

# WELCOME TO THE FALL FAMILY ADVOCACY CAMP AND MEDICAL SYMPOSIUM

## “Stronger Together: One Voice”



**YOUR VOICE FOR POSITIVE CHANGE**



**fall family advocacy camp &  
medical symposium**  
october 19-20, 2024

# Our Mission

To raise awareness for and advocate on behalf of persons with bleeding disorders and their families; provide education and supportive services; and promote ongoing research to improve the quality of life for those affected.

# Our Vision

To be recognized as a leading organization providing valued services; as ambassadors of public outreach to enlighten and foster an understanding of what matters most to those affected by hemophilia and bleeding disorders; and to be our community's first choice in partnership to achieve their highest potential through empowerment, connection to their community, and being part of the solutions that affect them the most, until a cure is achieved.

**BDASC**  
Engage. Empower. Educate.



**BLEEDING DISORDERS  
ASSOCIATION  
OF SOUTH CAROLINA**

# With Appreciation to our Sponsors!



# Welcome! Making Our Voices Heard

- ❖ **Overview of the Weekend Agenda**

- ❖ **Who's who in bleeding disorders and how are we all connected in Advocacy and Access to Care:**

  - National Bleeding Disorders Foundation – MASAC (Medical and Scientific Advisory Council)

  - Hemophilia Federation of America

  - World Federation of Hemophilia

  - Hemophilia Alliance and Foundation

  - Coalition for Hemophilia B

  - Hope for Hemophilia

  - FAIR Time for Women Coalition

- ❖ **Believe Limited: Digital Content Agency (Sharing our Stories) NBDF's Voices for Policy Change, Bloodstream Podcasts, (Global Hemophilia Report)**

- ❖ **BDASC Advocacy Partnerships and Memberships**

  - NBDF State Based Coalition

  - HFA's Advocacy Coalition

  - All Copays Count Coalition

  - SC Palmetto Health Collective

  - Cover SC - Strengthen the health and economy of SC through affordable, sustainable healthcare coverage. Advocacy Allies Peer Network

  - Together SC – Advocacy Coalition Team Member



# Advocacy is Within All of US!

## ❖ South Carolina Hemophilia Treatment Centers:

- ❖ New Name, new locations; Serving the Rural Communities
- ❖ A Whole Life Approach; Birth throughout the Lifespan
- ❖ Advancing Treatment Care for Women and Girl; including Symptomatic Carriers
- ❖ Educating for earlier diagnosis and treatment care for Von Willebrand's Disease
- ❖ Transitioning Our Teens for Adulthood; HTC Priority Partnership – BDASC Approach
- ❖ Participation in the CDC Community Counts Registry: Aims to improve the medical care and healthcare outcomes for people with bleeding disorders
- ❖ HTC's partnership with ATHN Affiliates – affiliated HTCs across the nations contributing to the ATHN dataset: de-identified data contributed by persons with BD in the US. Helping researchers answer scientific, public health, and policy questions- prevent complications and improve health outcomes.

[Athn.org](http://Athn.org)

[cdc.gov/communitycounts](http://cdc.gov/communitycounts)

[cdc.gov/ncbddd](http://cdc.gov/ncbddd) (National Center on Birth Defects and Developmental Disabilities)

[Clinicaltrials.gov](http://Clinicaltrials.gov)

- ❖ National Programs of NBDF: Ambassador for Research and Own your Own Path Program



PRISMA  
HEALTH®

## ❖ Are You A Good Steward?

### ❖ Making and KEEPING your Annual HTC Appointment

What happens when you miss your appointment; what could it cost us one day

### ❖ Working with your Specialty Pharmacy

Do you answer the calls, are you proactive, or a last-minute thinker

### ❖ Advocating for your personal healthcare needs; shared decision -making

Do not be afraid to ask your questions, you know your bleeding disorder the best.



AlejandaLopez:

Unlocking Hemophilia Care: Your HTC, a gateway to expert care and support.

[https://youtu.be/AA8q\\_XdC6EU](https://youtu.be/AA8q_XdC6EU)

# Taking Control of Your Own Health Care

# South Carolina Resources for Access

## ❖ BDASC Financial Assistance Program

### ❖ Disaster Relief Financial Assistance

Sponsored by the Hemophilia Alliance Foundation Grants and private donations to BDASC



## ❖ State Hemophilia Assistance Program (HAP)

Malerie Hartsell, MPH, CHES, APM

Section Director

Children and Youth with Special Health Care Needs

2100 Bull Street

Columbia, SC 29201

Main Line: 803-898-0784

Email: [hartsem@dph.sc.gov](mailto:hartsem@dph.sc.gov)

DPH Site: [Blood Disorders Assistance Program](#)



# Understanding Health Care Access

Welcome James Romano, BDASC Legislative Coordinator and President of Care and Cure Partners

- ❖ Open Enrollment
- ❖ Patient Assistance Programs
- ❖ SC Disability



# Insurance Open Enrollment Periods

- Medicare Open Enrollment —Dates
  - o October 15 through December 7
- Exchange Open Enrollment —Dates
  - o November 1 through January 15
  - o December 15<sup>th</sup>, is the last day to enroll or change plans for coverage to start January 1<sup>st</sup>
  - o January 15<sup>th</sup>, 2025, the last day to enroll or change plans for
- Employer Open Enrollment
  - o Enrollment dates can fluctuate but now is the time to begin asking questions of your or your spouses HR.
- What do you need to Know?
  - o Physician/Treatment Center in Network
  - o Treatment on the Formulary
  - o Does your plan have cost -containment policies such as a:
    - § Copayment Accumulators
      - Alternative Funding Programs

# Patient Assistance Programs for Bleeding Disorder Pat

- ACCESSIA HEALTH
- THE ASSISTANCE FUND
- PAN FOUNDATION
- OTHER OPTIONS

## AH- Inherited § Inherited and Acquired Factor Deficiencies—Public

- Program is at Capacity
- Federal FPL 500%--
  - FPL in SC for family of four is \$31,200 / \$156,000
  - Maximum Assistance: \$5300
  - Assistance Types
    - § Copay
    - § Premium
    - § Medical Expenses
    - § Travel Expenses—Limited to \$500
- [www.AccessiaHealth.org](http://www.AccessiaHealth.org)

# AH: Inherited and Acquired Factor Deficiencies—Private

Federal FPL Limit 500%

Maximum Assistance Amount \$6000

Assistance Types

- Copay
- Premium
- Medical Expenses
- Travel Expenses—limited to \$500

# TAF–Hemophilia and ITP Programs

## The Assistance Fund Hemophilia Program

- Waitlist Currently
- Assistance–
  - Prescription Drug Assistance (Copay/Deductible/Coinsurance)
  - Health Insurance Premiums
  - Treatment Related Travel Costs
  - Genetic Testing
- Eligibility
  - US Citizen
  - Diagnosis
  - Meet Financial Qualification

## The Assistance Fund Thrombocytopenia Program

- Waitlist Currently
- Copayment Assistance Only

# PANF–Hemophilia Program

## Pan Foundation Hemophilia Program

- Open
- Total Grant Amount: \$5,100
- Income at or below 500% FPL (\$31,200)
- Prescription Drug (Copayment/Deductibles/Coinsurance)

## Pan Foundation Hemophilia Premium Program

- Closed
- Total Grant Amount: \$4,700
- Income at or below 500% FPL
- used for premiums

[www.panfoundation.org](http://www.panfoundation.org)

# Other Patient Assistance Programs for Bleeding Disorder Patients

## Hope Charities

- Resource Connection
- Direct Patient Assistance
  - Cap of \$1500
- Access To Care
  - Premium Assistance

[www.hopeforhemophilia.org](http://www.hopeforhemophilia.org)

## Colbert Keenan Foundation

- \$2000 grant
- Only for Inherited Bleeding Disorders
  - Purchase Medical Alert Bracelets
  - Rent
  - Transportation to Treatment
  - Purchase Small Appliances
  - Utility Bills
  - Unexpected Medical Expenses

[www.cokeen.org](http://www.cokeen.org)

# South Carolina Disability Information

**Social Security Disability:** is a federal program for Americans who worked for years but can no longer work due to an injury or disability. Most citizens pay into Social Security through taxes once they begin working and the amount you receive for monthly disability benefits depends on the number of years you worked and your income.

- Qualifications
  - Must be under 67 years of age
  - Disability keeps you from working, lasts over 1 year, or is terminal
  - Must have enough work credits to qualify

**Supplemental Security Income:** is another federal program available to Americans who can't work due to disability. However, this program is an option if you've never worked or haven't worked in a number of years. It's also needs-based, and you can only qualify if you meet certain income requirements. You can apply for SSI through the same application as SSDI, so applying for both at the same time is often a good idea.

- Qualifications:
  - have a disability, for over one year or terminal
  - Have little or no savings and other assets — less than \$2,000 if you're single and less than \$3,000 if you're married.
  - Have less than about \$1,000 of income from any source.

## **Access Health ACCESS Program**

- Free Legal Assistance for Bleeding Disorders Community
- 888.700.7010
- Can Assist with Disability



# South Carolina Medicaid

Welcome: Ayesha Coney &  
William Brown

SOUTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES

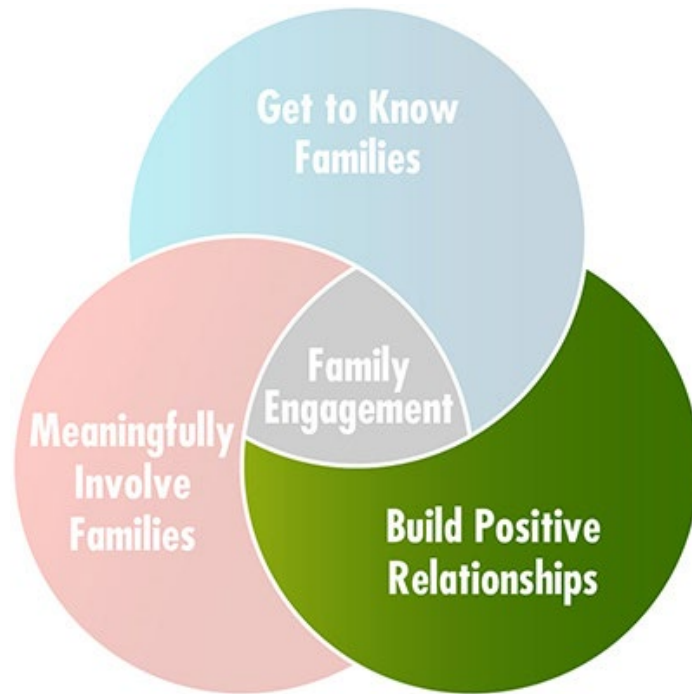
Healthy Connections

MEDICAID



# Advocacy Plenary: Session 2

## Know Your SC Legislators



# 2025 Legislative Session Outlook

**Welcome Seth Rose (D) District 72**



# 46 COUNTIES – 7 CONGRESSIONAL DISTRICTS YOUR VOICE MATTERS!

The South Carolina Hemophilia and Bleeding Disorders Coalition and Ambassadors

*20 Counties Represented to Date*

*52 Members Strong*

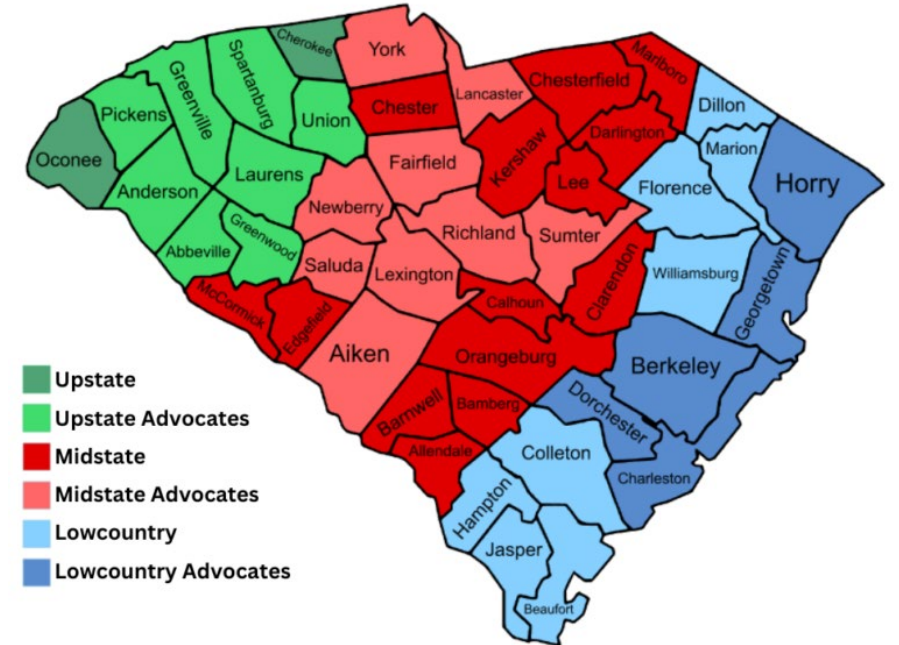
*16 Stakeholder Partnerships*

*Several Advocacy Coalition Partnerships*

*Goal – one advocacy representative in every county!*

*All (7) Congressional Districts are NOW represented*

***Ambassador Program:*** To help drive the efforts of Hemophilia of South Carolina's Advocacy Coalition, we have **Advocacy Ambassadors who are volunteers in a leadership position** responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within South Carolina. The goal is to help increase awareness of Hemophilia, Von Willebrand Disease, and other rare bleeding disorders and the challenges persons affected and their families face. Ambassadors increase awareness and support of Hemophilia of South Carolina and the Advocacy Coalition's mission. Ambassadors serve as liaisons between the Coalition and the public, state agencies, and officials working towards improving the quality of life of individuals and their families who are affected by bleeding disorders. The Coalition team is committed to our volunteer's engagement and contributions to the bleeding disorders community.



# 2025 Legislative Timeline

## Legislative Timeline & Process

**Our House Bill Assigned to Labor, Commerce, and Industry**

**Bill Introduced in the House**

Our House Bill Is Introduced  
William G. "Bill" Herbkersman ?

**Referred to Committee**

Labor, Commerce and Industry

**Co-Sponsors Added to the Bill**

## Current Step In Process

**1 Step**

**Sub-Committee Hearings**  
Labor, Commerce and Industry  
Chairman:

**2 Step**

**Full Committee Hearings**  
Labor, Commerce and Industry  
Chairman:

**3 Step**

**Sent to House Floor for 2nd & 3rd Reading Vote**  
**What happens after a bill is passed in one House of the legislature?**  
If the bill passes by simple majority\*, the bill moves to the Senate.

## Cross Over Deadline: TBD in April

*When a bill must cross a chamber. A "crossover" deadline is the last day for a bill to pass out of the chamber in which it was introduced and move forward for consideration in the opposite chamber. Once the house passes a bill, it crosses over to the senate. There is a deadline for bills to get to the other legislative body, known as the crossover deadline. In South Carolina, crossover deadline is TBD in April.*

**1 Step**

**Bill is read across the desk of the Senate**

**2 Step**

**Sub-Committee Hearings**  
Banking and Insurance  
Chairman:

**3 Step**

**Full Committee Hearings**  
Banking and Insurance  
Chairman:

**4 Step**

**Once on the Senate floor the bill can be debated and will require a 2nd and 3rd reading vote**

**5 Step**

**Governor McMaster Signs the Bill**



*\*The South Carolina House of Representatives consists of 124 members: Republicans and Democrats. A Simple Majority will be comprised of 63 members.*

# 2025 Focus - Looking Ahead

## Recapping 2024

Legislative Breakfast January 15, 2024: State Capitol, 8am – in need of strong advocate voices and children

Legislative Days: February 25 and February 26, 2025 (Virtual Trainings: Jan & Feb for new members & legislative priorities)

- State Legislative Training on the 25<sup>th</sup> Meetings on the 26<sup>th</sup>
- Rare Disease Day February 28, 2025

## Washington Days:

March 6-8<sup>th</sup>, 2024

## Legislative Priorities:

General education on bleeding disorders patient stories  
Support for our State Hemophilia Assistance Program (HAP)  
Support passing our bill that Bans Accumulator Adjusters and Maximizers  
Programs in insurance plans / need for education  
Medicaid Expansion Education and Support  
Other bills we may support



# Welcome Nathan Schaefer, NBDF

## National Update and Trends

Welcome Nathan, Senior Vice President of  
Public Policy and Access for the National  
Bleeding Disorders Foundation (NBDF)

52 Chapters State Policy Priorities



# Patient Stories are KEY Voices for Policy Change

## Featuring: Patient Advocate, Whitney G.

Navigating the complexities of healthcare access for bleeding disorders, a heartfelt journey urging policymakers to support fair legislation like the HELP Copays Act for accessible and equitable healthcare.

■ <https://www.youtube.com/watch?v=rbZBMWqk03c>

## Featuring: Advocate Expert, Sue Martin

Navigating the treacherous terrain of rare disease healthcare, battling copay accumulator adjusters, and fighting for fair access to life-saving treatments.

■ <https://www.youtube.com/watch?v=0fShsplS6YQ>

## Featuring: Advocate, Maria S.

Navigating life pre and post copay accumulators and maximizers: the hidden language that pushes families to the brink of bankruptcy and denying patients vital access to essential treatments.

□ <https://www.youtube.com/watch?v=UUvD4U6RRiY>



My Health  
is Not Up  
For Debate

Voices for Policy Change brought to you by NBDP and Sanofi.



I'm using my  
voice for  
policy change!

Voices for Policy Change brought to you by NBDP and Sanofi.



# Welcome to our Guest Speakers

**Virginia Maxwell, Coalition for Rare Skin Diseases**

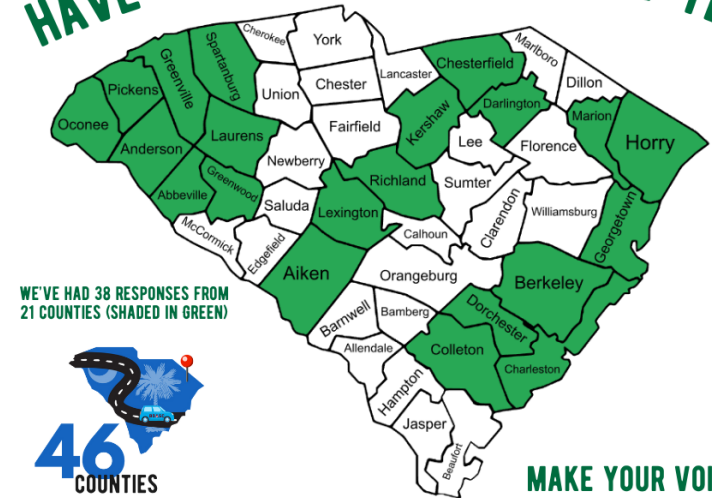
**Cori Ann Harris, BDASC Member, Von Willebrand Disease**

**Candi Mitchum, BDASC Member, Advancing Women with Bleeding Disorders**

Please take our Fall Advocacy Camp Evaluation and the “46 Voices” Survey in your program  
Thank you for your voices!!!



HAVE YOU TAKEN OUR SURVEY YET?



MAKE YOUR VOICE COUNT BY TAKING OUR SURVEY TODAY!



fall family advocacy camp & medical symposium  
october 19-20, 2024



**BDASC's got**  
★ ★ ★ *Talent*

**Karaoke Talent  
Show at 7:30pm in  
Graystone Hall**

**Escapology at 7:00pm  
Parents Cars or Hotel  
Shuttle**

ESCAPOLOGY.  
Columbia, SC