

# UPDATED WORKSHOP INFORMATION

As of 7/19/22

## SATURDAY WORKSHOPS

	SESSION 1 1:30-2:30 PM	SESSION 2 2:45-3:45 PM	SESSION 3 4:00-5:00 PM
Salons 1-2	<b>Aging with Marfan Syndrome</b> <i>Juan Bowen, MD Reed Pyeritz, MD, PhD</i>	<b>Aortic and Mitral Valve Surgery in Adults with Marfan</b> <i>Joseph Coselli, MD D. Craig Miller, MD</i>	<b>Management of Foot &amp; Ankle Issues</b> <i>Adam Bitterman, DO Gennady Kolodenker, DPM</i>
Salon 3	<b>Marfan 101</b> <i>Kathryn Holmes, MD, MPH S. Chris Malaisrie, MD Mary Roman, MD</i>	<b>Dislocated Lenses, Eyeglass Fitting and Eye Surgery for Marfan Children</b> <i>Rachel Kuchtey, MD, PhD Irene Maumenee, MD</i>	<b>Management of Neonatal &amp; Severe Forms of Marfan</b> <i>Kathryn Holmes, MD, MPH Shaine Morris, MD, MPH</i>
Riviera Lawn 1	<b>LDS 101</b> <i>Hal Dietz, MD Ismail El-Hamamsy, MD, PhD</i>	<b>Hearing and Ear Issues in LDS</b> <i>Daniela Carvalho, MD, MMM Keri Colio, AuD, CCC-A</i>	
Riviera Lawn 2	<b>Managing Dissections and Aneurysms in LDS</b> <i>Joseph Coselli, MD Sherene Shalhub, MD, MPH</i>	<b>Aortic Surgery in Adults with LDS</b> <i>Pedro Catarino, MD Ismail El-Hamamsy, MD, PhD</i>	<b>Effective Ways to Relieve Pain without Medicine</b> <i>Beth Darnell, PhD</i>
Coral Cove	<b>VEDS 101</b> <i>Peter Byers, MD</i>	<b>Answering Your Questions about the Enzastaurin Trial</b> <i>Hal Dietz, MD Shaine Morris, MD, MPH</i>	<b>Managing Dissections and Aneurysms in VEDS</b> <i>Sahar Naderi, MD, MHS Sherene Shalhub, MD, MPH</i>
Diamond Cove	<b>Management of VEDS in Children</b> <i>Mark Lindsay, MD, PhD Shaine Morris, MD, MPH</i>	<b>Aging with VEDS</b> <i>Peter Byers, MD Sherene Shalhub, MD, MPH</i>	<b>Answering Your Questions about the Celiprolol Trial</b> <i>Ian Harris, MD Adrian Quartel, MD</i>
Salon 4	<b>MRI, MRA, CT, Echo, TTE: Which Imaging Modality is Right for My Aorta?</b> <i>Heidi Connolly, MD Humberto Wong, MD</i>	<b>A Hidden Danger: Heritable Thoracic Aortic Mutations</b> <i>Kim Eagle, MD Dianna Milewicz, MD, PhD</i>	<b>Post-Dissection Care</b> <i>Heidi Connolly, MD Matthew Solomon, MD</i>

# SATURDAY WORKSHOPS CONTINUED

<b>Marea Canvas 1</b>	<b>Cardiac Care for Children with Marfan/LDS</b> <i>Tom Collins, MD Luciana Young, MD</i>	<b>Aortic Surgery in Children</b> <i>Duke Cameron, MD Mark Lindsay, MD, PhD</i>	<b>Orthopedic Care for Children</b> <i>Lawrence Rinsky, MD Paul Sponseller, MD</i>
<b>Mariner Cove</b>	<b>Family Planning &amp; Genetics</b> <i>Rebecca Allen, MD, MPH Gretchen MacCarrick, MS, CGC Melissa Russo, MD</i>	<b>Menstruation, Pregnancy, and Menopause</b> <i>Kristen Matteson, MD, MPH Mary Roman, MD Melissa Russo, MD</i>	<b>Creating a Care Team</b> <i>Juan Bowen, MD Peter Byers, MD Gretchen MacCarrick, MS, CGC</i>
<b>Sapphire Cove</b>	<b>Retinal Detachment in Stickler Syndrome</b> <i>Rachel Kuchtey, MD, PhD Irene Maumenee, MD</i>	<b>An Uncommon Occurrence: Managing SCAD</b> <i>Sahar Naderi, MD, MHS Matthew Solomon, MD</i>	<b>Hearing Loss in Stickler Syndrome</b> <i>Daniela Carvalho, MD, MMM Keri Colio, AuD, CCC-A</i>
<b>Del Mar</b>	<b>Orthopedic Care for Adults</b> <i>Adam Bitterman, DO Paul Sponseller, MD</i>	<b>Diagnosis &amp; Management of Scoliosis</b> <i>Larry Rinsky, MD Paul Sponseller, MD</i>	<b>Cardiac Care for Adults</b> <i>Alan Braverman, MD Mary Roman, MD</i>
<b>Marea Canvas 2</b>	<b>Headaches &amp; Migraines</b> <i>Ian Carroll, MD Addie Peretz, MD</i>	<b>Physical Activity</b> <i>Alan Braverman, MD Siddharth Prakash, MD</i>	<b>Managing Pain</b> <i>Ardin Berger, DO</i>
<b>Salon 5</b>	<b>Keeping Your Teeth and Gums Healthy</b> <i>Sylvia Frazier-Bowers, DDS, PhD</i>	<b>Dental Issues</b> <i>Sylvia Frazier-Bowers, DDS, PhD</i>	<b>Eye Care in Adults with Marfan Syndrome</b> <i>Rachel Kuchtey, MD, PhD Irene Maumenee, MD</i>
<b>Laguna &amp; Sunset</b>	<b>COVID-19</b> <i>Kim Eagle, MD Enid Neptune, MD</i>	<b>Asthma, Emphysema &amp; Pneumothorax</b> <i>Enid Neptune, MD</i>	<b>Genetic Testing - When, Why, Where</b> <i>Dianna Milewicz, MD, PhD Reed Pyeritz, MD, PhD</i>
<b>Cardiff</b>	<b>Postural Orthostatic Tachycardia Syndrome (POTS)</b> <i>Sahar Naderi, MD Matthew Solomon, MD</i>	<b>Caregiving Through Puberty</b> <i>Kathryn Holmes, MD Luciana Young, MD</i>	<b>Dural Tears, Spinal Fluid Leaks</b> <i>Ian Carroll, MD</i>

# SUNDAY WORKSHOPS

	SESSION 1 9:45-10:45 AM	SESSION 2 11:00 AM-12:00 NOON	SESSION 3 12:15-1:15 PM
Laguna & Sunset	<b>Parenting a Child with VEDS</b> <i>Sarah Jeffs</i>	<b>From Ticking Time Bomb to Bomb Diffuser: Taking Control of Your Life (VEDS)</b> <i>Karen MountainJohnson, MA, LPCC</i>	<b>Newly Diagnosed Support Group for Adults with VEDS</b> <i>Dominick Corso Katie Wright</i>
Riviera Lawn 1	<b>Parents of Adults with VEDS Support Group</b> <i>Joy Foote Fran Marin</i>		<b>VEDS Connect: For Adults Living with VEDS</b> <i>Mariah Wessel-Draper, MS, LIMPH, LIMHC, RPT</i>
Cardiff	<b>Aging with VEDS Support Group</b> <i>Dominick Corso Kristi Posival</i>	<b>From Ticking Time Bomb to Bomb Diffuser: Taking Control of Your Life (Marfan)</b> <i>Carole Nowak, NBC-HWC</i>	<b>Parenting a Child with Marfan</b> <i>Heather Earnhart Sydney Lerman Chelsey Weatherill, MS, CGC</i>
Salon 3	<b>Marfan Connect: For Adults Living with Marfan</b> <i>Kathy Flynn RN, PHN Betsy Matarrita</i>	<b>Unaffected Partners &amp; Spouses Support Group (Marfan, LDS, and VEDS)</b> <i>Heather Bergstrom</i>	<b>Newly Diagnosed Support Group for Adults with Marfan</b> <i>Steve Marpman</i>
Salon 4	<b>Parenting a Child with LDS</b> <i>Dawn Reiner Julie Wilson</i>	<b>From Ticking Time Bomb to Bomb Diffuser: Taking Control of Your Life (LDS)</b> <i>Gretchen MacCarrick, MS, CGC</i>	<b>Aging with Marfan Support Group</b> <i>Chris Heaney</i>
Salon 5		<b>New to Conference/Newly Diagnosed with LDS</b> <i>Dawn Reiner</i>	<b>Aging with LDS Support Group</b> <i>Susan Grossi</i>
Salon A	<b>LDS Connect: For Adults Living with LDS</b> <i>Taylor Beecroft, MS, CGC Susan Grossi</i>	<b>Parenting a Severely Affected Child with Marfan/LDS</b> <i>Jennie Bange Barbara Lerman</i>	<b>Dealing with the Emotional Stress of the Inevitable Heart Surgery (Marfan/LDS)</b> <i>Stephanie Randazzo, PsyD</i>
Salons 1-2	<b>Dating and Relationships with a Chronic Medical Condition</b> <i>Brandon Crawford Bella Marin BSN, RN Lindsey Weisman</i>	<b>Teen Perspective (Part 1)</b> <i>Teen Council: Katie Dammann, Faith Frazier, Grace Meyers</i>	<b>Teen Perspective (Part 2)</b> <i>Teen Council: Cassie Jennings, Sam Molitor</i>
Salon B	<b>Grief and Loss Support Group</b> <i>Karen MountainJohnson, MA, LPCC</i>	<b>Avoiding Caregiver Burnout</b> <i>Cristol Barrett O'Loughlin</i>	<b>Self-Care Strategies</b> <i>Rita Weise, MSN, ACAPC-AG</i>
Marea Canvas 1	<b>Emergency Preparedness</b> <i>Meg Boeglin, BSN, RN Steve Marpman</i>	<b>Body Image &amp; Self-Acceptance</b> <i>Brandon Crawford</i>	<b>Mental Health Issues: Recognizing the Signs in Yourself or Loved Ones and How to Get Help</b> <i>TBD</i>

# SUNDAY WORKSHOPS CONTINUED

Salon C	<b>Stress and Your Health: The Impacts on Your Body</b> <i>Rachael Nowak, DPT</i> <i>Stephanie Randazzo, PsyD</i>	<b>Coping with COVID Stress</b> <i>Kathy Flynn</i>	<b>Parenting Challenges when Living with a Disability</b> <i>Maya Brown-Zimmerman, MPH</i>
Marea Canvas 2	<b>Advocating for Yourself and Others</b> <i>Stephanie Cooper-Noe</i> <i>Chris Heaney</i>	<b>Navigating the School System</b> <i>Sarah Jeffs</i> <i>Heide Padilla</i>	<b>Health Insurance and Disability</b> <i>Kathleen Kane, Esq</i> <i>Jennifer Rios, MS, CGC</i>
Baycliff	<b>Parents' Toolbox: How to Handle Bullying</b> <i>Judy French</i>	<b>Stress and Your Health: The Impacts on your Body</b> <i>Rachael Nowak, DPT</i> <i>Stephanie Randazzo, PsyD</i>	<b>Living Your Best Life: Mindfulness and the Mind-Body Connection</b> <i>Carole Nowak, NBC-HWC</i>
Salon D	<b>The Emotional Side of Family Planning Decisions</b> <i>Maya Brown-Zimmerman, MPH</i> <i>Katherine Doehring</i>	<b>Getting Crafty/Craft and Color</b> <i>Stephanie Cooper-Noe</i>	<b>Looking for the Right College &amp; Requesting (and Receiving) Accommodations</b> <i>Barbara Lerman</i>
Salon E	<b>TBR (To Be Read) Book Club</b> <i>Heather Bergstrom</i>	<b>BIPOC with a Chronic Condition</b> <i>Meg Boeglin, BSN, RN</i> <i>Sylvia Frazier Bowers, DDS</i>	<b>Cooking Corner: Life Hacks</b> <i>Stephanie Cooper-Noe</i>
Salon F	<b>Sports Appreciation: For Those who Love Sports, but Can't Play Them</b> <i>Ben Weisman</i>	<b>Chronic Illness in Film</b> <i>Ben Weisman</i>	<b>Art as Therapy</b> <i>Kristi Posival</i>
Spa Lawn	<b>Moms Support Group</b> <i>Regina Korochnik</i> <i>Alix McLean Jennings, LCSW</i>		<b>Jam Session: Connecting through Music</b> <i>Josh Lim</i>
Riviera Lawn 2			<b>Dads Support Group</b> <i>Dave Donato</i>



## HELP & RESOURCE CENTER

We are always here for you! Submit medical questions on Marfan, LDS, VEDS, and other genetic aortic and vascular conditions to us at any time at [Marfan.org/Ask](https://Marfan.org/Ask).

# CHILDREN – SUNDAY WORKSHOPS

	SESSION 1 9:00-9:45 AM	SESSION 2 10:00-11:15 AM	SESSION 3 11:30 AM-12:30 PM
Diamond Cove	<b>Ask the Expert (Ages 10-12)</b> <i>Kathryn Holmes, MD, MPH</i>	<b>Creating a Graphic Novel (Ages 10-12)</b> <i>Lucas Mullen</i>	<b>Bullying 101 (Ages 10-12)</b> <i>Judy French</i>
Coral Cove	<b>Ask the Expert (Ages 5-9)</b> <i>Shaine Morris, MD, MPH</i>	<b>Creative Time (Ages 5-7)</b> <i>Dawn Marisch</i> <i>Ashley Rose Marisch (Koenigeter)</i>	<b>Kindness is Cool (Ages 5-7)</b> <i>Judith M. Marshall, MS, APN</i>
Crystal Cove		<b>Express Yourself (Ages 8-9)</b> <i>Chelsey Weatherill, MS, CGC</i>	<b>You Have the Power (Ages 8-9)</b> <i>Heather Earnhart</i> <i>Alix McLean Jennings, LCSW</i>

# TEEN – SUNDAY WORKSHOPS

	SESSION 1 9:45-10:45 AM	SESSION 2 11:00 AM-12:00 NOON	SESSION 3 12:15-1:15 PM
Emerald Cove	<b>Pain Management</b> <i>Ardin Berger, DO</i>	<b>Depression and Anxiety</b> <i>Shoshana Leeder, PhD</i>	<b>Communicating Your Diagnosis</b> <i>Shaine Morris, MD, MPH</i>
Sapphire Cove	<b>Eyes</b> <i>Rachel Kuchtey, MD, PhD</i>	<b>Art as Therapy</b> <i>Josh Law, Liam Nelson,</i> <i>Kristi Posival, Catie Sheley</i>	<b>Body Image &amp; Self-Esteem</b> <i>Isaac Brodsky, Dominga Noe</i>
Del Mar	<b>Physical Activities</b> <i>Siddharth Prakash, MD, PhD</i>	<b>Transitions</b> <i>Kathryn Holmes, MD, MPH</i> <i>Andrea Witte</i>	<b>Transitions</b> <i>Kathryn Holmes, MD, MPH</i> <i>Andrea Witte</i>
Mariner Cove	<b>Connective Tissues 101</b> <i>Juan Bowen, MD</i>	<b>Friends of Chronic Illness</b> <i>Shaine Morris, MD, MPH</i>	<b>Depression and Anxiety</b> <i>Shoshana Leeder, PhD</i>