Patient Advocates and Stakeholders Meet In Greenville To Discuss 2020 Outlook

By Jeremy Williams

On Friday, November 8, more than 30 advocates, healthcare professionals, policy experts, government officials, and industry representatives met in Greenville to continue ongoing discussions begun at HSC's "South Carolina Bleeding Disorders Challenge" forum in 2018, regarding access to healthcare for persons with bleeding disorders living in the state. The day kicked off with heartfelt and moving personal stories from four HSC advocacy members: Cristal Day (Advocacy Coalition chair), Jameelah Malcolm, Eric Dunton, and Meggan Burton (Advocacy Ambassadors). Each of them offered compelling life lessons involving their (and their family members') persistence in confronting the challenges of living with a bleeding disorder. They talked about experiencing the loss of loved ones during the tainted blood crisis, and how advancements have afforded themselves and their children very different lives and life experiences than their parents and grandparents. Their stories are unique as well, since they stem from different experiences, whether associated with challenges in obtaining or retaining health coverage, to limitations on prophylactic treatment, to the formidable challenges of dealing with an inhibitor. But a common theme among all four presenters was the resounding call for the bleeding disorders community to never "move backwards," to continue advocating and fighting. After detailing all the ways that her family remains optimistic, Meggan concluded her talk with the cautionary call to action: "My son's future depends on access to care." The presentations were a fitting way to frame the advocacy and policy discussions going forward in the meeting. Sue Martin, executive director of HSC and Advocacy Coalition member ended the session with the 2019 stakeholders report of the accomplishments, successes, and challenges still facing the community, and HSC's 2020 forecasted healthcare policy initiatives.

The next segment of the meeting featured a discussion on national and state healthcare policies and trends. Nathan Schaefer, vice president of public policy at the National Hemophilia Foundation (NHF), began with a federal perspective, starting with--due to impeachment hearings and the two chambers of Congress being held by different parties--the inert environment in Washington. A number of concerns arise from this, not the least of which is the ability of Congress to continue funding the federal government, which they must do by either passing a budget bill or another (temporary) continuing resolution by November 21. Mr. Schaefer was, however, optimistic that hemophilia-related programs would remain in any appropriations bills in the near future. He then turned to a description of various major projects and programs being addressed by NHF, including federal legislation dealing with skilled nursing facilities (currently trying to find bipartisan support in the House of Representatives); a "Product Safety Summit" to be held in January; a recap of the 2019 Washington Days; a snapshot of state advocacy successes (he noted that, of the 54 state and local resolutions obtained throughout the country last year, 17 came from South Carolina!); and some perspective on what various state and federal elections in 2020 could mean for the bleeding disorders community.

Next, Kimberly Ramseur, senior manager of policy and advocacy at the Hemophilia Federation of America (HFA), gave a "states outlook" for the upcoming year. She began by talking about how, although legal and legislative attacks on the Affordable Care Act (ACA) so far have failed, there has been a steady "chipping away" of the various protections the ACA affords, through rulemaking in the Centers for Medicare and Medicaid Services (CMS) and other federal agencies. This has resulted in shortened enrollment periods; the elimination of reimbursements to insurers for cost-sharing reductions; states' ability to more broadly define "essential health benefits"; expanded availability of "skinny" health insurance plans; lengthening of the duration of "short term" health plans; and the authorization of states to waive ACA coverage standards. This, in turn, has resulted in the proliferation of plans that exclude people with pre-existing conditions; an uptick in plans that lead to confusion, underinsurance, and potential fraud or abuse; and essentially the emergence of two separate insurance markets: one (affordable) for individuals with fewer health needs, and another (expensive) one for people with pre-existing conditions, who need comprehensive insurance coverage. Ms. Ramseur also addressed the ongoing challenge to the ACA's constitutionality through the federal court case, *Texas v. United States*, which is currently before the 5th Circuit Court of Appeals in New Orleans (they heard oral arguments last July, and will be ruling on the case in the upcoming months). HFA and 16 other patient groups have filed an amicus brief defending the ACA. Ms. Ramseur emphasized that, if the ACA is struck down, then 21 million people could lose health insurance, 12 million could be kicked off Medicaid, and 133 million with pre-existing conditions would be in danger of not getting coverage. Ms. Ramseur concluded the presentation with a survey of South Carolina bills that would address Medicaid expansion and other ACA-related policies, as well as the status of the Medicaid work-requirement waiver currently filed with CMS. She also talked a bit about potential reforms on federal drug pricing, a proposed state tax on prescription drugs, and bipartisan interest in Congress on addressing the issue of "surprise" or "balance" billing.

The morning concluded with a presentation by Jeff Blake, senior vice president for payer relations at the Hemophilia Alliance, who talked about the organization's work to ensure that Hemophilia Treatment Centers (HTC) have access to the "expertise, resources, and public support, to sustain their integrative clinical and pharmacy services for individuals with bleeding and clotting disorders." Currently, the Alliance has 107 member HTCs, to which they help provide a variety of benefits, including group purchasing contracts (saved over $100 million total last year); payer contracting and payer relations support; operational and technical support; legal and regulatory support; and advocacy and education services. Mr. Blake emphasized the Alliance's commitment to the community, and talked about the valuable connections made with regional directors and coordinators, patient advocacy groups, as well as national and state policy organizations. Mr. Blake continued his talk with a look at many of the challenges present in today's healthcare environment, including the impact of mergers and acquisitions; specialty drug carve-outs; shifts towards managed care Medicaid structures in states; reduced reimbursement rates; and drug class management (e.g., prior authorizations, preferred drugs lists, "closed" formularies). He then catalogued existing and emerging drug treatments for bleeding disorders, including new clotting factor medications, and developments in gene therapy. He concluded his presentation with insistence upon the importance of HTC efforts to provide emblematic patient care, and strategies they can use to improve revenue, such as growing pharmacy businesses internally or working closely with local and national organizations for support.

The afternoon sessions kicked off with talks by Dr. Stephanie Ambrose and Robin Jones, director and nurse coordinator, respectively, at the HTC at Prisma Health Richland Hospital in Columbia. They talked about the status of the HTC program and the need for expansion of "HTC-caliber care to all areas of the state." They stressed the importance of the exemplary model of care received at the HTC, and the common misconception that comprehensive treatment necessarily exists at other clinics, who might, for instance, merely employ a hematologist. The HTC has recently added a research coordinator and a dedicated HTC pharmacist, and--due in part to access to the 340B drug purchasing program--affords access to many other services, such as psychologists and physical therapists, that other clinics cannot. Dr. Leslie Gilbert, pediatric hematologist at Prisma Health-Upstate, then talked about how they are trying to expand the "comprehensive care model" they already have in place for sickle cell patients, to the hemophilia and bleeding disorders clinic. They are working with the HTC in Columbia to see what they can do to further expand the services bleeding disorders patients are receiving in the Upstate.

Next, Bryan Amick, deputy director of the Office of Health Programs at the South Carolina Department of Health and Human Services (DHHS), gave a presentation on the status of the state Medicaid program, as it relates to persons with bleeding disorders. He mentioned that, at any given time, the Medicaid population in South Carolina sits at around 1.2 million beneficiaries. He spoke on the status of the state work-requirement waiver, and explained the various exemptions for the standard, should it be implemented, including children and people with disabilities. He spoke about the potential gap in coverage for someone who, due to a work requirement, is pushed beyond the 67 percent of the federal poverty level (FPL), loses Medicaid, but is not at the 100 percent FPL demarcation, where federal subsidies kick in for health coverage. He also emphasized the existence of broad “good cause exemptions,” for persons with extenuating medical conditions, such as hemophilia, that could possibility exempt someone from the work requirement. Mr. Amick then talked about targeted benefits expansions at DHHS, including a push to lengthen postpartum coverage Medicaid termination from 60 to 365 days. He talked about the five managed care organizations operating in the state (75 percent of Medicaid recipients in the state receive care through one of these). Mr. Amick touched briefly on the ongoing efforts of the governor’s Opioid Emergency Response Team, and their efforts to focus on treatment for opioid addiction in the state. He also talked about the lack of intent to pursue clotting factor formulary criteria for drug benefits in fee-for-service (FFS) Medicaid. He concluded by urging the audience to inform DHHS of barriers to care that they see, both for managed care and FFS beneficiaries.

Afternoon programs continued with a presentation by Tammy McKenna, nurse consultant and director for the Division of Children and Youth with Special Health Care Needs in the South Carolina Department of Health and Environmental Control, who gave an update on their hemophilia assistance program, which pays premiums, co-pays, and deductibles for enrollees. They also partner with the DHHS FFS program to provide pharmacy benefits to beneficiaries with bleeding disorders. Ms. McKenna emphasized that they are working to expand their programs.

Formal presentations concluded with a demonstration by Drew Clawson, president of Kinard Consulting, of the Medical Assistance Tool (MAT.org), a web portal developed by pharmaceutical partners to aggregate information about resources for accessing medication. This search tool utilizes criteria like health insurance and diagnosis to display data on what treatments and medications are available to the individual searching, including links to companies and service organizations related to those medications and therapies.

The meeting wrapped up with a presentation by Sue of ongoing advocacy and policy initiatives HSC is pursuing, such as involvement in the development of a Rare Disease Council in South Carolina, and emergency room standards of care legislation. She concluded the meeting with a heartfelt message of thanks and appreciation to all in attendance with the excitement of ongoing collaboration and partnerships for quality access to treatment in South Carolina. Sue committed the chapter’s advocacy support to the SC Rare Diseases Coalitions in raising collective concerns within healthcare access and thanked Rachel Goddard, Health Access Advocate from the Immune Deficiency Foundation for joining the stakeholders meeting in partnership.

2019 Stakeholder attendees:

Sue Martin	Executive Director, HSC / Advocacy Coalition Member
Dr. Leslie Gilbert	Assistant Professor Clinical Pediatrics, Prismahealth-Upstate
Eric Dunton	Advocacy Coalition Ambassador / HSC Board Member
Jameelah Malcolm	Advocacy Coalition Ambassador
Courtney Alexander	Prisma Health Upstate- Clinical Pharmacy Specialist, Pediatric Heme / Onc
Shannon Cearley	Prisma Health Midlands- Program Associate
Alison Clifford	Director, Therapeutic Policy and Advocacy, Takeda
Cathy King	Prisma Health BILO Charities, Nurse Manager

Renita Johnson	Advocacy Coalition Member / HSC Board Member
Jeff Blake	Hemophilia Alliance, SR. VP Payer Relations
Anna Bleasdale	SC DHEC Nurse Coordinator for CYSHCN
Robin Jones	SCHTC Nurse Navigator
Tammy McKenna	Division Director for CYSHSN
Nathan Schaefer	VP of Public Policy, National Hemophilia Foundation
Kimberly Ramseur, JD, MPH	Senior Manager for Policy & Advocacy, Hemophilia Federation of America
Meggan Burton	Advocacy Coalition Ambassador
Drew Clawson	President, Kinard Consulting
Amy Newman	Advocacy Coalition Member
James Bradford, MD	Senior Consultant / SCDHHS
Stephanie Ambrose, DO	Ped. Hematology / Onc Attending, Children's Center for Cancer & Blood Disorders, Prisma Health-Midlands
Katie Bull, PharmD	Prisma Health Midlands- HTC Pharmacist
Rachel Goddard	Immune Deficiency Foundation / Health Access Advocate
Bryan Amick	Deputy Director, Office of Health Programs, South Carolina Department of Health & Human Services
Sherlene Maloy	Advocacy Coalition Ambassador
Mike Maloy	Advocacy Coalition Ambassador
Cristal Day	Advocacy Coalition Chair, HSC Board Member
Abigayle Campbell	Prisma Health Upstate- Pharmacy Resident
Marcus Downs	Director, US Public Affairs, Southern Region, Takeda
Aaron Smith	Advocacy Coalition Member, HSC Board Member
Jeremy Williams	HSC Advocacy Assistant
Diane Bolin, RN,MSN	Nurse Consultant, CYSHCN, DHEC