

Time	2026 Conference Agenda	Speaker
Thursday		
4:00 PM	Early Registration Open	
5:00 PM	Family Meet and Greet Social	
Friday		
7:30 AM	Registration & Exhibitors are available all-day Friday and Saturday	
7:00am	Breakfast Buffet	
8:00am	Sibling Camp	
8:00am-5pm	Sibling Camp	Registration Required-Details will be sent to families and in app. Camp Leaders will be identified and kids will join from general
8:00am-12pm General Session in Main Ballroom		
8:00 AM	IFCR Welcome and Orientation and Brief Description of Biosample Collection	
8:30-10:00AM	Industry Panel Updates	Immedica- Tom D'amato and Christine Ochoa Escamilla, PhD Lundbeck TBD Praxis: Raquel Miralles, PhD
10:00-10:15 Break		
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
Lunch 12-1pm		
1:00-1:45pm Break-out Sessions		
Session 1	Overview of CVI: From Identification to Education	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 Considerations	Mary McDermid, ChSNC, ChFC
2:00-2:45 Break-out Sessions		
Session 1	Precision Epilepsy Care for CDKL5 Deficiency Disorder	Judith Weisneberg, MD
Session 2	PM&R	Sally Evans, MD
Session 3	Practical Approach to Improving Sleep in Neurodevelopment Disorders	Erin Prange, MSN CRNP
Session 4	Joy In Chaos: Marriage/Relationships	Brad Thompson, MA
2:45-3:00	Snack Break	

3:00-3:45		
Break-out Sessions		
Session 1	Strategies to Maximize Physical Therapy Effectiveness for Children with CDKL5	Samuel Pierce, PT, PhD
Session 2	Complex Communication Needs: An Update on "The Communication Guidelines"	Patricia Remshifski, PhD, CCC-SLP Jamie Rosenstein MS.Ed.CCC-SLP
Session 3	Considerations of Orientation and Mobility for Individuals with CVI. It's Not Business as Usual "Advocacy in Action: Supporting Your Child with a Disability" Empowering Families to Navigate Systems and Support Success.	Christine Roman Lantzy, PhD
Session 4		Stacy Philips, MS Ed
4:00-4:45		
Break-out Sessions		
Session 1	Clinical Trials: What to expect; What do they look like?	Raj Rajaramen, MD
Session 2	Behavior	Jung Kim, MD William Hong, MD, Erin Prange, MSN CRNP
Session 3	Movement Disorders	Bernhard Suter, MD
Session 4	Dad's Session	
4:45-5pm		
Closing Remarks in Ballroom		
6:30pm		
Group photo		
7:00pm		
Tribute Dinner & Reception		

Saturday		
7:00am	Continental Buffet Breakfast	
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: What if Burnout is NOT Inevitable?	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. Bernhard Suter, MD
12:15pm-12:45	Lunch - Remaining in room for next talk.	
12:45-1:15	Industry Update: UCB Fenfluramine Clinical Trial Results	Brian Moseley, MD (UCB)
1:30-2:15pm		
Break-out Sessions		
Session 1	Common GI Concerns in CDKL5 and How They're Managed	Faith Ihekweazu, MD, MS

Session 2	Pediatric to Adult Medical Care Transition: Guidance & Support for CDKL5 Families Modes of Respiratory Support in Children with Progressive Neuromuscular	Laurie Bailey (UCB) Judith Weisneberg, MD
Session 3	Disease	Danna Tauber, MD, MPH
Session 4	Informing Long-Term Health in CDKL5 Disorders	Dana Price, MD

2:30-3:15pm ***Break-out Sessions***

Session 1	Learn About How to Switch Adapt Toys "Bridging Home and School for Student Success" Strengthening	Laura Slotkoff
Session 2	Collaboration Between Families and Educators.	Stacy Philips, MS Ed
Session 3	Mom Session	
Session 4	Tentative OT session	Sarah Jamieson, MS,BS,OTR/I

3:15-3:30 ***Reconvene and say good bye***