



ADULT PROGRAM

2022 ADULT PRELIMINARY PROGRAM

On both Saturday and Sunday, July 9 and 10, 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 and social service leaders. The Condition Connection Meet and Greet will open the retreat and there will be many opportunities to network at events such as the Creating Connections Luncheon and Dessert Social during the weekend.

In striving to save lives and improve the quality of life with those with Marfan, Loeys-Dietz, Vascular Ehlers-Danlos, and Stickler Syndrome, there are new 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 will be in English.

THURSDAY JULY 7

- 8:00 AM – 5:00 PM Health Fair heart and eye screenings at the VEA Newport Beach Hotel in association with Hoag Hospital.
- 8:00 – 11:00 PM Zen Den: Quiet place for informal get-togethers with new and old friends.

FRIDAY JULY 8

- 8:00 AM – 4:00 PM Health Fair screenings with multidiscipline experts at VEA Newport Beach in association with Hoag Hospital.
- 9:00 AM – 5:30 PM Registration and Check In
- 2:00 – 5:00 PM Condition Mixers Meet and Greet
- 7:00 – 9:00 PM Welcome Dinner and Awards
Enjoy dinner and celebrate as awards are presented to those who have made extraordinary contributions.

9:00 – 11:00 PM Zen Den: Quiet place for informal get-togethers with new and old friends.

SATURDAY JULY 9

7:00 – 8:30 AM Continental Breakfast

7:00 AM – 5:30 PM Registration and Check-In

8:30 AM – 12:00 PM GENERAL SESSION
PART 1

8:40 Research Update

9:00 Developing a Healthy Physical Lifestyle

9:20 Coping and Mental Health Issues for Those with Chronic Conditions

9:45-10:15 Q & A + Break

PART 2

10:15 Open Repair Aortic Root Surgery: Marfan, LDS and VEDS

10:35 Vascular Surgery: Who May Need It, When to Intervene, What To Expect

10:55 Foot and Ankle Health: Orthotics to Surgery

11:15 -11:45 Q & A + Break

12:00 – 1:30 PM Creating Connections Lunch

1:30 – 5:00 PM SATURDAY MEDICAL WORKSHOPS – Informal opportunity to ask questions of physicians

7:30 – 10:00 PM Dessert Social for Adults and Children

10:00 – 11:00 PM Zen Den: Quiet place for informal get-togethers with new and old friends.

SUNDAY JULY 10

8:00 – 9:30 AM Breakfast, Volunteer Awards Ceremony, and Farewell Photo Presentation

9:45 – 1:15 PM SUNDAY MENTAL HEALTH AND FUN ACTIVITY WORKSHOPS



SATURDAY WORKSHOPS 2022 ADULT PRELIMINARY PROGRAM

Session 1: 1:30 – 2:30 PM

A1 Marfan 101 Are you newly diagnosed? Need to learn the basics? Join renowned experts in Marfan syndrome to learn about what to expect and how to manage this condition.

B1 Aging with Marfan Syndrome People with Marfan syndrome who are diagnosed and treated still deal with progressive issues related to their diagnosis, but also the aging issues that affect the general population. Learn what you can do take care of yourself as you get older.

C1 LDS 101 Are you newly diagnosed? Need to learn the basics? Join renowned experts to learn about what to expect and how to manage this condition.

D1 Management of Allergies in Loeys-Dietz Syndrome Learn about the diagnosis and management of allergic disease, including asthma, food allergy, eczema, allergic rhinitis, and eosinophilic gastrointestinal disease.

E1 VEDS 101 Are you newly diagnosed? Need to learn the basics? Join renowned experts to learn about what to expect and how to manage this condition.

F1 Management of VEDS in Children This session will provide a review of the management of VEDS in children, the good and bad 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.

G1 MRI, MRA, CT, Echo, TTE: Which Imaging Modality is Right For My Aorta? This workshop addresses imaging (evaluating) the aorta. Topics include advantages and disadvantages of various types of imaging, and how to interpret your Z-score.

H1 Cardiac Care for Children with Marfan/LDS Increase your overall understanding of heart-related issues in children, including sign and symptoms of heart failure, valve issues, and arrhythmias. Learn about medications and lifestyle modifications to improve your child's heart health.

I1 Family Planning and Genetics 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.

J1 Retinal Detachment in Stickler Syndrome Retinal detachments are common in Stickler syndrome. Learn about the treatments available to address eye emergencies, as well as how to optimize and retain the best vision.

K1 Orthopedic Care for Adults Increase your overall understanding of bone and joint issues in adults with connective tissue conditions and how to treat them.

L1 Postural Orthostatic Tachycardia Syndrome (POTS) Learn about the symptoms of POTS which include lightheadedness, fainting, and rapid heartbeat. Find out what medications and/or lifestyle changes can improve this condition.

M1 Keeping Your Teeth and Gums Healthy Get answers to your questions about keeping teeth and gums healthy when a connective tissue condition makes your gums recede. You will also learn how to detect and manage gum disease.

N1 COVID-19 Meet with experts in heart and pulmonary care to ask your questions about COVID-19, vaccines, new treatments, and management of long-term effects.

O1 Headaches and Migraines Many people with connective tissue conditions suffer from reoccurring headaches. This workshop addresses causes and treatments.

SATURDAY WORKSHOPS

Session 2: 2:45 – 3:45 PM

A2 Dislocated Lenses, Eyeglass Fitting and Eye Surgery for Marfan Children 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 you utilize your vision to its fullest potential.

B2 Aortic and Mitral Valve Surgery in Adults with Marfan Learn about the signs that mean it might be time for aortic or mitral valve surgery and considerations for choosing different surgical options.

C2 Management of Gastrointestinal Issues in LDS Learn about management of gastrointestinal complaints which can include the feeling of food getting stuck in your throat, diarrhea, abdominal pain, or difficulty gaining weight. Ask questions about when stricter intervention is required to reduce severe inflammatory disease of the esophagus or the need for feeding tubes to help with caloric intake.

D2 Aortic Surgery in Adults with LDS Learn about the procedures available for aortic surgery in LDS, including indications, timing, benefits, and risks.

E2 Answering Your Questions about the Enzastaurin Trial Learn about eligibility to participate in the trial, what to expect, the time commitment involved, and other important trial-related information.

F2 Aging with VEDS Those with VEDS have to deal with progressive issues related to their diagnosis, as well as aging issues that affect the general population. Learn what you can do take care of yourself as you get older.

G2 An Uncommon Occurrence: Managing SCAD Learn about an uncommon occurrence in MFS, LDS, and VEDS, called spontaneous coronary artery dissections. Learn the signs, treatment, and long-term management options.

H2 Aortic Surgery in Children Learn how to be prepared for aortic surgery in children and teens -- whether it's planned or unplanned.

I2 Menstruation, Pregnancy, and Menopause Come ask your questions about menstruation, pregnancy, and menopause for those with Marfan, LDS, and VEDS. Topics include painful menstruation, the risk of pregnancy and its effect on the uterus and associated fragile arteries, and more.

J2 A Hidden Danger: Heritable Thoracic Aortic Mutations Learn about the many genes responsible for these conditions, getting a diagnosis, medical and surgical management, and implications for the family.

K2 Diagnosis and Management of Scoliosis Learn what degree of curvature is needed for a scoliosis diagnosis, how can it be managed in the early stages, and when it's time for more invasive intervention.

L2 Physical Activity Learn about the guidelines for physical activity for children and adults and how to monitor exercise. Hear about recent exercise studies.

M2 Dental Issues In this workshop, an orthodontist answers questions about dental care and connective tissue conditions. Topics include management of high palate/crowded teeth, use of expanders and braces, maxillofacial surgery, and the appropriate age to attempt corrections.

N2 Asthma, Emphysema & Pneumothorax Learn about diagnosis of asthma and emphysema through pulmonary testing and how to manage these symptoms. Become acquainted with symptoms of pneumothorax and which management and surgical options are available for those with connective tissue conditions.

O2 Caregiving Through Puberty Learn tips to navigate the medical aspects of a teenager with a chronic condition and how best to prepare your teen to transition to self-care. Hear what a parent should expect both physically and emotionally during these critical years.

SATURDAY WORKSHOPS

Session 3: 4:00 – 5:00 PM

A3 Management of Neonatal and Severe Forms of Marfan Ask questions regarding difficult issues, such as cardiac care, pulmonary care, and feeding issues in children who are severely affected with Marfan syndrome.

B3 Eye Care in Adults with Marfan Learn about management of glaucoma, cataracts, and retinal detachment. Learn what visual aids can help you utilize your vision to its fullest potential.

C3 Bone Density & LDS (Back, Leg, Hip Issues) Learn about osteoporosis and how this bone condition affects those with LDS. This workshop also addresses effective treatments that can lessen the impact during the aging process.

D3 Managing Dissections and Aneurysms in LDS Learn about methods for successful arterial repairs for aneurysms throughout the body through a variety of surgical interventions.

E3 Managing Dissections and Aneurysms in VEDS Learn about methods for successful arterial repairs for aneurysms throughout the body through a variety of surgical interventions.

F3 Answering Your Questions about the Celiprolol Trial Learn about eligibility to participate in the trial, what to expect, the time commitment involved, and other important trial-related information.

G3 Post Dissection Care Learn about the benefits and issues of physical and occupational therapy for adults, as well as the best treatments to expect from your practitioner. Learn the ins and outs of post-dissection care in aortic and non-aortic arteries. Discussion to include the importance of correct

imaging and understanding when additional intervention is necessary.

H3 Orthopedic Care for Children This session addresses managing scoliosis, bone, joint, and pectus issues. Meet the experts and find solutions to improve curvature and pain.

I3 Cardiac Care for Adults Increase your overall understanding of heart-related issues, such as arrhythmias, in adults. Learn about medications, lifestyle modification, and how to prevent aortic dissection and other emergency situations.

J3 Hearing Loss in Stickler Syndrome Learn how to detect hearing loss in children, understand how hearing loss may become more severe over time, and get information about treatments such as hearing aids and cochlear implants.

K3 Dural Tears and Spinal Fluid Leaks Spontaneous spinal cerebrospinal fluid (CSF) leaks are increasingly recognized as a cause of postural headaches. Learn about diagnosis and management of these issues.

L3 Limits and Benefits of Genetic Testing Learn the limits and benefits of genetic testing and why it is more important than ever for your family.

M3 Management of Foot and Ankle Issues Learn about management for flat feet, hammer toes, and other foot issues.

N3 Managing Pain Learn about the options for using medications to help relieve pain. Which are the safest and most effective? This workshop will also address the future for this important group of medications.

O3 Creating a Care Team A care team should consist of day-to-day general care that is handled by a primary care physician knowledgeable in genetic aortic conditions, a cardiologist, or a physician who is willing to learn about your specific condition. You should speak to your physician about developing these goals. The care team should include several specialists depending on your condition and how your diagnosis affects you.



SUNDAY WORKSHOPS

Session 1: 9:45 -10:45 AM

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A4 Parenting a Child with VEDS Join this group to meet other parents of younger children with VEDS, ages 18 or younger, and discuss the unique challenges and joys of parenting a child with this condition.

B4 Parents of Adults with VEDS Support Group Join this group to meet other parents of adults with VEDS, who are over age 18, to discuss your experiences. You may also find this discussion useful for helping your young adult transition to adulthood and live more independently.

C4 Aging with VEDS Support Group Getting older with VEDS can be very complicated. This is a group for sharing your struggles and strategies. Learn what works for other community members.

D4 Marfan Connect: For Adults Living with Marfan Meet other adults living with Marfan syndrome and share your experiences with people who can truly understand what it's like to have a Marfan syndrome diagnosis.

E4 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.

F4 Unaffected Partners & Spouses Support Group (LDS) Are you the partner or spouse of someone with LDS? Being the unaffected partner in a relationship can have unique challenges. Connect with others who can relate.

G4 LDS Connect: For Adults Living with LDS Meet other adults living with LDS. Connect with your community, share your experiences, and make new friends.

H4 Parenting a Child with Stickler Syndrome Join this group to meet other parents and discuss the unique challenges and joys of parenting a child with Stickler syndrome.

I4 Dating and Relationships with a Chronic Medical Condition 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.

J4 Grief and Loss Support Group 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.

K4 The Emotional Side of 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.

L4 Stress and Your Health: The Impacts on Your Body Stress can have an impact on your health. Learn about the health implications of stress and strategies for managing your stress in order to optimize your overall wellness.

M4 Emergency Preparedness 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.

N4 Parents' Toolbox: How to Handle Bullying When, to whom, and how should I advocate and/or intervene for my child? How can I equip my child with tactics? Bullying is an unfortunate reality in schools and elsewhere, and this workshop will explore what parents and children can do to combat it.

O4 Advocating for Yourself and 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.

P4 TBR Book Club There are many times that you need a book to read -- in doctors' offices, waiting rooms, post-op, or even just for fun! Join this session to find and share new reads for your "To Be Read" list!

Q4 Sports Appreciation: For Those Who Love Sports But Can't Play Them Do you like watching sports? Do you like talking about sports? Do you just like SPORTS? Come to the Sports Appreciation group for a good time!

R4 Moms Support Group This support group offers a space to talk, offer advice, and share your concerns and feelings with other mothers of children and teens with a connective tissue condition. There are many ways to be a mom! Please attend if motherhood is meaningful to you.

SUNDAY WORKSHOPS

Session 2: 11:00 -12:00 PM

A5 From Ticking Time Bomb to Bomb Diffuser: Taking Control of Your Life (VEDS) Have you ever felt like your VEDS diagnosis makes you a ticking time bomb? Learn strategies for taking greater control of your life and becoming more of a bomb diffuser.

B5 Unaffected Partners & Spouses Support Group (VEDS) Are you the partner or spouse of someone with VEDS? Being the unaffected partner in a relationship can have unique challenges. Connect with others who can relate.

C5 From Ticking Time Bomb to Bomb Diffuser: Taking Control of Your Life (Marfan) Have you ever felt like your Marfan syndrome diagnosis makes you a ticking time bomb? Learn strategies for taking greater control of your life and becoming more like a bomb diffuser.

D5 Unaffected Partners & Spouses Support Group (Marfan) Are you the partner or spouse of someone with Marfan syndrome? Being the unaffected partner in a relationship can have unique challenges. Connect with others who can relate.

E5 From Ticking Time Bomb to Bomb Diffuser: Taking Control of Your Life (LDS) Have you ever felt like your LDS diagnosis makes you a ticking time bomb? Learn strategies for taking greater control

of your life and becoming more of a bomb diffuser.

F5 Newly Diagnosed Support Group for Adults with LDS Have you recently been diagnosed with LDS? This group is for you. Share your questions and concerns with other community members who can truly relate.

G5 Parenting a Severely Affected Child with Marfan/LDS How can you help your medically fragile child have a happy, normal life? What are some parenting strategies you can use to maintain family dynamics in times of crisis? This group will cover these topics and more.

H5 Unaffected Stickler Partners and Spouses Support Group This workshop will encourage you to discover what makes you happy, what gives you a sense of well-being, and how can you find more of it in your life.

I5 Marfan/LDS/VEDS/Stickler Teen Perspective 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.

J5 Self-Care Strategies All too often, people with chronic illness focus solely on their medical issues and neglect their other needs. Attend this workshop to learn self-care strategies important to maximizing your overall wellness.

K5 Avoiding Caregiver Burnout Being a caregiver for someone you love can be demanding and stressful, especially if the individual has a chronic condition. Learn how to take better care of yourself while navigating the challenges of the caregiver role.

L5 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.

M5 Coping with COVID Stress COVID has had a significant impact over the past two years. This is a space to process the effects it has had on your life and the lives of your loved ones. This group will also look at strategies that have worked for coping now and in the future.

N5 Navigating the School System Getting the right accommodations in school for your child's unique needs can be complex. This workshop will break down the process and provide steps for ensuring the proper accommodations are received, including partnering with the school nurse.

O5 Stress and Your Health: The Impacts on Your Body Stress can have an impact on your physical and mental health. Learn about the health implications of stress and strategies for managing your stress in order to optimize your overall wellness.

P5 Getting Crafty/Craft and Color Have fun coloring and creating your own art projects alongside others who also enjoy all things crafty!

Q5 BIPOC with A Chronic Condition: A Support Group Are you a member of the BIPOC (Black, Indigenous and People of Color) AND disability community? Join this support group to discuss your unique experiences with others who can truly relate.

R5 Let's Go to the Movies/Tick, Tick...Boom! Discussion This session is an open discussion about movies that resonate with our community, such as "Tick, Tick...Boom!" and "Tall Girl."

SUNDAY WORKSHOPS

Session 3: 12:15-1:15 PM

A6 Newly Diagnosed Support Group for Adults with VEDS Join other adults who have recently been diagnosed with VEDS and share your questions and concerns with members of the community who can truly relate.

B6 VEDS Connect: For Adults Living with VEDS Meet other adults living with VEDS and share your experiences with people who can truly understand what it's like to have a VEDS diagnosis.

C6 Parenting a Child with Marfan Join this workshop to discuss the unique challenges and joys of parenting a child with Marfan syndrome. Different perspectives will be shared.

D6 Newly Diagnosed Support Group for Adults with Marfan Have you recently been diagnosed with Marfan syndrome? This group is for you. Share your journey with other "Marfamily" members who have recently received a diagnosis.

E6 Aging with Marfan Support Group Getting older with Marfan syndrome brings its own set of challenges. Join this group to learn how others are coping with the issues they face, whether related or unrelated to having Marfan syndrome.

F6 Aging with LDS Support Group Getting older with LDS can be very complicated. This is a group for sharing your struggles and strategies. Learn what works for other community members.

G6 Dealing with the Emotional Stress of the Inevitable Heart Surgery (Marfan/LDS) Most people with Marfan and related conditions have heart surgery at some point in their lives. Learn how to prepare yourself mentally and emotionally for this experience and how to cope post-surgery.

H6 Stickler Connect: For Adults Living with Stickler Meet other people living with Stickler syndrome. Connect with your community, share your experiences, and make new friends.

I6 Marfan/LDS/VEDS/Stickler Teen Perspective 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.

J6 Mental Health Issues: Recognizing the Signs in Yourself or Loved Ones and How to Get 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 -- and deserved.

K6 Parenting Challenges when Living with a Disability Living with a disability comes with a number of challenges. Living with a disability AND being a parent can increase those challenges tenfold. This session will explore some of the issues commonly faced by parents who live with chronic illness and ways to address them. You don't need to be a "super parent" to be a super parent!

L6 Health Insurance and Disability In this session you will be armed with knowledge about health insurance and how to obtain coverage. If you are considering social security disability, learn about the process of social security disability, eligibility, and steps to take to apply for it.

M6 Living Your Best Life: Mindfulness and the Mind-Body Connection Learn mindfulness techniques to take better care of yourself -- physically and emotionally.

N6 Looking for the Right College & Requesting (and Receiving) Accommodations Are you or your child considering college? The accommodations process for college is very different than that of high school, but with the knowledge gained in this workshop, you'll be better equipped to ask for what you

need -- and receive the accommodations you or your child are entitled to.

O6 Cooking Corner: Life Hacks It's not too hot to get in this kitchen! Join the fun for a recipe exchange and discussion on the love of cooking. Bring recipes for your favorite dishes and snacks to share and engage with your fellow foodies.

P6 Art as Therapy (Adults) Art is a fun activity that has many benefits. Share your love of art and learn how something as simple as a coloring book can be an amazing coping strategy.

Q6 Jam Session: Connecting Through Music We have many talented people in the community! Do you like to play an instrument or sing? Come jam with us!

R6 Dads Support Group This support group offers a space to share your thoughts, experiences, or concerns with other fathers of children and teens with a connective tissue condition. There are many ways to be a dad! Please join if fatherhood is meaningful to you.