

Thursday – Pre-Meeting Activities

1-4 pm Pool Time

4-8 pm Registration

4-7 pm Community Dinner (at own expense): Location TBD

Friday, July 10, 2026 – Two Tracks

07:00 All: Registration, Breakfast and Vendors Open

08:30 All: Welcome and Award

09:00 Professional Track: Rare-X for Research & Medical

Family Track: What is Homocystinuria?

09:45 Professional Track: Establishing MTHFR- and MTR-deficient Cerebral Organoids

Family Track: Treatment Guidelines

10:30 Professional Track: Break

Family Track: Q&A (Exhibits open)

10:45 Professional Track: Aminoglycosides for the Treatment of Inborn Errors of Vitamin B12 Metabolism (cblG)

Family Track: Break (Exhibits open)

11:00 Family Track: What is: ERT, Chaperone Therapy, Gene Editing, and Gene Therapy?

11:15 Professional Track: Combining Taurine and Formate/Betaine Treatment to Improve Clinical Outcome and Drug Safety in Classical CBS Deficient HCU

12:00 All: Lunch (Exhibits open)

01:30 Professional Track: Harmony Study, Phase 3 Clinical Trial of Pegitbatinase

Family Track: Classical HCU & Remethylation Research Overview

02:15 Professional Track: Break (Exhibits open)

02:30 Professional Track: Investigating the Therapeutic Potential of Intestinal Methionine Elimination via Oral Enzyme Therapy in HCU

Family Track: Break (Exhibits open)

02:45 Family Track: What You Should Know and Ways to Get Involved

03:15 Professional Track: Ask the Experts

03:45 All: HCU Hero Award Recipient: Optimizing self-care

04:30 All: Cocktails and Posters (Exhibits open)

05:30 All: Dinner

05:50 All: HCU Hero Award: Dr. George Spaeth

Saturday, July 11, 2026 – One track

07:00 Registration, Breakfast, and Exhibits open

08:30 Day 2 Keynote & HCU Champion Award

09:00 Panel: "It's a Family Affair"

10:00 Break (Exhibits open)

10:30 Family Planning Panel

12:00 Lunch

01:30 Diagnostics and Monitoring Session

02:30 Break (Exhibits open)

02:45 Breakout Sessions 1: Emergency Planning (TBD) or Sex, Drugs, and Rock and Roll with HCU

03:30 Break (Exhibits open)

03:45 Breakout Sessions 2: Insurance or Exercise and Athletics with HCU

04:45 Break

05:00 Day Closing comments

Sunday, July 11, 2026

07:00 Breakfast

08:30 Welcome

09:00 Tribute to Dana Hunt
Other - TBD

10:00 Bus leaves for Franklin Park and come back to hotel. Bus will be making trips every 15-20 minutes.

12:00 Lunch at Franklin Square

02:00 Final bus leaves Franklin Square

Schedule is subject to change