

# Gaucher Community Patient & Family Conference

## Schedule of Events

### Sunday, September 15

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|-----------------|--|
| 3:00 - 9:00 PM  | Registration Open  |
| 1:00 - 6:00 PM  | Patient and Family Video Production  |
| 6:00 - 9:00 PM  | Welcome Dinner and Program: Sara Stock Mayo of the Pittsburgh Playback Theater: Improvisational Storytelling |
| 9:00 - 10:00 PM | Teen Hangout and Pizza Party: Facilitated by Madelyn Schloss/Icebreakers by Sara Stock Mayo                  |

### Monday, September 16

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| 7:30 AM - 9:00 AM  | Breakfast   |
| 7:30 AM - 6:00 PM  | Registration Open   |
| 9:00 AM - 12:00 PM | Workshops for Patients and Families Only  |
| 11:50 AM - 1:15 PM | Buffet Lunch and Program  |
| 1:30 - 4:30 PM     | Workshops for Patients and Families Only  |
| 4:30 - 6:15 PM     | Sponsor Tables  |
| 6:15 - 6:45 PM     | Cocktail Hour - Cash Bar  |
| 6:45 PM - 9:00 PM  | Dinner Buffet and Program: Dr. G: Debi Gilboa – Transforming Stress to Resilience |

### Tuesday, September 17

|                     |   |
|---------------------|---|
| 7:30 AM - 9:00 AM   | Breakfast   |
| 7:30 AM - 12:00 PM  | Registration Open   |
| 7:30 - 8:30 AM      | Sponsor Tables  |
| 8:30 - 8:45 AM      | Welcome: Aviva Rosenberg & Cyndi Frank  |
| 8:45 - 9:00         | Stefanie Rubin: Meditation and Focusing Exercise  |
| 9:00 - 9:30 AM      | Dr. Damara Ortiz: Pittsburgh: Welcome and History of Lysosomal disorders at PGH                         |
| 9:35 - 10:05 AM     | Prevail: Gene Therapy Trials  |
| 10:05 - 10:30       | Sponsor Tables  |
| 10:30 - 11:00       | Takeda  |
| 11:05 AM - 11:50 PM | Dr. Natalia Gomez-Ospina: Stanford Research on Gene Editing   |
| 11:50 - 1:00 PM     | Lunch & Program & Raffle  |
| 12:15 - 12:30       | Lorna Chebon-Bore, PhD: G-CAN Initiative  |
| 12:30 - 12:45       | Aviva Rosenberg & Jim Romano: Governmental and Legislative Advocacy – How You Can Get Involved & Raffle |
| 12:45 - 1:00 PM     | Teens Sophie and Emily: Panel for Newborn Screening   |
| 1:00 - 2:30 PM      | Medical Panel: Dr. Ozlem Goker-Alpan, Dr. Pramod Mistry, Dr. Ellen Sidransky                            |

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|----------------|--|
| 2:35 - 3:20 PM | Dr. Deepa Rajan: Neuronopathic Gaucher disease |
| 3:20 - 4:30PM  | Sponsor Tables                                 |
| 5:00 PM        | Dinner at Wintergarden                         |