



## 2019 ANNUAL REPORT

**Gateway Hemophilia Association**  
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### **Mission Statement**

Gateway Hemophilia Association is a non-profit, community-based organization, dedicated to the advocacy, education and support of families affected by bleeding disorders.

Greetings Friends,

We are thankful for all that was accomplished in 2019. GHA's success is measured in how well we support the people we serve. GHA is dedicated to the advocacy, education and support of families affected by bleeding disorders. Every day we look for ways to improve our programs and services. We are dedicated to create valuable resources and meaningful programs for the bleeding disorders community.

In 2019 our membership grew by 29 families and 89 individuals. We had 56 various activities and trainings, providing over 300 hours of educational programming for the local bleeding disorder's community. We value the support from our industry partners, Hemophilia Treatment Centers, National Organizations, stakeholders, and volunteers.

GHA is fortunate to receive many acts of generosity by individuals and have seen true philanthropy. Our members give from their heart and expect nothing in return except the gratification that they have touched a life of another, this is the true meaning of unselfishness. Regardless of the size of the donation or amount of hours volunteered, giving to GHA is a wonderful way of making an impact in the world. Never underestimate the importance of giving.

At the Holiday Party we acknowledged 164 volunteers that assisted our mission, accumulating over 2,500 hours. According to Independent Sector, the value of a volunteer hour is \$25.43 – up 3% from the previous year. That's a \$63,000 savings to GHA in volunteer hours! This world is a better place because of our volunteers, and we thank them for it.

As treatments improve for bleeding disorders there has been much discussion about gene therapy. At the winter membership meeting, we held a program on basic research focusing on gene therapy of blood diseases. The speaker is actively developing gene therapies for Hemophilia A and B, von Willebrand Disease, and other disorders.

Having a bleeding disorders is not political, it's personal for this community. GHA's year-round advocacy has increased relationships and awareness for bleeding disorders with elected representatives. In March a group went to Jefferson City to help spread awareness about bleeding disorders because March is Bleeding Disorders Awareness Month. Scholarships were offered to attend Washington Days in Washington D.C. in late March. Participants learned about the history of bleeding disorders, the importance of having a voice in the community, access to quality and affordable healthcare and how to speak with public officials about bleeding disorders.

We collaborated with Midwest Hemophilia Association to host a Women's Retreat in March. Sessions focused on education, personal growth, and bleeding disorders treatment options.

On April 17, GHA celebrated 50 years at the Missouri History Museum. The event included history boards, and an awards presentation.

The Unite for Bleeding Disorders Walk and 5K was held in at Forest Park in May with over 300 attendees. This is the largest fundraiser, which allowed us to expand educational scholarships to national conferences.

GHA believes in supporting research, how that is supported is through a donation each year to NHF's Judith Graham Pool (JGP). The JGP Postdoctoral Research Fellowships have provided a long legacy of support for basic science and pre-clinical research in bleeding disorders. JGP research fellowship award projects have contributed to the development of safer concentrates, enhanced methods of testing and screening, and have laid the groundwork for current advances in gene therapy for hemophilia.

The continued membership of The World Federation of Hemophilia, improves and sustains care for people with inherited bleeding disorders around the world. In addition to expanding our world outreach, GHA awarded \$9,000 in college scholarships.

Camp Notaclotamongus moved to a new location in June, to Camp Wyman, in Eureka, MO. Camp Wyman's engaging, empowering and experiential programs and services help kids build skills, develop a sense of self, and connect to their world. Camp makes a difference in the lives of today's campers and tomorrow's leaders.

In July Family Education Weekend (FEW) was held, the only program of its kind in the Greater St. Louis area. Members gather to meet, talk, and share with other members in the community and healthcare professionals. This conference provides terrific educational opportunities, engaging roundtable topics and breakout sessions.

GHA is building a roadmap for financial and organizational stability that will keep GHA prospering for many years to come. Thank you to GHA's Board of Directors, committee members, donors, and all of our members, for the hard work and dedication that makes GHA's mission possible. 2019 was a year to connect, learn and grow.

## **Financial Overview**

The following is an overview of GHA's income and expenses for the fiscal year that ended December 31, 2019:

### **Sources of Funds**

Contributions and Grants	\$229,953
Programs and Services	\$79,999
Investment Income	\$788
Other Revenue	\$19,438
Net unrealized gains on investments	\$79,309
Total Income:	\$407,911

### **Expenses**

Program Expenses	\$210,088
Fundraising Expenses	\$20,768
Administrative Expenses	\$45,790
Total Expenses	\$276,646

Net assets at end of year \$635,865

## **2019 – 2019 GHA Board of Directors**

Chris Schneider, **Vice President**

Lori Moore, **Vice President**

Stephanie Bauman, **Secretary**

Ben Moramarco, **Treasurer**

Kristina Klein

Mike Miller

Kari Moellenhoff

Maria Mohler

Nikole Schroeder

Bridget A. Tyrey, Executive Director

*Terms of service for voting Board members shall be two (2) years. No members shall serve more than three (3) consecutive two-year terms.*

**GHA is tax exempt under Section 501(c)(3) of the Internal Revenue Code.  
Donations are tax deductible to the extent allowed by law.**