

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	A bird’s eye view of Galactosemia • Gerard T. Berry, M.D.
9:35 AM- 9:55 AM	Galactosemia Funded Research Overview • Kelley Foley
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 • Gillian Sapia RN
11:45 AM – 1:15 PM	Lunch On Your Own (hotel restaurant- Borealis & WongWayVeg 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 • Daniel Gallo, PhD
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, Treatment options, Adult Care, Diet, Patient Perspective) Not live streamed or recorded

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! • Location: Boardroom B & C
5:15PM- 5:30PM	Volunteer orientation • Location: Conference Room VII
5:30 PM - 6:30 PM	Galactosemia 101 • Location: Conference room VIII
6:00 PM - 8:00 PM	Age group registration & activity • Location: Conference Foyer I
6:00 PM - 8:00 PM	Thursday Night Ice Cream Social: • Location: Aurora Ballroom and Conference Foyer

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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
8:50 AM - 9:00 AM	Childcare dropoff	Conference Foyer I
7:00 AM - 7:00 PM	On-Site Research: Please participate!	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 • Albert Freedman, Ph.D.	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-1:00 PM	Galactosemia Foundation sponsored lunch	Aurora Ballroom
1:00 PM -1:15 PM	Travel to breakout sessions	
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	Pick up children from childcare	Conference Foyer I
5:00 PM - 8:30 PM	Designated meet-up space for families that want to connect	Conference Foyer I
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!	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 • Logan Greenberg	
9:30 AM - 9:50 AM	Rare Disease and Public Awareness • Caden Halberg	
9:50 AM- 10:05 AM	Outreach Activities & Newborn Program • Julia Friar	Aurora Ballroom
10:05 AM- 10:15 AM	Mentor Program • Nicole Casale	
10:15 AM - 10:30 AM	CK Kids Camp • Amy Morrow	
10:30 AM - 10:45 AM	Treasurer's Report & Fundraising • Jessica Taylor	
10:45 AM - -11:05 AM	Morning Bingo Connection Activity	
11:05 AM - 11:35 AM	Research Team- Give Updates • Kelley Foley	
11:35 AM - 12:00 PM	Natural History & Registry Data: Insights & Gaps • Gillian Sapia RN	
12:00 PM - 1:15 PM	Galactosemia Foundation sponsored lunch	
1:15 PM - 1:35 PM	Welcome Back- Next Steps	
1:35 PM - 1:55 PM	Speed Friending	
1:55 PM - 2:25 PM	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	Conference Foyer I
5:00 PM - 7:30 PM	Dinner on your own	
7:30 PM - 10:30PM	Saturday Night Social and Silent Disco Dance	Aurora Ballroom



Galactosemia
Foundation
Linked for Life

Thursday

Scientific Day

Social

AURORA I

AURORA II

AURORA BALLROOM

AURORA IV

Breakout
Tract 2

AURORA III

Breakout
Tract 1

Friday & Saturday

General Session

Breakfast & Lunch

Friday Talent Show

Saturday Silent Disco

Guttsy-Bio Table

Dr. Zhang ABA Table

Advocacy Table

Galactosemia
Podcast Table

AURORA FOYER

Visit Aurora Table

Jaguar Table

Registration Table

RESTROOMS

**Thursday
Social**

RESTROOMS

**BUSINESS
CENTER**

**STORAGE/
COAT ROOM**

**BOARDROOM
C**

**BOARDROOM
B**

**BOARDROOM
A**

GF War Room

Dr. Judy
Research/Study

Dr Summit
Research/Study

**CONFERENCE
FOYER II**

**CONFERENCE
ROOM
II**

G-Force
(12-18)

**CONFERENCE
ROOM
I**

Gen-G
(19-25)

**CONFERENCE
FOYER I**

**CONFERENCE
ROOM
VII**

Breakout
Tract 3

**CONFERENCE
ROOM
VIII**

Breakout
Tract 4

**CONFERENCE
ROOM
VI**

Childcare
(3-8)

**CONFERENCE
ROOM
V**

Mighty-G
(9-11)

O.G.G.
(Ages 26+)

**CAFE
LOUNGE**

No Whey
Cafe

**CONFERENCE
ROOM
IV**

Childcare
(0-2)

**CONFERENCE
ROOM
III**

Arcade
Room

WEST TERRACE

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Friday, July 17, 2026

	Room → Time ↓	Aurora III	Aurora IV	Conference RM VII	Conference RM VIII
1	11:00AM - 12:00PM	NIH: Ovarian tissue cryopreservation trial in classic galactosemia Dr. Veronica Gomez-Lobo (Presenting Virtually)	Growing Up with Galactosemia: What to Expect in the First 9 Years Gerard T. Berry, M.D. William Brucker, M.D. Alissia Gilmartin, M.D. Didem Demirbas, Ph.D.	Advocating for Your Child: Educational Planning IEP's and 504's Tracey Miller	Adults with Galactosemia: Connection, Conversation, and Support Facilitated by Dr. Al Freedman
2	1:15PM - 2:15PM	Reshaping the landscape of treatment in Classic Galactosemia Dr. Rubio Gozalbo	Effective Speech-language Therapy for Preschool through School Age Children Dr. David Jenson, Dr. Nancy Potter, & David Trainor, Jr.	Nutrition management for Galactosemia in Infants & Toddlers Dr. Sandy Van Calcar	Adults with Galactosemia: A New Treatment Approach Using tACS (Transcranial Alternating Current Stimulation) Dr. Bianca Panis
3	2:30PM - 3:30PM	Hormone Replacement Therapy (HRT) and Bone Health Dr. Judy Fridovich-Keil	Babble Boot Camp – Teaching Babies and Toddlers to Talk Dr. Nancy Potter and Dr. David Jenson	Behavior and Self-Management in School-Age Children Using Applied Behavior Analysis (ABA) Dr. Dorothy Zhang	Transitioning from School to Adulthood Gillian Sapia, R.N.
4	4:00PM -5:00PM	Neurological Outcomes in Classic Galactosemia Dr. Verma Sumit	Gene Therapy: An overview and what it could mean for Galactosemia Jaguar Team: Brian Moy & Blair Ornstein, PhD	Nutrition Management for Galactosemia: From School Age Through Adulthood—Bones, Calcium, Vitamin D & Beyond Dr. Sandy Van Calcar	Mental Health for New Parents (Birth–5): A Group Conversation Facilitated by Dr. Al Freedman

Friday, July 17, 2026

Tract ↓	Original Galactosemic Group (26 +) Suggested Breakout Schedule (Will not be able to attend all sessions, if going off-site)		
1		Conference RM VIII 11:00AM - 12:00PM Adults with Galactosemia: Connection, Conversation, and Support Facilitated by Dr. Al Freedman	
2	Aurora III 1:15PM - 2:15PM Reshaping the landscape of treatment in Classic Galactosemia Dr. Rubio Gozalbo	Conference RM VIII 1:15PM - 2:15PM Adults with Galactosemia: A New Treatment Approach Using tACS (Transcranial Alternating Current Stimulation) Dr. Bianca Panis	
3	Aurora III 2:30PM - 3:30PM Hormone Replacement Therapy (HRT) and Bone Health Dr. Judy Fridovich-Keil	Conference RM VIII 2:30PM - 3:30PM Transitioning from School to Adulthood Gillian Sapia, R.N.	Cafe Lounge 2:30PM - 3:30PM Adults w/ Galactosemia No Whey Café Nick Casale & Tracey Miller
4	Aurora III 4:00PM -5:00PM Neurological Outcomes in Classic Galactosemia Dr. Verma Sumit	Aurora IV 4:00PM -5:00PM Gene Therapy: An overview and what it could mean for Galactosemia Jaguar Team: Brian Moy & Blair Ornstein, PhD	Conference RM VII 4:00PM -5:00PM Nutrition Management for Galactosemia: From School Age Through Adulthood— Bones, Calcium, Vitamin D & Beyond Dr. Sandy Van Calcar