

**NEW YORK STATE RARE DISEASE WORKGROUP  
AGENDA  
November 16, 2023  
11am-1pm**

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- 1. Welcome by Workgroup Co-Chairs** *5 minutes*  
*Melissa Pittel Wasserstein*  
*Chief, Division of Pediatric Genetic Medicine*  
*Children’s Hospital at Montefiore*

*Mary Wootten*  
*Member Coordinator, The Oley Foundation*  
*Volunteer, New York Rare Action Network Ambassador, NORD*
- 2. Patient and Caregiver Support: Report out and Discussion** *45 minutes*  
*Bob Graham*  
*Patient & Public Policy Director*  
*New York State Bleeding Disorders Coalition*
- 3. NORD’s RDAC Members Meeting in Washington, DC: Report Out** *20 minutes*  
*Ashley Appell*  
*Hermansky-Pudlak Syndrome Network, Inc.*
- 4. Next Steps – Report and Website** *20 minutes*  
*Barbara Wallace*  
*Director, Division of Chronic Disease Prevention*  
*NYS Department of Health*
- 5. Open Discussion** *20 minutes*  
*All members led by Co-Chairs*
- 6. Closing** *5 minutes*  
*Melissa Pittel Wasserstein, Co-Chair*  
*Mary Wootten, Co-Chair*  
*Barb Wallace, NYSDOH*