



6th Annual ECD Patient & Family Gathering
Orlando, FL | November 15 – 16, 2018
Meeting Agenda DRAFT

Please join the ECD Global Alliance and the ECD community of patients, caregivers, and medical professionals for this year's annual event held in Orlando, Florida. Find out more on our website: <http://erdheim-chester.org/news/eCd-patient-family-gathering/>.

SCHEDULE of EVENTS

DATE	TIME	ACTIVITY	ORLANDO HEALTH LOCATION
Thursday, Nov. 15	5:00 – 6:00 pm	Registration/Sign-in/Help	North Tower Lobby / Bamboo Garden
	6:00 – 8:00 pm	Welcome Social with Families & Medical Professionals	North Tower Lobby / Bamboo Garden
Friday, Nov. 16	9:00 am - 6:00 pm	Registration/Sign-in/Help	Multipurpose Room's Foyer
	9:00 - 9:30 am	American Breakfast	Multipurpose Room's Foyer
	9:00 am - 6:00 pm	ECD Patient & Family Gathering Presentations	Multipurpose Room

STAY CONNECTED & SHARE

During the event week we encourage all to participate in sharing meeting progress, highlights, and photos with others. Attaching **#ECDGA18** to each social post about the event will help us find your posts. Those that could not attend would love to hear about your experiences!

HAVE YOU REGISTERED FOR THIS EVENT?

Please be sure to let us know you are planning to attend. Thank you for helping us make this a successful event! **Go here to register today:** <https://conta.cc/2tZNGs1>.

PRESENTATION SCHEDULE

The following table is the drafted presentation schedule for Friday, November 16, 2018, 9:00 am to 6:00 pm. Some details may change. You will be provided an event program upon your arrival at our registration desk.

TIME	SUBJECT	PRESENTER
9:00	Breakfast & Registration Enjoy a hot American breakfast before the meeting kicks off. Be sure to sign-in and get your name badge and welcome bag at our registration desk.	
9:30	Welcome & Overview of ECD Hear from our co-host, Julio Hajdenberg with Orlando Health. The basic, genetic, and clinical aspects of the disease will be shared.	Julio Hajdenberg, MD <i>Orlando Health</i>
9:45	The Drug Trial Process How is the trial process developed and progressed to drug approval, what are the benefits and affects to consider when joining a trial, and more in this session.	Eric Jacobsen, MD <i>Dana-Farber Cancer Institute</i>
10:00	Treatment Options for ECD Learn about the treatments used to treat ECD, what to expect over time, and the side-effects that may be involved.	Ronald Go, MD <i>Mayo Clinic</i>
10:30	Drug Management Combining multiple drugs can be part of ECD patients' regimens, learn the effects of common combinations and how to maintain a medication schedule. The latest information on opioid usage will also be shared.	Cassie Nguyen <i>Orlando Health</i>
10:50	Break	
11:00	ECD & the Brain Gain insight into what effects ECD has on the brain and how these are managed.	Eli L. Diamond, MD <i>Memorial Sloan Kettering</i>
11:30	Question & Answer with the Experts <i>Moderator: Matthew Collin, MD, PhD</i> Find answers to your questions from the most ECD-knowledgeable doctors in the world. It is recommended that you come prepared with some questions and concerns for this session.	Eli L. Diamond, MD Ronald Go, MD Julien Haroche, MD, PhD Mark Heaney, MD Eric Jacobsen, MD, PhD
12:25	Group Photo of Attendees	
12:40	Lunch	
1:40	Speech & Swallowing These particular functions can weaken with ECD, learn how to effectively manage these fundamental tasks.	Annette May <i>Orlando Health</i>

2:10	<p>Psychological Aspects of ECD Managing mental health is part of your ECD care, learn what impact chronic illness can have on you and your family, changes to expect over time, and how to cope.</p>	<p>Diane Robinson <i>Orlando Health</i></p>
2:40	<p>Endocrinology & Hormones Learn about the hormones affected by ECD, Diabetes Insipidus management, and how to treat deficiencies.</p>	<p>Fady Hannah-Shmouni, MD <i>National Institutes of Health</i></p>
3:10	<p>Break</p>	
3:20	<p>Physical Therapy & Exercise Improve mobility, understand the benefits and limitations, and know when to seek professional help with your exercise regimen.</p>	<p>Patricia Bobryk <i>Orlando Health</i></p>
3:50	<p>Nutrition Get your tips and tricks to stay healthy! Attend this session to learn about making healthy choices and establishing habits for overall health, as well as supplement information.</p>	<p>Rebecca E. Donnenberg <i>Orlando Health</i></p>
4:20	<p>ECDGA Close & Evaluations Learn more about your advocacy support group, how to get more involved, and tell the team how you liked the meeting.</p>	<p>Kathy Brewer <i>ECDGA Founder & President</i></p>
4:35	<p>Room Transition</p>	
4:50 – 6:00	<p>Patient Discussion & Fellowship Join other patients to exchange stories and information with your peers.</p>	<p>Teresa Mesa</p>
	<p>Caregiver Discussion & Fellowship <i>Separate meeting room</i> Caregivers gather to share tips and information about caring for an ECD patient at home.</p>	<p>Julie Jones, CRNA</p>