

Thursday, July 16, 2026

Galactosemia Foundation Conference

Aurora, CO 2026

TIME	SCIENTIFIC DAY ACTIVITY HELD IN THE AURORA BALLROOM
8:00 AM- 9:00 AM	Scientific Day Registration/Check-In (Scientific Day attendees only) • Location: Aurora Foyer
9:00 AM – 9:15 AM	Welcome & Purpose of the day • Galactosemia Foundation updates
9:15 AM – 9:35 AM	State of Galactosemia Research: What We Know Now
9:35 AM- 9:55 AM	Galactosemia Funded Research Overview
9:55 AM – 10:40 AM	Research 1 (Funded by GF) Granulosa Cell Gene Therapy for Classic Galactosemia • Dr. Kevin Elias & Dr. Kent Lai
10:40 AM- 11:25 AM	Research 2 (Funded by GF) • Navigating POI in Galactosemia • Dr. Judy Fridovich-Keil
11:25 AM – 11:45 AM	Natural History & Registry Data: Insights & Gaps
11:45 AM – 1:15 PM	Lunch On Your Own (hotel restaurant- Borealis & food truck on-site)
1:15 PM- 1:20 PM	Welcome Back: Overview for rest of day
1:20 PM-1:50 PM	Emerging tools for the patients • Juan Estruch- Gutsy Bio
1:50 PM – 2:35 PM	Research 3 (Funded by GF) • Functional Outcomes from Pediatrics to Adulthood in Classic Galactosemia • Dr. Nancy Potter and Dr. David Jenson
2:35 PM – 3:05 PM	Industry Update: Jaguar Gene Therapy
3:05 PM – 3:50 PM	Research 4 (Funded by GF) • Detailed Phenotyping of Movement Disorders in Classical Galactosemia, Moving Towards a Guideline for Individualized Treatment • Dr. Rubio Gozalbo and Ellen Hulshof
3:50 PM- 4: 10 PM	Disease Concept Model: Understanding the Galactosemia Experience in partnership with "Combined Brain"
4:10 PM – 4:15 PM	Closing Remarks & Next Steps
4:15 PM – 5:00 PM	Collaborative Roundtable: Research Needs & Priorities (Biomarkers, Neurological outcomes, Adult Care, Diet, Patient Perspective)

TIME	GENERAL EVENING ACTIVITY
1:00 PM - 8:00 PM	Conference Registration & Check-In (All conference attendees) • Location: Aurora Foyer
2:00 PM - 8:00 PM	On-Site Research: Please participate in the on-site research! • Location: Boardroom C B
5:00PM- 5:30PM	Volunteer orientation • Location: Conference Room VII
5:30 PM - 6:30 PM	Galactosemia 101 • Location: Conference Room VII
6:00 PM - 8:00 PM	Age group registration & activity • Location: Conference Foyer I
6:00 PM - 8:00 PM	Thursday Night Social: Sweet Treats • Location: Conference Foyer, Café Lounge & West Terrace

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TIME	PRE-CONFERENCE ACTIVITY	LOCATION
7:30 AM - 8:30 AM	Galactosemia Foundation sponsored Breakfast	Aurora Ballroom
8:00 AM - 8:30 AM	Late Registration- packet pick -up	Aurora Foyer
8:30 AM - 9:00 AM	Childcare dropoff	Conference Foyer I
7:00 AM - 7:00 PM	On-Site Research: Please participate in the on-site research!	Boardroom B & C

TIME	GENERAL CONFERENCE ACTIVITY	LOCATION
9:00 AM - 9:20 AM	Welcome to the 2026 Conference	
9:20 AM - 9:30 AM	Meet the Board- What we do and how to get involved!	
9:30 AM - 10:20 AM	Key Note: 30 years of Lessons Learned	Aurora Ballroom
10:20 AM - 10:35 AM	Galactosemia Angels--We will remember! & Paul Pruszyński Scholarship award	
10:35 AM - 10:50 AM	Close of General Session & Our Community in the Room	
10:50 AM - 11:00 AM	Travel to breakout sessions	
11:00 AM - 12:00 PM	Breakout Series #1	Various Rooms
12:00 PM - 1:10 PM	Galactosemia Foundation sponsored lunch @12:00	Aurora Ballroom
1:15 PM - 2:15 PM	Breakout Series #2	Various Rooms
2:15 PM - 2:30 PM	Travel to breakout sessions	
2:30 PM - 3:30 PM	Breakout Series #3	Various Rooms
3:30 PM - 4:00 PM	Travel to breakout sessions w/ tea and coffee	
4:00 PM - 5:00 PM	Breakout Series #4	Various Rooms

TIME	EVENING ACTIVITY	LOCATION
5:00 PM - 5:15 PM	Pick up children from childcare	Conference Foyer I
5:00 PM - 8:30 PM	Designated meetup space for families that want to connect	Cafe Lounge
5:00 PM - 7:00 PM	Dinner on your own	
7:00 PM - 8:30 PM	A Grand Day for Talent Together	Aurora Ballroom

Saturday, July 18, 2026

Galactosemia Foundation Conference

TIME	PRE-CONFERENCE ACTIVITY	LOCATION
7:30 AM - 8:30 AM	Galactosemia Foundation sponsored breakfast	Aurora Ballroom
8:30 AM - 9:00 AM	Childcare dropoff	Conference Foyer I
7:00 AM - 7:00 PM	On-Site Research: Please participate in the on-site research!	Boardroom B & C

TIME	GENERAL CONFERENCE ACTIVITY	LOCATION
9:00 AM - 9:10 AM	General Session- Opening Remarks	
9:10 AM -9:30 AM	Keynote -Living with Galactosemia	
9:30 AM - 9:50 AM	Rare Disease and Public Awareness	
9:50 AM- 10:05 AM	Outreach Activities & Newborn Program	Aurora Ballroom
10:05 AM- 10:15 AM	Mentor Program	
10:15 AM - 10:30 AM	CK Kids Camp	
10:30 AM - 10:45 AM	Treasurer's Report; Fundraising	
10:45 AM - -11:05 AM	Morning Bingo Connection Activity	
11:05 AM - 11:35 AM	Research Team- Give Updates	
11:35 AM - 12:00 PM	Natural History & Registry Data: Insights & Gaps	
12:00 PM - 1:15 PM	Galactosemia Foundation sponsored lunch @12:00	
1:15 PM - 1:35 PM	Welcome Back- Next Steps	
1:35 PM - 1:55 PM	Speed Friending	
1:55 PM - 2:25 PM	Round Tables / Activities / Networking	Aurora Ballroom
2:25 PM- 3:20 PM	Doctor Panel Q & A	
3:20 PM - 4:15 PM	Round Tables / Activities / Networking	
4:15 PM - 4:30 PM	Conference Closing Remarks & 2028 Location Announcement	
4:30 PM - 5:00 PM	Open Networking/ Meet the Doctors/ Photos / Informal Discussion	

TIME	EVENING ACTIVITY	LOCATION
5:00 PM	Pick up children from childcare	Conference Foyer I
5:00 PM - 6:00 PM	Designated Meet-Up	Cafe Lounge
5:00 PM - 7:30 PM	Dinner on your own	
7:30 PM - 10:30PM	Saturday Night Social and Dance	Aurora Ballroom



Galactosemia Foundation
Looked for Life

AURORA I

General Session

AURORA II

AURORA BALLROOM

AURORA IV

Breakout Tract 2

AURORA III

Breakout Tract 1

CONFERENCE ROOM VI

Mighty-G 9-11

CONFERENCE ROOM V

Childcare 4-8

O.G.G.26+

CAFÉ LOUNGE

No Why

CONFERENCE ROOM VII

Breakout Tract 3

CONFERENCE ROOM VIII

Breakout Tract 4

CONFERENCE ROOM IV

Childcare 0-3

CONFERENCE ROOM III

Arcade Room

CONFERENCE FOYER I

Thursday Social

RESTROOMS

Registration Table

Galactosemia Podcast Table

AURORA FOYER

Advocacy Table

Dr. Zhang ABA Table

Jaguar Table

Gutsy-Bio Table RESTROOMS

BUSINESS CENTER

STORAGE/ COAT ROOM

BOARDROOM C

Dr. Judy Research/Study

BOARDROOM B

Dr Summit Research-Study

BOARDROOM A
GF War Room

CONFERENCE FOYER II

CONFERENCE ROOM II

G-Force 12-18

CONFERENCE ROOM I

Gen-G 19-25

LOBBY

Friday Talent Show

Saturday Dance

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Friday, July 17, 2026

	Room → Time ↓	Aurora III	Aurora III	Conference RM VII	Conference RM VIII
1	11:00AM - 12:00PM	<p>NIH: Ovarian tissue cryopreservation trial in classic galactosemia</p> <p>Dr. Veronica Gomez-Lobo (Presenting Virtually)</p>	<p>Growing Up with Galactosemia: What to Expect in the First 9 Years</p> <p>Dr. Gerard Berry</p>	<p>Advocating for Your Child: Educational Planning IEP's and 504's</p> <p>Tracey Miller</p>	<p>Adults with Galactosemia: Connection, Conversation, and Support</p> <p>Facilitated by Dr. Al Freedman</p>
2	1:15PM - 2:15PM	<p>Reshaping the landscape of treatment in Classic Galactosemia</p> <p>Dr. Rubio Gozalbo</p>	<p>Effective Speech-language Therapy for Preschool through School Age Children</p> <p>Dr. David Jenson, Dr. Nancy Potter, & David Trainor, Jr.</p>	<p>Nutrition management for Galactosemia in Infants & Toddlers</p> <p>Dr. Sandy Van Calcar</p>	<p>Adults with Galactosemia: A New Treatment Approach Using tACS (Transcranial Alternating Current Stimulation)</p> <p>Dr. Bianca Panis</p>
3	2:30PM - 3:30PM	<p>Hormone Replacement Therapy (HRT) and Bone Health</p> <p>Dr. Judy Fridovich-Keil</p>	<p>Babble Boot Camp – Teaching Babies and Toddlers to Talk</p> <p>Dr. Nancy Potter and Dr. David Jenson</p>	<p>Behavior and Self-Management in School-Age Children Using Applied Behavior Analysis (ABA)</p> <p>Dr. Dorothy Zhang</p>	<p>Transitioning from School to Adulthood</p> <p>Gillian Sapia, R.N.</p>
4	4:00PM -5:00PM	<p>Neurological Outcomes in Classic Galactosemia</p> <p>Dr. Verma Sumit</p>	<p>Gene Therapy: An overview and what it could mean for Galactosemia</p> <p>Jaguar Team: Brian Moy, and Dan Gallo</p>	<p>Nutrition Management for Galactosemia: From School Age Through Adulthood—Bones, Calcium, Vitamin D & Beyond</p> <p>Dr. Sandy Van Calcar</p>	<p>Mental Health for New Parents (Birth–5): A Group Conversation</p> <p>Facilitated by Dr. Al Freedman</p>