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AL*LIANCE*
FOR RARE DISEASE COLLABORATION

DAY ONE

1.12.2022

MORNING FOCUS: PATIENTS

*Subject to Change

9:15 AM ET | The 4th Annual Rare Fair Kickoff Live from RTP

9:30 AM ET | Oversharing: Managing Social Media with Your Child in Mind

10:30 AM ET | Pursuing a Diagnosis: Building a Team to Forge a Treatment Path

| Keeping the Faith: Exploring the Intersection of Rare Disease and Faith (A Panel Discussion)

11:30 AM ET | Rare Disease and Your Mental Health

| Mitigating the Impact of a Rare Disease Diagnosis on Family Life

DAILY NETWORKING BREAK

12:00 PM ET | **Networking Session**

(Meet up with other attendees for video chats or join our dedicated networking session to be randomly matched with other attendees based on your interests identified at registration.)

AFTERNOON FOCUS: NON-PROFITS

1:00 PM ET | **Building Your Non-Profit: A Workshop**

| **Building Partnerships with Your Government Representatives**

2:00 PM ET | **Newborn Screening - What Your Non-Profit Needs to Know**

3:00 PM ET | **The Race for Data: Understanding Data Sharing and Your Options**

4:00 PM ET | **Day One Wrap-Up**

EVENING SUPPORT GROUPS

7-8 PM ET

Mens' Support

Single Adults

Single Parents

Family/Friends

Womens' Support

Married Couples

Caregivers/Care Partners



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DAY TWO

1.13.2022

MORNING FOCUS: PHYSICIANS/RESEARCHERS/STUDENTS

*Subject to Change

9:15 AM ET | Day Two Kickoff

9:30 AM ET | Undiagnosed: Resources for Physicians

10:00 AM ET | The Path to an Expedited Diagnosis: Partnering with Primary Care

10:30 AM ET | Inequities of Care: Recognizing and Bridging Gaps

11:00 AM ET | Rare Disease, Rural Health & Developing Nations

11:30 AM ET | Diagnostic Pediatrics & Rare Disease

DAILY NETWORKING BREAK

12:00 PM ET | Networking Session

(Meet up with other attendees for video chats or join our dedicated networking session to be randomly matched with other attendees based on your interests identified at registration.)

AFTERNOON FOCUS: INDUSTRY

12:00 PM ET | Patients as Opinion Leaders: Partners in Education

1:00 PM ET | Early Access: Moving the Needle

2:00 PM ET | Decentralized Clinical Trials and Accessibility

3:00 PM ET | Continuing the Inclusion Discussion: Recognizing Diversity as a Standard of Care

4:00 PM ET | Day Two Wrap-Up

EVENING NETWORKING SESSIONS

7-8 PM ET

Join other attendees on the platform to meet up and discuss common challenges in the rare disease space in our lounges or via direct message.



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DAY THREE

1.14.2022

DAY THREE FOCUS: COMMON CHALLENGES IN THE RARE DISEASE SPACE

*Subject to Change

9:15 AM ET | Rare72 Overview and Kickoff

R72 Challenge Thread Sessions

10:00 AM ET | Diagnostic Challenges in Pediatric Neuro-Ophthalmology
| Genetic Testing

11:00 AM ET | Barriers and Challenges in Newborn Screening
| Barriers to Early Access

DAILY NETWORKING BREAK

12:00 PM ET | Networking Session

(Meet up with other attendees for video chats or join our dedicated networking session to be randomly matched with other attendees based on your interests identified at registration.)

R72 Challenge Thread Sessions

1:00 PM ET | Clinical Trial Recruitment and Decentralization: Challenges and Opportunities

| Building Patient Support Programs & Supporting Patient Engagement

2:00 PM ET | Expedited Diagnosis & Misdiagnosis Prevention

| Ongoing Barriers in Diversity, Equality, and Inclusion

3:30 PM ET | Challenges Facing Specific Disease Populations

4:45 PM ET | Day Three Wrap-Up

EVENING NETWORKING SESSIONS | 7-8 PM ET

Rare72 teams will have the opportunity to meet for a team kick-off prior to the Rare72 cycle launch on January 17th.



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DAY FOUR

1.15.2022

DAY FOUR: RARE FAIR JUNIOR EDITION

*Subject to Change

9:15 AM ET | Rare Fair Jr. - Welcome Kickoff

9:45 AM ET | Keynote

10:15 AM ET | Rare Fair Jr. - Kids' Lounge Opens

**11:00 AM ET | Young and Rare: A Panel Discussion on Coping as a Kid
| The Intersection of Parenting and Caregiving: When Mom/Dad
Becomes Nurse**

**12:00 PM ET | Staying Positive: Living with Rare Disease as a Kid (A Panel
Discussion)**

1:00 PM ET | Rare Fair Jr. - More Than Rare Workshop

2:00 PM ET | Balancing the Demands of Rare Disease Care with Family Life

3:00 PM ET | Day Four Wrap-Up

4:00 PM ET | Kids Dance Party

Gamification will be on for the duration of Rare Fair Junior Edition to allow attendees the opportunity to interact with other attendees, learn about available event resources, and win prizes.