

## ONE RARE EXPERIENCE AGENDA

### DAY 1: MONDAY, AUGUST 24, 2020

- 9 AM**                      **Welcome and Introductions with Attendees and One Rare Board**  
*Attendees will have the opportunity to meet one another and our Board of Directors. We will give you an idea of what to expect from the week ahead.*
- 11 AM**                      **Relationship Real Talk with Shane Burcaw and Hannah Aylward**  
*This presentation will focus on the true reality of being in an inter-abled relationship, including some highlights and lowlights from their own personal love story. Their intention is to identify and debunk the damaging misconceptions and stigmas that society holds about disability.*
- 3 PM**                        **Mindfulness with Marcelle Longlade**  
*Mindfulness is the psychological process of purposely bringing one's attention to experiences occurring in the present moment without judgment, which one develops through the practice of meditation and through other training.*
- 7 PM**                        **Our Odyssey Meet Up with Anna Laurent, Head of Programs and Initiatives**  
*Join this meet-up hosted by Our Odyssey – they connect young adults impacted by a rare or chronic condition with social and emotional support in the hope of improving their quality of life.*

### DAY 2: TUESDAY, AUGUST 25, 2020

- 9 AM**                        **A Book Reading with Taylor Kane**  
*Registrants will receive a copy of Taylor's memoir, Rare Like Us: From Losing My Dad to Finding Myself in a Family Plagued by Genetic Disease.*
- 11 AM**                      **Health Insurance 101 with Jennifer Shumsky from Little Hercules Foundation**  
*Learn from experts at Little Hercules to find resources available in your area to help with day to day living; this can include Medicaid Waivers, SSDI, Vocational Rehab, ABLE accounts, etc.*
- 1 PM**                        **Session: The Power of Self Advocacy: Navigating Healthcare as a Young Adult with Carla Lewis & Channell – Semira Javorsky**  
  
*At the end of this Session, the learner should be able to: 1. State the benefits of effective self-advocacy / patient advocacy. 2. Understand the effective skills while managing a chronic illness & navigating healthcare as a young adult. 3. Discuss resources available to strengthen self advocacy / patient advocacy efforts.*
- 3 PM**                        **Meditative Crafting with Deborah Vick**  
*Crafting can be a peaceful exercise - join Rare Zebra Deborah for and learn the Japanese craft of Kumihomo boards. You'll leave this session with a rare keychain!*
- 7 PM**                        **Online Gaming with Seth Rotberg, Founder of Our Odyssey**

DAY 3: WEDNESDAY, AUGUST 26, 2020

- 9 AM**                      **Personal Health Advocacy with Dakota Fisher-Vance**
- 11 AM**                      **Legislative Advocacy with YARR's Amy Hansen, Dan Pezzetta, Lindsey Cundiff and Swapna Kakani**  
*Topics include: Using your voice as a superpower. How Titanium Amy got the attention of Congresswoman Katie Porter through her super hero powers (Amy Hansen); Legislative advocacy from your dorm room. How to continue with your advocacy efforts while staying safe and sheltering in place. (Dan Pezzetta); Advocacy trivia with prizes! Put your advocacy know-how to the test. (Lindsey Cundiff & Swapna Kakani).*
- 1 PM**                        **Chat with Erin Smith from Backpack Health**  
*Backpack Health is a health tech company building tools to help people manage their health journey – including wellness, illnesses, injuries, and chronic health conditions. The Backpack Health mission is to make it easy for everyone to access, own and control their health information to support better health care and attain better health for themselves, their loved ones and their communities.*
- 3 PM**                        **#Rareis Workshop with Dakota**  
*Dakota comes back to lead registrants in a fun and interactive storytelling event. Bring your creativity! #RAREis™ began as a social media campaign launched by [Horizon Therapeutics](#) to elevate the voices, faces and experiences of the rare disease community. It has since grown into a program that provides individuals and families access to resources that connect, inform and educate as they navigate their daily lives. The hashtag (#) is a way to follow the conversation and remains in the name and logo to represent the broader program and community.*
- 7 PM**                        **Our Odyssey Meet Up with Anna Laurent and Seth Rotberg**  
*The Our Odyssey team is back to socialize and network!*

DAY 4: THURSDAY, AUGUST 27, 2020

- 9 AM**                        **Career Path with Lilly Stairs**  
*In a keynote style format, Lilly will bring her experience, strength and hope to participants, sharing her journey to building a career she only dreamed about years ago. She's worked at non-profits, start-ups and just recently launched her own company.*
- 11 AM**                      **Resume Workshop with Abby Brockman**  
*Translating your real-life experience into words on paper can be challenge. Abby will lead a session on writing resumes, and will share her pro tips on positioning yourself to be a lead candidate for any job.*
- 1 PM**                        **Proper Financial Planning for Exceptional People with Scott Gordon Macey**  
*Scott will teach us how to look at options for your future financial welfare without affecting government benefits.*

**3 PM**

**Patients Rising with Terry Wilcox**

*Patients Rising was launched to fight for access to vital therapies and services for patients with life-threatening diseases. This patient advocacy organization will educate, advocate and communicate the importance of access to essential treatments and diagnostics. We will be focused on ensuring that the patients' voice is heard, access to new therapies is paramount, and the pipeline of progress is not threatened.*

**7 PM**

**Movie Night with Lexi Pappas**

*Grab your favorite snack and join us for a documentary about challenges living with FSHD.*

**DAY 5: FRIDAY, AUGUST 28, 2020**

**9 AM**

**Yoga with Miranda McCarthy, Karen Russell and Paulo Concepcion**

*Start the morning right with a yoga session. Adaptive positions will be featured so all registrants can participate. @adaptiveyogalive*

**11 AM**

**Virtual Reality with Miranda McCarthy and Jazz Rasool**

*Miranda leads us into our next session --Ever wanted to try virtual reality? Grab your cardboard google glasses and explore a whole new world.*

**1 PM**

**Social Security 101 with Amy Aikens, Little Hercules Foundation**

*Learn from experts at Little Hercules to find resources available in your area to help with day to day living; this can include Medicaid Waivers, SSDI, Vocational Rehab, ABLÉ accounts, etc.*

**3 PM**

**Grace Trail® with Anne Jolles**

*Participants will gain an understanding of how to build resilience, access hope and strengthen their relationships/ community with Anne's 5 step method.*

**7 PM**

**Comedy Night with Gabe Mollica**

*Get ready to LAUGH.*