

# NHF'S STATE BASED ADVOCACY COALITION (SBAC) PROGRAM

## WHAT IS THE SBAC PROGRAM?

The NHF State Based Advocacy Coalition (SBAC) program began in 2012 with 5 key states to respond to various advocacy challenges affecting access to care for the USA bleeding disorders community. Now in its 6<sup>th</sup> year, the SBAC program is providing support to 21 states that include over 30 NHF chapters, representing thousands of families with bleeding disorders across the USA.

## WHAT ARE COMMON ISSUES ADDRESSED?

- Awareness Campaigns
- State Programs for Patients with Chronic Diseases
- Step Therapy
- Medicaid: Managed Care, Preferred Drug Lists, Drug Reimbursement
- Co-Pay and Premium Assistance
- Out of Pocket Costs to Patients



*Raising Awareness, Bleeding Disorders Awareness Month, March 2017, Boston, MA*

## RECENT STATE SUCCESSES:

### CALIFORNIA:

- Continued protection of adequate funding for state programs that serve bleeding disorder patients
- Youth advocate development programs that have led to high rates of participation of teens in state and federal advocacy efforts

### COLORADO:

- Increased attendance significantly at state Advocacy Day
- Planned Inaugural Advocacy Summit for 2018

### OHIO:

- Provided patient testimony to state Medicaid office resulting in improved patient access to the state's Preferred Drug List

### PENNSYLVANIA:

- Saved a \$949K budget line item that supports patients with bleeding disorders, and established relationships with key legislators

### TEXAS:

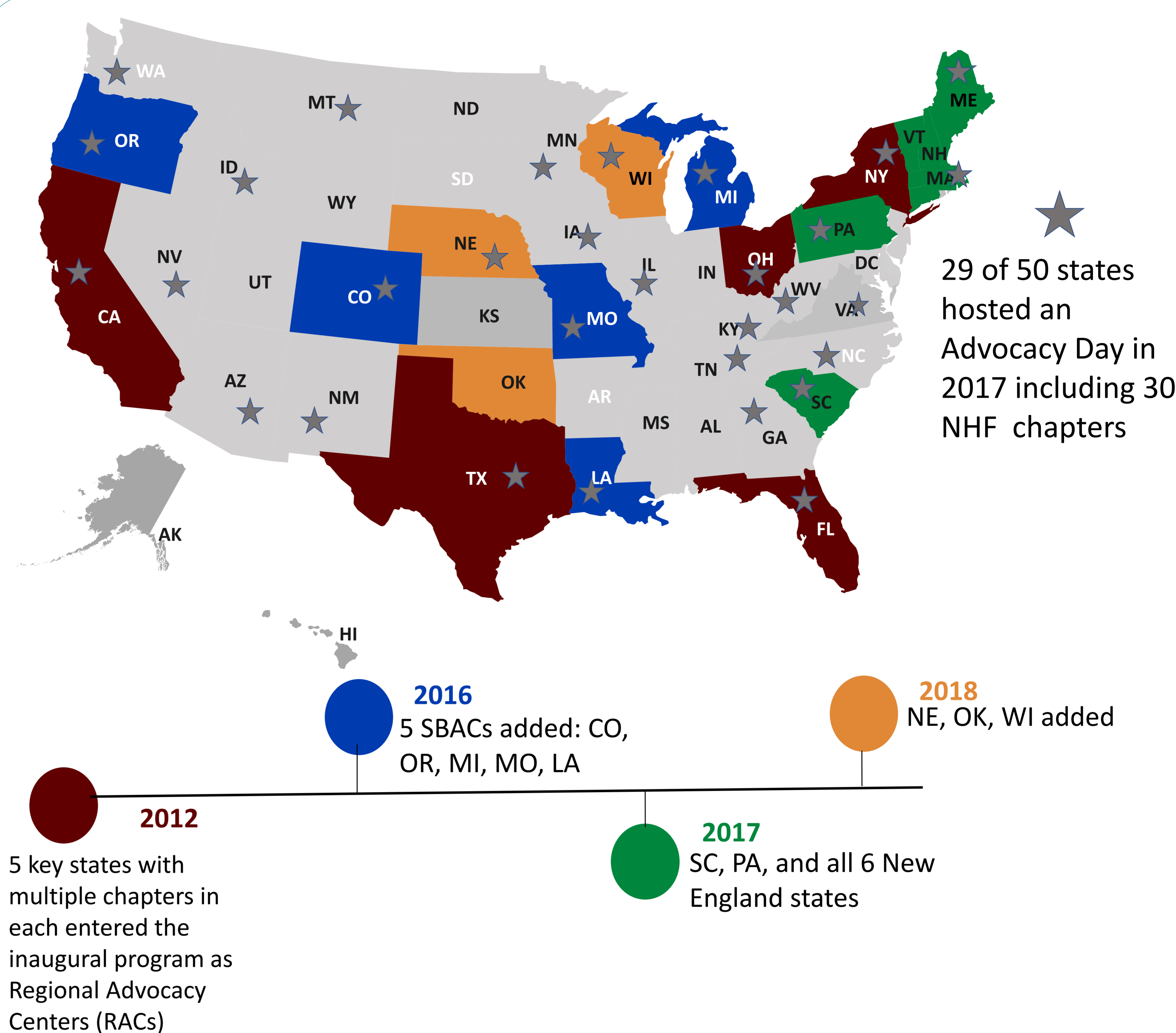
- Passed legislation to utilize funds in the Hemophilia Assistance Program to pay for insurance premiums for qualified participants
- Worked in coalition with other chronic conditions to pass favorable step therapy legislation

## RESULTS:

One measure of success of the SBAC program is the increased interest in advocacy by NHF chapters and an expressed desire to be part of the program. Our collective presence at state capitals around the country and relationship building with agency officials has substantially increased awareness and improved access to care. An important byproduct of the program is record breaking participation from grassroots advocates at both the state and federal levels.

## CONCLUSIONS:

We have found the greatest success has come from the technical expertise that is offered to chapters along with the opportunity for ongoing education and networking. Another key area of success stems from the accountability to objectives required to participate in the program.



## SBAC PROGRAM EXPECTATIONS:

### YEAR ONE:

- Host a Strategic Advocacy Strategy Session facilitated by NHF
- Identify state advocacy priorities for the year
- Establish an Advocacy Committee with appropriate leadership positions filled (chair, vice chair, secretary etc.) that meets monthly
- Develop a 3-year Strategic Advocacy Plan
- Host an Advocacy Day at the state capital with training for volunteer advocates the evening prior

### YEAR TWO:

- Demonstrate year round advocacy through chapter programming
- Define a mechanism for advocacy communications (newsletter, social media, web)
- Adhere to a regularly scheduled advocacy committee meeting (monthly or quarterly)
- Host a stakeholder meeting in preparation for the upcoming legislative season (fall)
- Demonstrate success in growing grassroots advocates

NHF is thankful to the SBAC Program Sponsors: Novo Nordisk (Founding sponsor), Bayer, Bioverativ, CSL Behring, Genentech, Pfizer, and Shire.