

Agenda



Thursday, June 18th

Time	Session	Speakers	Location
4:00 PM	Early Registration Open		Pre-function
6:00 PM - 8:00 PM	Family Meet and Greet Social		Pre-function

Friday, June 19th

7:00 AM Breakfast Buffet			
7:30 AM	Registration & Exhibitors Available All Day		Exhibitors/Princeton Foyer
8:00 AM - 5:00 pm Sibling Camp sponsored by UCB - Registration Required and schedule details in the app!			
8:00 - 10:00 AM General Session in University Ballroom			
8:00 AM - 8:30 AM	IFCR Welcome and Orientation and Bio sample Collection Logistics & Instructions		University
8:30 AM - 9:45 AM	Welcome from Immedica - Industry Updates	Immedica: Tom D'amato; Christine Ochoa Escamilla, PhD Lundbeck: Amy Lin, PhD Praxis: Raquel Miralles, PhD	University
9:45 AM - 10:00 AM	Loulou Foundation Update	Dan Lavery, PhD	University
10:00 - 10:15 AM Break			
10:15 - 12:00 PM General Session in University Ballroom			
10:15 AM - 12:00 PM	CDKL5 Science Update/ ICCRN Update/CANDID Update	Tim Benke, MD, PhD	University

*Please note: Bio sample collection details will be updated in the event app.

Agenda



Friday, June 19th – Continued

Time	Session	Speakers	Location
10:15 - 12:00 PM General Session in University Ballroom - Continued			
10:15 - 12:00 PM	ICCRN Clinical Care Panel Discussion: Keeping our Loved Ones as Healthy as Possible	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	University
12:00 - 1:00 PM Lunch			
1:00 - 1:45 PM Break-out Sessions			
Session 1	Overview of CVI: From Identification to Education	Christine Roman Lantzy, PhD	University
Session 2	Ketogenic Diet & Nutrition	Sarah Brooks, MS, RD, CSP, LDN and Liza Miller, BA	Princeton
Session 3	Living Fully with CDKL5: The Role of Palliative Care	Tristen Dinkel, FNP-PC, MSPC, CNRN CPN	Villanova
Session 4	Financial Planning Considerations	Mary McDermid, ChSNC, ChFC	Penn
2:00 - 2:45 PM Break-out Sessions			
Session 1	Precision Epilepsy Care for CDKL5 Disorder	Judith Weisneberg, MD; William Hong, MD	University
Session 2	What Rehabilitation Can Add to the Care of Children with CDKL5	Sally Evans, MD	Villanova
Session 3	Practical Approach to Improving Sleep in Neurodevelopment Disorders	Erin Prange, MSN CRNP	Princeton
Session 4	Marriage/Relationships - “Joy in Chaos”	Brad Thompson, MA, LPC-S	Penn

Agenda



Friday, June 19th - Continued

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

Agenda



Saturday, June 20th

Time	Session	Speakers	Location
7:00 AM Continental Buffet Breakfast			
8:00 - 10:00 AM General Session in University Ballroom			
8:00 AM	Welcome and Housekeeping		University
8:05 AM - 8:30 AM	Elaaj Bio	Steve Maricich, MD	University
8:30 AM - 9:00 AM	Keynote: Gene Therapy Experience Story	Nate Plasman - Duchenne Community	University
9:00 AM - 10:00 AM	Workshop: What if Burnout is NOT Inevitable?	Brad Thompson, MA, LPC-S	University
10:00 - 10:15 AM Snack Break			
10:15 - 12:15 PM General Session in University Ballroom			
10:15 AM - 12:15 PM	Gene Therapy Trials: Hope and Honest Conversations	Scott Demarest, MD; Jenny Downs, BApplSci, MSc PhD; Wendy Gold, PhD; Peter Jacoby, BA MSc; Jess Keeley, BPsych, PhD; Eric Marsh, MD, PhD; Bernhard Suter, MD	University
12:15 - 12:45 PM Lunch			
12:45 - 1:15 PM General Session in University Ballroom			
12:45 PM - 1:15 PM	Industry Update: UCB Fenfluramine Clinical Trial Results	Brian Moseley, MD	University

Agenda



Saturday, June 20th - Continued

Time	Session	Speakers	Location
1:30 - 2:15 PM Break-out Sessions			
Session 1	Common GI Concerns in CDKL5 & How They're Managed	Faith Ihekweazu, MD, MS	University
Session 2	Pediatric to Adult Medical Care Transition: Guidance & Support for CDKL5 Families	Laurie Bailey, BCPA; Judith Weisenberg, MD	Princeton
Session 3	Modes of Respiratory Support in Children with Progressive Neuromuscular Disease	Danna Tauber, MD, MPH	Villanova
Session 4	Informing Long-Term Health in CDKL5 Disorders	Dana Price, MD	Penn
2:30 - 3:15 PM Break-out Sessions			
Session 1	Learn About How to Switch Adapt Toys	Laura Slotkoff	University
Session 2	"Bridging Home and School for Student Success" Strengthening Collaboration Between Families and Educators.	Stacy Philips, MS Ed	Princeton
Session 3	Mom's Session		Penn
Session 4	More Than Meets the Eye: CVI and Sensory Processing	Sarah Jamieson, MS, BS, OTR/L	Villanova
3:15 - 3:30 PM Reconvene & Say Goodbye in University Ballroom			