

We are stronger  
because we have each other.



2012 ANNUAL REPORT

# A Message from the Board President and Executive Director

*Dear Friends,*

**H**emophilia Federation of America has always understood the unique responsibility of exclusively focusing on the needs of individuals and families with bleeding disorders. Every day, we use multiple resources and strategies to support the lives of families with bleeding disorders. We have done our best to support the many individual voices of people with bleeding disorders.

We deeply appreciate the support of our donors. Each gift, large or small, comes with our commitment to use every dollar to make the greatest impact possible. We are pleased that 94.5% of all of revenue raised in 2012 went to directly support our programs and outreach services for community families.

As we look to the future, we are committed to finding new and innovative ways to support our community members. We look forward to working together to continue the progress we have made.

*Thank you,*



*Kimberly Haugstad*

**Kimberly Haugstad, MBA**  
Executive Director



*Matthew T. Compton*

**Matthew T. Compton**  
Board President

## About HFA

Hemophilia Federation of America (HFA) is a community-focused organization that serves people with bleeding disorders.

HFA employs a grassroots community federation model consisting of 35 member organizations. Collaboratively, we address needs by implementing community-centric programming, support services, and advocacy outreach initiatives. We serve as a consumer advocate for safe, affordable, and obtainable blood products and *health coverage*, as well as a better quality of life for all persons with bleeding disorders. HFA's ongoing consumer advocacy agenda includes product safety as well as accessibility, affordability, and availability of the products that the individuals of this community require.

# 94.5%

**of all of revenue raised in 2012** went to directly support our programs and outreach services for community families.

Hemophilia Federation of America (HFA) is a national 501c3 non-profit organization that assists and advocates for the bleeding disorders community.



## **Our Mission makes us Stronger.**

HFA advocates for and assists the bleeding disorders community.

Collaboratively with our member organizations, we address community needs by implementing community-centric programming, support services, and advocacy outreach initiatives.

# We are STRONG.



## In 2012,

HFA held a robust volunteer board of directors of 42 individuals designated by the organization's member organizations and several independent members. Each local member organization is separately incorporated as its own charitable entity.

HFA utilized a staff of seven full-time and six part-time individuals. Our staff strives to demonstrate and model our values in actions, personal work behaviors, decision making, contribution, and interpersonal interaction!

# 2012

## Focus: Fitness • Technology • Advocacy

- **IMPROVE** the health and wellness outcomes of our community members
- **RAISE** public and legislative awareness of the bleeding disorders community
- **CHANGE** or protect policies that impact the needs and quality of life for community members
- **COLLABORATE** with other organizations that share similar goals

## Major Accomplishments

### ADVOCACY INITIATIVES

- Released **“Advocacy, It’s In Your Blood.”** A series of educational materials, buttons, and legislative leave-behind folders and materials to unite advocacy efforts across the country.
- Launched the **CHOICE project**. HFA’s goal for CHOICE is to learn about the experiences of people living with a bleeding disorder who do not receive care at a federally-funded hemophilia treatment center. HFA will utilize the findings to further focus advocacy efforts.

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### PROGRAMMING ACTIVITIES

- Offered over **100 local events** and **20 educational webinars** across the country.
- Hosted our **largest Symposium ever**, attended by over 650 community members and stakeholders.
- Reached over **10,000 people** via our outreach programs and social media.
- Launched the **Get in Gear** fitness app which reached **7,000 downloads** within 8 months of its release.

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### SUPPORT SERVICES

- Assisted 214 households amounting to **\$152,601.63 in aid**. A total of 612 people living with a bleeding disorder received assistance during their temporary financial crisis via the Helping Hands program.

## YEAR IN REVIEW | **ADVOCACY**

In 2012, HFA remained committed to changing or protecting policies to positively impact the needs and quality of life for people with bleeding disorders. HFA has, on an ongoing basis, raised public and legislative awareness of the needs of the bleeding disorders community and actively collaborated with other organizations to ensure that those needs are met.

HFA accomplished its 2012 organizational objectives by engaging policymakers on the state and federal level in the areas of access to affordable and safe therapies, appropriate and accurate data collection of the bleeding disorders community, and the multitude of issues around the implementation of the Patient Protection and Affordable Care Act (ACA). HFA increased engagement and community participation in advocacy activities by utilizing social media tools, including our Voices Campaign, Facebook, and Twitter.

**HFA released its “Advocacy, It’s In Your Blood” brand to unite member organizations across the country under one tagline. Educational materials, buttons, and legislative leave-behind folders and materials all incorporated this theme.**



# HFA...

...regularly and proactively collaborated with national organizations on issues affecting all plasma users and other rare chronic disorder advocacy organizations.

...actively engaged state advocates at its member organizations in policy discussion through participation and presentations at state meetings as well as monthly ongoing conference calls through our national office.

...issued letters to Congress and the administration on topics ranging from deficit reduction to funding for hemophilia programs and health care reform funding.

...wrote letters advocating on behalf of community members seeking access to Medicaid, Medicare and HIV programs.

...created downloadable tools and print resources for state advocates.

...enhanced our online web presence utilizing Action Alerts and Policy Updates.



## **CHOICE Project –** *It's your CHOICE, it's your voice.*

CHOICE (Community Having Opportunity to Influence Care Equity) is a three year cooperative agreement awarded to the Hemophilia Federation of America (HFA) and supported by the Centers for Disease Control and Prevention (CDC). CHOICE collects information through an online and paper-based survey. This survey collects information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally-funded hemophilia treatment center (HTC). HFA's goal for the CHOICE Project is to put the survey results to work to improve the lives of those in the bleeding disorders community.

To learn more about the CHOICE survey visit:  
[www.hemophiliafed.org/programs/choice/](http://www.hemophiliafed.org/programs/choice/)

## YEAR IN REVIEW | SYMPOSIUM



Establishing strong connections and building a solid network of support is the cornerstone of maintaining a healthy lifestyle for many within the bleeding disorders community. HFA's Symposium offered a community-centered educational event in the heart of the Silicon Valley, Santa Clara, CA. Community members from across the country came together to share information, network, and build camaraderie in a relaxed and supportive environment.

Through two days of multiple breakout sessions, keynote speakers, exhibit hall, and numerous special forums and receptions, participants discussed state and federal advocacy issues, learned about new HFA evidence-based programming, and shared insight, awareness, knowledge, and experience of living with and treating bleeding disorders. At this meeting,



HFA launched a new event mobile app and over 30% of attendees logged in to utilize the online event tool.

HFA awarded 110 transportation or room scholarships to first time attendees in 2012. The meeting drew over 600 people from across the nation.

**Check out the video from our 2012 Symposium:**

[www.youtube.com/watch?v=aryqHptfbd0](http://www.youtube.com/watch?v=aryqHptfbd0)

*“ At Symposium, we learned that **ONE** family, **ONE** person can make a difference. People are listening—we all have something to say. ”*



## YEAR IN REVIEW | OUTREACH & PROGRAMMING



The Blood Brotherhood program provides a forum in which adult men with hemophilia and von Willebrand disease can come together to share their experiences and knowledge about health and quality of life issues. In 2012, HFA hosted over 70 Blood Brotherhood events in 13 local

**OVER 70 EVENTS**  
**OVER 350 PARTICIPANTS**

sites around the country, uniting over 350 Blood Brothers face-to-face across the U.S. The program also connects approximately 300 men through a national online chat forum. **The number of adult men enrolled in the Blood Brotherhood program grew by more than 26% in 2012.**



HFA's Dads in Action program is committed to creating a network of men in the bleeding disorders community who educate, support, and challenge each other as they strive to be proactive and responsible role models for their children and families. In 2012, HFA offered thirty Dads in Action (DIA) events nationwide. HFA welcomed two new Dads in Action

local sites in 2012, and proudly has thirteen participating member organizations across the country, including Puerto Rico. In 2012, HFA hosted training to increase our total number of community facilitators to eight. We developed new education modules that these trained dads can present at local events. Two of the seven modules were offered in English and Spanish. The program also provides education to dads across the country through a series of webinars. In 2012, HFA saw an increase in the attendance of our webinar series by 52%. **Overall, HFA reached over 300 dads—an increase of 130% over 2011.**

**REACHING OVER 300 DADS ACROSS  
THE NATION WITH MATERIALS  
IN ENGLISH AND SPANISH**





**156 MILES**  
**\$38,000 RAISED**

Gears for Good is HFA's annual fundraiser that promotes health and wellness. The 2nd annual bike ride was a great success. **Twenty-two participants biked 156 miles along the C&O Canal from VA to DC and raised over \$38,000.** In 2012, the funds were assigned to **HFA's Helping Hands program**, which directly benefited over 50 families in the bleeding disorders community.





FitFactor offers services designed to improve health, fitness, and quality of life through regular physical activity and proper nutrition. In 2012, HFA added 44 educational posts, including nutrition segments in English and Spanish. HFA facilitated 4 face-to-face wellness sessions at local organizations and added two new physical activity video modules: swimming and biking. **In 2012, HFA also launched the Get in Gear Mobile Fitness App which reached over 7,000 downloads in the first eight months post-release!**



**44 EDUCATIONAL POSTS  
OVER 7,000 GET IN GEAR APP DOWNLOADS**



Blood Sisterhood is a network of women supporting women with bleeding disorders on their life's journey through diagnosis, treatment, and day to day living. The network focuses on **improving the health outcomes and quality of life of women** with bleeding disorders. HFA continues to bring Blood Sisters together via facilitated women's education and support sessions at its annual Symposium. In addition, HFA connects women via educational webinars throughout the year.



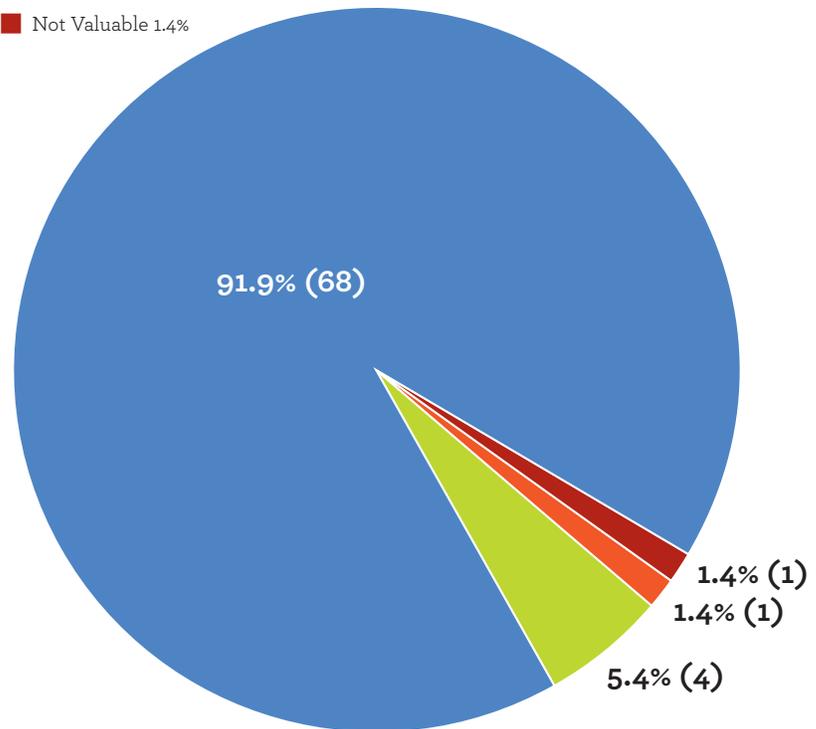
# YEAR IN REVIEW | SUPPORT SERVICES

The Helping Hands program is a one-of-a-kind assistance program designed to establish a rapid, non-invasive source of relief in emergency situations for people and families affected by a bleeding disorder. Helping Hands provides a critical, temporary safety net and connects families with tools and resources for future stability. Applicants must be referred by an approved agency and the maximum amount distributed per applicant is \$750 every two years. Helping Hands directly assisted 214 households amounting to over \$125,296 in aid, a growth of 19.8% compared to previous year. Housing (rent and mortgage) continues to be the most requested need.

In 2012, HFA added Items Reimbursement to our Support Services. The service provides reimbursement for the costs of durable medical equipment and other items such as Medic Alert bracelets for those with financial need. HFA assisted with \$27,305 in aid and reimbursement for medical items.

## Program Participant Satisfaction Rating

- Very Valuable 91.9%
- Valuable 5.4%
- Somewhat Valuable 1.4%
- Not Valuable 1.4%



*“Healthcare costs are soaring and many times the families I work with struggle to afford their **MOST BASIC NEEDS** simply because they must use a large portion of their income to pay for life-sustaining medical care.”*



## Helping Hands Case – Working Mom Doing Everything Right

In December, the Helping Hands program assisted a single working mother and her young son. The applicant's eleven month old son has severe hemophilia A with inhibitors.

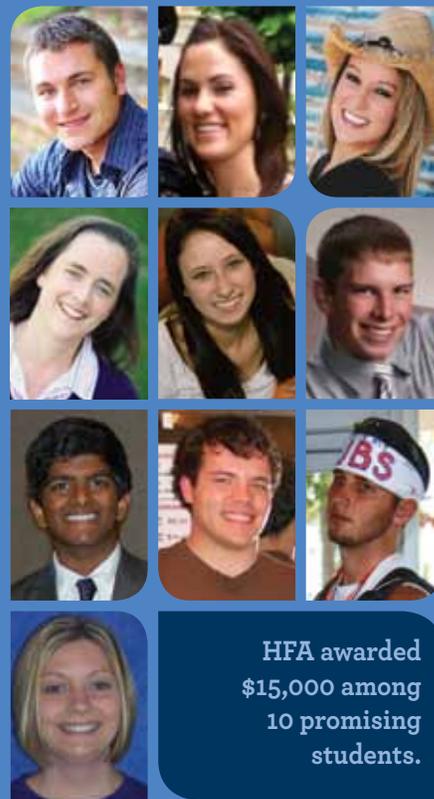
For several weeks, the mother was in and out of the hospital with her son due to a malfunctioning port. After many appointments and tests, doctors discovered a hole in the back of his port which required surgery. The mother missed nearly two weeks of pay from her job. With no other financial supports besides her own income, she was concerned about meeting the cost of the following month's rent.

Helping Hands was able to pay one month of rent for this hard working single mother while her son recovered and she returned to work.



## EDUCATIONAL SCHOLARSHIP WINNERS

In 2012, HFA awarded \$1,500 in educational scholarships to ten promising students. These educational scholarships are in four areas: General Educational Scholarship, Sibling Continuing Educational Scholarship, Parent Continuing Educational Scholarship, and Artistic Encouragement Grant.



HFA awarded  
\$15,000 among  
10 promising  
students.

## Financial Position

### ASSETS

Cash and Equivalents	\$610,007.06
Receivables	\$183,328.16
Other	\$61,488.78
Furniture & Fixtures	\$21,057.28

**TOTAL ASSETS** **\$875,881.28**

### LIABILITIES

Accounts Payable	\$63,854.68
Accrued Liabilities	\$21,592.51
Deferred Revenue	\$50,000.00

**TOTAL LIABILITIES** **\$135,447.19**

### NET ASSETS

Net Assets	\$740,434.09
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**TOTAL NET ASSETS** **\$740,434.09**

**TOTAL LIABILITIES & NET ASSETS** **\$875,881.28**

## 2012 Financial Highlights

### REVENUE

Donations & Memorials	2.2%	49,079.81
General Funding	15.3%	337,990.88
Membership	2.0%	44,212.50
Grants	17.7%	390,211.31
Government Grants	27.9%	615,355.46
Publications	5.6%	123,000.00
Symposium	29.3%	646,500.00
Interest Income	0.1%	2,175.64

**TOTAL REVENUE** **100.0%** **2,208,525.60**

### EXPENSES

Programs	94%	1,985,198.66
Administrative	4%	90,440.25
Fundraising	2%	39,743.55

**TOTAL EXPENSES** **2,115,382.46**

**NET INCOME** **93,143.14**

*\*The financial statements of Hemophilia Federation of America are audited by the accounting firm Winter, Kloman, Moter & Repp, S.C. Complete audited financial statements for Hemophilia Federation of America can be obtained by request from: [www.hemophiliafed.org](http://www.hemophiliafed.org), by mailing 210 7th St SE, Ste 200B Washington DC 20003 or by calling 202-675-6984.*

## REAL VOICES OF BLEEDING DISORDERS:

“They say blood is thicker than water, and I believe that is what ties this community together. It’s the thought ‘they are the same as me’ that helps to bind me to the community of people with bleeding disorders and their families. In going deeper, I found the kindness and strength of other people who have gone through ordeals related to blood disorders grounding.”

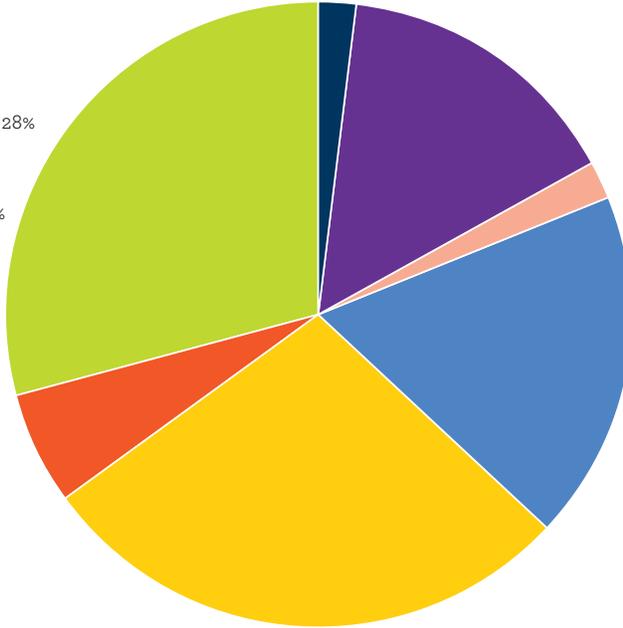
— Blood Sister 2012

## DID YOU KNOW?

According to the Centers for Disease Control and Prevention (CDC), von Willebrand disease (vWD) is the most common bleeding disorder, affecting 1-2% (3-6 million people) of the U.S. population--most of which are undiagnosed.

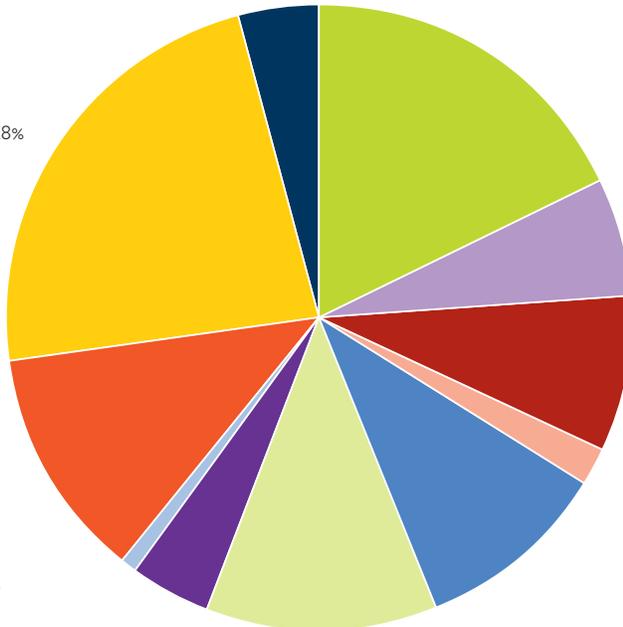
## Revenue

- Symposium 29%
- Government Grants 28%
- Grants 18%
- General Funding 15%
- Publications 6%
- Donations and Memorials 2%
- Membership 2%
- Interest Income 0%



## Expenses

- Symposium 23%
- Blood Brotherhood 18%
- Other Outreach 12%
- Choice 12%
- Helping Hands 10%
- Fit Factor 8%
- Dads in Action 6%
- Administrative 4%
- Dateline 4%
- Fundraising 2%
- Voices 1%
- Blood Sisterhood 0%



## REAL VOICES:

“I love the Get in Gear app.

It has motivated me to exercise after many years of being out of shape and having high cholesterol. I’m 46 years old, 195 lbs, and a smoker. Thanks to your app, I have been exercising consistently for 2 months. Next I’ll work on dieting and then quitting the smoking.”

— *Get in Gear app user*

“We are so grateful

that we have been approved to receive assistance with this utility bill... our deepest thank you for assisting us with this.

It is a huge burden that has been lifted from us.”

— *Helping Hands Applicant 2012*

# Working Together!

**Hemophilia Federation of America** acts as a national organization, working directly with its 35 local member organizations around the country to share a common vision of improving the quality of life for those with bleeding disorders. We have hundreds of active volunteers across the country educating and advocating.

## 2012 MEMBER ORGANIZATIONS, BOARD OF DIRECTORS REPRESENTATIVES, AND OFFICERS:

### Hemophilia Foundation of Arkansas

Robin Parker

### Arizona Hemophilia Association

Melinda Cadena

### Hemophilia Foundation of Southern California

Mickey Price

### Hemophilia Foundation of Northern California

Doug Hartsough

### Central California Hemophilia Foundation

Sean Hubbert

### Connecticut Hemophilia Society, Inc.

Mandy McCullough

### Florida Hemophilia Association

Steve Tejiram\*

### Snake River Hemophilia & Bleeding Disorders

Scott Boling

### Bleeding Disorders Alliance Illinois

Rocky Williams

### Hemophilia of Indiana

Scott Ehnes

### Hemophilia of Iowa

Josh Hemann

### Louisiana Hemophilia Foundation

Edgar Guedry

### New England Hemophilia Association

Diane Lima

### Hemophilia Foundation of Maryland

Ryan Melton

### Hemophilia Foundation of Minnesota/Dakotas

Aaron Reeves

### Hemophilia of North Carolina

Matt Igelman\*

### Hemophilia of New Jersey

Teri Doran-Rogers

### Sangre de Oro Hemophilia Foundation

Lori Long\* Secretary

### Bleeding Disorders Association of the Southern Tier

Gina Salemm

### Mary M. Gooley Hemophilia Center

Homer Everson

### Hemophilia Association of New York, Inc.

Linda Mugford

### New York City Hemophilia Chapter

Wendy Chou

### Bleeding Disorders Association of NE NY

David Huskie

### Northern Ohio Hemophilia Foundation, Inc.

Ray Volney

### Gateway Hemophilia Association

Suzanne Carney

### Hemophilia Foundation of Oregon

Stewart Worthington

### Tri-State Bleeding Disorder Foundation

Detrice Barry

### Hemophilia Outreach of El Paso

Adriana Hernandez

### Oklahoma Hemophilia Foundation

Open Seat

### Tennessee Hemophilia and Bleeding Disorder Foundation

Stanford Murry

### Texas Central Hemophilia Association

Ryan Crowe\* Vice President

### Lone Star Hemophilia Chapter

James Setliff

### Hemophilia Association of the Capital Area

Mark Antell

### Virginia Hemophilia Foundation

Nick Cady

### Wisconsin Bleeding Disorders Network

Joe Zwier

## INDEPENDENT MEMBERS

Linda Wyman-Collins

Tom Russamano

Matthew Compton, President

Tracy Cleghorn\* Vice President

Carlos Ruis\* Treasurer

Paul Brayshaw\* Past President

*\*Indicates HFA Board Officers & Executive Committee*

# THANK YOU

HFA is proud to acknowledge the following corporate donors and federal partners in 2012.

## **Visionaries \$500,000+**

Centers for Disease Control and Prevention, CDC National Center on Birth Defects and Developmental Disabilities

## **Champions \$300,000+**

Baxter  
Novo Nordisk, Inc.

## **Benefactors \$150,000+**

Bayer HealthCare  
Pfizer  
CSL Behring  
CVS Carmark  
Grifols USA  
Biogen Idec

## **Patron \$50,000+**

Patient Services, Inc.

## **Believers \$25,000+**

AHF, Inc.  
Inspiration Biopharmaceuticals, Inc.  
ARJ Infusion Services  
National Cornerstone Healthcare Services  
Hemophilia Alliance

## **Fans \$10,000+**

Factor Support Network  
Walgreens-OptionCare

### REAL VOICES:

“I am humbled

and grateful to be part of a community of supporters who never tire of figuring out how to get it right.”

— *Dad's In Action Participant*

“I feel that the world is a small and unified place—a laudable thing; just as the hemophilia community is a small and unified place. And yet, our community is spread all over the country, and sometimes all over the globe. How do we stay in touch? How do we stay connected? Blood Brotherhood!”

— *Blood Brother*

Please don't stop giving.  
*People with bleeding disorders deeply appreciate your support!*

Making our community  
**STRONGER,**  
one person at a time.



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