

GOVERNMENT OFFICIALS, MEDICAL & POLICY EXPERTS, AND PATIENT ADVOCATES MEET IN COLUMBIA FOR BLEEDING DISORDERS FORUM

(Greenville, South Carolina) — On Thursday, August 16, and Friday, August 17, 2018, approximately 47 policy experts, government officials, medical professionals, and bleeding disorders advocates, met in Columbia, South Carolina, to address access to healthcare issues at a forum titled *The South Carolina Challenge*, coordinated by Hemophilia of South Carolina (HSC) and their Advocacy Coalition. On Thursday evening, the group assembled for dinner and an opening program, *Why Healthcare Matters*, which featured testimony by HSC community member **Mr. Gene Wilson** about living with severe hemophilia and an inhibitor, as well as an opening keynote address by **Representative Leon Howard**, chair of the Medical, Military, Public and Municipal Affairs Committee in the South Carolina House of Representatives, who shared a bit about his families personal experiences regarding challenges to accessing healthcare and roadblocks he sees within the healthcare system, as well as his vision of how government can work to ensure persons with chronic diseases can have better and more reliable access to healthcare.

On Friday morning, **Ms. Sue Martin**, executive director of HSC and Advocacy Coalition member, welcomed the group and facilitated introductions. Assisting in facilitating the forum was **Mr. Jeremy Williams**, HSC policy and advocacy assistant, who is also a member of the HSC Advocacy Coalition. The program then kicked off with testimony by **Mr. Shawn Sperry**, vice president of HSC's board of directors and chair of its Advocacy Coalition, who is a ninth generation with severe hemophilia. **Ms. Brendan Hayes**, government relations specialist with the public policy team at the National Hemophilia Foundation (NHF), initiated the *Bleeding Disorders 101: History of Bleeding Disorders; Our Past and Our Future* portion of the program, which included a brief understanding of bleeding disorders, the evolution of clotting factor treatment, and other major medical developments relevant to hemophilia and similar disorders. This program also included testimony by HSC board members **Ms. Cristal Day**, who serves as vice chair of the HSC Advocacy Coalition, and **Ms. Wendy Legrand**, who is the current secretary of the Advocacy Coalition.

The remainder of the morning was spent on a program *The Value of Hemophilia Treatment Centers (HTC)*, which explored the importance of the nationwide network of centers that provide comprehensive care to persons with bleeding disorders through continuous supervision of all medical and psychosocial aspects of a patient's health. The program began with a look at the sole HTC located in South Carolina, at Palmetto Health Richland Hospital in Columbia, through a presentation by **Dr. Stephanie Ambrose**, director of the HTC, and **Ms. Robin Jones**, the HTC's nurse coordinator. The session included testimony of the importance of patient access to treatment centers, funding support for staff, and access for the adult population by **Ms. Martin** and **Ms. Connie Graham**. Next, **Dr. Paulette Bryant**, director of the newly designated HTC at St. Jude Affiliate Clinic at Novant Hemby Children's Hospital in Charlotte, North Carolina, gave a talk on the processes involved, and obstacles overcome, in their development as a newly designated HTC. Dr. Bryant was joined by their HTC nurse coordinator, **Ms. Elizabeth Lineberger**. This portion of the program concluded with a presentation by **Mr. Sean Singh**, senior vice president of marketing and operations at the Hemophilia Alliance, an organization that advises, advocates for, and even negotiates on behalf of the 142 HTCs throughout the country. Mr. Singh emphasized the importance of the HTC model as an exemplary standard of bleeding disorders care.

The afternoon program began with *Access to Healthcare Part 1: Medicaid*, and featured talks by **Mr. Nathan Shaefer**, senior policy director at NHF, and **Ms. Miriam Goldstein**, associate director at the Hemophilia Federation of America (HFA), to give an overview of the current, national Medicaid landscape, including some of the common challenges faced by the bleeding disorders population who are also Medicaid beneficiaries, such as limits on access to preferred

therapies; restraints on access to HTC and comprehensive care; restrictions pertaining to prescriptions and ancillary services; and vast variations in coverage by managed care organizations from state to state. The program then featured a talk by **Mr. Bryan Amick**, deputy director of the Office of Health Programs at the South Carolina Department of Health and Human Services, who spoke about drug pricing issues in the state, incentivizing high quality care, policy solutions tailored to fit the competitive healthcare landscape, as well as an overview of the prospective solutions his office is seeking to provide better care for the more than 1 million Medicaid recipients in the state. **Ms. Renita Johnson**, HSC board member and member of the Advocacy Coalition, then provided testimony regarding her family's experiences with bleeding disorders and the South Carolina Medicaid program. The forum then featured an open discussion of the challenges with access to care and treatment services, led by the three main hospital networks in the state. Representing Children's Hospital of Greenville Health System was **Dr. Leslie Gilbert**, assistant professor of clinical pediatrics in the Pediatric Hematology-Oncology department; representing the Medical University of South Carolina was **Dr. Shayla Bergmann**, assistant professor and director of the Pediatric Hemophilia Clinic, and **Dr. John Lazarchick**, director of the Hematology and Hematopathology Fellowship Program; and representing the HTC at Palmetto Health Richland, was **Dr. Ambrose** and **Ms. Jones**. The Medicaid program concluded with a presentation by HSC's **Ms. Martin** on the prospect of implementing a model standard of care for Medicaid beneficiaries with bleeding disorders in South Carolina, focusing on access to HTCs; better monitoring, engagement, and support services; product availability and assay management; and timely delivery of services.

The concluding portion of the afternoon program, *Access to Healthcare Part 2: Threats and Protections*, turned to a discussion of the existing instabilities in private and public healthcare plans and treatments, as well as programs that seek to mitigate these threats for bleeding disorders patients. The program featured talks by **Mr. Shaefer** from NHF, and **Ms. Goldstein** from HFA, on existing threats and challenges, followed by **Ms. Tammy McKenna**, director of the Department of Children with Special Health Care Needs at the South Carolina Department of Health and Environmental Control, on the hemophilia assistance program that exists within her division. **Mr. James Romano**, director of government relations with Patient Services, Inc., then gave a talk on his organization's national premium assistance program. HSC's **Ms. Martin** gave an overview of the various manufacturers' patient assistance programs available to persons with bleeding disorders. Advocacy Coalition ambassador and HSC member **Mr. Will Beaty**, concluded the program with a testimony about the importance of such safety-net programs to the continuity of healthcare for people with chronic diseases.

The day concluded with a summary by NHF's **Ms. Hayes** of the goals and objectives laid out by the forum, and an open discussion of "next steps forward." **Ms. Martin** also gave some concluding remarks and warmly thanked the attendees for their time, commitments, and willingness to work with HSC and its Advocacy Coalition. The forum was a huge success and proved to be a useful conduit for bringing together the wide variety of expertise and experience from throughout the nation in order to share ideas and formulate solutions to the many challenges facing the South Carolina bleeding disorders community.

ATTENDANCE LIST
The South Carolina Challenge Forum
August 16 – 17, 2018
Hilton Columbia Center
Columbia, South Carolina

- Ms. Courtney Alexander*, Pediatric Hematology/Oncology Clinical Pharmacist, Greenville Health System
- Dr. Stephanie Ambrose*, Medical Director, HTC at Palmetto Health Richland
- Mr. Bryan Amick*, Deputy Director, Office of Health Programs, South Carolina Department of Health & Human Services
- Mr. Will Beaty*, Member and Ambassador, Hemophilia of South Carolina Advocacy Coalition
- Mr. Keith Bish*, Lead for U.S. Regional Patient Advocacy, Shire
- Dr. Shayla Bergmann*, Assistant Professor of Pediatric Hematology/Oncology, Medical University of South Carolina
- Ms. Anna Bleasdale*, Registered Nurse, South Carolina Department of Health & Environmental Control
- Ms. Diane Bolin*, Nurse Consultant, Children & Youth with Special Health Care Needs, South Carolina Department of Health & Environmental Control
- Dr. James Bradford*, Clinical and Medical Affairs, South Carolina Department of Health & Human Services
- Dr. Paulette Bryant*, Medical Director, HTC at St. Jude Affiliate Clinic at Novant Health Hemby
- Ms. Martha Breitwieser*, Member and Ambassador, Hemophilia of South Carolina Advocacy Coalition
- Ms. Shelley Crisp*, Member, Hemophilia of South Carolina Board of Directors and Advocacy Coalition
- Ms. Cristal Day*, Vice Chair, Hemophilia of South Carolina Advocacy Coalition, and Member, Hemophilia of South Carolina Board of Directors
- Dr. Carley Howard Draddy*, Vice Chair of Pediatric Quality and Medical Staff Affairs, Greenville Health System
- Ms. Ebone' Gadson*, Program Manager, Children & Youth with Special Health Care Needs, South Carolina Department of Health & Environmental Control
- Dr. Leslie Gilbert*, Assistant Professor of Clinical Pediatrics, Greenville Health System
- Ms. Miriam Goldstein*, Associate Director of Policy, Hemophilia Federation of America, and Member, Hemophilia of South Carolina Advocacy Coalition
- Ms. Connie Graham*, Ambassador, Hemophilia of South Carolina Advocacy Coalition
- Mr. Dwayne Graham*, Ambassador, Hemophilia of South Carolina Advocacy Coalition
- Dr. George Haddad*, Vice Chair of Pediatric Clinical Services, Greenville Health System
- Ms. Brendan Hayes*, Government Relations Specialist, National Hemophilia Foundation, and Member, Hemophilia of South Carolina Advocacy Coalition
- Rep. Leon Howard*, Chair of the Medical, Military, Public & Municipal Affairs Committee, South Carolina House of Representatives
- Ms. Robin Jones*, Nurse Coordinator, HTC at Palmetto Health Richland

Ms. Renita Johnson, Member, Hemophilia of South Carolina Board of Directors and Advocacy Coalition
Dr. John Lazrchick, Professor of Pathology and Laboratory Medicine, Medical University of South Carolina
Ms. Wendy Legrand, Secretary, Hemophilia of South Carolina Advocacy Coalition, and Member, Hemophilia of South Carolina Board of Directors
Ms. Elizabeth Lineberger, Nurse Coordinator, HTC at St. Jude Affiliate Clinic at Novant Health Hemby
Ms. Sue Martin, Executive Director, Hemophilia of South Carolina, and Member, Hemophilia of South Carolina Advocacy Coalition
Ms. Tammy McKenna, Division Director, Children & Youth with Special Health Care Needs, South Carolina Department of Health & Environmental Control
Mr. Bryan Merrell, Government Customers & Medicaid, Bayer
Ms. Shari Miles, Life, Accident & Health Manager, Market & Consumer Services Division, South Carolina Department of Insurance
Mr. Toni Mitchell, Senior Manager of State Government Affairs, CSL Behring
Dr. Tan Platt, Medical Director, South Carolina Department of Health & Human Services
Mr. James Romano, Director of Government Relations, Patient Services, Inc., and Member, Hemophilia of South Carolina Advocacy Coalition

Ms. Brenna Raines, Senior Manager of Health Policy, North America & Global Health, Plasma Protein Therapeutics Association
Mr. Monty Robertson, Manager, Alliance for a Healthier South Carolina
Mr. Nathan Shaefer, Senior Policy Director, National Hemophilia Foundation
Mr. Sean Singh, Senior Vice President, Hemophilia Alliance
Ms. Jennifer Sperry, Ambassador, Hemophilia of South Carolina Advocacy Coalition
Mr. Shawn Sperry, Chair, Hemophilia of South Carolina Advocacy Coalition, and Vice President, Hemophilia of South Carolina Board of Directors
Ms. Nikki Stafford, Administrator, Greenville Health System
Mr. Fred Verde, Director of Government Customers, Bayer
Mr. Mike Walden, President, Hemophilia of South Carolina Board of Directors, and Ambassador, Hemophilia of South Carolina Advocacy Coalition
Ms. Amanda Williams, Director, Division of Coverage & Benefit Design, South Carolina Department of Health & Human Services
Mr. Jeremy Williams, Advocacy & Policy Assistant, Hemophilia of South Carolina, and Member, Hemophilia of South Carolina Advocacy Coalition
Mr. Gene Wilson, Member, Hemophilia of South Carolina
Ms. Karen Wilson, Member, Hemophilia of South Carolina