



2019

# ANNUAL REPORT

NEVADA CHAPTER OF THE  
NATIONAL HEMOPHILIA FOUNDATION



NEVADA CHAPTER  
NATIONAL HEMOPHILIA FOUNDATION  
*for all bleeding and clotting disorders*

## Dear Friends,

I want to extend a heartfelt thank you to everyone who made 2019 a success. We have had a year of constant changes, new challenges, and amazing success stories. I hope you take a minute to look through the 2019 Annual Report and celebrate the success because every single community member, donor, supporter, and volunteer helped make them happen.

The resilience, perseverance and dedication of our Nevada bleeding disorders community continues to inspire me to find new ways to meet our mission of finding the highest quality of care and quality of life through peer support, education, and advocacy for those affected by bleeding disorders.

Watching a community of support grow for the bleeding disorders is amazing – as new donors, supporters and volunteers join our dedicated community of supporters to make a difference every day.

Thank you. It is through your support that we are able to look to the future with a sense of possibility as we work to make positive change for the bleeding disorders community.

Here are just a few of the highlights from this year that you helped accomplish:

- Improved access to care by advocating for less barriers to accessing care and treatments
- Held 35 events offering over 180 hours of educational programming and 49 hours of peer support and community building programming
- Helped 32 families when they needed it most with emergency financial assistance

With warmest regards and heartfelt thanks,



Betsy VanDeusen  
Executive Director



## MISSION

The Nevada Chapter of the National Hemophilia Foundation's mission is to improve the quality of care and life for people with hemophilia, von Willebrand disease and other inherited bleeding disorders through education, peer support and advocacy.

# COMMUNITY SPOTLIGHTS

The stories of diagnosis, courage and strength from some of our Community Members.



## HENDRICKSON FAMILY

Some of our biggest challenges are with work. Not only do I have a severe bleeding disorder, but I am a mother of someone who has a bleeding disorder. **Often people don't understand the severity of it and tend to brush it off.**

Explaining that even though I look fine, I have a very severe disorder is the hardest thing. It's hard to explain to my boss that I must leave for my son or for myself to take medication or go and get factor treatments. I have to maintain a full-time job and still be chronically sick.



## CERVANTES FAMILY

Having a bleeding disorder while playing sports is tough because sometimes, they don't want me to play. They think I might get hurt or they just put me on the outside of games. But I really do think it's a part of me. **My bleeding disorder is like a living thing in me.** It is something that can hurt me when something happens but, it also is something that makes me more aware of myself and my own safety. It's something that alerts me.



## WOLFF FAMILY

Due to family medical history, Ethan was tested before his circumcision, and our pediatrician came back with a scary diagnosis. They said Ethan had a severe bleeding disorder and only 14 years to live. It was terrifying to hear. We were sent to a specialist, Dr. Bernstein diagnosed Ethan with VWD. Remember that you're the parent and if for some reason you don't trust what's happening, get a second opinion. Look up networks of people who are going through the same thing, and go to their events, because it's a place to breathe. **Being involved in a community takes away the fear of being alone.**

# 2019 BY THE NUMBERS

## 2019 PROGRAMS REVIEW

### FAMILY PROGRAMS 113 hours in 18 events

Our family programs include Spring Fest, Northern NV Family Weekend, Annual Meetings, Family Bowling Days & more.

### YOUTH PROGRAMS 132 hours in 9 Events

Our youth programs include Camp Independent Firefly, Leadership in Training Weekend, Back to School & playgroups.

### ADULT PROGRAMS 5 hours in 3 events

These programs include our Women's Retreats, Couple's Retreats & our Men's Group.

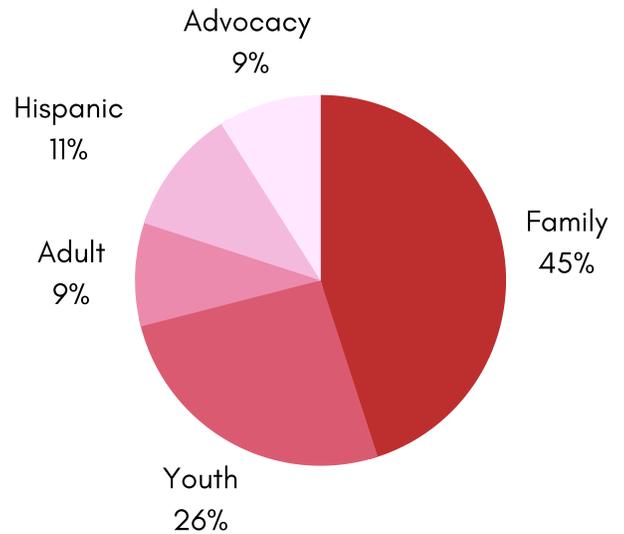
### HISPANIC PROGRAMS 12 hours in 4 events

Our programs specifically given to the Hispanic bleeding disorders community including Latinos Unidos & Spanish Education Dinners.

### ADVOCACY PROGRAMS 29 hours in 3 events

These programs include Washington Days, Carson City Advocacy Days & Advocacy Education Days.

## 2019 Number of Events



## FINANCIAL ASSISTANCE

Families Served

40

Funds Distributed

\$18,282

# 2019 BY THE NUMBERS

## 2019 SOCIAL MEDIA



Facebook @NHFNV

- Posts - 221
- Likes - 830
- Followers - 825



Instagram @nevadanhf

- Posts - 71
- Likes - 1,018
- Followers - 479



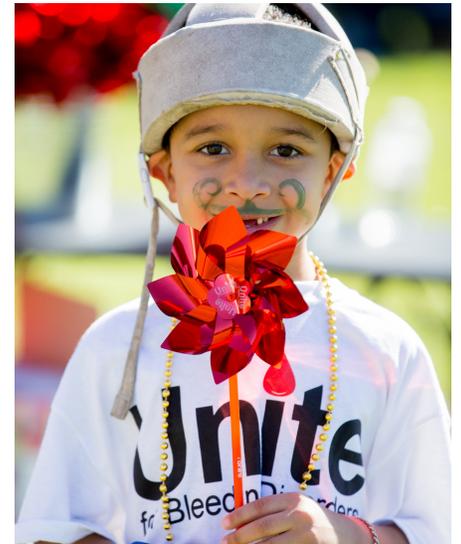
Twitter @nevadanhf

- Tweets - 49
- Impressions - 33,315
- Followers - 680

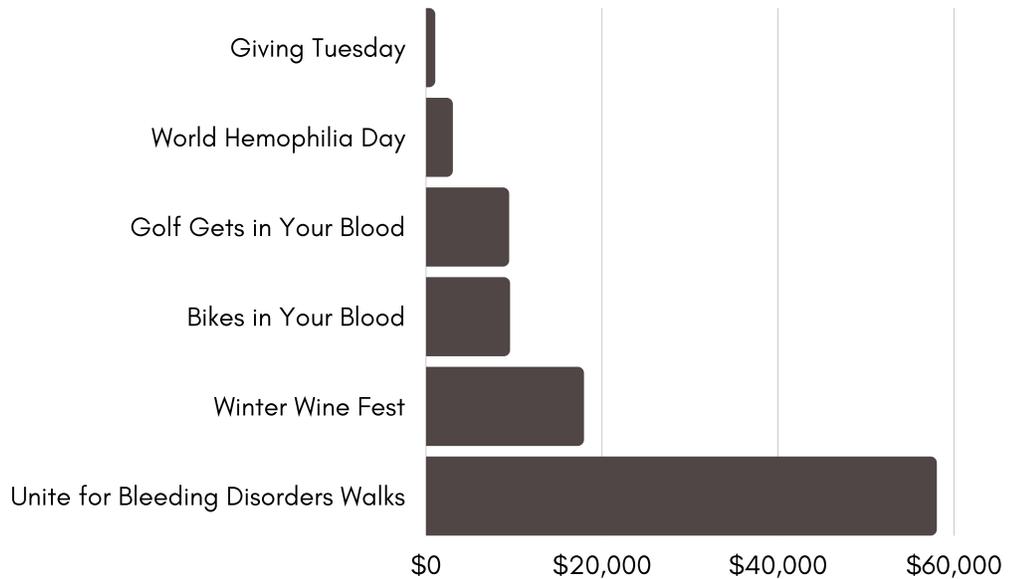
## 2019 FINANCIALS

### Total Overview

- Individual Support
  - \$70,232.94 (11%)
- Corporate Support
  - \$471,276.44 (76%)
- Foundation Support
  - \$81,730.53 (13%)
- TOTAL
  - \$623,239.91



## 2019 SPECIAL EVENTS FUNDS RAISED



## VOLUNTEERS

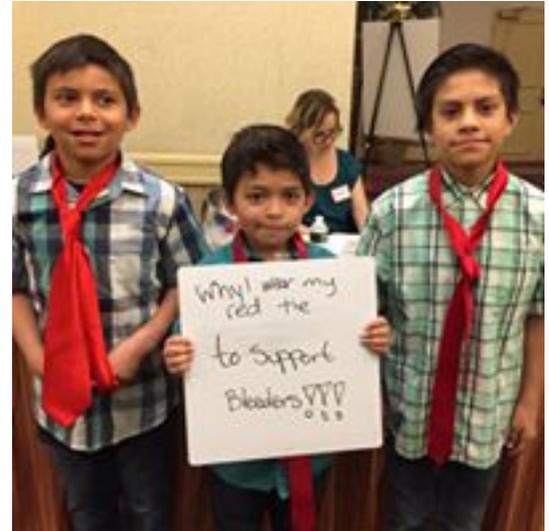
294  
Volunteers

3,039  
Hours of  
Service

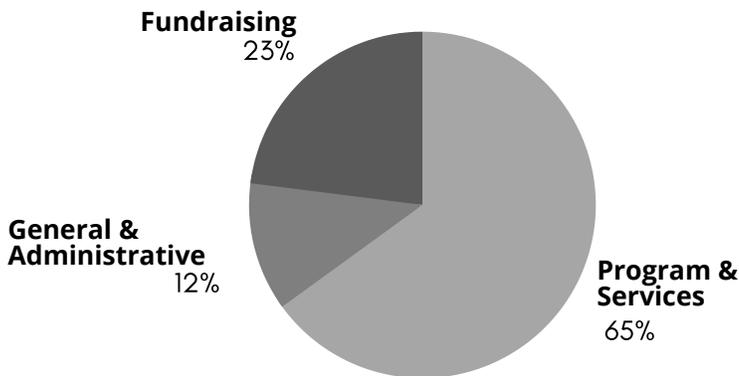
# FINANCIAL REPORT

## 2019 PROGRAMS & SERVICES EXPENSES

- Family Programs - \$82,262
- Youth Programs - \$110,880
- Adult Programs - \$49,831
- Hispanic Programs - \$16,066
- Outreach & Communications - \$22,235
- Advocacy - \$42,531
- Assistance & Awards - \$32,946



## 2019 TOTAL EXPENSES



Total Program & Services - \$356,751  
General & Administrative - \$67,016  
Fundraising - \$128,572

**TOTAL EXPENSES: \$552,339**



## REVENUE

Programs & Services  
**\$474,212**

Fundraising  
**\$148,962**



CELEBRATING  
**30**  
... YEARS ...



## NEVADA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

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

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