Rare Diseases Advisory Council Quarterly Meeting

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

Meeting agenda:

- Welcome

- RDAC Updates
    - Annual Report + RD Prevalence Data
        - The Annual Report was submitted in June and will be available on the website soon.
        - Dr. Kit Simpson has been working on the RD prevalence data, expanding data analysis to 100 conditions, with the goal of including Medicaid records to address data gaps, especially for younger populations.
            - The team aims to publish the expanded prevalence data beyond symposium and annual report presentations, inviting interested council members to participate as co-authors and reviewers.
                - KK volunteered to assist with this process.
    - 2027 Symposium
        - The group discussed early planning for the next symposium, including potential topics, strategies to increase attendance, addressing technical issues, and considering a new venue to improve experience.
            - Venue Exploration: Exploring Riverbanks Zoo as a new location, aiming to keep the event centrally located for statewide accessibility
            - Outreach and Promotion Strategies: Avoiding scheduling conflicts with other meetings and enhancing visibility and information sharing about the symposium, including leveraging resources and networks.
                - Involving medical, genetic counseling, and other health professional students, possibly through incentives or virtual participation (satellite viewing), to raise awareness of rare diseases among future professionals.
            - Potential Topics and Speakers: Ideas for symposium topics included multidisciplinary care (highlighting exemplars), policy impacts on health, updates on newborn screening (Dr. Bair), and infrastructure/capacity for emerging therapies.
                - Dr. Champaigne shared about the work of one of her mentees, highlighting personal patient/family stories to engage students/professionals
        - Convene another meeting in late August/early September to get a head start on planning

- Chair and Member Transition
    - Per the RDAC Charter: “The term for a Council member will be for 3 years; The Council member may be reappointed for up to three terms (for a total potential membership of 9 years) in the manner they were appointed pursuant to state law as reflected in Article 2, Section1. Note: Some entities required to have representation on the council may have a limited number of persons capable of serving as a member. In those instances, exceptions may be made to extend term limits, to ensure continued representation from those entities as required by law.”
        - Since most members started at the same time, we need to be strategic in rolling some members off to maintain historical context while also introducing new perspectives.
    - Dr. Champaigne is taking over the role of Chair from Dr. Flume.
    - Dr. Daguise is rotating off from the Department of Public Health, with Dr. Beth Bair joining as her replacement; other transitions are being planned to avoid excessive turnover.
    - NC proposed Kristen Lancaster for the pediatric geneticist role and suggested Chris Cowan and Rich Steet for research positions, inviting further nominations from the group.
    - Members discussed the importance of including representatives from various institutions (e.g., Prisma Health, Clemson, biotechnology sectors) and disciplines (e.g., nursing, engineering) to broaden the council's expertise. Members discussed reviewing requirements for representation per the Charter and Proviso.

- What’s Next for SC RDAC?
    - Web Updates – SC resources
        - Kimberly and Tara have updated the website to improve usability and are seeking input on additional resources, such as information on the drug development process and disaster preparedness for rare disease patients.
        - The council plans to highlight member achievements and activities, both to raise awareness within the group and to inform the broader rare disease community.
        - NC proposed cataloging centers of excellence, clinical trials, and support groups in South Carolina, with input from JH on best practices from other RDACs, to help patients and providers navigate available resources.
        - The group acknowledged the challenge of covering all 10,000 rare diseases and agreed to focus on common needs and more prevalent conditions, while encouraging feedback on gaps and needed additions.
    - Other Initiatives?
        - The group discussed the difficulties in collecting and analyzing data on ultra-rare diseases due to privacy constraints and coding limitations, and considered how understanding these populations could inform future state policy and resource allocation.

        - The group discussed opportunities to collaborate with other state RDACs:
            - JH offered to coordinate guest speakers from other RDACs to share experiences and best practices, particularly from states like New York, Pennsylvania, New Jersey, Delaware, Florida, and Michigan.
            - NC described ongoing participation in the NORD Breakthrough Summit and Southeastern Regional Genetics Group meetings, aiming to strengthen regional collaboration and policy alignment.
            - JH shared examples from Florida, where legislative advocacy led to expanded genetic testing options and direct presentations to health care committees.

- Member Updates

- Adjourn
    - The group discussed shifting the meeting schedule to better align with tasks and updates (August/November/February/May).
    - The group discussed setting up an August or September meeting to better flesh out ideas for the 2027 symposium.

Follow-up tasks:

- Symposium Planning and Venue: Finalize and confirm the venue for the next symposium. (Kimberly and Tara)
- Symposium Outreach to Learners: Assemble a comprehensive list of medical, health professions, and genetic counseling programs and engage with their learner groups to promote symposium participation and explore incentives for student attendance. (team)
- Symposium Topic Suggestions: Collect and collate additional symposium topic and speaker suggestions from members and prepare for discussion at the next planning meeting. (team)
- Membership Transitions: Send official letters to confirm membership transitions, including welcoming Dr. Beth Bair and other new members, and notify the group of finalized new members by the next meeting. (Neena)
- Website Resource Updates: Identify and add resources to the website on drug development, disaster preparedness for rare disease, and other relevant topics, and solicit feedback from members on additional resources or gaps. (team)
- Website Member Spotlights: Develop a format and begin spotlighting council members and their activities on the website. (Neena, Kimberly, Tara)

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) Neena Champaigne, MD (MUSC)	A P
Department of Public Health	Ginie Daguise, PhD (SCDPH) Beth Bair, PhD (SCDPH)	A P
Department of Health and Human Services	Kevin Wessinger, MD (SCDHHS)	P
Greenwood Genetic Center	Steve Skinner, MD (President & CEO)	A
Prisma Health - University of South Carolina	Divya Ahuja, MD, MRCP (Infectious Diseases)	A
South Carolina Hospital Association	Kate Wink, MPA (Santee Cooper)	A
South Carolina Primary Healthcare Association	Vicki Young, PhD (SCPHCA)	A
Biopharma Industry	Jonathan Hawayek (Genentech)	P
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 A
Patient (2)	Karen Kemper, PhD (scleroderma) Bridget Downing	P A
Rare Disease Organization	Yvonne Donald, M.A., CSCEC (James R. Clark Memorial Sickle Cell Foundation)	A
Caregiver of person with rare disease	Cara O'Neill, MD, FAAP (Cure Sanfilippo Foundation)	P
State Health Plan	Tripp Jennings, MD (VP and Clinical Innovations Officer, BCBS South Carolina)	A
Program Coordinator	Tara Pittman Kimberly Brown	A 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 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.