



February 1, 2022

The Honorable Sharon Cooper  
 Chair  
 House Health and Human Services Committee  
 436 State Capitol  
 Atlanta, GA 30334

**Re: Support for House Bill 918: Rare Disease Advisory Council**

Dear Chair Cooper and Members of the House Health and Human Services Committee:

On behalf of the 20 undersigned organizations representing individuals with rare diseases in Georgia, we urge you to add House Bill 918 (HB 918) to the House Health and Human Services Committee’s next meeting agenda. HB 918 establishes a Rare Disease Advisory Council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in Georgia.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community’s needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While RDACs are organized differently in each state, they provide a forum for patients, families, and experts across the state to analyze the needs of the community and make recommendations on how to improve public policy related to rare diseases. RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials. The council may conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts to improve access to quality health care, or publish and compile resources related to rare diseases.

In creating this council, Georgia will join twenty-one other states that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can an invaluable resource. Those states are Alabama, Connecticut, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Chair Cooper, we thank you, Vice Chair Newton, and Representative Cheokas for your leadership and sponsorship of HB 918 and urge you to add HB 918 to the House Health and Human Services Committee's next meeting agenda. For any questions, please feel free to contact Annissa Reed with the National Organization for Rare Disorders via email at [areed@rarediseases.org](mailto:areed@rarediseases.org). Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders  
Alliance for Patient Access  
American Cancer Society Cancer Action Network  
American Kidney Fund  
Be The Match/National Marrow Donor Program  
Black Women's Health Imperative  
CFC International  
Children's Cardiomyopathy Foundation  
Cure VCP Disease, Inc.  
Haystack Project  
IGA Nephropathy Foundation  
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)  
International Pemphigus Pemphigoid Foundation  
Malan Syndrome Foundation  
National Niemann Pick Disease Foundation  
National Scleroderma Foundation  
Rare Strides  
SATB2 Gene Foundation  
Sick Cells  
Southeastern Sarcoidosis Support Group (SSSG)