

Time	2026 Conference Agenda	Speaker
<b>Thursday</b>		
4:00 PM	Early Registration Open	
5:00 PM	Family Meet and Greet Social	
<b>Friday</b>		
7:30 AM	Registration & Exhibitors are available all-day Friday and Saturday Sibling Camp	Registration Required
<b>7:00am</b>	<b>Breakfast</b>	
<b>8:00am-12pm</b>	<b>General Session in Main Ballroom</b>	
8:00 AM	IFCR Welcome and Orientation and Brief Description of Biosample Collection	
8:30-10:00 AM	Industry Session: Welcome from Immedica	Industry Panel: Immedica, Lundbeck, Praxis
<b>10:00-10:15 AM</b>	<b>Snack Break</b>	
10:15-12:00 AM	CDKL5 Science Update/ ICCRN Update/CANDID Update ICCRN Clinical Care Panel Discussion: Keeping our Loved Ones as Healthy as Possible	Tim Benke, MD, PhD; Xavier Liogier, PhD Tim Benke, MD, PhD; Scott Demarest, MD; Eric Marsh MD, PhD, Heather Olson, MD; Elia Pestana-Knight, MD; Dr. Dana Price, MD; Dr. Raj Rajaramen, MD, MS; Dr. Bernhard Suter, MD; Judith Weisneberg, MD
<b>12:00-1:00 PM</b>	<b>Lunch</b>	
<b>1:00-1:45 PM</b>	<b>Break-out Sessions</b>	
Session 1	CVI Introduction	Christine Roman Lantzy, PhD Sarah Brooks, MS, RD, CSP, LDN and Liza Miller, BA
Session 2	Keto and Nutrition	
Session 3	Palliative Care	Tristen Dinkle, MSPC, BSN, CNRN, CPN
Session 4	Financial Planning	Mary McDermid, ChSNC, ChFC
<b>2:00-2:45 PM</b>	<b>Break-out Sessions</b>	
Session 1	Seizures: More personalized to CDKL5	Judith Weisneberg, MD
Session 2	PM&R	Sally Evans, MD
Session 3	Sleep	Erin Prange, MSN CRNP Brad Thompson, MA, LPC-S & Karen Thompsonm LPA
Session 4	Marriage/Relationships	
2:45-3:00	<b>Snack Break</b>	
<b>3:00-3:45</b>	<b>Break-out Sessions</b>	
Session 1	PT Session	Samuel Pierce, PT, PhD
Session 2	Communications and best practices	Patricia Remshifski, PhD, CCC-SLP
Session 3	CVI Strategies	Christine Roman Lantzy, PhD
Session 4	How to Advocate for Your Child with a Disability	Stacy Philips, MS Ed
<b>4:00-4:45</b>	<b>Break-out Sessions</b>	

Session 1	Clinical Trials: What to expect; What do they look like?	Raj Rajaramen, MD
Session 2	Behavior	Erin Prange, MSN CRNP
Session 3	Movement Disorders	Bernhard Suter, MD
Session 4	Dad's Session	
<b>4:45-5pm</b>	<b><i>Closing Remarks in Ballroom</i></b>	
<b>6:30pm</b>	<b><i>Group photo</i></b>	
<b>7:00pm</b>	<b><i>Tribute Dinner &amp; Reception</i></b>	

## Saturday

7:00am	<b>Breakfast</b>	
8:00am	Welcome and Housekeeping	
8:05am-8:30am	LouLou Foundation and Elaaj Bio	
8:30m-9:00am	Keynote: Gene Therapy Experience Story	Nate Plasman (Duchenne Community)
9:00-10:00	Workshop: Self Care for the Caretaker	Brad Thompson, MA, LPC-S
10:00-10:15am	Snack Break	
10:15Am-12:15PM	Gene therapies: What do we need to know? Gene Therapies: Risk Benefit Workshop	MSc PhD; Wendy Gold, PhD; Peter Jacoby, BA MSc; Jess Keeley, BPsych, PhD; Eric Marsh MD, PhD
12:15pm-12:45	Lunch - Remaining in room for next talk.	
12:45-1:15	Industry Update: UCB Fenfluramine Clinical Trial Results	Brain Moseley, MD
<b>1:30-2:15pm</b>	<b><i>Break-out Sessions</i></b>	
Session 1	GI Session	TBD
Session 2	Adult transition UCB	Laurie Bailey with UCB Judy Weisenberg, MD giving clinician perspective
Session 3	Respiratory/Pulmonary	Danna Tauber, MD, MPH
<b>2:30-3:15pm</b>	<b><i>Break-out Sessions</i></b>	
Session 1	Converting a toy workshop Building Collaborative Partnerships Between Families and	
Session 2	Schools	Stacy Philips, MS Ed
Session 3	TBD	
Session 4	Mom's Session	
<b>3:15-3:30</b>	<b><i>Reconvene and say good bye</i></b>	