortic and vascular conditions medical experts as well as allied and mental health professionals. There will be many opportunities to network at events such as the Creating Connections Luncheon and Victory Party during the weekend.

In striving to save lives and improve the quality of life with those with Marfan, Loeys-Dietz, Vascular Ehlers-Danlos, and other connective tissue conditions, there are condition-specific offerings this year as well as topics that affect all conditions such as imaging, genetics, etc. Our focus on mental health on Sunday includes multiple condition-specific issues such as parenting, coping with stress, and the unknown of having a life-threatening condition. All conference programming is in English. One workshop session will be offered in Spanish.

### THURSDAY, JULY 13

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| 8:00 AM – 5:00 PM | Registration and Check In   |
| 8:00 AM – 4:00 PM | Health Fair echocardiograms, eye exams, and lung function testing at Lurie Children's Hospital. By appointment only. Health Fair application is required. |

### FRIDAY, JULY 14

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| 8:00 AM – 4:00 PM | Health Fair screenings with experts from various disciplines at Lurie Children's Hospital. By appointment only. Health Fair application is required. |
| 9:00 AM – 5:30 PM | Registration and Check In  |
| 7:00 – 9:00 PM    | Welcome Dinner and Awards<br>Enjoy a buffet dinner and celebrate as awards are presented to those who have made extraordinary contributions.         |

**SATURDAY, JULY 15**

7:00 – 8:30 AM

Continental Breakfast

7:00 AM – 5:30 PM

Registration and Check In

8:30 – 11:40 AM

**GENERAL SESSION  
PART 1**

8:40 Understanding the New ACC/AHA Aortic Disease Guidelines

9:00 Advances in Cardiac Imaging

9:20 Aortic Surgical Options for Adults

9:40 - 10:20 Q&A + Break

**PART 2**

10:20 When is Vascular Surgery an Option?

10:40 Gastroenterology in Connective Tissue Conditions

11:00 Life with Aortic Disease: Caring for Your Mental Health

11:20 -11:40 Q&A

12:00 – 1:30 PM

Creating Connections Luncheon

1:30 – 5:00 PM

**SATURDAY MEDICAL WORKSHOPS**

Informal opportunity to ask questions of physicians.

7:30 – 10:00 PM

Victory Party (All ages)

**SUNDAY, JULY 16**

7:00 – 8:30 AM

Continental Breakfast

9:00 AM – 12:30 PM

**SUNDAY MENTAL HEALTH AND FUN ACTIVITY WORKSHOPS**



## SATURDAY WORKSHOPS

### Session 1: 1:30-2:30 PM

**A1 Marfan 101** The key points of Marfan diagnosis and 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.

**B1 Exercise & Physical Activity** Learn about the guidelines for physical activity for children and adults and how to monitor exercise.

**C1 Post-Dissection Aortic Care** Learn the ins and outs of post-dissection care in aortic and non-aortic arteries. Discussion includes the importance of correct imaging and understanding when additional intervention is necessary.

**D1 Dislocated Lenses & Eyeglass Fitting for Children with Marfan** Learn from experts about how to achieve better vision in children in hopes of delaying surgery. Learn about the eye issues associated with Marfan syndrome and options for care. Issues for children are addressed, including correction and rehabilitation options. Learn what visual aids can help your child utilize their vision to its fullest potential.

**E1 Medical Approaches to Pain Management** Learn about the causes and medical management of chronic pain.

**F1 VEDS 101** Are you newly diagnosed with VEDS? Need to learn the basics? Join renowned experts to learn what to expect and how to manage this condition.

**G1 Managing Dissections and Aneurysms in VEDS** Learn about where aneurysms and dissections are found in VEDS and when surgery is needed. Ask your questions about the variety of surgical interventions and recovery as well as post-operative monitoring.

**H1 LDS 101** Are you or someone you care for newly diagnosed with Loeys-Dietz syndrome? Need to learn the basics? Join renowned experts to learn about what to expect and how to manage this condition.

**I1 Bone and Joint Issues in Adults** Learn about bone, hypermobile joint, and ligament issues in people with connective tissue conditions. Discuss posture, exercises, joint supports, and medication, and which can prove to be helpful treatments.

**J1 Family Planning & Genetics & Reproductive Health** Increase your knowledge about medical and non-medical options for planning a family, including prenatal and postnatal genetic testing, preimplantation genetic diagnosis, surrogacy, and adoption.

# SATURDAY WORKSHOPS

## Session 2: 2:45-3:45 PM

**A2 Developing a Multi-Discipline, Surgical & Local Care Team** Learn the importance of creating a care team that includes a local team and a surgical team knowledgeable about genetic aortic and vascular conditions as well as multiple specialists that understand your specific circumstances and management needs.

**B2 Aging in Marfan/LDS/VEDS** People who are diagnosed with genetic aortic and vascular conditions deal with progressing issues related to their diagnosis, as well as the aging issues that affect the general population. Learn what you can do take care of yourself as you get older and arm yourself with the tools you need to face life-threatening issues.

**C2 Neurovascular Complications** Learn about symptoms of transient ischemic attack (TIAs), brain and spinal cord strokes, subdural dissections, and hemorrhages, as well as the available medical treatments and surgical options.

**D2 Orthopedic Issues in Children and Teens** This session addresses managing scoliosis as well as other bone and joint issues such as hypermobility, ligament issues, etc. in children. Meet the experts and find solutions to improve outcomes and reduce pain.

**E2 Management of Neonatal and Severe Forms of Marfan and LDS** Ask questions regarding difficult issues, such as cardiac care, pulmonary care, and feeding in children who are severely affected with Marfan syndrome or LDS.

**F2 Management of VEDS in Children** This session will provide a review of the management of VEDS in children, the positive and negative effects of medication, maintaining follow-ups, and emergency situations for children. Find out how to encourage a safe but active lifestyle for children with VEDS.

**G2 Managing Gastrointestinal Health with 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.

**H2 Dental Issues** In this workshop, ask questions about dental care and connective tissue conditions. Topics include receding gums, management of high palate/crowded teeth, use of expanders and braces, maxillofacial surgery, and the appropriate age to attempt corrections. Learn about when antibiotics are needed during dental care.

**I2 Management of Lung Issues in Marfan/LDS** Learn how Marfan/LDS result in asthma, emphysema, and sometimes life-threatening pneumothorax. This session also addresses the medical treatment options as well as surgical options for the best outcomes.

**J2 Pediatric Cardiac Surgery** When is heart surgery needed for your child? Learn about mitral valve, and aortic valve, and aortic root surgery for children. What can be expected and what does recovery look like?

# SATURDAY WORKSHOPS

## Session 3: 4:00-5:00 PM

**A3 Cardiac Care for Children with Marfan/LDS** Increase your overall understanding of heart-related issues in children, including signs and symptoms of heart failure, valve issues, and arrhythmias. Learn about medications and lifestyle modifications to improve and protect your child's heart health.

**B3 Aortic Surgery Options for Adults** Learn 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.

**C3 Genetic Testing: Limits and Benefits in Diagnosis** Learn the limits and benefits of genetic testing and why it is more important than ever for your family.

**D3 Orthopedic Surgery in Children** What do you need to know about scoliosis and pectus surgery? When is surgery needed? What can be expected? What is the follow-up that needs to take place after surgery. Learn about these procedures and the recovery period.

**E3 Pediatric to Adult Cardiology: Transitioning Care for Marfan/LDS/VEDS** Learn about transition preparedness and implementation needed for your child to manage their own health care and effectively use health services. Learn about the timing and progression of transition to adult care and identify qualities of readiness for transition.

**F3 Answering Your Questions on Menstruation, Pregnancy, and Menopause with VEDS** Come ask your questions about menstruation, pregnancy, and menopause for those with VEDS. Topics include painful menstruation, pregnancy and its effect on the uterus and associated fragile arteries, and more.

**G3 Managing Lung Complications in VEDS** Learn about lung complications that can occur in VEDS, such as pneumothorax and hemothorax, and methods to address them.

**H3 Management of Allergies and Gastrointestinal Issues in LDS** Learn about the increased incidence of asthma, food allergy, eczema, and allergic rhinitis in LDS. Ask your questions about management, nutrition, and medications to help ease the symptoms and safe-guard from serious consequences.

**I3 Managing Foot and Ankle Issues in Marfan/LDS/VEDS** Learn about management for flat feet, hammertoes, club foot, and other foot issues.

**J3 Marfan, LDS, VEDS 101 in Spanish** Hosted by a Spanish-speaking expert.



## SUNDAY WORKSHOPS

### Session 1: 9:00-10:00 AM

**A4 Emergency Preparedness with VEDS, Marfan, LDS** 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 kit.

**B4 Coping with Pain: Strategies for Relief & Recovery through OT & PT** 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, including mental exercises, and occupational and physical therapy activities.

**C4 Partners & Spouses** Are you the partner or spouse of someone with VEDS, LDS, or Marfan syndrome? Being the unaffected partner in a relationship can have unique challenges. Connect with others who can relate.

**D4 Living with LDS (For Patients)** Join this support group for individuals with a diagnosis of Loays-Dietz syndrome. Connect with your community, share your experiences, and learn from others who share your condition.

**E4 Parents Toolbox: How to Navigate the School System and Handle Bullying** School can be challenging for a variety of reasons. This workshop will help you understand the process of getting the right accommodations for your child, learn tips for partnering with the school nurse, and strategies for addressing bullying.

**F4 Art as Therapy** Art is a fun activity that has many benefits. Share your love of art and learn how something as simple as coloring can be an amazing coping strategy.

**G4 Newly Diagnosed Support Group (For Patients with Marfan, LDS, VEDS)** Have you recently been diagnosed with LDS, Marfan, or VEDS? This group is for you. Share your questions and concerns with other community members who can truly relate.

**H4 Mental Health Issues: Recognizing Signs and Getting Help** Mental health is important for everyone, and the burden of a chronic illness makes it even more challenging. Attend this workshop to learn about some of the most common mental health issues (depression, anxiety, etc.), how to identify them in yourself or a loved one, and steps that can be taken to get the help needed.

**I4 Stress and Heart Disease: The Mind-Body Connection** Having a heart condition extends well beyond the heart. Learn the protective role of our stress response - what it is, how it protects us from danger, and why cardiac and stress symptoms overlap. We'll review strategies to keep your stress at

bay and practice some exercises that may help reverse your stress response by tapping into your body's parasympathetic nervous system, or built-in relaxation response.

**J4 Self-care** All too often, people with chronic illness are so focused on their medical issue that they neglect to take care of their other needs. Self-care is an important part of maximizing one's overall wellness. Attend this session to learn strategies for self-care, which goes way beyond bubble baths.

## SUNDAY WORKSHOPS

### Session 2: 10:15-11:15 AM

**A5 Taking Control of Your Life with VEDS, Marfan, LDS & Coping with the Unexpected** Have you ever felt like your VEDS, Marfan, or LDS diagnosis makes you a ticking time bomb? Learn strategies for coping with the unexpected, taking greater control of your life, and becoming more of a bomb diffuser.

**B5 Teen Perspectives Panel** Do you wonder when and how to share information with your child about their condition? This workshop, developed by our Teen Council, features teen panelists who share their unique perspective on topics they hope parents discuss with their children.

**C5 Advocating for Yourself & Others** In a world of people who don't understand what it's like to be disabled, how can you get understanding and accommodations? Learn more about fighting for your rights with activists.

**D5 Grief and Loss** Join this support group to connect with others who have lost a loved one with a genetic aortic or vascular condition. Grief is a normal part of loss, and sharing your thoughts and feelings with others who can relate is often very helpful.

**E5 Living with Marfan Syndrome (For Patients)** Meet other adults with a diagnosis of Marfan syndrome and share your experiences with people who can truly understand what it's like to have your condition.

**F5 Dads' Support Group** This support group offers a space to share your thoughts, experiences, and feelings with other fathers of children with a connective tissue condition. There are many ways to be a dad, so if fatherhood is meaningful to you, you are welcome to join.

**G5 Moms' 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 mom, so if motherhood is meaningful to you, you are welcome to join.

**H5 Family Planning** Connect with other parents who have experienced the emotional side of making choices concerning the risk associated with having biological children, ethics in genetic selection, and the joy and loss associated with adoption and surrogacy. In addition, discuss the importance of taking care of yourself throughout the process.

**I5 Coping with Medical Trauma and Surgery: Cultivating Resilience over Distress** Learn about the range of emotions that are appropriate when facing a medical stress like a diagnosis, procedure, or surgery. Also learn about our innate capacity to be resilient in the face of adversity. Learn strategies to overcome fears and rebuild your sense of mastery.

**J5 Dating and Relationships** Dating may come with additional stresses when you have a chronic medical condition. When do you disclose your medical issue? How do you talk about it? Share your experiences, learn from others, and talk about the impact of health issues on relationships.



# SUNDAY WORKSHOPS

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

**A6 Body Image and Self-Acceptance** Living with a connective tissue condition can mean looking different from others. If height, weight, facial features, skin elasticity, limb flexibility, surgery scars, or reliance on a wheelchair has you feeling self-conscious and struggling emotionally, you are not alone. This session will explore body image and strategies for greater self-acceptance.

**B6 Mental Health and Aortic Dissection** Aortic dissections occur in a significant percentage of individuals with genetic aortic and vascular conditions. Whether you've been affected personally or are concerned about an aortic dissection in the future, this session will address the mental and emotional issues related to aortic dissections (potential or actual) and tips for coping.

**C6 Parenting a Child with VEDS** Join this group to meet other parents of both younger children and adults with VEDS and discuss the unique challenges and joys of parenting a child with this condition.

**D6 Parenting a Child with LDS** Join this support group to meet other parents and discuss the unique challenges and joys of parenting a child with LDS.

**E6 Parenting a Child with Marfan Syndrome** Join this support group to meet other parents and discuss the unique challenges and joys of parenting a child with Marfan syndrome.

**F6 Aging with a Connective Tissue Condition** Getting older with a connective tissue condition brings its own set of challenges. Join this group to learn how others with Marfan syndrome, LDS, and VEDS are coping with the issues they face, whether related or unrelated to having your diagnosis.

**G6 Living with VEDS Support Group (For Patients)** Meet other adults living with a diagnosis of VEDS and share your experiences with people who can truly understand what it's like to have VEDS. This group is for those with a confirmed diagnosis of VEDS.

**H6 Ever Changing Nutrition Needs in the Connective Tissue Community** Nutrition is a key component contributing to one's overall health and well-being. In this session, you will learn about nutrition and its impact on the body, common concerns for individuals with connective tissue conditions, and tips for meeting your body's nutritional needs.

**I6 Health Insurance & Disability** In this session, you will be armed with knowledge about health insurance and how to obtain coverage. If you are considering applying for social security disability, learn about the steps to take, eligibility, and the appeals process.

**J6 Living with VEDS, Marfan, LDS (For Caregivers and Loved Ones)** Whether you're a family member, significant other, caregiver, or friend of someone with a connective tissue condition, this group will provide an opportunity to share your thoughts, experiences, and feelings with others who can relate.