Rare Diseases Advisory Council Quarterly Meeting

January 16, 2026

9:00 AM-10:00 AM

Meeting agenda:

- Welcome

- Planning for the 3rd Annual Rare Disease Symposium
    - General theme surrounding the different aspects of transition, including healthcare, independence, life skills and aging
    - Discussed different points of the agenda
        - RD Prevalence - will cover top 10 or 20 prevalent conditions
        - Health Economics 101 - for the community/lay audience; won't be specific to only rare diseases
        - Technical Assistance and Training
        - Resources Panel and Q&A - Able SC and Family Connection SC will share what they offer and how it impacts the rare disease community
        - Patient, Parent/Caregiver, Provider Panel
            - KW has patient and caregiver connections that might be helpful
            - Needs look different for more dependent adults and that might be valuable to address in part of the panels
            - Disabilities can be an important topic surrounding rare disease and could be a valuable element of future events

- Bill Tracking
    - General Assembly is back in session as of this week. In session every Tuesday, Wednesday and Thursday and that is when new bills can be proposed. It's an election year for the House and constitutional officers but not the Senate. We are in the second year of a 2-year legislative session. Any bills that have been submitted that haven't become law will be lost after this year and would have to be submitted again.
    - KW to update spreadsheet of tracked bills, reflecting first readings and any new introductions relevant to rare diseases. No committee meetings scheduled for any of the bills at this time but KW to keep checking and let the RDAC know when something is up for discussion.
        - LCI committee stands for Labor, Commerce & Industry
        - Mark Sweatman can help the RDAC to get before the committees to share information
    - May be helpful to develop a website page to share bill information and general advocacy resources, including disclaimers and links to help users find their representatives.
        - Necessary to include disclaimer language that says that the RDAC is just providing information and not advocating for anything in particular.

        - Necessary to establish a plan for regularly updating the page to ensure accuracy as bills are introduced, amended, or removed; include language that mentions that this is not an exhaustive list.
        - <u>TP and KB to identify other RDAC websites that effectively present resources for reference in developing the new page.</u>

- Responding to requests received to our RDAC email
    - There has been an increase in the volume and complexity of inquiries received. The group <u>discussed the need for a standardized response process and the formation of a subcommittee to address these challenges</u>.
        - Creating stock responses
            - How are other RDACs triaging messaging?
            - Free text v. drop-down message selections (limit free text to prevent oversharing of PHI)
            - Could there be an office at universities that field questions like this?
            - Risk management (legal review of statements)
        - Triaging potential resources for inclusion on the website
            - Potential resources to recommend:
                - NORD Information & Resources Services Team
                - Able SC
                - Family Connections of SC
                - SC Rare
    - Tracking data related to incoming messages would be a good metric to report on over time.
    - JH, KK interested in the subcommittee
        - Outlined the need for broader participation in the subcommittee; suggested involving external stakeholders such as legal, risk management, and state agencies
        - <u>TP and KB to provide summary of types of emails that our coming through the request box.</u>

- 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)	X
Department of Public Health	Ginie Daguise (SCDPH)	
Department of Health and Human Services	Kevin Wessinger (SCDHHS)	X
Greenwood Genetics	Steve Skinner, MD (President & CEO)	
Prisma Health -University of South Carolina	Divya Ahuja, MD, MRCP (Infectious Diseases)	
South Carolina Hospital Association	Kate Wink (Santee Cooper)	X
South Carolina Primary Healthcare Association	Vicki Young (SCPHCA)	X
Biopharma Industry	Jonathan Hawayek (SPARK Therapeutics)	X
Research and Treatment of Rare Diseases (3)	Maysen Mesaros, MS (MUSC, neuroscience) Neena Champaigne, MD (Pediatric Genetics) Chip Norris, PhD (MUSC, connective tissue)	X
Patient (2)	Karen Kemper, PhD (scleroderma) Bridget Downing	X X
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)	X
State Health Plan	Tripp Jennings, MD (VP and Clinical Innovations Officer, BCBS South Carolina)	X
Program Coordinator	Tara Pittman Kimberly Brown	X 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.