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.
Location: TOWN & COUNTRY BALLROOM C

2:00pm – 4:30pm PT | Global Advocacy Alliance Meeting
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 on a number of different areas of expertise and topics of interest. Not sure if you're a current GAA member? Please email us at gaa@rareproject.org
Location: TOWN & COUNTRY BALLROOM B

4:00pm – 5:30pm PT | Freshman Orientation
Location: TOWN & COUNTRY BALLROOM D

5:30pm – 7:30pm PT | RARE Patient Advocacy Summit Opening Reception and Exhibits
Location: GOLDEN STATE BALLROOM

8:30pm – 10:30pm PT | “After Hours” Networking, Music, and Karaoke
Location: GOLDEN STATE BALLROOM

TUESDAY, SEPTEMBER 13TH, 2022

6:00am – 7:00am PT | Sunrise Yoga with Katie Stevens
Location: FLAMINGO LAWN

8:15am – 9:00am PT | Breakfast & Industry Session sponsored by UCB
Moments That Matter for Individuals with Rare Disease
Location: TOWN & COUNTRY BALLROOM A

9:00am – 9:15am PT | Opening Remarks
• Daniel DeFabio, Director, Community Engagement, Global Genes
• Effie Parks, Community Engagement Coordinator, Global Genes
• Craig Martin, CEO, Global Genes
Location: TOWN & COUNTRY BALLROOM BCD

*agenda subject to change
Times in PST
9:15am – 10:15am PT | **Keynote: Boats on the Water: Navigating Life with a Terminally Ill Child**  
**Speaker:** Emily Black-Rapp, Bestselling Author, Professor of Creative Writing, University of California-Riverside  
**Location:** TOWN & COUNTRY BALLROOM BCD

10:15am – 10:45am PT | **Exhibit Hall & Break**  
**Location:** GOLDEN STATE BALLROOM

10:45am – 11:45am PT | **Keynote**  
**Speaker:** Gail Devers, Olympic Gold Medalist  
**Location:** TOWN & COUNTRY BALLROOM BCD

12:00pm – 12:45pm PT | **Lunch & Industry Session sponsored by PTC Therapeutics**  
**Industry’s Commitment to Patient Education and Community Resources**  
**Speaker:** Paula Orandash, Patient Engagement Liaison, Community Education  
**Location:** TOWN & COUNTRY BALLROOM A/FLAMINGO LAWN

12:45pm – 1:45pm PT – **CAREGIVERS TRACK | 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?  
**Moderator:** Emily Holl, Director, Sibling Support Project  
**Panelists:**  
• Rian Edwards, RARE Sibling  
• Aprill Lane, US Advocacy Lead, Rare Disease, UCB  
• Abby Turnwald, Genetic Counseling Student  
**Location:** TOWN & COUNTRY BALLROOM B

12:45pm – 1:45pm PT – **SKILL BUILDING TRACK | 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.  
**Moderator:** Effie Parks, Community Engagement Coordinator, Global Genes  
**Panelists:**  
• Sanath Kumar Ramesh, Founder and CEO, OpenTreatments Foundation  
• Nikki McIntosh, Founder and Creator, RARE Mamas; Host, Rare Mamas Rising Podcast  
• Gerald Nebeker, PhD, President, Orange Socks  
• Jessica Patay, RARE Mom, Host of ‘We Are Brave Together’ Podcast  
• Kara Ryska, Host and Creator, ‘The Special Needs Mom’ Podcast  
**Location:** TOWN & COUNTRY BALLROOM C

12:45pm – 1:45pm PT – **RARE ADULTS TRACK | Mental Health for RARE Adults**  
How can we normalize and increase access to mental health care for adults diagnosed with RARE disease?  
**Moderator:** David Rintell, Vice President, Head of Patient Advocacy, BridgeBio  
**Panelists:**  
• Wendy Erler, Vice President, Patient Experience and Patient Advocacy, Alexion AstraZeneca Rare Disease  
• Dakota Fisher-Vance, Global Patient Advocacy Senior Manager, BioCryst Pharmaceuticals, Inc.  
• Al Freedman, PhD, Psychologist, Freedman Counseling Associates  
• Adam Johnson, Host of ‘Parents as RARE’ Podcast  
**Location:** TOWN & COUNTRY BALLROOM D

1:45pm – 2:00pm PT  
**Transition to Breakouts**
### CAREGIVERS TRACK | 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.

**Moderator:** Parvathy Krishnan, Director, Foundation Alliance, Global Genes

**Panelists:**
- Lily Gillmor, Associate Vice President of Palliative Care, Transitions LifeCare
- Liz Morris, Caregiver Advocate
- Jennifer Seidman, President, Ben's Dream: Sanfilippo Foundation; Director of Community Engagement, Courageous Parents Network

**Location:** TOWN & COUNTRY BALLROOM B

### Skill Building Track | Fundraising Do’s and Don’ts

Find out how to (and how not to) raise and spend funds for RARE research.

**Moderator:** Sarita Edwards, CEO and President, The E. We Foundation

**Panelists:**
- Kristina Bowyer, Vice President, Patient Centric Drug Development, Ionis Pharmaceuticals, Inc.
- Gina Hann, RARE Mom, Co-Founder, Rare Village

**Location:** TOWN & COUNTRY BALLROOM C

### RARE Adults Track | How to be Your Own Caregiver

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

**Moderator:** Mary Morlino, RARE Concierge Patient Services Manager, Global Genes

**Panelists:**
- Mackenzie Abramson, Operations Associate Manager, AllStripes
- Danae Bartke, Executive Director, HCU Network America
- Dakota Fisher-Vance, Global Patient Advocacy Senior Manager, BioCryst Pharmaceuticals, Inc.

**Location:** TOWN & COUNTRY BALLROOM D

### Exhibit Hall & Break

**Location:** GOLDEN STATE BALLROOM

### CAREGIVERS TRACK | 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.

**Panelists:**
- Mariana Parks, Grandparent Caregiver
- Darlene Shelton, President and Founder, Danny's Dose Alliance

**Location:** TOWN & COUNTRY BALLROOM B

### Skill Building Track | Finding and Retaining Volunteers

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

**Moderator:** Taylor Kane, Community Engagement Manager, AllStripes; Founder, Remember The Girls

**Panelists:**
- Tuesdi Dyer, CFRE, Executive Director, CFC International
- Maryann Wahmann, Co-Founder and Executive Director, Neuroendocrine Cancer Awareness Network

**Location:** TOWN & COUNTRY BALLROOM B

*agenda subject to change*
3:45pm – 4:45pm PT – RARE ADULTS TRACK | 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.
Moderator: Brianna Cardenas, Physician Assistant, Advocate, Owner, Healed and Empowered
Panelists:
  • Mackenzie Abramson, Operations Associate Manager, AllStripes
  • Maisy Cyr, Reproductive Empowerment Project Coordinator, Maine Family Planning
Location: TOWN & COUNTRY BALLROOM D

6:30pm – 7:15pm PT | RARE Champions of Hope Reception (pre-registration required)
Location: FLAMINGO LAWN

7:15pm – 10:00pm PT | RARE Champions of Hope Awards and Dinner (pre-registration required)
Location: TOWN & COUNTRY BALLROOM A

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 – 9:30am PT | Breakfast & Industry Session sponsored by Jazz Pharmaceuticals
Topic to be announced
Location: TOWN & COUNTRY BALLROOM A/FLAMINGO LAWN

9:30am – 10:30am PT | Starting Your Legislative Advocacy Journey at Your State House, Washington DC, or Your Kitchen Table
Moderator: Katelyn Laws, RDLA Program Manager, EveryLife Foundation for Rare Diseases
Panelists:
  • Angela Ramirez Holmes, President, CAL Rare
  • Laura Romano (They/Them), Young Adult Representative, RDLA
  • Ali SP, Patient Advocate
Location: TOWN & COUNTRY BALLROOM A

9:30am – 10:30am PT – CAREGIVERS TRACK | Preventing Caregiver Burnout
How we can avoid the burnout and depression that may come from caregiving.
Moderator: Parvathy Krishnan, Director Foundation Alliance, Global Genes
Panelists:
  • Julie Burns, DNP, APRN-CNP, Senior Manager, Patient Advocacy Relations, Genentech
  • Stephanie Duffy, Global Director, Patient Advocacy and Engagement, Johnson & Johnson
  • Jessica Patay, RARE Mom, Host of ‘We Are Brave Together’ Podcast
Location: TOWN & COUNTRY BALLROOM B

9:30am – 10:30am PT – SKILL BUILDING TRACK | Fundraising - Where to Place Your Bet
If you can only fund one thing, what is the thing? Gene Replacement? ASO? Basic science?
Moderator: Mike Graglia, Rare Disease Dad, Advocate, Founder and CEO, Syngap Research Fund
Panelists:
  • Kristin Gray, Founder, Charlotte and Gwenyth Gray Foundation
  • David Dimmock, Chief Medical Officer, Creyon Bio
  • Ethan Perlstein, Founder and CEO, Perlara PBC
Location: TOWN & COUNTRY BALLROOM C

*agenda subject to change
9:30am – 10:30am PT – RARE ADULTS TRACK | 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?
Moderator: Mary Morlino, RARE Concierge Patient Services Manager, Global Genes
Panelists:
- Tom D’Amato, Director of Patient Advocacy, Horizon Therapeutics
- Casey McPherson, Founder and President, To Cure a Rose Foundation
- Felicia Morton, RARE Mom, Executive Director, CGD Association of America
Location: TOWN & COUNTRY BALLROOM D

10:30am – 11:00am PT | Transition to Breakouts & Exhibit Hall
Location: GOLDEN STATE BALLROOM

11:00am – 12:00pm PT – CAREGIVERS TRACK | 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?
Moderator: Megan Fox, CCLS, Program Director, Me Fine Foundation
Panelists:
- Becky Benson, Family Services Manager, Certified Peer Support Specialist, NTSAD, Child Neurology Foundation
- Jessica Fein, Board Member, Mitoaction; Rare Disease Writer and Advocate
- Julia Vitarello, Founder and CEO, Mila’s Miracle Foundation
Location: TOWN & COUNTRY BALLROOM B

11:00am – 12:00pm PT – SKILL BUILDING TRACK | 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.
Moderator: Ryan Sheedy, Rare Disease Caregiver and Founder, Mejo
Panelists:
- Kristy Dickinson, Founder and Managing Director, Chronically Simple
- Katheron Intson, CEO, Varient, University of Toronto
Location: TOWN & COUNTRY BALLROOM C

11:00am – 12:00pm PT – RARE ADULTS TRACK | 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?
Moderator: Adam Johnson, Host of ‘Parents as RARE’ Podcast
Panelists:
- Mary Morlino, RARE Concierge Patient Services Manager, Global Genes
- Robin Powers, President and Co-Founder, RareABILITY
- Deborah Vick, Ms. Wheelchair California, CEO, VICKtorious
Location: TOWN & COUNTRY BALLROOM D

11:00am – 12:00pm PT | The Emergency 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.
Moderator: Darlene Shelton, President and Founder, Danny’s Dose Alliance
Panelists:
- Jessica Duis, MD, Associate Professor of Pediatrics and Genetics, Children’s Hospital Colorado
- Brian Froelke, MD, FAEMS, Assistant Professor, Washington University School of Medicine, Division of Emergency Medicine
Location: TOWN & COUNTRY BALLROOM A

*agenda subject to change*
12:00pm – 12:30pm PT | **Exhibit Hall & Networking**
Location: GOLDEN STATE BALLROOM

12:30pm – 1:15pm PT | **Lunch & Industry Session sponsored by Ovid Therapeutics**
Topic to be announced
Location: TOWN & COUNTRY BALLROOM A/FLAMINGO LAWN

1:15pm – 1:45pm PT | **Keynote: The Past and Future of Patient-Centered Rare Disease Innovation**
Speaker: Jim Geraghty, Chairman, BVGH Guests
Location: TOWN & COUNTRY BALLROOM BCD

1:45pm – 2:45pm PT | **Undiagnosed? Misdiagnosed? Issues Related to Obtaining a Genetic Diagnosis**
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.
Moderator: Maria Della Rocca, Senior Director, Patient Services, Global Genes
Panelists:
- Shruti Mitkus, PhD, Director, Genetic Education and Navigation, Global Genes
- Mickey Sumner, RARE Mom, Actress
- Gina Szajnuk, Co-Founder and Executive Director, Rare and Undiagnosed Network
Location: TOWN & COUNTRY BALLROOM BCD

2:45pm – 3:30pm 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.
Moderator: Effie Parks, Community Engagement Coordinator, Global Genes
Panelists:
- Khrystal Davis, RARE Mom; Founder, Texas Rare Alliance
- Jill Hawkins, Founder and President, FAM177A1 Research Fund
- Neena Nizar, Rare Disease Advocate, Executive Director, The Jansen's Foundation
- Durhane Wong-Rieger, President, Canadian Organization for Rare Disorders
Location: TOWN & COUNTRY BALLROOM BCD

3:30pm – 4:00pm PT | **Closing Remarks**
- Daniel DeFabio, Director Community Engagement, Global Genes
- Effie Parks, Community Engagement Coordinator, Global Genes
- Parvathy Krishnan, Director Foundation Alliance, Global Genes
- Taylor Kane, Community Engagement Manager, AllStripes; Founder, Remember The Girls
- Craig Martin, CEO, Global Genes
Location: TOWN & COUNTRY BALLROOM BCD

6:00pm – 8:00pm PT | **RARE Patient Advocacy Summit Evening Reception**
Location: FLAMINGO LAWN
TUESDAY, SEPTEMBER 13TH, 2022

9:00am – 4:00pm PT | **Film Screenings from The Disorder Channel and Global Genes RAREly Told Stories**
Watch short films from The Disorder Channel and Global Genes RAREly Told Stories, or participate in Q&As with the filmmakers. The films and filmmakers will be available both days during these times:

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Location: PALM BALLROOM 5 & 6

9:00am – 12:00pm PT | **Share YOUR Story - Walk-ins Welcome!**
Got a few minutes to tell your story? The Global Genes team will be on site to record video that can be shared on Global Genes’ social media, and that you can use for your own needs.
Location: PALM BALLROOM 4

1:00pm – 2:00pm PT | **Storytelling Through Instagram**
A picture (or video!) is worth a thousand words. Learn why Instagram is an ideal platform to tell your story, and how to get the most out of this channel by better using hashtags and other IG features from some of Instagram’s finest in rare disease!

**Panelists:**
- Soniya Vahder-Patel, RARE Patient, @soniyafit
- Tameka Diaz, RARE Caregiver, @thediazgirls

Location: PALM BALLROOM 3
9:30am – 4:30pm PT | **Podcast Recording Sessions**

Your favorite rare disease podcasters are recording live from the RARE Patient Advocacy Summit! Do you want to share your story on their podcast? Submit a story pitch directly to one of these rock stars and they could reach out to interview you here on site or after the Patient Advocacy Summit. E-mail effiep@globalgenes.org and specify which podcast you are interested in.

*Note: This is not a walk-in opportunity*

**Location:** PALM BALLROOM 1

9:30am – 11:30am: Kevin Freiert & Sanath Kumar Ramesh, Raising Rare podcast
2:30pm – 4:30pm: Kara Ryska, The Special Needs Mom podcast

**Location:** PALM BALLROOM 2

9:00am – 11:00am: David Rintell, On Rare Podcast
11:00am – 12:30pm: Effie Parks, Once Upon A Gene Podcast
2:30pm – 4:30pm: Adam Johnson, Owning My Story Blog

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**WEDNESDAY, SEPTEMBER 14TH, 2022**

9:00am – 4:00pm PT | **Film Screenings from The Disorder Channel and Global Genes RAREly Told Stories**

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*Location: PALM BALLROOM 5 & 6*

10:00am – 12:00pm PT | **How to Make A RAREly Told Story**

One of the most impactful ways to tell your story is through video and film-making. Join an expert filmmaker, as she talks about the ins and outs of what to shoot, how to edit, and creating the story to tell.

**Panelist:** Kimberly Warner, Unfixed Media

*Location: PALM BALLROOM 3*

1:00pm – 2:30pm PT | **Writing Rare: How and Why to Put Your Story on the Page**

Telling your story through the written word can be healing, while also educating your audience. Learn from two expert storytellers in the rare community, as they explain how words become a story that you can share with the world.

**Panelists:**
- Jessica Fein, Writer; Board Member, Mitoaction
- Liz Morris, Parent & Caregiver Collaborator, Courageous Parents Network

*Location: PALM BALLROOM 3*
9:00am – 4:00pm PT | **Podcast Recording Sessions**
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**Location: PALM BALLROOM 1**
9:00am – 11:00am: Gerald Nedeker, Orange Socks Podcast
11:30am – 1:30 pm: Nikki McIntosh, Rare Mamas Podcast & Blog
2:00pm – 4:00pm: Kevin Freiert & Sanath Kumar Ramesh, Rising Rare Podcast

**Location: PALM BALLROOM 2**
9:00am – 11:00am: Effie Parks, Once Upon A Gene Podcast
11:30am – 1:30 pm: Kara Ryska, The Special Needs Mom Podcast
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