

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
7:00am	<b>Breakfast Buffet</b>	
8:00am-12pm	<b>General Session in Main Ballroom</b>	
8:15 AM	IFCR Welcome and Orientation and Brief Description of Biosample Collection	
8:30-10:00AM	Industry Session: Welcome from Immedica Industry Panel: Immedica, Lundbeck, Praxis	
10:00-10:15	<b>Break</b>	
10:15AM-12:00PM	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 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>Lunch 12-1pm</b>		
1:00-1:45pm	<b>Break-out Sessions</b>	
Session 1	CVI Introduction	Christine Roman Lantzy, PhD
Session 2	Keto and Nutrition	Sarah Brooks, MS, RD, CSP, LDN and Liza Miller, BA
Session 3	Palliative Care	Tristen Dinkle, MSPC, BSN, CNRN, CPN
Session 4	Financial Planning	Mary McDermid, ChSNC, ChFC
2:00-2:45	<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
Session 4	Marriage/Relationship	Brad Thompson, MA, LPC-S
2:45-3:00	<b>Snack Break</b>	
3:00-3:45	<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
4:00-4:45	<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	
4:45-5pm	<b>Closing Remarks in Ballroom</b>	
6:30pm	<b>Group photo</b>	
7:00pm	<b>Tribute Dinner &amp; Reception</b>	
<b>Saturday</b>		
7:00am	<b>Continental Buffet Breakfast</b>	
8:00am	LouLou Foundation and Elaaj Bio	
8:05am-8:30am	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 Therapy Trials: Hope and Honest Conversations	Scott Demarest, MD; Jenny Downs, BAppSci, 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>Break-out Sessions</b>	
Session 1	GI Talk	TBD
Session 2	Adult transition UCB	Laurie Bailey with UCB and Judy Weisenberg, MD giving clinician perspective
Session 3	Respiratory/Pulmonary	Danna Tauber, MD, MPH
Session 4	How can we reduce the risk of death in CDKL5	Dana Price, MD
<b>2:30-3:15pm</b>	<b>Break-out Sessions</b>	
Session 1	Converting a toy workshop	
Session 2	Building Collaborative Partnerships Between Families and Schools	Stacy Philips, MS Ed
Session 3	Mom's Session	
<b>3:15-3:30</b>	<b>Reconvene and say good bye</b>	