

TEEN PROGRAM

2023 39th CONFERENCE PRELIMINARY PROGRAM

Teens (13-18) have a complete program designed for their needs and interests. We kick-off our program Friday, July 14, with a group dinner just for teens to get to know each other. This is followed by ice-breakers and activities to continue to bond. On Saturday, July 14, the teens can ask their medical questions at a Breakfast Q&A with expert doctors and then attend small group workshops created specifically for them before traveling to their field trip! Sunday's activities will involve workshops covering a wide range of topics created specifically for them. All activities will promote friendship and self-esteem to complete their conference experience.

THURSDAY JULY 13

8:00 – 5:00 PM Registration and Check In

8:00 - 5:00 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

8:00 – 5:00 PM Health Fair screenings with experts from various

disciplines at Lurie Children's Hospital. By

appointment only. Health fair application is

required.

9:00 - 5:30 PM Registration and Check In

1:00 – 2:00 PM Is this your first conference? Meet the

members of the Teen Council who will help

you get acquainted.

6:30 - 11:00 PM Teen Dinner and Evening Activities - Meet

all the unique and amazing teens at this year's conference over dinner and get an overview of the weekend from our Teen Group Leaders. Gender breakouts with community leaders and doctors will give you time to ask your questions in a safe and inclusive environment. We encourage all teens to attend the group that

they are most comfortable with.

SATURDAY JULY 15

7:00 - 8:15 AM Breakfast with the Docs

8:30 - 9:15 AM WORKSHOP SESSION 1

Please register in advance for workshops. Note that changes are permitted on-site.

9:30 - 10:15 AM WORKSHOP SESSION 2

10:30 - 11:15 AM WORKSHOP SESSION 3

11:30 AM - 12:30 PM Check-In/Lunch

12:45 - 1:00 PM Load Buses for Field Trip

1:15 – 1:45 PM Travel to Museum of Illusions

2:00 – 4:00 PM Museum of Illusions Visit

4:15 - 5:00 PM Load Buses & Return to Hotel

7:30 – 10:00 PM Victory Party

SUNDAY JULY 16

| 7:00 - 8:30 AM | Continental Breakfast |
|------------------|-------------------------|
| 7.00 0.00 / NI I | Continuental Di Carrast |

9:00 - 10:00 AM WORKSHOP SESSION 1

10:15 - 11:15 PM WORKSHOP SESSION 2

11:30 - 12:30 PM WORKSHOP SESSION 3

^{*}Please register in advance for workshops. Note that changes are permitted on-site.

WORKSHOP TOPICS

SATURDAY

Transitions There are many transitions in the teenage years, such as moving from pediatric medical care to adult care, and moving on from high school to college, and how to create an emergency plan. This workshop will address these changes and how to go through them smoothly.

Eyes Learn about potential dangers and what to do to prevent injury.

Physical Activities Learn what physical activities are safe when you have a connective tissue condition and what moderation means. What are the limits for these activities, and how can you exercise safely?

Pain Management What are the options for pain relief? Learn medical and non-medical methods for coping with the pain associated with connective tissue conditions.

Connective Tissues 101 If you have a connective tissue condition and would like a better understanding of it or have medical questions about it, then this workshop is for you.

Nutrition 101 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.

Genetic Allyship This workshop is for those who do not have a Marfan or a related condition diagnosis but have a friend or family member who does. We will discuss your feelings and how you can be supportive.

SUNDAY

Depression and Anxiety Mental health is important for everyone, and the weight 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.

Communicating Your Diagnosis Living in a world with family and friends who do not have Marfan syndrome or a related condition isn't always easy. Knowing what to share and when can be difficult. Helping them to understand your world is important. Learn how others have handled this so you can decide what's best for you.

Art as Therapy In these interactive sessions, explore the art of visual art, performance and writing, and music as forms of therapy. If you are looking to express yourself through a creative outlet, this session is for you!

Body Image & Self Esteem From long, flexible limbs to surgery scars, living with the physical markers of Marfan, Loeys-Dietz, VEDS, and related conditions can weigh on a person's body image. Leaders of this workshop will share their thoughts and experience with body image and living chronic conditions, answer questions, and discuss coping strategies.