

# 2025 JdVS Summit Program



\*Details can be found using the Team Reach App

JdVS Summit 2025

Group Code: JdVS2025

## FRIDAY July 11th

3:00-5:00 pm Registration - check in at registration to receive your bag and nametag

5:00-6:00 pm Welcome Reception (drinks and light snacks in the Atrium)

6:00-7:30 pm Opening Remarks and Dinner (Ballroom CD)

## SATURDAY July 12th

### MAIN PROGRAM

8:00-9:00 am Continental Breakfast (Atrium)

8:30 am Childcare Opens (Conference Room 205)

9:00-10:30 am Adult Caregiver Panel Followed by Roundtable Discussions

- Tips and Tools for Behavior Management
- Medication Management for Anxiety and ADHD
- Gastrointestinal Issues: From CVS to Intestinal Issues to Nutrition
- Social Challenges: Hypersociability, Anxiety, and Relationships

10:30-10:45 am Break

10:45-11:15 am Supporting Neurotypical Child(ren) and Enhancing the Sibling Experience  
-Abby Turnwald, M.S.

11:15 am-12:00 pm News from Radboud - Drs. Bert de Vries and Jolijn Verseput

12:00-12:45 pm Lunch in the Atrium

12:45-1:15 pm JdVS Clinical Update 2025 - Dr. Cynthia Curry

1:15-1:45 pm Molecular Analysis of Microglia and Neurons Derived from PPM1D  
Mutated iPSCs - Dr. Herb Lachman (Pre-recorded)

1:45-2:15 pm Novel Animal Models of JdVS - Dr. Jay Vivian

2:15-2:30 pm Break

2:30-3:30 pm Updated Treatment Guidelines for Cyclic Vomiting Syndrome - Dr. B Li

3:30-4:30 pm Office Hours with Healthcare Professionals (optional, sign up at registration)

EXTENDED BREAK: Please note, Saturday's Childcare closes at 4 pm

6:00-10 pm JdVS Champion Reception - Ballroom CD

- 6:00-6:30 pm Buffet Dinner
- 6:30-7:30 pm JdVS Champion Panel and Hall of Champions Presentations
- 7:30-10 pm Silent Disco

# SUNDAY July 13th



8:00-9:00 am Continental Breakfast served in Atrium

8:30 am Childcare Opens (Conference Room 205)

## MAIN PROGRAM

9:00-9:45 am Neurodevelopment and Neuropsychological Testing - Dr. Jenny Klein-Sosa

9:45 -10:30 am JdVS Community Connection Roundtables

- Growth Hormone Treatment
- What about Me? Caregiver Self-care
- Navigating the Educational Arena
- Navigating Independence Safely for your JdVS Champion

*Pool outing (optional) 10:30 am-12 pm , please have your child ready to join lifeguards at the pool!*

10:45-11:00 am Break

11:00 am- 12:00 pm JdVS Foundation Annual Report

JdVS Foundation Development Roundtables: From Building Community to Taking Action

- Fundraising 101
- Aligning Expertise with Action
- Becoming a Research Ready Organization

12:00 pm Bagged Lunches (to go)



## Team Reach App

- \* JdVS Summit 2025
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# Childcare Program



## SATURDAY, July 12th

Conference Room 205

8:30 am-12 pm Chicago Super Sitters

12:00-12:40 pm Lunch (in Atrium with all conference participants)

12:45-4:00 pm Chicago Super Sitters

*Creative Arts Music and Movement Groups led by practitioners from the*  
***Institute for Therapy Through the Arts Chicago***

## SUNDAY, July 13th

Conference Room 205

8:30 am - 12:00 pm

9:00-11:00 am Myla the therapy dog visits!

10:30 am-12 am Pool Outing \*supervised by JdVS Foundation Volunteers

\*Parents will need to check their children out of the childcare room to attend the swimming outing. We have three JdVS Siblings (trained lifeguards) who will be supervising children in the pool.

# Sibling Program

## SATURDAY, July 12th

10:45 am-11:15 am Presentation and Panel with Abby Turnwald - Ballroom CD

11:15 am-12:00 pm Sibling Meeting (Ballroom AB)

12:00-12:45 pm Lunch (in Atrium with all conference participants)

12:45-2 pm SibShops

2pm-3:30 pm Pool/Outing

## \* Sensory Friendly Room Available

Conference Room 235 will be sensory friendly. It will have calming toys, fidgets and low lighting to accommodate any attendees who need a sensory break.