



**Galactosemia  
Foundation**  
*Linked for Life*



**NORD®**

***Externally-Led Patient Focused Drug Development Meeting for Galactosemia  
September 1, 2022***

- 11:00am      Opening Remarks  
*Peter Saltonstall, President & CEO, NORD*  
*Nicole Casale, President, Galactosemia Foundation*
- 11:10am      Clinical Overview of Galactosemia  
*Judith Fridovich-Keil, PhD, Professor, Department of Human Genetics, Emory University  
School of Medicine*
- 11:30 am      Welcome Remarks  
*Sheila Farrell, MD, Reviewer, Division of Rare Disease and Medical Genetics, FDA*
- 11:40am      Discussion Format and Meeting Overview  
*Debbie Drell, Director of Membership, NORD*  
*Scott Saylor, Board Member, Galactosemia Foundation*
- 11:45 am      Demographic Polling Questions
- 11:55 am      Topic 1: Living with Galactosemia—Burdens and Symptoms  
*DJ Trainor, Patient*  
*Gillian Sapia, Caregiver*  
*Elaine & Jerry Olson, Caregiver and Patient*  
*Cassidie Archuleta, Caregiver*  
*Natalie Whittington, Caregiver*  
*Maureen Bell, Patient*
- 12:25pm      Polling Questions and Facilitated Audience Discussion on Topic 1  
*Debbie Drell, Director of Membership, NORD*
- 1:25pm      Break
- 1:45pm      Topic 2: Current & Future Treatments  
  
*Amber Jones, Caregiver*  
*Tiffany Platt, Caregiver*  
*Heather Scharff, Caregiver*  
*Tara Tanella, Caregiver*

*Amy Morrow, Caregiver*

2:15pm Polling Questions and Facilitate Audience Discussion on Topic 2  
*Debbie Drell, Director of Membership, NORD*  
*Scott Saylor, Board Member, Galactosemia Foundation*

3:15pm Summary Remarks  
*Brittany Cudzilo, Vice President, Galactosemia Foundation*

3:25pm Wrap Up and Next Steps  
*Scott Saylor, Board Member, Galactosemia Foundation*

3:30pm Adjourn

\*Agenda subject to change