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

Workshop #4 Agenda (4th of 4 Part Series)

*Becoming a Data-Centric Community*

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**FEBRUARY 3 - 5, 2020**

Houston Marriott Medical Center/Museum District • 6580 Fannin Street, Houston, Texas 77030

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**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*

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5:00 pm – 7:00 pm CT

**Welcome Reception**

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**TUESDAY, FEB 4**

8:00 am – 8:45 am CT

**Registration & Breakfast**

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8:45 am – 9:00 am CT

**Welcome and Introduction to Workshop**

*Speaker: Christian Rubio, VP, Strategic Advancement, Global Genes*

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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*

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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

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11:00 am – 11:15 am CT

**Break**

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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
Lunch

1:15 pm – 1:30 pm CT
Welcome Back
Speaker: Christian Rubio, VP, Strategic Advancement, Global Genes

1:30 pm – 2:30 pm CT
Drug Repurposing and the Wisdom of Crowds
Speakers:
  • Lara Pullen, PhD, Co-founder, Chion Foundation
  • Maria Picone, Co-Founder/CEO at TREND Community

2:30 pm – 3:30 pm CT
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

3:30 pm – 3:45 pm CT
Break

3:45 pm – 4:45 pm CT
Expanding Your Engagement to Underserved Populations
Moderator: Liz Horn, PhD, LHC BioSolutions
Speakers:
  • Linda Wade, President & CEO, Sickle Cell Association of Texas - Marc Thomas Foundation
  • Jordan Shumway, Social Worker, Sickle Cell Association of Texas - Marc Thomas Foundation
  • Khrystal K. Davis, JD, Founder, Texas Rare Alliance
  • Robyn Correll Carlyle, MPH, CHWI, Dia de la Mujer Latina, Inc. (DML)

4:45 pm – 5:00 pm CT
Wrap Up, Final Questions and Next Steps
Speaker: Christian Rubio, VP, Strategic Advancement, Global Genes

WEDNESDAY, FEB 5
8:00 am – 12:00 pm CT
In-depth mentoring