Rare Diseases Advisory Council Quarterly Meeting

April 10, 2026
9:00 AM-10:00 AM

Meeting agenda:

- Welcome

- Rare Disease Symposium Debrief
    - The symposium had 130 attendees, evenly split between online and in-person participation, marking a slight increase from the previous year.
    - The event received positive feedback regarding its overall impact and participants' likelihood of attending future events.
    - Dr. Chen’s presentation on healthcare economics was received positively, as was Drs. Simpson and Flume’s presentation on state incidence data.
        - Dr. Simpson continues to refine incidence data for the top 100 rare disease conditions, addressing data limitations, collaborating with experts, and plans to incorporate additional datasets.
            - KK suggested Dr. Silver as a potential connection.
    - While the symposium intentionally covers broad topics to avoid singling out specific rare diseases, some attendees expressed a desire for more condition-specific content.
    - Feedback related to Segra Park focused on audio/visual and logistical concerns, including problematic backlighting and changes in parking arrangements. The group briefly discussed whether other venues in the Columbia area could be explored.
        - VD suggested the Health Campus auditorium.
    - KK observed that the symposium fostered cross-engagement among attendees and suggested that motivated participants could be invited to join subcommittees for future initiatives.
    - TP responded to a chat question by confirming that advocacy groups are invited to attend and may be offered table space at future events, provided a fair vetting process is established. The team is open to increasing the use of shared resources and engagement with advocacy organizations.
    - NC noted that the symposium sometimes coincides with national rare disease events and with other state-level meetings. The team discussed the need to consider timing to maximize attendance and representation.
        - Karen suggested highlighting concurrent rare disease activities across the state during the symposium to raise awareness and foster a sense of broader community engagement, even when scheduling conflicts are unavoidable.
    - The group reviewed the challenges of securing venues and organizing content for future symposiums, discussed funding timelines, and emphasized the need for earlier support from council members in identifying speakers and topics.

- Planning for the Annual Report
    - The annual RDAC report is due to the legislature in June. The group outlined plans for the upcoming annual report, including highlighting symposium outcomes, initiatives on incidence data, participation in the NORD Breakthrough Summit, improvements in managing community outreach, and policy engagement.

- What's Next for SC RDAC?
    - NC discussed opportunities for collaboration with other southeastern RDACs, including the possibility of convening at the Southeastern Regional Genetics Group meeting to share policies and resources, and the group considered the benefits of cross-state engagement for rare disease communities.

- Old Business
    - Website Management
        - Responding to requests received to our RDAC email.
        - Policy Webpage Updated
        - The group discussed the current structure and limitations of the council's website, addressed feedback on resource accessibility for caregivers and families, and invited suggestions for improving the site's organization and usability.

- 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	Patrick Flume, MD (MUSC)	-
Department of Public Health	Ginie Daguise (SCDPH)	P
Department of Health and Human Services	Kevin Wessinger (SCDHHS)	P
Greenwood Genetics	Steve Skinner, MD (President & CEO)	P
Prisma Health -University of South Carolina	Divya Ahuja, MD, MRCP (Infectious Diseases)	P
South Carolina Hospital Association	Kate Wink (Santee Cooper)	-
South Carolina Primary Healthcare Association	Vicki Young (SCPHCA)	-
Biopharma Industry	Jonathan Hawayek (SPARK Therapeutics)	-
Research and Treatment of Rare Diseases (3)	Maysen Mesaros, MS (MUSC, neuroscience) Neena Champaigne, MD (Pediatric Genetics) Chip Norris, PhD (MUSC, connective tissue)	P P -

Patient (2)	Karen Kemper, PhD (scleroderma) Bridget Downing	P P
Rare Disease Organization	Yvonne Donald, M.A., CSCEC (James R. Clark Memorial Sickle Cell Foundation)	-
Caregiver of person with rare disease	Cara O’Neill, MD, FAAP (Cure Sanfilippo Foundation)	-
State Health Plan	Tripp Jennings, MD (VP and Clinical Innovations Officer, BCBS South Carolina)	P
Program Coordinator	Tara Pittman Kimberly Brown	P P

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 people with rare diseases in South Carolina and develop recommendations that include safeguards against discrimination of 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.