

## GEORGIA RARE DISEASE ADVISORY COUNCIL AGENDA

October 4, 2024 | 12:00-1:00pm

Virtual Option: <https://us02web.zoom.us/j/84653031401>

12:00-12:05	Call to Order & Review of Meeting Objectives	Beth Nguyen, Chairperson
12:05-12:20	Guest Presentation	Sharon Lamberton, MS, RN, FAAN Deputy VP State Policy & External Outreach, PhRMA
12:20-12:30	Post Presentation Open Discussion & Q&A	All
12:30-12:50	Updates Impacting the Rare Community Working Groups	Beth Nguyen, Chairperson
12:50-1:00	Housekeeping & Next Steps Communication & Website Meeting Location	Beth Nguyen, Chairperson & Maria Thacker, Secretariat
1:00	Adjourn	All

### **Action Items for Committee Members**

Working Groups Meet/Sign-Ups

- Survey Working Group: John, Kojo, Faizal, Sarah P., Jaime
- Website Working Group: Maria/GaBio, John, Nathan
- Best Practices Working Group: No volunteers yet. Mel and GaBio can support
- Newborn Screening Working Group: Hold for now.
- Rare Disease Day Event Planning Group: No volunteers yet.

Submit a bio & headshot to [Mcarter@gabio.org](mailto:Mcarter@gabio.org)