

RARE LIFE.  
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# 2022 RARE Patient Advocacy Summit Agenda

*\*agenda subject to change  
Times in PST*

## MONDAY, SEPTEMBER 12TH, 2022

2:00pm – 4:30pm PT

### **Corporate Alliance Meeting**

**Invite Only:** Join us for our annual in-person meeting! All Corporate Alliance members are welcome.

2:00pm – 4:30pm PT

### **Global Advocacy Alliance Meeting**

**Invite Only:** Join us for a networking event exclusively for Global Advocacy Alliance members. This event allows us all to come together in one place for interactive programming designed for organizations to engage, learn and build off one another. Collaborate with your peers in the RARE disease space in similar geographic locations, with similar years of experience as an organization, in specialties/topics of interests and similar areas of expertise. “

4:00pm – 5:30pm PT

### **Freshman Orientation**

5:30pm – 7:30pm PT

### **RARE Patient Advocacy Summit Opening Reception and Exhibits**

## TUESDAY, SEPTEMBER 13TH, 2022

8:00am – 7:00pm PT

### **Films from The Disorder Channel**

A selection of short films about the RARE disease patient experience from The Disorder Channel

8:15am – 9:00am PT

### **Breakfast & Industry Session**

Topic to be announced

9:00am – 9:15am PT

### **Opening Remarks**

9:15am – 10:15am PT

### **Keynote**

Topic to be announced

10:15am – 10:45am PT

### **Exhibit Hall & Break**

10:45am – 11:45am PT

**Keynote**

Topic to be announced

12:00pm – 12:45pm PT

**Lunch & Industry Session**

Topic to be announced

12:45pm – 1:45pm PT

**The RARE Siblings Experience**

Sometimes called glass children, the siblings of a person with a RARE disease have unique demands put on them. How can you best care for a sibling or be that sibling? How can they split their focus between having their own life apart from their sibling's needs? *TRACK – CAREGIVERS*

12:45pm – 1:45pm PT

**How to be a Podcast Guest**

A panel of five leading RARE disease podcasters will get you ready for prime time, help you have your story ready to go, and show you how to find interview opportunities and be a well prepared guest. *TRACK – SKILL BUILDING*

12:45pm – 1:45pm PT

**Mental Health for RARE Adults**

How can we normalize and increase access to mental health care for adults diagnosed with RARE disease?

*TRACK – RARE ADULTS*

1:45pm – 2:00pm PT

**Transition to Breakouts**

2:00pm – 3:00pm PT

**Guide to Palliative Care and Complex Care**

When RARE patients with complex medical issues need palliative care or complex care, a coordinator can make a huge difference. Learn the difference between the two and how to add one to your care team. *TRACK – CAREGIVERS*

2:00pm – 3:00pm PT

**Fundraising Do's and Don'ts**

Find out how to (and how not to) raise and spend funds for RARE research. *TRACK – SKILL BUILDING*

2:00pm – 3:00pm PT

**How to be Your Own Caregiver**

What if you're a RARE disease family of one? Adults with no family support face unique challenges.

*TRACK – RARE ADULTS*

3:00pm – 3:30pm PT

**Exhibit Hall & Break**

3:45pm – 4:45pm PT

### **Grandparents as Caregivers**

A look at the unique caregiving demands on grandparents of RARE children, including best practices, pitfalls to avoid, and communicating the hand off to parents. *TRACK – CAREGIVERS*

3:45pm – 4:45pm PT

### **Finding and Retaining Volunteers**

Sometimes getting the volunteer is the easy part, but keeping them can be trickier. Tips on how to engage your team of volunteers to keep them coming back. *TRACK – SKILL BUILDING*

3:45pm – 4:45pm PT

### **F\*\*\* This 2.0 - Sex When You're RARE**

Real talk from adults with RARE disease who (shock! horror!) like to have sex. Maybe it's different, but it's not less important. *TRACK – RARE ADULTS*

6:15pm – 7:00pm PT

### **RARE Champions of Hope Reception (pre-registration required)**

7:15pm – 10:00pm PT

### **RARE Champions of Hope Awards and Dinner (pre-registration required)**

## **WEDNESDAY, SEPTEMBER 14TH, 2022**

8:00am – 7:00pm PT

### **Films from The Disorder Channel**

A selection of short films about the RARE disease patient experience from The Disorder Channel

8:30am – 9:00am PT

### **Breakfast & Industry Session**

Topic to be announced

9:30am – 9:45am PT

### **Opening & Day 1 Recap**

9:45am – 10:00am PT

### **EveryLife Foundation - Call to Advocacy**

9:45am – 10:45am PT

### **Preventing Caregiver Burnout**

How we can avoid the burnout and depression that may come from caregiving. *TRACK – CAREGIVERS*

9:45am – 10:45am PT

### **Fundraising - Where to Place Your Bet**

If you can only fund one thing, what is the thing? Gene Replacement? ASO? Basic science? *TRACK – SKILL BUILDING*

9:45am – 10:45am PT

### **Stress on Partnerships/Marriage**

Whether a couple includes one partner who is RARE, or a couple is raising a RARE child, medical challenges are an added stressor on the relationship. How can you best manage that stress and keep a relationship healthy?

*TRACK – RARE ADULTS*

10:45am – 11:00am PT

**Transition to Breakouts**

11:00am – 12:00pm PT

**Grieving as a Community**

When someone in your same disease community passes on, how do you lead support for that family and for all your members? *TRACK – CAREGIVERS*

11:00am – 12:00pm PT

**Data Tech for RARE Care**

PHI apps and tools--end users speak on what data you should want to collect and the importance of data.

*TRACK – SKILL BUILDING*

11:00am – 12:00pm PT

**Parenting While RARE**

How do adults with a RARE disease balance their own care needs with the typical burdens of parenting? Do children feel like caregivers? *TRACK – RARE ADULTS*

11:00am – 12:00pm PT

**The EMS Guide to RARE**

Doctors and EMTs aren't used to you knowing more about a medical situation than they do. How to get your key points across quickly and kindly so you get the best care when dealing with a new provider. *TRACK – SKILL BUILDING*

12:00pm – 12:30pm PT

**Exhibit Hall & Networking**

12:30pm – 1:15pm PT

**Lunch & Industry Session**

Topic to be announced

1:30pm – 2:10pm PT

**Undiagnosed? Misdiagnosed? Finding Answers with Genetic Counselors**

How and when do you seek a genetic test, what to do if the result is inconclusive, when to retest, and can a genetic counselor advocate for you? Secondary findings.

2:10pm – 2:50pm PT

**Lighting a Fire in RARE**

We all want more awareness and some people seem to have a knack for being seen and heard. What can we learn from them and apply to our own awareness efforts, including increasing social media success.

2:50pm – 3:30pm PT

**Keynote - James Gergherty**

3:30pm – 4:00pm PT

**Closing Remarks**

6:00pm – 8:00pm PT

**RARE Patient Advocacy Summit Closing Reception**

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