NORD National Organization for Rare Disorders
HEMOPHILIA of South Carolina SERVING ALL BLEEDING DISORDERS
Cancer Action Network American Cancer Society 20 YEARS
NATIONAL MARROW DONOR PROGRAM BE THE MATCH
Chronic Disease Coalition
EPILEPSY FOUNDATION
GBS|CIDP Foundation International
GLOBAL HEALTHY LIVING FOUNDATION
HFA Hemophilia Federation of America
IDF Immune Deficiency Foundation
INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS (AiArthritis)
LEUKEMIA & LYMPHOMA SOCIETY
NATIONAL HEMOPHILIA FOUNDATION for all bleeding disorders
Neuropathy Action Foundation Awareness • Education • Empowerment
Sara's Cure Stamping out Sarcoma

March 8, 2021

The Honorable Leon Howard
Chair
House Medical, Military, Public and Municipal Affairs Committee
425 Blatt Building
Columbia, SC 29201

Re: Support for House Bill 3956 - Rare Disease Advisory Council

Dear Chairman Howard,

On behalf of the undersigned organizations representing hundreds of thousands of individuals with rare diseases in South Carolina, we thank you for your work during COVID-19 and for introducing House Bill 3956 (H3956). H3956 would establish a rare disease advisory council (RDAC) within the state and would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in the state of South Carolina. We write to urge you to help move H3956 this session.

The unprecedented challenges created by the COVID-19 pandemic have severely impacted rare disease patients. Rare diseases are present across a broad spectrum of medical conditions and their needs have not subsided during this crisis. For example, across the country, 74% of rare disease patients have had a medical appointment cancelled due to COVID-19 and approximately 70% are concerned about medication and medical supply shortages.[1]

Creating an RDAC in South Carolina will give rare disease patients a unified voice in our state government and help to address these COVID-19 challenges and many others faced by the rare disease community outside of the pandemic. Additionally, the RDAC will act as the advisory body on rare diseases to the South Carolina Legislature and state departments. It will also be tasked with: 1) convening public hearings, making inquiries, and soliciting comments from the general public; 2) consulting with experts to develop policy recommendations; 3) researching and identifying policy priorities related to treatment and services to develop policy recommendations, including safeguards against discrimination, or on issues including emergency preparedness; 4) publishing a list of resources on the state's website; 5) identifying and distributing educational resources for health care providers; and 6) researching and identifying best practices to reduce health disparities and achieve health equity.

The RDAC represents enormous value to our organizations and the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, the RDAC would help expeditiously deliver direct feedback, solutions, and resources to South Carolina government decisionmakers with one community voice.

In creating this council, South Carolina would join sixteen other states that have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource. Those states include: Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia.

On behalf of the undersigned organizations, we thank you for your support and urge swift consideration of H3956 before the House Medical, Military, Public and Municipal Affairs Committee. Please feel free to contact Annissa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org or Sue Martin with the Hemophilia of South Carolina at sue.martin@hemophiliasc.org if you have any questions. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders
Hemophilia of South Carolina
American Cancer Society – Cancer Action Network
Be The Match/ National Marrow Donor Program
Chronic Disease Coalition
Epilepsy Foundation of South Carolina
GBS|CIDP Foundation International
Global Healthy Living Foundation
Hemophilia Federation of America
Immune Deficiency Foundation
International Foundation for Autoimmune & Autoinflammatory Arthritis
The Leukemia & Lymphoma Society
National Hemophilia Foundation
Neuropathy Action Foundation
Sara's Cure (Rare Pediatric Sarcoma)

CC: Members of the House Committee on Medical, Military, Public and Municipal Affairs