



POWERED BY



September 28th 7a EDT - 7p EDT

## The 2018 Rare Fair Agenda

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**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.**

[www.therarefair.com](http://www.therarefair.com)



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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**