



# 2023 iCAN Summit Agenda Presented by Jumo Health

"Transforming Pediatric Healthcare Together"

#### Sunday

3:00 PM- 6:00 PM: Check In at Tamarack Apartments, UCSD Campus

## Monday

- 7:30 AM 8:15 AM: Breakfast at the UCSD Pines Dining Hall
- 8:15 AM: Additional Check In at Tamarack Apartments, UCSD Campus
- 9:00 AM: Opening Remarks and iCAN Overview by iCAN President, Leanne West
- 9:15 AM: KIDS Moorsfield Eye Statement on Summit Accessibility,
  - Annegret Dahlmann-Noor (Dr med PhD FRCOphth FRCS(Ed) DipMedEd), Honorary Clinical Associate Professor, Consultant in paediatric ophthalmology and strabismus, Divisional Director, Moorfields at City Road, Clinical trials lead in paediatric ophthalmology
- 9:25 AM: Breaking into Pods
- 9:40 AM: Get to Know You Activities with Your Pods
- 10:40 AM: iCAN Councils and Introduction of New Programs
  - Parent Council Deb Discenza, Co-Chair
  - Youth Council
  - Siblings Chapter Heather Peterson, Chapter Leader
  - Young Adult Professionals Program Uma Subrayan, Co-Chair

#### 11:10 AM: Poster Session

11:55 PM: BioCryst Sponsor Session

- Dakota Fisher-Vance, Global Patient Advocacy Associate Director
- Lauren Syring, Senior Manager
- Diane Ramsey-Paige, Sr. Nurse Advocate Manager
- 12:55 PM: Sponsor Table Visits at Jeannie Auditorium and Lunch at
  - UCSD Pines Dining Hall \* (Lunch hours are 1:15 2:00 pm)
- 2:00 PM: Activity of the Week Hosted by Empath Labs
  - Aaron Horowitz, CEO & Founder Sproutel, Empath Labs
  - Joel Schwartz, Founder & CTO, Empath Labs
  - Sam Martinez, Director of Programs, Empath Labs
  - Nick Mead, Senior Designer at Empath Labs
- 3:00 PM: Break
- 3:05 PM: Jumo Sponsor Session
  - Joe Brady, AVP Customer & Creative Strategy, Jumo Health
  - Julianna Rinaldi, Associate Director, Strategic Solutions at Jumo Health
  - Marni Garfinkel, Associate Account Director at Jumo Health | M.S. CCC-SLP
  - Triparna Ghosh-Choudhury, Director of Strategic Solutions at Jumo Health
  - Chris Moreno, Senior Director Business Development at Jumo Health
  - Jesse Jankewicz, Director of Video Services at Jumo Health
- 4:05 PM: End of Day Wrap Up
- 4:15 PM: Break Get Excited for the Welcome Party!
- 6:00 PM: Welcome Party with DJ The Faculty Club, UCSD

#### **Tuesday**

7:30 AM - 8:15 AM: Breakfast at the UCSD Pines Dining Hall 8:30 AM: Overview of the Day - Leanne West, iCAN President at the Jeannie Auditorium 8:35: Fortrea Sponsor Session

- Louise Kearney, Executive Director specialising in Rare and Pediatrics
- Marlene Brown, PMP, CPM, Director / Rare Diseases, Advanced Therapeutics and Pediatrics Team (RAPT)
- 9:35 AM: Become an Advocacy Superhero!
  - Courtney Felle, YARR Program Manager at EveryLife Foundation for Rare Diseases

10:15 AM: Internet Safety Project Update

- Alberto Tozzi, MD, Head of Predictive and Preventive Medicine Research Unit at Ospedale Pediatrico Bambino Gesù

10:45 AM: Break

11:00 AM: Live Like Jojo Service Project

12:00 PM: End of Day Wrap Up, Leanne West

12:10 PM: Lunch and Sponsor Table Visits at Jeannie Auditorium

12:50 PM: Meet infront of Tamarack Apartments for Buses and Please be on time!

- Check with Volunteer in front of Tamarack Apartments for Ticket

1:30 - 2:50 PM: Birch Aquarium

3:00: Buses Return to Tamarack Apartments

After Lunch and/or Aquarium: Family Free Time! Enjoy San Diego!

#### \*Don't Forget to Meet with Your Pod Today!

## Wednesday

7:30 AM - 8:15 AM: Breakfast at the UCSD Pines Dining Hall
\* After Breakfast: Good Time to Meet with Your Pods!
9:00 AM: Overview of the Day - Leanne West, iCAN President at Jeannie Auditorium

9:05 AM: Eli Lilly Sponsor Session

- Courtney Tate, Ph.D. Clinical Research Scientist Senior Director, Pediatric Development, Eli Lilly and Company
- Sokum Kit-Decker, PharmD Project Management & Clinical Research Scientist Advisor, Pediatric Development, Eli Lilly and Company

10:05 AM: Break

- 10:15 AM: PTN Session
  - Meagan Daly, Duke Clinical Research Institute, Research Communications & Engagement
  - Phyllis Kennel, MS RD LDN, PMP, Assistant Director, Clinical Operations at Duke Clinical Research Institute, and Pediatric Trials Network
- 11:15 AM: FDA Tech Assessment Program and How you can be Involved
  - Tracy Gray, MBA, RN, MS, Health Scientist, Patient Engagement Lead, Patient Science & Engagement (PSE), FDA
- 12:05 AM: Lunch and Sponsor Table Visits at Jeannie Auditorium, Therapy Dogs
- 1:15 PM: Understanding Document Requirements with respect to the Pediatric Patient Voice
  - Elisabeth Oehrlein, PhD, MS, Founder & Principal Scientist, Applied Patient Experience, LLC.
  - Omar A. Escontrías, DrPH, MPH, Senior Vice President, Equity, Research & Programs National Health Council

1:55 PM: Transition of Care

- Mitali Vedula, Previous Youth Coucil Co-Chair
- Reny Partain, LCSW, MPH, Transition Program Manager, Adolescent to Adult Bridge Program (A2B) CHOC
- Gloria Marquez, iCAN Parent

2:40 PM: "Diversity in Clinical Trials"

- Lisa Koppelman, MSW, LICSW, MPH, Program & Team Director Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard
- Annegret Dahlmann-Noor (Dr med PhD FRCOphth FRCS(Ed) DipMedEd), Honorary Clinical Associate Professor, Consultant in paediatric ophthalmology and strabismus, Divisional Director, Moorfields at City Road, Clinical trials lead in paediatric ophthalmology
- Phyllis Kennel, MS RD LDN, PMP, Assistant Director, Clinical Operations at Duke Clinical Research Institute, and Pediatric Trials Network
- Deb Disenza, Founder of PreemieWorld and Co-Founder of Alliance for Black NICU Families

3:20 PM: Travel to Estancia for iSPI PEDS2040 Conference, Meet at the Buses outside of Jeannie Auditorium.

\*For Those Who Want to, it is a Short 10 Minute Walk.

3:55-4:25: iSPI Keynote address with Gary Puckrein & Joya Delgado Harris

- 4:30 5:00 PM: What I Want Doctors to Know
  - Meg Wike, iCAN Youth Member
  - Kalee Polk, iCAN Youth Member
  - Berkley Blust, iCAN Youth Member
  - Veida Marquez, iCAN Youth Member
  - Deb Disenza, Founder of PreemieWorld and Co-Founder of Alliance for Black NICU Families

- Leanne West, iCAN President, Moderator

5:00 PM - 7:00 PM: iCAN/iSPI Mixer, the Estancia

6:00, 6:30, 7:00 PM: Buses Back to Tamarack Apartments

### Thursday

- 7:30 AM 8:15 AM: Breakfast at the UCSD Pines Dining Hall
- 9:00 AM: Overview of the Day, Leanne West, iCAN President at Jeannie Auditorium
- 9:05 AM: Remarks by iCAN Founder Charlie Thompson
- 9:10 AM: Career Paths in Medicine
  - Courtney Felle, YARR Program Manager at EveryLife Foundation for Rare Diseases
  - Tracy Gray, MBA, RN, MS, Health Scientist, Patient Engagement Lead, Patient Science & Engagement (PSE), FDA
  - Leanne West, Chief Engineer Pediatric Technologies, Georgia Tech, Moderator
  - Omar Escontruas, DrPH, MPH, Senior Vice President, Equity, Research & Programs National Health Council
  - Joe Brady, AVP Customer & Creative Strategy, Jumo Health
  - Emily Blum, MD, BA, Pediatric Urologist and Medical Innovations Consultant
- 10:10 AM: Pfizer Session
  - Betty Glass, Enrollment Strategist Vaccines, Pfizer Global Product Development
  - Adriana Mason, Participant Experience Lead Vaccines, Pfizer Global Product Development
- 11:10 AM: Activity of the Week Hosted by Sproutel
  - Aaron Horowitz, CEO & Founder Sproutel, Empath Labs
  - Joel Schwartz, Founder & CTO, Empath Labs
  - Sam Martinez, Director of Programs, Empath Labs
  - Nick Mead, Senior Designer at Empath Labs

12:00 PM - 1:00 PM: Lunch and Sponsor Table Visits at Jeannie Auditorium

11:40 PM - If you are going on the Lab Tour, go to the Tamrack Apartments for buses!

12:10 PM - 3:00 PM: Special Pfizer Lab Tour and Lunch for 16+ and Young Adult Professionals

\* After Lunch: Family Free Time, Enjoy San Diego!

#### 5:30 PM: iCAN Advisory Board Meeting, Meeting Room NTPLLN KA1406

#### Friday

- 7:30 AM 8:15 AM: Breakfast at the UCSD Pines Dining Hall
- 8:30 AM: Overview of the Day, Leanne West, iCAN President at Jeannie Auditorium
- 8:35 AM: Extra time to prepare Activity of the Week Presentations at Tamarack Apartments
- 9:35 AM: Travel to Estancia, Buses Arrive at Tamarack Apartments
- 10:30 AM: Activity of the Week Presentations, the Estancia Room
- 11:00 AM: Meet Outside Estancia for Buses to Travel Back to the Jeannie Auditorium
- 11:30 AM: Supporting Mental Health in Young People Session
  - Eve Nguyen, Ph.D., Rady Children's Hospital, Program Lead Psychologist, Gastroenterology, Endocrinology & Neurology Assistant Clinical Professor, Psychiatry, University of California -San Diego

12:10 PM: Lunch and Sponsor Table Visits at Jeannie Auditorium

1:10 PM: Jumo Health Second Session

- Joe Brady, AVP Customer & Creative Strategy, Jumo Health
- Julianna Rinaldi, Associate Director, Strategic Solutions at Jumo Health
- Marni Garfinkel, Associate Account Director at Jumo Health | M.S. CCC-SLP
- Triparna Ghosh-Choudhury, Director of Strategic Solutions at Jumo Health
- Chris Moreno, Senior Director Business Development at Jumo Health
- Jesse Jankewicz, Director of Video Services at Jumo Health
- 2:10 PM (Parallel): Parents Session
- 2:10 PM (Parallel): Siblings Session
- 2:10 PM (Parallel): Young Adult Professionals
- 2:10 PM (Parallel): Youth Council
- 2:40 PM: Andrew Meadows, General Partner and Founder Health Innovation Capital
- 3:10 PM: Genomics Session
  - Cheyenne Camp, Strategic Business Development, Rady Children's Institute for Genomic Medicine
  - Erica Haviland, Client Service Representative, Rady Children's Institute for Genomic Medicine
  - Lisa M. Salz, MS, LCGC, Alliance Manager and Genetic Counselor-Genomics, Rady Children's Institute for Genomic Medicine
- 4:40 PM: End of Summit Wrap Up, Leanne West
- 5:00 PM: Break. Get Excited for the End of Summit Celebration!
- 6:00 PM: End of Summit Celebration with Band The Faculty Club, UCSD

## 8:00 AM - 12:00 PM: Check Out, Tamarack Apartments

Thanks for coming to the iCAN Summit! We look forward to Summit 2024!

# Thank you to our Sponsors and Volunteers for Making this Summit a Huge Sucess!













