



## ONE RARE EXPERIENCE 2022: EMPOWERMENT

### DAY 1: WEDNESDAY, JULY 20, 2022

- 1 PM ET**      **One Rare Experience Kick-Off Event**  
*360° Virtual Escape Room by Raid the Room*  
Log onto the Raid the Room Zoom for an overview and then you will be randomly assigned to teams of 4 people (including mentors & speakers) and work with your team to escape the room as fast as possible!
- 
- 3 PM ET**      **One Rare Experience Resource Fair**  
*with Our Odyssey, YARR, Patients Rising Now, Rare By Design, The Sumaira Foundation, All Wheels Up, Rare Youth Revolution*  
You will hear short presentations from our collaborators and their programs; they have unique offerings for young adults living with rare conditions like you. Come learn about these awesome organizations!

### DAY 2: THURSDAY, JULY 21, 2022

- 1 PM ET**      **Self-Advocacy in the Workplace**  
*with Hannah Olson, CEO and Co-Founder, Disclo, Founder, Chronically Capable*
- 
- 2 PM ET**      **Transforming Obstacles into Opportunities**  
*with Sumaira Ahmed, Founder, The Sumaira Foundation*
- 
- 4 PM ET**      **Overcoming Challenges: Reducing Barriers**  
*with Austin Leclair, Co-founder, One Rare*
- 
- 5 PM ET**      **The Journey from Athlete, To Patient, To Advocate**  
*with Rob Long, Executive Director, Uplifting Athletes*
- 
- 7 PM ET**      **Chess Night – Come learn and play!**  
*with Yuva Gambhir*

### DAY 3: FRIDAY, JULY 22, 2022

- 1 PM ET**      **Resume Writing**  
*with Chelsea Wong, Rare Youth Revolution*
- 
- 2 PM ET**      **Legislative Advocacy**  
*with Amelia Williams, YARR*
- 
- 5 PM ET**      **Limitless Vision**  
*with Tucker Dupree, Decorated Paralympic Swimmer,*
- 
- 6 PM ET**      **Sugar Social with Seth Rotberg**  
*with Seth Rotberg, Patient Advocate, Connector and Motivational Speaker*  
Get a sweet treat on us through Sugarwish!
- 
- 8 PM ET**      **Comedy Night**  
*with Gabe Mollica*  
Gabe is back this year - get ready to LAUGH! Please note, this will have adult (and hilarious) content.

### DAY 4: SATURDAY, JULY 23, 2022

- 1 PM ET**      **Positivity is Key!**  
*with Kendra Gottsleben, Author, Founder and Executive Director, Rare by Design*
- 
- 2 PM ET**      **Discovering the Root Cause Biology of Every Rare Disease**  
*with Lynsey Chediak, Head of Impact, Rarebase*
- 
- 3 PM ET**      **Making |Air Travel More Accessible through Research and Advocacy**  
*with Alan Chaulet and Shannon Healey, All Wheels Up*
- 
- 5 PM ET**      **How Medical PTSD Taught Me Better Self-Advocacy**  
*with Emily Parks, Founder POP!, Medical PTSD Advocate, Patient Advocate, Unlicensed Speaker*
- 
- 6 PM ET**      **Workshop on Navigating Healthcare Systems**  
*with Emily Parks*  
**Trigger warning** – Listening to others talk about trauma can activate one’s own feelings or memories of past trauma. This session is intended to allow for sharing and provide education. If you find yourself feeling activated, you can step back from the discussion by choosing to mute or turn off your camera or sign off. The facilitators will provide tools for mental health support at the end of the session, or you can contact them via chat if you would like this information before signing off of the Zoom session.

---

7 PM ET

**Adventures of a Hemophiliac: Climbing the Seven Summits**

*with Chris Bombardier, Executive Director, Save One Life*

**DAY 4: SUNDAY, JULY 24, 2022**

1 PM ET

**Program Wrap Up - Rare Experience Trivia**

*with One Rare*

Join us to connect one last time for this year's program. We will have a few trivia questions with prizes for the winners!

---

---