

Rare Diseases Advisory Council Quarterly Meeting Minutes

August 28, 2026

9:00 AM-10:00 AM

Meeting agenda:

- Welcome & Introductions
 - Dr. Champaigne briefly reviewed charter components related to membership
 - All council members and admin provided brief introduction
- Planning for the 2027 Symposium
 - RS - Proposed highlighting a condition each year and then showing the arc of how it comes from research to treatment
 - NC commented council's requirement to not focus on one disease, but what can be extrapolated from one and applied across diseases/conditions
 - AG - proposed title "From Rare To Ready" - building a stronger rare disease community in South Carolina with following potential agenda elements:
 - After the diagnosis, what comes next?
 - Discussion of resources
 - Different support/resource stakeholders on a panel to show different areas of support
 - JH - Asked KW if Medicaid group could present on eligibility and Medicaid processes
 - KW said as an expansion state SC still be allowed to pay 110% of Medicare, non-expansion states will be 100%
 - NC and VY commented on value of a Medicaid discussion, even just to remind people to reenroll in Medicaid
 - VY suggested a panel on this topic
 - Could include community organizations (Community Thrive, Family Connections, SC Solutions) or community health centers speaking about enrollment, overall.
 - CO - Impact on the approval of technologies on access to interventions for patients
 - KW said FDA accelerated approval carries the same weight as standard approval for Medicaid for those in the Medicaid Drug Rehab Program, which is reassuring
 - Access to emerging therapies could be a broader topic that covers this (EveryLife Foundation did a presentation on emerging therapies and access in FL that went over well)
 - KL - Could have presentation on the gaps of care
 - EB offered to talk about various aspects around newborn screenings
 - JH - Could have presentation by Florida RDAC member pushed forward a new policy in Florida for opting in to whole genome sequencing. Got his report heard in Florida by the health subcommittee.
 - NC mentioned similar SC project through Bridges, making potential presentation more SC focused
 - NC - Could have an AI presentation/discussion
 - VY - need to make sure we address guardrails around AI to address concerns and preconceived notions

- Disaster Preparedness Toolkit
 - AG - Needs more sections. She will send draft language for new sections
 - Section on medical equipment emergency profile
 - MEPS information, to let people know which hospital to go to in emergency based on medical needs
 - When to evacuate early if you have medically complex needs
 - Stronger power outage section addressing licensing and equipment, temperature control, communication access points, etc.
 - An after the emergency section
 - JH said there are provisions for utility companies for them to prioritize those with medical needs so it could be useful to share a link if we have one for our state power companies
 - KK also offered to send some draft additions
- RDAC Dissemination & News
 - NC - we should have bidirectional information sharing
 - RS - will link RDAC to the media at Greenwood Genetics Center
 - RS - suggested subcommittee for dissemination and resource sharing
 - EB - can share news through her existing channels
- Member Updates
- Adjourn

Mission: The council shall advise the Governor, the General Assembly, and other stakeholders on research, diagnosis, treatment, and education related to rare diseases

Definition: For purposes of this council, a rare disease is defined as one affecting fewer than 200,000 persons combined in a particular rare disease group

Membership:

Representation	Member	Presence
Chair	Neena Champaigne, MD (MUSC)	X
Department of Public Health	Beth Bair, MS, PhD (SCDPH)	X
Department of Health and Human Services	Kevin Wessinger, MD (SCDHHS)	X
Greenwood Genetic Center	Steve Skinner, MD (President & CEO)	
Prisma Health - University of South Carolina	TBD – In transition	
South Carolina Hospital Association	Kate Wink, MPA (Santee Cooper)	X
South Carolina Primary Healthcare Association	Vicki Young, PhD (SCPHCA)	X
Biopharma Industry	Jonathan Hawayek (Genentech)	X
Research and Treatment of Rare Diseases (3)	Maysen Mesaros, MS (MUSC, neuroscience)	X
	Kristen Lancaster, MD (MUSC, Pediatric Genetics)	X

	Rich Steet, PhD (Greenwood Genetic Center)	X
Patient (2)	Karen Kemper, PhD (Scleroderma)	X
	Bridget Downing (Friedreich's ataxia)	X
Rare Disease Organization	Aneesa Gracen (The Jeremiah Gracen TK2D Foundation)	X
Caregiver of person with rare disease	Cara O'Neill, MD, FAAP (Cure Sanfilippo Foundation)	X
State Health Plan	Tripp Jennings, MD (VP and Clinical Innovations Officer, BCBS South Carolina)	
Program Coordinator	Tara Pittman	X
	Kimberly Brown	X

Responsibilities of the Advisory Council:

- Solicit comments from stakeholders, including patients and patient caregivers in South Carolina impacted by rare diseases, to assess the needs of rare-disease patients, caregivers, and providers in the State;
- Consult with experts on rare diseases to develop recommendations to improve patient access to and quality of rare-disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services;
- Research and identify priorities related to treatments and services provided to persons with rare diseases in South Carolina and develop recommendations that include safeguards against discrimination for these populations on such issues, including disaster and public health emergency-related planning;
- Publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to the rare diseases in South Carolina;
- Identify and distribute educational resources to foster recognition and optimize treatment of rare diseases in South Carolina; and
- Identify best practices to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare diseases in South Carolina.
- Report annually (by June 30) to the Governor, the Chairman of the Senate Finance Committee, the Chairman of the Senate Medical Affairs Committee, the Chairman of the House Ways and Means Committee, and the Chairman of the House Medical, Military, Public and Municipal Affairs Committee.