



connect.
learn.
share.

CAREGIVER WEEKEND

Hyatt Regency O'Hare, Chicago, Illinois • #ATcaregiver2017

AGENDA

Day 1: FRIDAY, OCTOBER 20

Registration

6:00 – 7:00 PM • International Ballroom

Welcome Dinner

7:00 PM • International Ballroom

Nightcaps for Night Owls

9:30 PM • Red Bar, Lobby Level

Day 2: SATURDAY, OCTOBER 21

The Caregiver Lounge (aka hospitality suite) will be open all weekend in the Paris Ballroom, International (Lower) Level, and available as a casual place to connect with others, ask questions, and take a breath.

All general sessions will take place in the International Ballroom, International (Lower) Level, unless otherwise indicated.

Coffee Talk

7:30 – 8:30 AM

Early birds can chat over breakfast before the sessions get underway.

Welcome

8:30 – 8:45 AM

Brad Margus & Beth Hughes

Managing the Symptoms of A-T

8:45 – 10:45 AM

Howard Lederman, MD, PhD and Thomas Crawford, MD

Doctors from the A-T Clinical Center at Johns Hopkins will discuss the clinical management of A-T.

Break

10:45 – 11:00 AM

Q & A with the Doctors

11:00 AM – 12:00 PM

Please note: The clinicians will be able to answer general questions about the clinical management of A-T. They are not planning on making recommendations for individuals, as they will not have access to evaluations or medical records.

Lunch

12:00 – 2:00 PM • London Ballroom

Linger over lunch, spending time connecting with each other.

Afternoon Fireside Chat

2:00 – 3:30 PM

Brad Margus will interview Phil Reilly, MD, JD about advancing treatments for rare diseases and recent advances in gene therapy and gene editing techniques. Dr. Reilly is a venture partner at Third Rock Ventures and author of *Orphan: The Quest to Save Children with Rare Genetic Disorders*.

Break

3:30 – 4:00 PM

Break-Out Sessions

4:00 – 5:00 PM

Session A:
***School Issues and Individualized
Education Programs (IEPs)***
International Ballroom

Share ideas that help make school a positive learning environment and social experience.

Session B:
Adult Life ("La Vida Loca!")
Florence Ballroom,
International Level

Discuss ideas about what makes post-secondary school life fun and productive for adults with A-T.

Live Your Best Life

5:00 – 6:00 PM

From adaptive sports, to family travel, to other recreational activities, brainstorm ideas for living life to the fullest.

Dinner & Evening Fireside Chat

7:00 PM • International Ballroom

Brad Margus will interview Recursion Pharmaceuticals' Strategic Development Senior VP, Tim Considine, about how cellular imaging, machine learning and massively parallel drug screening approaches have led his company to a potential path for treating A-T.

Nightcaps for Night Owls

9:30 PM • Red Bar, Lobby Level

Day 3: SUNDAY, OCTOBER 22

Coffee Talk

7:30 – 8:30 AM

Early birds can chat over breakfast before the sessions get underway.

Life Hacks

8:30 – 9:30 AM

Learn from each other about how assistive technology, adaptive equipment, and home modifications can make life a little easier.

Caring for Yourself (While Caring for Everyone Else)

9:30 – 10:15 AM

What are your best tips to make sure that you stay energized and healthy?

More Q & A with the Doctors

10:15 – 10:45 AM

Dr. Lederman and Dr. Crawford will take any additional clinical questions that come up during the weekend.

What's Happening in A-T Research?

10:45 – 12:00 PM

Brad Margus will discuss paths towards therapies for A-T and answer questions.

It's Not Goodbye... It's See You Soon!

12:00 PM

The weekend may be officially over, but new and old friends will continue to support each other over the miles!