

# OHIO RARE DISEASE SUMMIT

Thursday, September 26, 2024

Columbus Zoo - Africa Center

8:00 am - 4:00 pm

## AGENDA

<b>8:00-9:00</b>	<b>REGISTRATION</b>	Enjoy a continental breakfast before the event starts
<b>9:00-9:15</b>	<b>OPENING REMARKS/ OVERVIEW OF RARE DISEASE</b>	Kelly Maynard, Little Hercules Foundation Randi Clites, Ohio Bleeding Disorders Council
<b>9:15-9:45</b>	<b>KEYNOTE SPEAKER</b>	
<b>9:45-10:30</b>	<b>PRESENTATION</b>	Managing Prescription Drug Costs: Navigate today's pharmacy benefits efficiently, effectively and ethically <b>Ashira Vantrees</b> , Counsel, Aimed Alliance
<b>10:30-10:45</b>	<b>BREAK</b>	
<b>10:45-11:15</b>	<b>PRESENTATION</b>	Measuring the Lived Experience of Rare Disease: The National Economic Burden of Rare Disease Study <b>Emily Stauffer</b> , State Policy Manager, EveryLife Foundation for Rare Diseases
<b>11:15-NOON</b>	<b>ACCESS POLICY PANEL</b>	<b>Matt Delaney</b> , Government Relations Specialist, National Bleeding Disorders Foundation <b>Emily Stauffer</b> , State Policy Manager, EveryLife Foundation for Rare Diseases, <b>State Representative Scott Lipps</b> <b>State Representative Bride Rose Sweeney</b>

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<b>NOON- 12:30</b>	<b>LUNCH</b>	Grab lunch and network!
<b>12:30- 1:15</b>	<b>GENE THERAPIES</b>	A primer on gene therapies-what are they? What do they do? Why are they so important for patients living with rare diseases? <b>TBA</b>
<b>1:15- 2:00</b>	<b>GENE THERAPY LANDSCAPE</b>	Gene Therapy Pipeline Analysis Modeling Study <b>Sharon Phares</b> , Tufts New Digs
<b>2:00- 2:45</b>	<b>SOLUTIONS FOR EMPLOYERS PANEL</b>	Industry experts will present several financial solutions for gene therapy coverage <b>Kirby Eng</b> , OutcomeRX <b>Yutong Sun</b> , Quantile Health <b>TBA</b>
<b>2:45</b>	<b>CLOSING REMARKS</b>	We'll close out the day with final thoughts and questions.
<b>3:00</b>	<b>ANIMAL ADVENTURE!</b>	Join us for a up close and person wild animal encounter!

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