



**West Virginia Chapter**

**NATIONAL BLEEDING DISORDERS FOUNDATION**

**2023  
Annual  
Report**



## 2023 Chapter Leadership

### Staff

Kristen Dansereau- Administrative Assistant  
Chelsea Hilty- Executive Director

### Board

Kelly Coen  
Lisa Nick  
Megan Sinyard

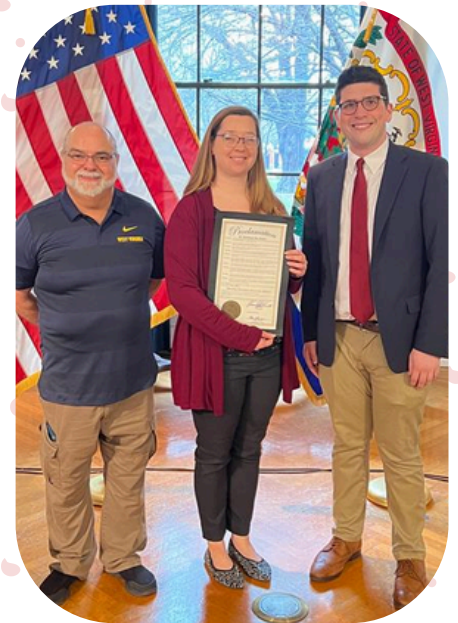
## Advocacy

Click the headlines to  
learn more about our  
programs.



During the chapter's state advocacy day, we successfully advocated for an extension of the WV Advisory Council on Rare Diseases, helped to stop a bill that would have increased copay costs, and shared information to help ensure West Virginians wouldn't lose access to Medicaid benefits.

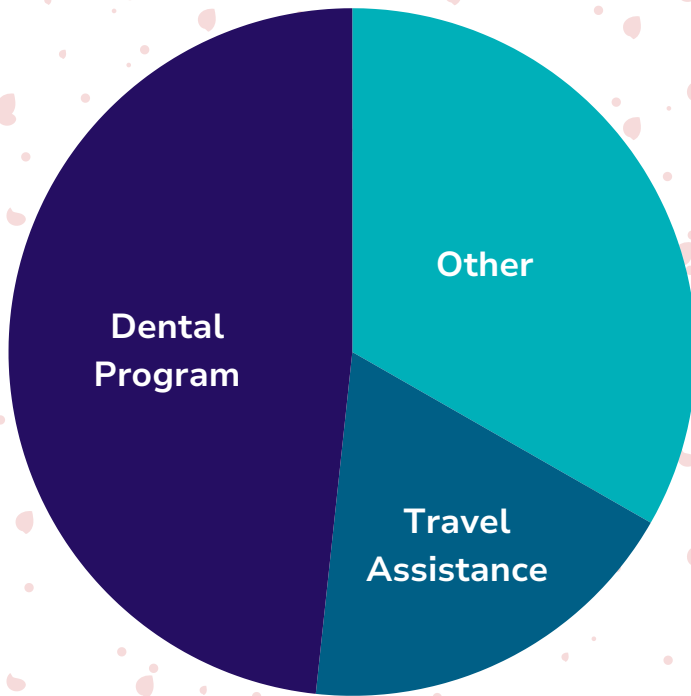
We also went to Washington, D.C. to advocate for funding for Hemophilia Treatment Centers (HTCs) and to stress the need to keep copay costs low for patients.



In 2023, the chapter and community members advocated for the WV Bleeding Disorders Community in Charleston, WV and Washington, D.C.

# Financial Assistance

Nearly \$10,000 was awarded to community members in 2023 for financial assistance, with about half of that being through the chapter Dental Program. Other financial assistance included medical ID jewelry, travel assistance to events and doctor visits, bills, and other necessities.



## Dental Program

Our state-wide Dental Program aims to increase access to oral health care for people with bleeding disorders through outreach to the community and dental providers.

The chapter has created education for providers across the state to better educate them on working with the bleeding disorders community. We also support community members by helping them find dentists who are able to treat them and providing financial assistance to cover the costs of dental procedures.

16

Community Members at the Bleeding Disorders Conference

24

Medical IDs Purchased

15

Scholarships to Summer Camp

600

Dental Offices Sent Education

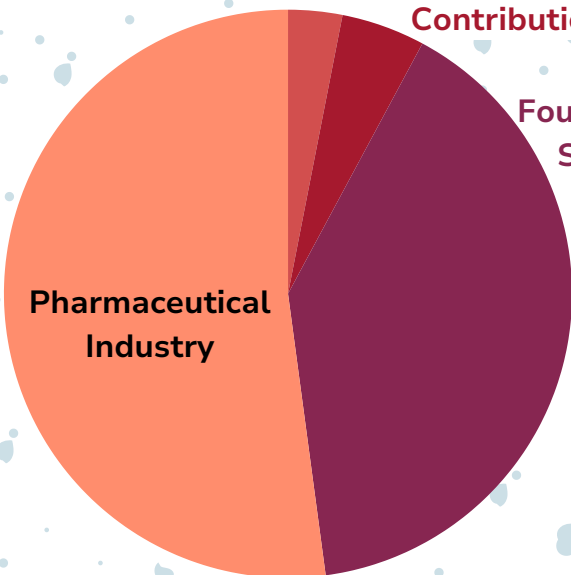
100

Views of the Online Bleeding Disorders Dental Course

# Chapter Finances

Corporate Sponsorship  
Individual Contributions  
Foundational Support

Pharmaceutical Industry



## Revenue

52% of the 2023 revenue came directly from event sponsorship and advertising by the pharmaceutical industry including drug manufacturers and specialty pharmacies.

In planning for the future, diversifying income sources so that the chapter doesn't rely so heavily on pharma will be key.

## 2023 Operating Budget

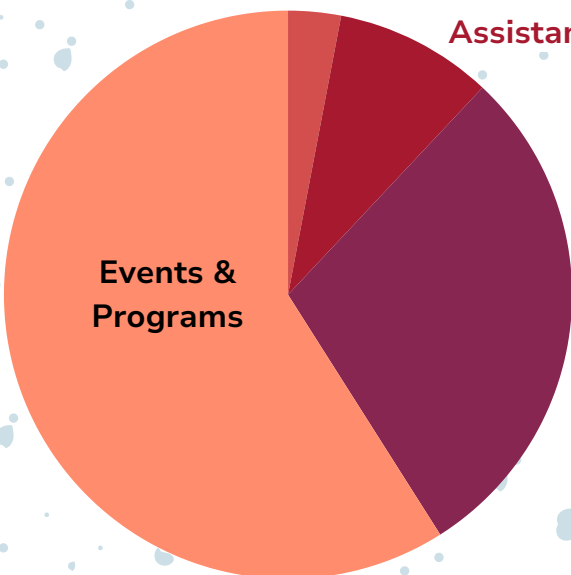
For the 2023 fiscal year, the chapter's budget was set \$175,000. This was the estimate for the cost to run the chapter, and the amount that needed to be raised to break even.

For 2023 the chapter came about \$17,000 short of breaking even.

Fundraising & Outreach  
Financial Assistance

Events & Programs

General Management



## Expenses

29% of 2023's expenses fell into the general management category. This includes all of the little things that keep the chapter running smoothly, like hosting the website and paying the phone bill.

71 cents of every dollar raised by the chapter go directly towards the programs and services that support the community.



# Unite for Bleeding Disorders Walk



The Unite for Bleeding Disorders Walk is a nationwide event that raises funds and awareness for all bleeding disorders. All funds raised stay with the chapter and support local programs and initiatives.

**In 2023, the Unite Walk raised \$13,000, a 22% increase over the previous year.**

## Spokes Men for Bleeders

Created in 2015 by Steve & Lisa Nick, Spokes Men for Bleeders raises awareness for bleeding disorders & funds to help the WV Bleeding Disorders Community. Steve gathers friends for a 100-mile bike ride which ends with a finish line party planned by Lisa.

**The 2023 event raised over \$15,500, bringing their total close to \$80,000.**



## Community Fundraising

We are always looking to connect with local sponsors for community fundraising events.



# First Ever WV Chapter Retreat for Women & Girls



Throughout 2023, the chapter put emphasis on the often-overlooked group of people affected by bleeding disorders, women and girls.

We released 14 issues of *The Monthly Periodical*, a newsletter focused on topics for women, girls, and people with the potential to menstruate.

## Chapter Events



## Kid's Programming

In 2023 the chapter raised over \$14,000 for Camp Winaca HemoVon, a statewide camp for kids with a bleeding disorder or cancer diagnosis.

We also had 4 kids compete in CSL Behring's Junior National Championship sports competition in Nevada.





The chapter held 17 events throughout the state of West Virginia during 2023 and had over 400 event attendees.

