

The learning objectives for this fourth in a series of four workshops are to enable patients and patient advocates to:

- ⌘ Fine-tune a research strategy and attract investors
- ⌘ Leverage data to support early diagnosis and better clinical care
- ⌘ Manage multi-stakeholder collaborations

MONDAY, FEB 3

3:00 pm – 5:00 pm CT

Working Backwards to Success: Applying Amazon's Innovation Method to Better Meet Your Community's Needs

Presenter: [Ben Butler](#), Global Head of Cloud Innovation, AWS

Facilitator: [Victoria Condron](#), Principal, Digital Innovation, AWS

5:00 pm – 7:00 pm CT

Welcome Reception

TUESDAY, FEB 4

8:00 am – 8:45 am CT

Registration & Breakfast

8:45 am – 9:00 am CT

Welcome and Introduction to Workshop

Speaker: [Christian Rubio](#), VP, Strategic Advancement, Global Genes

9:00 am – 10:00 am CT

Refining Your Strategy: Building a Bridge to Treatment Options

Speaker: [David Spencer, PhD](#), Vice-Chairman of the Board, BioPontis Alliance for Rare Diseases

10:00 am – 11:00 am CT

Funding DIY: EB Research Partnership's Multi-Stakeholder Platform Powered by Venture Philanthropy

Speakers:

- [Michael Hund, MBA](#), Chief Executive Officer, EB Research Partnership
- [Ryan Jancaitis](#), Global Head, Product Management, Amazon Web Services

11:00 am – 11:15 am CT

Break

11:15 am – 12:15 pm CT

Leveraging the Power of Partnership: Managing Multi-Stakeholder Collaborations

Speaker:

- [Kristin Schneeman](#), Director, Programs at FasterCures

continued on back

12:15 pm – 1:15 pm CT

1:15 pm – 1:30 pm CT

1:30 pm – 2:30 pm CT

2:30 pm – 3:30 pm CT

3:30 pm – 3:45 pm CT

3:45 pm – 4:45 pm CT

4:45 pm – 5:00 pm CT

WEDNESDAY, FEB 5

8:00 am – 12:00 pm CT

Lunch

Welcome Back

Speaker: [Christian Rubio](#), VP, Strategic Advancement, Global Genes

Drug Repurposing and the Wisdom of Crowds

Speakers:

- [Lara Pullen, PhD](#), Co-founder, Chion Foundation
- [Maria Picone](#), Co-Founder/CEO at TREND Community

What More Can You Do with Data? Clinical Guidelines

Speakers:

- [Paige Nues](#), Director of Family Empowerment, Rettsyndrome.org
- [Bernhard Suter, M.D.](#), Assistant Professor, Pediatrics & Neurology, Baylor College of Medicine & Texas Children's Hospital
- [Daniel G. Glaze, M.D., FAASM](#), Professor, Pediatrics and Neurology, Baylor College of Medicine

Break

Expanding Your Engagement to Underserved Populations

Moderator: [Liz Horn, PhD](#), LHC BioSolutions

Speakers:

- [Linda Wade](#), President & CEO, Sickle Cell Association of Texas
- [Khrystal K. Davis, JD](#), Founder, Texas Rare Alliance
- [Robyn Correll Carlyle, MPH, CHWI](#), Public Health Consultant

Wrap Up, Final Questions and Next Steps

Speaker: [Christian Rubio](#), VP, Strategic Advancement, Global Genes

In-depth mentoring

