



September 28th 7a EDT - 7p EDT

The 2018 Rare Fair Agenda

7:00a - 8:00a Welcome & Networking

8:00a - 8:30a Transitional Care - The Shift When You're Over 18: Shira Strongin

9:00a - 9:45a Keynote, Managing Grief: Claire Bidwell Smith, Author & Therapist

10:00a - 10:30a Self-Care for the Caregiver: Stacey Feuer, PSYD, MLD

11:00a - 11:30a The Many Colors of Advocacy: Self Advocacy & Finding Help: Trisha Torrey, Author

12:00p - 12:30p Pursuing Legislation that Matters: Taylor Kane, Author & Activist

1:00p - 1:30p Clinical Trials: An Overview: Scott Schliebner, MPH

2:00p - 2:30p Managing Your Diagnosis: Jim Cavan, MS

3:00p - 3:30p Advocacy Primer: Setting Goals: Stephanie Fischer, Advocate

4:00p - 4:30p What Your Rare Disease Patient Wants You To Know: Ilana Jacqueline, Author & Advocate

5:00p - 5:15p Rare Disease: The Legislative Landscape: Congressman Kevin Yoder

5:30p - 5:45p Network to a Cure: Monica Weldon, Advocate & CEO

6:00p - 6:30p Why Zebras Need Special Care: Corey Iqbal, MD, FAAP, FACS

7:00p Closing

* The Exhibit Hall, Patient Education Room & Patient Networking Rooms are open all day

** All presentations will be recorded and posted within 3 hours of the posted time.



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A ROAD MAP FOR EVERY DIAGNOSIS.

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Keynote Speakers

Managing Grief
What's Ahead in Rare

Claire Bidwell Smith
Congressman Kevin Yoder

Breakout Track #1 : Patients

The Many Colors of Advocacy: Self Advocacy & Finding Help
Clinical Trials: An Overview
Managing Your Diagnosis

Trisha Torrey
FDA - TBA
Anne Bruns

Breakout Track #2 : Caregivers

Self-Care for the Caregiver
Getting Organized: Managing Medical Care
Resources: What's Available and How to Find Assistance

Stacey Feuer
Eden Lord
TBD

Breakout Track #3: Physicians

What Your Rare Disease Patient Wants You To Know
Networking a Cure
Why Zebras Need Special Care

Ilana Jacqueline
Monica Weldon
TBD

Breakout Track #4: Advocacy

Advocacy Primer: Setting Goals
Rare Disease: The Legislative Landscape
Pursuing Legislation that Matters

Stephanie Fischer
Kevin Yoder
Lisa Schill