



GEORGIA RARE DISEASE ADVISORY COUNCIL AGENDA

May 29, 2024 | 12:00-1:30pm

Join on your computer, mobile app or room device

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Meeting ID: 291 322 568 371

Passcode: tCucUq

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[+1 470-344-9228,,872570779#](#) United States, Atlanta

Phone Conference ID: 872 570 779#

12:00-12:05	Call to Order & Welcome	Beth Nguyen, Chairperson
12:05-12:10	Review of Meeting Objectives	Maria Thacker, Secretariat
12:10-12:40	Guest Presentation	Carolyn G. Sheridan, MPH State Policy Manager, National Organization for Rare Disorders
12:40-1:00	Post Presentation Open Discussion & Q&A	All
1:00-1:10	RDAC Best Practices	Mel Carter, Georgia Bio & Carolyn Sheridan
1:10-1:25	Housekeeping & Next Steps Review of RDAC Statute* Communication & Website Meeting Location Funding	Beth Nguyen, Chairperson & Maria Thacker, Secretariat
1:25-1:30	Closing Remarks & Adjourn	All

*Specifically this language: “publish on the advisory council's website a list of existing, publicly accessible resources on research, diagnosis, treatment, and educational materials for *health care providers* relating to the rare diseases in Georgia.”

Event of Note

Georgia Patient Engagement Summit presented by Georgia Bio: Tuesday, August 27th | N. Fulton Chamber at Avalon – *RDAC is invited to attend, and a meeting room is available if need.*

Action Items for Committee Members

Submit a bio & headshot to MThacker@gabio.org