

SUNDAY, SEPTEMBER 26TH, 2021

2:00am – 4:00am PT | 5:00am – 7:00am ET

Australasia Regional Meeting

Join patients, physicians, and advocacy leaders from Australia, New Zealand, Malaysia, Singapore, and Thailand to hear patient stories and perspectives and gain understanding about the regional rare disease landscape. The meeting will feature patient and advocate stories for the first hour and will then move into a panel discussion with organizational leaders and experts. Key topics of discussion include clinical trial access, new therapeutic development in the region, diagnosis, gaps in healthcare, caregiver support, and more.

Patient & Advocate Perspectives:

- Ekawat Suwantaraj, Patient, Vice President, Thai Hemophilia Patient Club; Committee Member, National Hemophilia Foundation of Thailand | Thailand
- Sherena Loh, Co-Founder and Director, Muscular Dystrophy Association of Singapore | Singapore
- Sha Roose, Patient Advocate for Spinal Muscular Atrophy, Persatuan WeCareJourney | Malaysia
- Lisa Foster, Chief Executive, Rare Disorders NZ | New Zealand
- Samantha Lenik, Vice President, New Zealand Pompe Network | New Zealand
- Ursula Delaney, Committee Member, SCN2A Australia | Australia
- Heather Renton, CEO, Syndromes Without a Name (SWAN) Australia | Australia
- Elizabeth (Emma) Palmer PhD, Clinical Geneticist, Sydney Children's Hospitals Network (SCHN); Lecturer, University of New South Wales | Australia

Regional Panel Discussion:

Moderator:

Nadiah Hanim Abdul Latif, Representative (Southeast Asia, Qatar, Oman, S. Korea), Phelan-McDermid Syndrome Foundation | Malaysia

Panelists:

- Ch'ng Gaik Siew MD, MRCPCH, Clinical Geneticist, Pediatrician and Head, Department of Genetics, Penang Hospital, Ministry of Health Hospital | Malaysia
- Edmund Lim, Founder, We Care Journey | Malaysia
- Elizabeth (Emma) Palmer PhD, Clinical Geneticist, Sydney Children's Hospitals Network (SCHN); Lecturer, University of New South Wales | Australia
- Kris Pierce, RN, MHSc, MWellness, Co-Founder, Genetic Epilepsy Team Australia; Founder, SCN2A Australia | Australia
- James O'Brien, President, Prader-Willi Syndrome Australia; Founding Director, PWS Better Living Foundation (Housing); Director, International Prader-Willi Syndrome Organisation | Australia

5:00am – 7:00am PT | 8:00am – 10:00am ET

South Asia Regional Meeting

Join patients, physicians, and advocacy leaders from Pakistan, India, China, Bhutan, Bangladesh, and Sri Lanka to hear patient stories and perspectives and gain understanding about the regional rare disease landscape. The meeting will feature patient and advocate stories for the first hour and will then move into a panel discussion with organizational leaders and experts. Key topics of discussion include regional advocacy, disease awareness campaigns, educating key governmental and nongovernmental stakeholders, and access to diagnosis, care, and disease management.

Patient & Advocate Perspectives:

- Ugyen, Parent, Advocate & Speaker, Spinal Muscular Atrophy (SMA) | Bhutan
- Yiou Wang, Patient, Founder and Secretary-General, Illness Challenge Foundation (ICF); Founder, China-Dolls Center for Rare Disorders (CCRD) | China
- Pelyang Dechen, Rare Sibling & Medical Student, Spinal Muscular Atrophy (SMA) | Sri Lanka
- Dr. Shahla Sohail, Physician & Advocate, Lahore Hemophilia Patients Welfare Society | Pakistan
- Saida Hasaan, Parent & Advocate, Progressive Familial Intrahepatic Cholestasis (PFIC) | Pakistan
- Anil Kumar Choubey, Rare Dad & Founder Trustee, Indian Prader-Willi Syndrome Association (IPWSA) | India
- Archana Panda, Co-Founder & Director-In-Charge, Patient Advocacy, Policy and Government & Regulatory Affairs, North India, SMA Foundation of India | India
- Suyog Sathe, Director and Regional Manager (South Asia), International Gaucher Alliance (IGA) - UK, Maharashtra State Coordinator, Lysosomal Storage Disorders Support Society (LSDSS), India | India

Moderator: TBA

Regional Panel Discussion:

- Helen Shuang Zhou, Program Manager of Informational Research & Global Collaboration, Illness Challenge Foundation (ICF) | China
- Atif Qureshi, Founding Member & President, Lysosomal Storage Disorders Society | Pakistan
- Tanya Collin-Histed, Chief Executive Officer, International Gaucher Alliance (IGA) | United Kingdom
- Sheffali Gulati MD, FIAP, FIMSA, Professor, Coordinator, DM Pediatric Neurology Programme; Faculty In-charge, Centre of Excellence and Advanced Research for Childhood Neurodevelopmental Disorders; Chief, Child Neurology Division; Department of Pediatrics, All India Institute of Medical Sciences | India
- Prasanna Shirol, Co-Founder and Executive Director, ORDI - Organization for Rare Diseases India | India

1:00pm – 2:00pm PT | 4:00pm – 5:00pm ET

Patient Advocacy Summit Freshman Orientation

New to Summit or attending your first virtual event? Join the Global Genes team to build meaningful bonds with others who share your interest and learn from seasoned leaders how to get the most benefit from this year's Summit.

- Get connected with your peers and meet experienced advocates and leaders in the rare community
- Learn the best ways to make the most of a virtual conference/GG Summit
- Hear tips and tricks on networking and making new connections

Moderator(s):

- Rodney C. Samaco, Ph.D., Assistant Professor & Investigator, Dept of Molecular and Human Genetics | Baylor College of Medicine
- Global Genes Team

Alumni Panelists:

- Jeff D'Angelo, President, Founder & Research Committee Chair, CHAMP1 Research Foundation

4:00pm – 6:00pm PT | 7:00pm – 9:00pm ET

RARE Together, Watch Together – Selections from The Disorder Channel

RARE Together, Watch Together is a sampling of nine short documentaries on the rare patient experience. From very young children to adults and even a woman who wasn't diagnosed rare until age 64. These films show the courage and hope our community summons in the face of tough struggles. Films range from 3 to 18 minutes. A panel discussion will follow.

Moderator: Daniel DeFabio, Co-Founder, Disorder: The Rare Disease Film Festival

Panelists:

- Casey McPherson, Founder, To Cure a Rose Foundation
- Kimberly Warner, Founder, Unfixed Media
- Rhonda Rowland, Patient & Board Member, Wilson's Disease Association
- Trish Flanagan, President & Board Director, Yellow Brick Road Project (YBRP)

TUESDAY, SEPTEMBER 28TH, 2021

2:00am – 4:00am PT | 5:00am – 7:00am ET

Africa Regional Meeting

Join patients, physicians, and advocacy leaders from across Africa to hear patient stories and perspectives and gain understanding about the regional rare disease landscape. The meeting will feature patient and advocate stories for the first hour and will then move into a panel discussion with organizational leaders and experts. Key topics of discussion include formally defining rare diseases, gaining awareness with health ministries and other key governmental and nongovernmental stakeholders, challenges in diagnosis and access to diagnosis, and developing educational campaigns.

Regional Panel Discussion:

Moderator: Lara Bloom, President and CEO, Ehlers-Danlos Society

Patient & Advocate Perspectives:

- Kelly du Plessis, CEO & Founder, Rare Diseases South Africa | South Africa
- Christine Mutena, Co-Founder, Rare Disease Kenya; International Ambassador - Africa, Chromosome 18 Registry & Research Society | Kenya
- Samuel Agyei Wiafe, Clinical Psychologist, Founder/Executive Director, Rare Disease Ghana Initiative | Ghana

7:00am – 7:30am PT | 10:00am – 10:30am ET

Connecting Communities Around Symptoms That Impact Quality of Life

Presented by Harmony Biosciences

Moderator: Tim Turnham, Vice President, Client Services, VOZ Advisors

Panelists:

- Terry Jo Bichell PhD MPH, Executive Director, CombinedBrain
- Claire Crisp, Executive Director, Wake Up Narcolepsy
- Maria Picone, Co-Founder and Chief Executive Officer, TREND Community
- Rachel Radomski, Senior Director, Patient Advocacy, Harmony Biosciences

7:35am PT – 8:05am PT | 10:35am ET – 11:05am ET

ELEVATE: Taking Patient Engagement in Clinical Trials to a New Level

Presented by PTC Therapeutics

Moderator: Anne Bruns, Director, Clinical Patient Advocacy, PTC Therapeutics

8:05am – 8:10am PT | 11:05am – 11:10am ET

Break

8:10am PT – 8:20am PT | 11:10am – 11:20am ET

Welcome & Opening Remarks

▶ KEYNOTE ADDRESS

8:20am – 9:10am PT | 11:20am – 12:10pm ET

On the Cusp of Cures — Potential, Pragmatism, and Progress in Genomic Science

From the lab to the front line, learn about how gene-based diagnostics, therapies, and platforms like gene editing are providing hope for faster progress towards cures. Fyodor Urnov, PhD, a pioneering leader of CRISPR, will share his perspectives on the advances of gene-based therapies and the obstacles to making gene-based technologies more widely available and accessible. He will also discuss issues such as ethics, safety, affordability, and what the emergence of gene-based therapies truly means for patients and families.

Moderator: Charlotte Hobbs, MD, Vice President, Research and Clinical Management, Rady Children's Institute for Genomic Medicine

Keynote Presenter:

- Fyodor Urnov, PhD, Scientific Director, Innovative Genomics Institute

9:10am – 9:15am PT | 12:10pm – 12:15pm ET

Break

9:15am – 9:50am PT | 12:15pm – 12:50pm ET

Genomic Medicine – Navigating Between the Head and the Heart

Almost every day, new information, discoveries, and discussions are emerging in the field of genomic medicine. As discoveries in gene-based diagnostics and therapies have accelerated, understanding and trust between researchers, clinicians, patients, families, and advocates have never been more critical. Dr. Charles Steward will share his perspective as a rare dad and an advocate who also has a deep background in genetic research, including leading the initial gene analysis for human chromosome 10.

Speaker: Charles Steward PhD, Rare Dad and Patient Advocacy & Engagement Lead, Congenica

9:50am – 9:55am PT | 12:50pm – 12:55pm ET

Break

9:55am – 10:30am PT | 12:55pm – 1:30pm ET

Beyond the “Impossible Thing” – Breaking Barriers and Redefining Strength

What does it mean to challenge your own limitations and ask, “What thing can you do today that seemed impossible only yesterday?” While a rare disease diagnosis can sideline your life, join us to hear one patient's experience in redefining her own self-limitations, pushing past fear, and finding reinvigorated hope in challenging times.

Moderator: Brett Brackett, Co-Founder, Uplifting Athletes

Speakers:

- Marni Cartelli, Founder, Press4Hope
- Hunter Stark, PT, DPT, CSCS, Stark Performance PT

10:30am – 10:35am PT | 1:30pm – 1:35pm ET

Break

10:35am – 11:15am PT | 1:35pm – 2:15pm ET

From Awareness to Participation - Bridging Gaps in Representation in Research

Challenges in health equity are present throughout the rare disease journey. Accelerating scientific advances requires a collective approach. Extending from the diagnostic odyssey to participation in and access to clinical research and new therapies, to finding a cure, there is a large divide between where we are currently and where we want to be.

In this session, explore opportunities to improve awareness and education efforts within the rare communities and open ourselves to connecting with more families, especially those who are still not counted, not seen, and, even if aware, not participating.

Moderator: Barbara Goodman, President & CEO, Cures Within Reach

Speakers:

- Donna Cryer, President & CEO, Global Liver Institute
- Shonta Chambers MSW, Executive Vice President-Health Equity Initiatives and Community Engagement, Patient Advocacy Foundation
- Trishna Bharadia MFPM, Ambassador, MS Society UK, ADD International & Lyfebulb

11:15am – 11:30am PT | 2:15pm – 2:30pm ET

Break

11:30am – 1:10pm PT | 2:30pm – 4:10pm ET

Educational Sessions

Choose Between (2) Educational Sessions or (1) Extended Skills Lab

SESSION I

11:30am – 12:15pm PT | 2:30pm – 3:15pm ET

RARE LIFE & PATIENT SUPPORT

Redefining Resiliency – Building a Coping Toolbox as a Parent or Caregiver

The moment of receiving a diagnosis to becoming a medical expert can be overwhelming and exhausting for rare disease patients and caregivers. Coping strategies, community networks for support, and self-care are not often prioritized or available. Through their stories, rare parents will share their advice and perspectives on building a self-care toolbox and finding balance as a caregiver

- Building a plan forward and evaluating next steps for you and your family after diagnosis
- Determining your path as a parent, caregiver, and advocate
- Managing expectations, finding hope, and building support networks for the rare disease rollercoaster

Speakers:

- Albert Freedman, Ph.D., Rare Dad & Practice Founder, Freedman Counseling Associates
- Nikki McIntosh, Creator & Founder, Rare Mamas

SESSION I

11:30am – 12:15pm PT | 2:30pm – 3:15pm ET

TACTICS & CAPACITY BUILDING

Foundations of Organizational Planning for Nonprofits

Establishing, operating, and driving impact through a mission-centric advocacy organization is multi-faceted and complex. Join leaders from established and growing rare disease nonprofits to hear insights on the ways in which they have approached developing core organizational components and key programs and services for their communities.

Discuss governance and core operational components of running a patient advocacy organization

Build a checklist of key people, resources, and infrastructure to power forward organizational goals

Explore best practices, lessons learned, and ways to make the most of your limited resources

Moderator: Craig Martin, CEO, Global Genes

Speakers: TBA

SESSION II

12:20pm – 1:10pm PT | 3:20pm – 4:10pm ET

RARE LIFE & PATIENT SUPPORT

Managing Mental Health, Ambiguous Grief, and the Impacts of Diagnosis and Disease Progression

As we navigate through our rare life, mental health and the emotional wellbeing of the patient and family is often overlooked, while physical health is prioritized. Whether you are a patient, parent, partner or sibling, the emotional and psychological trauma associated with rare diseases must be addressed. Parents and experts will share their perspectives on opportunities to expand this conversation in the rare disease community and break down barriers to accessible care and resources.

- Understanding the impacts of diagnosis and continued disease progression on mental health and emotional wellbeing for patients, parents, and caregivers
- Redefining yourself and building a network of resources and support to managing ongoing shifts
- Understanding the impacts of ambiguous grief, anticipatory loss, and changes in baseline

Moderator: C. Virginia O'Hayer, Ph.D., Clinical Associate Professor and Director, Jefferson Center City Clinic for Behavioral Medicine, Thomas Jefferson University Hospital

Speakers:

- Darcy Cunningham Esiason, LICSW, Executive Director/Clinician-Researcher, Esiason-O'Hayer Institute for Behavioral Medicine
- Parvathy Krishnan, Speaker, Parent Advocate and Foundation Alliance Manager, Global Genes
- Jessica Fein, Board Member, Rare Disease Writer and Advocate, Mitoaction

SESSION II

12:20pm – 1:10pm PT | 3:20pm – 4:10pm ET

TACTICS & CAPACITY BUILDING

Developing Impactful and Relevant Communication and Education Tools for Your Community

For rare disease communities, patient, caregiver, and physician education is often one of the core elements of advocacy work. Join us for tactical insights on developing impactful educational materials, programs, and tools around relevant topics for patient communities.

- Demystifying emerging science and complexities of healthcare with accessible content
- Empowering patients, families, and caregivers to advocate for themselves in care and research
- Thinking outside the box – understanding how to build the right tools to fit your community

Moderator: Quita Christison MPH, Virtual Outreach Coordinator, Next Step

Speakers:

- Hope Newport CCLS MA, Family Services Manager, IFOPA
- Eszter Hars PhD, President and CEO, Shwachman-Diamond Syndrome Alliance
- Sarita Edwards, CEO & President, The E.WE Foundation

LEADERSHIP SKILLS LAB | 11:30am – 1:10pm PT | 2:30pm – 4:10pm ET

Beyond the Mission - Building a Sustainable Culture for Your Organization

What does it take to develop a sustainable culture in a patient advocacy organization? From team building and staff development to board planning and strategic planning, the diversity of skills required can often be daunting. Delve into these topics and explore critical challenges, including:

- Navigating diverse needs within your community and getting buy-in from patients and partners
- Building inclusive outreach plans and developing organizational capacity in equity, diversity, and inclusion
- Cultivating your leadership toolkit for sustainable organizational management
- Maximizing impact in scaling up organizations and programs
- Developing and building a board to support your organization and its goals

Speakers:

- Amanda Moore, Chief Executive Officer, Angelman Syndrome Foundation
- Andra Stratton, Program Associate, Rare As One at Chan Zuckerberg Initiative
- Tuesdi Dyer, Executive Director, CFC International

1:10pm PT | 4:10pm ET

Close of Day One

1:10pm – 2:00pm PT | 4:10pm – 5:00pm ET

Office Hours and Q&A

7:00am – 7:30am PT | 10:00am – 10:30am ET

Timing is Everything — A Look into Status Epilepticus

Presented by Marinus Pharma

Speakers:

- Alex Aimetti PhD, Vice President, Scientific Affairs, Marinus Pharmaceuticals, Inc.
- Henrikas Vaitkevicius MD, Vice President, Clinical Development, Marinus Pharmaceuticals, Inc.
- Nora Wong, Co-Founder and Executive Director, The NORSE Institute

7:30am – 8:00am PT | 10:30am – 11:00am ET

Gene Therapy for Treatment of Neurologic Diseases: Approaches and Challenges

Presented by Passage Bio

Speaker: David Weinstein, MD, MSc., Vice President of Clinical Development, Passage Bio

8:05am – 8:10am PT | 11:05am – 11:10am ET

Day Two Welcome & Kickoff

8:10 – 8:55am PT | 11:10am – 11:55am ET

► **Embracing Uncertainty - Rare Young Adults Leading for Change**

Emerging leaders and young adults in the rare disease community are driving new conversations and taking innovative approaches to their collective- and self-advocacy. Join us for a panel discussion featuring a group of these rare changemakers and hear their insights on coming of age and finding your voice with a rare disease.

- Discuss how organizations, awareness activities, and advocacy efforts can better include the voice of young adult patients
- Explore the challenges of living life as a rare young adult and what they see as the most pressing issues going forward for the rare community

Moderator: María Luisa Mendiola, Founder and CEO, MIGA Swimwear

Speaker: Keisha Greaves, CEO & Founder, Girls Chronically Rock

8:55am – 9:00am PT | 11:55am – 12:00pm ET

Break

9:00am – 9:45am PT | 12:00pm – 12:45pm ET

Educational Sessions

Choose Between (2) Educational Sessions or (1) Extended Skills Lab

SESSION I

9:00am – 9:45am PT | 12:00pm – 12:45pm ET

RARE LIFE & PATIENT SUPPORT

Addressing the Needs of Underserved Adult and Senior Patients in Rare Disease

While discussions around research and patient support often focus on pediatric patients and caregivers, it is critical to ensure that adult patients are not left behind. Discuss the complexities of advocating for yourself as an adult, managing your own care, and living while rare.

- Learn about the issues and needs faced by adult and senior rare disease patients in care and support, financial services, and navigating daily needs
- Challenges in accessibility – resources, research, home healthcare services, and more
- Barriers to adult diagnosis and understanding the adult diagnostic odyssey
- Opportunities to develop programming in your community to better support the needs of adult patients and raise awareness

Moderator: Maria Hadjidemetriou, Executive Board Member, Cooley's Anemia Foundation; Expert Patient Advisor, Thalassemia International Federation

Speakers:

- David Ross, Rare Disease & Male Mental Health Advocate
- Reverend Odell Cleveland, Caregiver, Author & Advocate
- Sarita Edwards, CEO & President, The E.WE Foundation

SESSION I

9:00am – 9:45am PT | 12:00pm – 12:45pm ET

TACTICS & CAPACITY BUILDING

Developing a Dynamic Plan for Impactful Self-Advocacy and Storytelling

Whether focused on advocating in research, clinical care, legislative issues, or other goals, driving impact through storytelling is critical. This discussion will highlight innovative approaches and strategies to empower you in your advocacy journey.

- Resonating with your audience – helping your patient community tailor their story for impactful advocacy
- Developing your voice and finding your lane in advocacy
- Building an advocacy plan with your community to drive awareness for a specific goal or issue
- Empowering advocates and patients in your community to raise their voices

Speakers:

- Shivani Vyas, High School Student and Founder & Host, The Rare Disorder Podcast
- J. Michael Graglia, MBA, MA, Managing Director, Syngap Research Fund, Inc.

9:45am – 9:50am PT | 12:45pm – 12:50pm

Break

SESSION II

9:50am – 10:35am PT | 12:50pm – 1:35pm ET

RARE LIFE & PATIENT SUPPORT

My Sister's Keeper? — Siblings, Stories, and Life on the Sidelines

As conversations around supporting patients and families have evolved, there has been increasing awareness around the need to support siblings of rare disease patients more deeply. In this session, hear from siblings and caregivers on the unique experience of growing up with a chronically ill sibling and how rare disease support groups and organizations can provide better sibling support and education.

- Navigating the emotional rollercoaster as a sibling - fear, guilt, resentment, and love
- Balancing life as a sibling of a rare disease patient
- Explaining to friends, fitting in, and the no one “gets it” factor
- Opportunities for caregivers and parents to better support siblings and find balance in family life

Moderator: Britta Dornan, Senior Director of Communications and Marketing, EveryLife Foundation

Speakers:

- Madison McLaughlin, Vice President, MacPac Foundation
- Mallory Cyr MPH, CYSHCN Program Manager, Association of Maternal and Child Health Programs
- Maisy Cyr, Rare Advocate and Podcaster, With Mais & Mal

SESSION II

9:50am – 10:35am PT | 12:50pm – 1:35pm ET

TACTICS & CAPACITY BUILDING]

Listening First - Researching Equity, Diversity, and Inclusion in Your Community

How do you create an inclusive environment within your organization and your community? Developing programs to support EDI requires an intentional and nuanced approach. In this session, explore organizational approaches to building partnerships, creating accessible materials, and analyzing opportunities to move the needle on access and health equity in rare disease research and care.

- Evaluating the landscape of your patient community and opportunities for inclusive outreach
- Identify gaps in diagnosis, care, and research for patients in your disease state or community
- Navigating diverse needs within your community and getting buy-in from patients and partners
- Building inclusive outreach plans and developing organizational capacity in equity, diversity, and inclusion

Moderator: Mary McGowan, Chief Executive Officer, Foundation for Sarcoidosis Research

Speakers:

- Dionne Stalling, Founder & Executive Director, Rare and Black
- Donna Appell, RN, Founder and Executive Director, Hermansky-Pudlak Syndrome Network
- Mohua Chakraborty Chaudhury, PhD, Post-Doctoral Policy Fellow, DST-Centre For Policy Research, Indian Institute Of Science, Bengaluru

LEADERSHIP SKILLS LAB | 9:00am – 10:35am PT | 12:00pm – 1:35pm ET

Developing Robust Approaches to Research Collaborations and Partnership Strategy

Setting yourself and your organization up for success when approaching a potential research partner or collaborator is critical but complex. Join advocacy leaders, researchers, and industry partners to discuss strategies for approaching a potential research partner. Gain insights on positioning the insights, data, and value of your community to spark interest from researchers and industry collaborators.

- Analyzing the current research landscape and positioning your community within that
- Steps to identifying and evaluating potential research partners in the context of your community
- Creating roadmaps for sustainable research collaborations and international partnerships
- Setting expectations for trust and transparency in collaborations and partnerships

Moderator: Christeen Moburg, Vice President of Patient Advocacy and Government Relations, Sangamo

Speakers:

- Benjamin Forred, Director, Clinical Research, The CoRDS Registry and Experimental Therapeutics Screening Facility, Sanford Research
- Richard Huang PhD, Founder & CEO, The 40%
- Chelsey McCarthy, Executive Director, DDX3X Foundation
- Sarah Glass, Chief Development Officer, n-Lorem Foundation

10:35am – 10:40am PT | 1:35pm – 1:40pm ET

Break

10:40am – 11:40am PT | 1:40pm – 2:40pm ET

Educational Sessions

10:40am – 11:40am PT | 1:40pm – 2:40pm ET

RARE LIFE & PATIENT SUPPORT

F This — Challenging Taboos in Sex, Gender, and Sexuality for Rare and Disabled Patients

Sex, gender, and sexuality are often stigmatized topics for rare, chronically ill, and disabled patients, both in the doctor's office and in their own lives. Supporting patients in medical care requires that we challenge these stigmas and open the conversation around empowering patients to explore these aspects of themselves and their lives. As rare disease patients, we visit many doctors and some of these issues get lost in translation. Learn about the importance of educating yourself, your patients and all the stakeholders involved in caring for a rare patient.

- Perspectives at the intersection of sex, gender, sexuality, and chronic illness
- Exploring the roots of taboos and stigmas around sexual empowerment for chronically ill patients
- Discuss opportunities for patients, advocates, and providers to raise awareness, dispel myths and stigmas, and provide support to patients in these conversations

Moderators:

- Lara Bloom, President and CEO, Ehlers-Danlos Society
- Anna Laurent, Head of Programs and Initiatives, Our Odyssey

Panelists:

- Ambre Minty, Founder, Living with Dys
- Kam Redlawsk, Advocate, Artist, Writer and Industrial Designer

10:40am – 11:40am PT | 1:40pm – 2:40pm ET

TACTICS & CAPACITY BUILDING

The Future is Hybrid (and Expensive) — Digital Strategy for the New Normal

The past year has forced almost all organizations and nonprofits to reevaluate their approach to patient education, community events, and conferences. As we look to the future, the imperative to develop robust virtual and hybrid approaches across the board is clear. Join us to discuss these impacts and key tactics for advancing your digital/hybrid programming.

- Understanding what technologies and tools can drive the most value for your organizational goals
- Impact and insights on pivoting programs, communities, and events to virtual
- Addressing challenges in online engagement, the digital divide, and community burnout

Moderator: Christian Rubio, MBA, Vice President of Strategic Advancement, Global Genes

Speakers:

- Kelly Conway, Co-Founder, The International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
- Trishna Bharadia MFPM, Ambassador, MS Society UK, ADD International & Lyfebulb

LEADERSHIP SKILLS LAB | 10:40am – 11:40am PT | 1:40pm – 2:40pm ET

Negotiating and Resolving Conflicts — Maintaining Trust through Tough Conversations

Negotiation and conflict resolution are core skills that are incredibly useful across many areas of work and can be a critical element of your advocacy toolbox. Whether in navigating a complex research agreement or resolving conflict with a partner organization, understanding how to come to a shared understanding and mutual agreement is critical for organizational success. Explore principles of negotiation and conflict resolution and how you can deploy those tools across your work.

- Explore strategies to build your own internal clarity
- Learn to build trust ‘across the table’ within challenging conversations
- Learn how to identify mutually beneficial goals and next steps

Speaker: Anne Yurasek MBA, Principal, Fio Partners

11:40am – 11:45am PT | 2:40pm – 2:45pm ET

Break

11:45am – 12:00pm PT | 2:45pm – 3:00pm ET

Closing Remarks & Take-Home Thoughts

Speaker: Craig Martin, CEO, Global Genes

12:00pm – 12:45pm PT | 3:00pm – 3:45pm ET

Office Hours and Q&A