



College of Human Medicine  
MICHIGAN STATE UNIVERSITY



# Rare Disease Day Symposium 2020

Local Impact, Global Vision



**8 a.m. Breakfast and Registration**

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**9 a.m. Welcome**

Michael Le Roy, PhD, President, Calvin University

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**9:15 a.m. Answering Questions and Questioning Answers - What to Do With Rare Disease**

Caleb Bupp, MD, Division Chief, Genetics, Helen DeVos Children's Hospital

**With Grit Not Grace - Raising a Child in the Uncertain World of Rare Disease**

Shannon Bennett, Rare Disease Mom and Advocate

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**10:15 a.m. Break**

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**10:45 a.m. Researching Rare Diseases**

André Bachmann, PhD, Professor and Associate Chair for Research, Michigan State University College of Human Medicine

**Common Experiences Across Rare Diseases: A Panel Discussion**

Elle Hazlett, Student, Calvin University

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**11:45 a.m. Lunch**

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**12:45 p.m. Breakout Sessions**

**Palliative Care: Helping Families Navigate Uncertainty**

Bradd Hemker, MD, Section Chief-Physician, Palliative Care, Helen DeVos Children's Hospital

**Transition From Pediatric to Adult Care**

Amy Tolliver, Family Nurse Practitioner, Helen DeVos Children's Hospital  
Brad Swiftney, Medical Social Worker, Helen DeVos Children's Hospital (tentative)

**Rare Disease Research: Technologies and Treatments**

Jeff MacKeigan, PhD, Professor and Assistant Dean for Research, Michigan State University College of Human Medicine

**Rare Disease 101: An Introduction to the Science of Rare Disease\***

Rachael Baker, PhD, Assistant Professor of Chemistry and Biochemistry, Calvin University

Amy Wilstermann, PhD, Associate Professor of Biology, Calvin University

**What Prehealth Students Should Know About Rare Disease:  
A Panel Discussion\***

Rare Disease Patients and Family Members

**Rare Disease Ed: Teaching Kids (K-5) and Their Families About  
Rare Disease\***

Elle Hazlett, Calvin University

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**1:15 p.m. Transition**

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**1:30 p.m. Breakout Sessions**

**Palliative Care: Helping Families Navigate Uncertainty**

Bradd Hemker, MD, Section Chief, Palliative Care, Helen  
DeVos Children's Hospital

**Transition From Pediatric to Adult Care**

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**What Prehealth Students Should Know About Rare Disease: A  
Panel Discussion\***

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**2 p.m. Transition**

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**2:15 p.m. Breakout Session Report Outs**

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**2:30 p.m. Poster Viewing, Vendor Tables, Networking**

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**3 p.m. Conclude**