

Summary of 2009 Consumer Needs Assessment

(36 Surveys Completed)

1. **Question:** For the person who has the bleeding disorder, what are the hardest or most frustrating parts of dealing with the disorder?
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- Limitations on Activities & Sports – 44%
- Bleeding, in General – 22%
- Treatment Compliance – 17%
- Pain – 14%
- Infusions – 14%
- Inconvenience of Hospitals – 11%
- Lack of Awareness in Medical & Insurance Field – 11%
- Lack of Awareness in General – 11%
- Inconveniences Brought on by Bleeds – 8%
- Lack of Awareness in Educational Settings – 8%
- Fear and Worry – 8%
- Travel-related Issues – 6%
- Unexpected or Unknown Bleeds – 6%
- Feelings of Isolation – 6%
- Cost of Treatment – 6%

2. **Question:** For the family members taking care of or living with the person who has the bleeding disorder, what are the hardest or most frustrating parts of dealing with the disorder?
-

- Placing Limitations on Them – 22%
- Seeing Them in Pain – 19%
- Worrying & Fearing for Them – 14%
- Insurance & Prescription Costs – 14%
- Lack of Awareness in General – 14%
- The Negative Effects of a Bleed – 11%
- Providing Medical Attention to Them – 8%
- Compliance Issues – 8%
- Lack of Awareness among Healthcare Professionals – 6%
- Trusting Others to Care for Them – 6%
- Concerns about Marriage and Reproduction Issues – 6%

3. **Question:** What bleeding disorder-related issues most confuse you or represent topics you'd most like to learn about?

- Insurance – 14%
- Von Willebrand Disease – 14%
- Treatment of Bleeds – 11%
- Research and Medical Advances – 8%
- Carriers – 8%
- Restrictions on Sports and Activities – 6%
- Types of Medication Available – 6%
- Joint Bleeds – 6%
- Aging Issues – 6%

4. **Question:** What would be the most exciting and beneficial changes that could occur in the future, as it relates to bleeding and clotting disorders?

- A Cure – 36%
- Treatment Advances – 25%
- Less Expensive Medicine – 17%
- Increased Awareness & Capabilities among Medical Staff – 14%
- Longer-acting Medicine – 11%
- Better Local Programming – 8%
- Viable Gene Therapy – 6%
- Health Insurance Reform – 6%
- Advances in Joint Care – 6%

5. **Question:** Other than issues related to bleeding disorders, what outside issues have the most potential to threaten the well-being of your family?

- Insurance Issues – 28%
- Financial Hardships – 22%
- Unemployment – 19%
- Stress – 19%
- Depression – 11%
- Work-related Issues – 8%
- School Issues – 6%
- High Cost of Healthcare – 6%
- Special Needs other than a Bleeding Disorder – 6%

6. **Question:** What are the top three things you think the Central Ohio Chapter of NHF does particularly well?

- Newsletter – 42%
- Family Fun Days – 33%
- Informational Programs in General – 19%
- Fundraising – 14%
- Informational Materials – 11%
- Retreats and Conferences – 8%
- Staff – 8%
- Emergency Financial Assistance – 8%
- Connecting Families – 8%
- Raising Awareness – 6%
- Facebook Page – 6%
- Availability – 3%

7. **Question:** What do you think the Central Ohio Chapter of NHF does not do well?

- Programming for Adult Men – 8%
- Connecting Families with Other Families – 8%
- Educating the Public – 6%

8. **Question:** Are there programs or services that you see a need for, but that the Central Ohio Chapter of NHF is not providing?

- Support Groups – 8%
- Education to Health Care Field – 8%
- Networking and Social Events – 6%
- Age-specific Programming – 6%

9. **Question:** How involved is your family with the activities of the Central Ohio Chapter?

- Not involved at all – 2 (6%)
- Very seldom involved – 10 (28%)
- Occasionally involved – 14 (39%)
- Often involved – 8 (22%)
- Did Not Answer – 2 (6%)

10. **Question:** What would it take to increase your family's involvement with the activities of the Central Ohio Chapter?

- More Free Time – 28%
- Proximity of Events – 8%
- More Information/Communication – 8%
- More Advanced Notice of Events – 6%
- The Addition of Specific Programming – 6%
- An Increased Effort – 6%
- More Programming in General – 6%

11. **Question:** What is the most appealing way for you and your family to help other families affected by hemophilia?

- 1-on-1 Mentoring or Sharing – 31%
- Networking and Social Events – 11%
- Remote Support via Phone or Internet – 8%
- Financial Contributions – 6%
- Volunteering – 3%

12. **Question:** Is there anything that the Central Ohio Chapter of NHF could do that would encourage you to start investing more of your time and money into helping us achieve our mission?

- More Communication and Information – 8%
- New Opportunities and Projects – 8%
- Information about Specific Needs – 6%
- Having More Money to Give – 6%

13. **Question:** What are the top three things you'd like your financial contributions to be used for?

- Educational Programming – 33%
- Research – 28%
- Emergency Financial Aid – 28%
- More Events – 14%
- Awareness and Advocacy – 14%
- Family Support Program – 8%

- Sending Kids to Hemophilia Camp – 6%
- Sending Families to Educational Conferences – 6%

14. Question: When speaking to the public about bleeding disorders, what are the three most important points we can convey?

- The Nature of the Disorders – 17%
- How Expensive it is to have a Bleeding Disorder – 17%
- The Burdens it Creates for Families – 14%
- Hemophiliacs Lead Normal Lives – 11%
- Lack of Awareness in the Medical Community – 11%
- Ways to Donate – 8%
- Prevalence – 8%
- The Hope We have for a Cure – 8%
- The Seriousness of the Disorders – 6%
- Recent Developments – 6%

15. Question: Which method do you prefer we use to communicate with you?

- US Postal Mail – 17 (47%)
- E-mail – 15 (42%)
- Telephone – 0 (0%)
- Facebook – 3 (8%)
- Did Not Answer – 1 (3%)

16. Question: When is the most convenient time for your family to attend an event?

- Weekdays – 4 (11%)
- Weeknights – 8 (22%)
- Weekends – 22 (61%)
- Did Not Answer – 2 (6%)

Individual Responses to Consumer Needs Assessment

1. **Question:** For the person who has the bleeding disorder, what are the hardest or most frustrating parts of dealing with the disorder?
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Limitations on Activities & Sports – 44%

- Not being able to do the things you want
- Bloody noses keep him out of some activities at times
- Understanding physical limits in sports (Perry Parker & Jesse Schrader were wonderful at the Junior National Championships!)
- Being told I can't do things or to be careful
- Not eating and drinking what she wants
- Not being able to play
- Limitations on life
- Limited activities
- Not being able to do things at times
- Restrictions
- Limitations on the activities he can participate in
- Playing sports
- Not being able to do certain activities
- Not being able to play certain sports
- Target ankle joint that no longer allows me to run
- Not being able to participate in athletics as I'd like to

Bleeding, in General – 22%

- Random nosebleeds
- Nosebleeds every day
- Non-stop nosebleeds
- Nosebleeds
- Hematoma
- Heavy periods
- Bruising with every little bump
- The bleeding

Treatment Compliance – 17%

- Taking my medicine when I need to
- Keeping a bleeding log
- The medicine (she's only five years old and hates it!)
- Taking the Stimate nasal spray

- Dedicating time to prophylaxis
- Having to take preliminary action with procedures and tests

Pain – 14%

- Having painful bruises
- Not being able to take arthritis medicine because most contribute to the possibility of bleeding. Quality of life lessens when I am in pain.
- Pain
- Hurting all the time
- The joint pain and not having a good way to deal with it

Infusions – 14%

- Getting shots
- Self-infusion
- Being stuck with a needle all the time
- Getting the I.V. started
- Having to be infused

Inconvenience of Hospitals – 11%

- Hospital trips
- The insistence at OSU Treatment Center that they must take blood every time I go without first having a reason to need it
- Hospital stays
- Time in the hospital for Humate P and staying overnight in the hospital

Lack of Awareness in Medical & Insurance Field – 11%

- Lack of healthcare professionals who know about the disease
- Dealing with rural hospitals who don't know about hemophilia
- Dealing with insurance carriers who don't know about hemophilia
- Doctors and medical staff not taking it seriously

Lack of Awareness in General – 11%

- People not understanding the disease and/or its seriousness
- Family members that misunderstand
- People not understanding my disorder
- People not understanding the disease and/or its seriousness

Inconveniences Brought on by Bleeds – 8%

- Missing work due to bleeds
- Missing daily activities due to bleeds

- The downtime that often results from injury (bleeds)

Lack of Awareness in Educational Settings – 8%

- Educators that don't understand
- Teachers not understanding how severe it is
- Sharing about bleeding disorder with classmates

Fear and Worry – 8%

- The fear of not knowing exactly what is happening clotting-wise when I get an injury or have pain
- Understanding and keeping calm when injured
- Being worried about how bad a bleed is

Travel-related Issues – 6%

- Traveling with bleeding medications to work, school, or on vacations
- Worries that Humate P isn't easily accessible when I travel

Unexpected or Unknown Bleeds – 6%

- Not knowing when a bleed is occurring
- Unexpected bleeds

Feelings of Isolation – 6%

- Loneliness
- Lack of getting together with other people who have bleeding disorders

Cost of Treatment – 6%

- Cost of treatment
- Price of Stimote

Other Answers

- Insurance
- Not knowing about all the different services available
- How to achieve the correct result to a problem with a bleed

2. **Question:** For the family members taking care of or living with the person who has the bleeding disorder, what are the hardest or most frustrating parts of dealing with the disorder?
-

Placing Limitations on Them – 22%

- Explaining to my daughter she can't do certain things
- Allowing certain sports to not be played

- Having to explain to other kids that they have to be careful
- Having him be limited on what he can and cannot do
- Telling the child he can't do something and him not understanding why
- Understanding their physical limitations
- Limiting his activities
- Not allowing her to play certain sports or games

Dealing with Pain – 19%

- Seeing her bleed and hurt in her legs (joints)
- Watching them in pain or with a permanent joint problem
- Seeing the pain and frustration on his face during a bleed
- Seeing them in pain
- Understanding their pain and frustrations
- Watching the bleeds happen but not being able to do a lot about it
- Not knowing when my child is hurting

Worry & Fear – 14%

- Worrying about him all the time
- Worrying about the future
- Worrying that he will get hurt
- Worrying about him getting hurt and having internal bleeding
- Worrying about unknown bleeds

Insurance & Prescription Costs – 14%

- Insurance
- The cost of his nasal spray (without good insurance)
- Insurance issues
- Very expensive prescriptions
- Insurance changes

Lack of Awareness in General – 14%

- People not understanding the disease and/or its seriousness
- Not living in an area where people can understand what they do not see.
- So many people “scared” of the disease when they shouldn't be
- People not knowing what VWD is
- People locally do not understand the signs and symptoms of the disorder

The Effects of a Bleed – 11%

- Not having dad up and around when he's recovering from a bleed
- Sleeping a lot when bleeding

- Having to cancel events due to a bleed
- Sleeping

Providing Medical Attention – 8%

- Knowing how to deal with the disorder
- Knowing when to seek medical attention or stay home
- Stopping the bleeding

Compliance Issues – 8%

- Tracking the bleed (lot numbers)
- Keeping the medicine refrigerated
- Giving her Stimate nasal spray

Lack of Awareness among Healthcare Professionals – 6%

- Lack of healthcare professionals who know about the disease
- Finding doctors who are informed

Trusting Others to Care for Them – 6%

- Not being able to get a sitter
- Trusting others to take care of him

Marriage and Reproduction Issues – 6%

- Our daughter giving it to her son (being a carrier)
- The future (i.e. marriage, grandchildren, etc.)

Other Answers

- Not having opportunities to get together with other parents
- Traveling
- Bleeding occurs anytime and anywhere
- Making sure all needs are met
- Dealing with psychological issues
- Understanding and keeping up with current and new medications
- Long stays at the hospital

3. **Question:** What bleeding disorder-related issues most confuse you or represent topics you'd most like to learn about?

Insurance – 14%

- Insurance
- Health insurance issues

- Insurance
- Insurance
- Insurance issues and coverage when transitioning off of parents' insurance

Von Willebrand Disease – 14%

- VWD
- Pregnancy and child birth for girls with Von Willebrand Disease
- Pre-teen females with VWD
- All the different types of VWD
- VWD Type 1

Treatment of Bleeds – 11%

- How to tell a muscle bleed from a regular bleed
- How to help the person with hemophilia. What to do at home when there is a bleed and when is it important to go to the hospital.
- How to control bleeding
- When to treat and who to call

Research and Medical Advances – 8%

- Research
- Gene therapy
- Current research and centers working on hemophilia research

Carriers – 8%

- How male carriers of hemophilia are affected
- At what age should other children in family get tested to see if they are a carrier
- Passing it onto children

Restrictions on Sports and Activities – 6%

- Mild Hemophilia, pertaining to playing sports such as football
- How much restrictions on sports there are

Types of Medication Available – 6%

- Current and new medications
- Pricing and what factor products are available

Joint Bleeds – 6%

- Joint bleeds and arthritis
- Joint bleeding

Aging Issues – 6%

- Aging with hemophilia
- Getting older

Other Answers

- Transfer from child to adult
- Factor 9 vs. Factor 8
- Infectious disease like hepatitis C or other blood-borne viruses
- History
- Causes
- How to read the test results
- Micro-granular storage pool defect of the platelets

4. **Question:** What would be the most exciting and beneficial changes that could occur in the future, as it relates to bleeding and clotting disorders?

A Cure – 36%

- A cure, even it's just a temporary "fix" for weeks or months
- A cure
- The cure of the disease
- Finding a cure
- A cure
- A cure!!!
- A cure
- To find a cure
- A cure
- Cure
- A cure
- Cure for blood disorders
- Of course, a cure

Treatment Advances – 25%

- Pill form
- Maybe a pill taken daily
- All drugs are plasma-free
- A better treatment for VWD
- Smaller volume for bigger doses

- Being able to take a dose of medicine a day, instead of carrying around the Stimate
- New medicine treatments
- New products available
- More options for products

Less Expensive Medicine – 17%

- Less expensive factor and/or better insurance options
- Decrease in the cost of the medicine
- Decrease in the cost of medication
- Cheaper factor product to reduce insurance burden
- Lower cost
- Cheaper drugs

Increased Awareness & Capabilities among Medical Staff – 14%

- Understanding by the healthcare community of the disease
- Medical staff, especially hospital staff, that are knowledgeable about hemophilia
- All doctors have information about hemophilia
- More hospitals are able to treat hemophiliacs
- Treatment available everywhere in case of an emergency

Longer-acting Medicine – 11%

- Longer acting
- Less frequency of shots per month
- Longer lasting medicine
- Not having to infuse so often (for severe cases)

Better Local Programming – 8%

- More information about how to help my child participate in any activity he wants to without being told how he can't
- More networking opportunities
- Local, educational mini-seminars

Genetic Advances – 6%

- Gene therapy
- A way to stop it from being transferred at birth

Health Insurance Reform – 6%

- More unlimited lifetime maxes on health insurance
- Insurance that completely covers the medicine for everyone.

Advances in Joint Care – 6%

- Arthritis “fix.”
- Effective treatments for joint damage; cartilage replacement with longevity

Other Answers

- Understanding by lay people of the disease
- Hoping that my son understands one day
- Some sort of technology that can give us an in-depth view of what’s going on.
- Not having so many blood tests

5. **Question:** Other than issues related to bleeding disorders, what outside issues have the most potential to threaten the well-being of your family?

Insurance Issues – 28%

- Keeping insurance
- How the cost of my insurance is affecting my company’s ability to provide insurance for its employees
- Loss of insurance
- Insurance
- Loss of medical insurance
- Insurance changes
- Having medical insurance
- Insurance
- Hitting the lifetime max on insurance
- Insurance transition

Financial Hardships – 22%

- The economy and its effects
- Paying bills
- Lack of money
- Trying to get bills paid
- Bills and not being able to have two incomes
- Paying bills

- Low income – bills way behind
- Adult children not making it on their own – needing financial assistance

Unemployment – 19%

- Finding a job
- Finding a job
- Finding a job with insurance
- Unemployment (job loss)
- Finding a job
- Searching for a job
- Finding a job

Stress – 19%

- Family stress
- Stress
- Stress
- Stress
- Stress
- Family stress
- Stress with family

Depression – 11%

- Depression
- Life limitations creates some depression
- Depression
- Depression

Work-related Issues – 8%

- Maintaining employment
- Job-related issues
- Stress with job

School Issues – 6%

- School issues
- School issues

High Cost of Healthcare – 6%

- Healthcare expenses
- Affordable healthcare

Special Needs other than a Bleeding Disorder – 6%

- ADHD
- Adult children with bleeding disorders and other special needs

Other Answers

- Relationship issues such as conflict management
- Making sure the kids have what they need
- Time management
- Becoming parents within the next ten years
- Cancer

6. **Question:** What are the top three things you think the Central Ohio Chapter of NHF does particularly well?

Newsletter – 42%

- More newsletters. I love them!
- Newsletter
- I like the new newsletter
- The newsletters
- Newsletter
- Newsletters
- Newsletter
- Newsletter
- Newsletter is great
- Newsletters
- Newsletter
- Newsletter
- Newsletter
- Newsletter
- Newsletter
- Love the newsletter

Family Fun Days – 33%

- Annual dinner
- Always have great events
- Der Dutchman
- The outings (zoo, FAMOHIO, Der Dutchman)
- Family events
- Providing activities on a limited budget

- Der Dutchman Dinner
- Outings
- The free meals (Der Dutchman, Brio) and events such as the zoo that are wonderful to take my family along
- Providing quality information and family activities
- Events
- Love the offers for activities

Informational Programs in General – 19%

- Information programs
- Informational gatherings
- Programs
- Adult program
- Educating
- Programs
- Programs with information I really, really love

Fundraising – 14%

- Keeping the chapter going through fundraisers like the Hemophilia Walk
- Both fundraisers have been wildly successful
- Fund raising
- Fund raising
- Hemophilia Walk

Informational Materials – 11%

- Making written information accessible
- Good info on children and women
- Providing information
- The amount of materials offered is not excessive and not too little ... just right

Retreats and Conferences – 8%

- Skills (Infusion) Weekend
- Infusion Weekend
- Conferences

Staff – 8%

- Rob Alexander is the best!
- Staff has made great strides

- I am impressed greatly by the human quality of the personnel ... equally as good as those at the Toledo chapter.

Emergency Financial Assistance – 8%

- Hoping families get by.
- Assisting with emergency needs
- Supports those of us with bleeding disorders

Connecting Families – 8%

- Getting families together
- A way to show we are not alone
- Getting families together

Raising Awareness – 6%

- Raising awareness
- NHF Walk in Columbus was a huge chance to increase awareness

Facebook Page – 6%

- Facebook
- Information, like the Facebook page

Availability – 3%

- Being available

7. **Question:** What do you think the Central Ohio Chapter of NHF does not do well?

Programming for Adult Men – 8%

- Information and events for aging with hemophilia
- Could always use more programming, especially for young men
- More support for people in the 15-25 age group. Little is offered to support the many men in this group.

Connecting Families with Other Families – 8%

- Support groups (like cell groups)
- Might be helpful to help people get to know each other at functions
- More time for parents to talk

Educating the Public – 6%

- Publicity
- Informing the public and health care professionals

Other Answers

- Some activities have been only offered during the day when I work
- Recruiting and managing volunteers

8. **Question:** Are there programs or services that you see a need for, but that the Central Ohio Chapter of NHF is not providing?

Support Groups – 8%

- Support groups
- A better support group for families that are new
- Support group for teens and young adults

Education to Health Care Field – 8%

- Educating doctors and hospitals
- Education to medical staff
- Education for health care professionals

Networking and Social Events – 6%

- Getting to know other people with bleeding disorders
- Programs to promote socialization amongst those with bleeding disorders

Age-specific Programming – 6%

- Activities that appeal to 15-25 year olds
- Aging with hemophilia

Other Answers

- More activities such as zoos, Magic Mountain, Wyandot Lake, etc.
- The promotion of advocacy at big meetings (such as Annual Dinner)
- Insurance seminars with classes and resources for the uninsured
- Classes or programs for specific bleeding disorders

9. **Question:** How involved is your family with the activities of the Central Ohio Chapter?

- Not involved at all – 2 (6%)
- Very seldom involved – 10 (28%)
- Occasionally involved – 14 (39%)
- Often involved – 8 (22%)
- Did Not Answer – 2 (6%)

10. **Question:** What would it take to increase your family's involvement with the activities of the Central Ohio Chapter?

More Free Time – 28%

- Time
- Times are difficult to attend during days (work until 5 PM then have 1 ½ hour drive or more)
- I wish I had time to volunteer. Unfortunately, I just don't have the time.
- Time
- My job giving me the days off
- My job to let me have time off. Better planning maybe?
- The main reason for not being more involved in activities is the conflict in our family schedule
- Time
- More time off from work
- I usually miss the times to RSVP by, due to our busy schedule

Proximity of Events – 8%

- Proximity (gas is expensive)
- Closer to home
- Closer to home

More Information/Communication – 8%

- More communication
- More information
- Invitations to assist within the chapter

More Advanced Notice of Events – 6%

- Me knowing more in advance would help a lot
- More advanced notice of events

The Addition of Specific Programming – 6%

- Increased opportunities for my age group (20s).
- VWD Groups

An Increased Effort – 6%

- We need to make it a priority to get involved again. Weekend activities might help
- More effort on our part

More Programming in General – 6%

- More opportunities
- More classes

Other Answers

- We had a wonderful time at the Junior National Championship. I love events for the whole family! We hope to increase our involvement
- Money
- The chapter to give money, support, and advice
- I do not participate because my disorder is minor compared to others'. Perhaps I should not, it does have the potential to kill me.

11. **Question:** What is the most appealing way for you and your family to help other families affected by hemophilia?

1-on-1 Mentoring or Sharing – 31%

- Talking to other families in person, one-on-one
- Making people feel like they are part of a family
- To talk and guide them and just be a shoulder
- To relate with them and let them know they are not alone and a shoulder to cry on.
- Mentor and help other families learn how to self-infuse
- Give people support and encouragement
- Supporting younger families with out advice
- Fellowship and emotional support
- Put us in communication with people that we can educate and support
- Sharing our experiences with different families
- Share information

Networking and Social Events – 11%

- Networking
- Getting to know the different families. Sometimes with the activities it's difficult to know the families due to the time that different families may want to spend with their particular family. If it was an event or day that all we did was get together to meet each other and share experiences.
- Talking to people at programs (dinner, meetings, etc.)
- Networking

Remote Support – 8%

- Helping people online
- Via e-mail or phone
- Talking to other families through the internet and phone. I have two kids and it's tough to find free time.

Financial Contributions – 6%

- Donations, if we had the money
- Fundraising

Volunteering – 3%

- Little things – behind the scenes like assisting with mailings, assisting with setups for meetings, etc.

12. **Question:** Is there anything that the Central Ohio Chapter of NHF could do that would encourage you to start investing more of your time and money into helping us achieve our mission?

More Communication and Information – 8%

- More communication (i.e. newsletters, e-mails, etc.)
- More information
- Give more assurance on where the money is being spent and maybe give a breakdown in the areas where time and/or cash is needed

New Opportunities and Projects – 8%

- Bring NHF volunteer opportunities and programs to OSU's campus so that students can get involved
- More activities
- More projects

Information about Specific Needs – 6%

- Hearing about real life struggles and stories
- Letters stating your specific needs

Having More Money to Give – 6%

- If I had money, I would invest more
- We have very little time and no money. Sorry.

Other Answers

- Helping people deal with insurance issues
- Time is an issue with a 2 and a 4 year old

13. **Question:** What are the top three things you'd like your financial contributions to be used for?

Education – 33%

- Education/information availability
- Education via the website
- Education
- Information sessions
- Educational programs
- Information
- Education
- More information about VWD
- Education
- Education
- Education/awareness for young families
- Education

Research – 28%

- Research for a cure
- Research
- Research
- Medicine research
- Research
- Research and a cure
- Research
- Developing new treatments
- Research

- Cheaper meds

Emergency Financial Aid – 28%

- Financial assistance for medical bills for families
- Families in need
- More help to poor people
- Products for those who cannot afford it
- Emergencies
- Low-income families
- To assist those in need of medication and medical care
- Helping members in financial trouble
- Medications
- Helping other families with medications

More Events – 14%

- Family activities
- Activities for adults and kids
- More events
- Activities
- Events

Awareness and Advocacy – 14%

- Education of health care professionals
- More publicity
- More advertising in television and newspapers
- More books on hemophilia and more teachers involved
- Advocacy (insurance and government related issues)

Family Support Program – 8%

- Support for families from families – talking, etc.
- Getting families together
- Support programs

Sending Kids to Hemophilia Camp – 6%

- Camps for kids
- Camps

Sending Families to Educational Conferences – 6%

- Assist a family to attend the national conference. Start early through the clinics. If the family contributes ½, maybe they would be more invested.

If we could assist two families then they would feel they weren't alone on the trip. But I would suggest paying ½ the expenses for two families, rather than all the expenses for one family.

- For the FAMOHIO Conference

Other Answers

- Transportation
- Developing the chapter
- Gym memberships for overweight patients
- Scholastic gifts for tuition (college, vocational school)
- To help connects folks with treatments

14. **Question:** When speaking to the public about bleeding disorders, what are the three most important points we can convey?

The Nature of the Disorders – 17%

- How clotting works and what can go wrong
- What the disorder is
- A clear explanation of the disease
- The different types of hemophilia
- Nature of the disorder
- Causes and types of bleeding disorders

How Expensive it is to have a Bleeding Disorder – 17%

- How expensive treatment is and insurance issues
- The expense to families
- How the disorder causes hardships on families
- How expensive the treatments are
- Costs and the burden it places on families
- Cost factor for families

The Burdens it Creates for Families – 14%

- How people are affected (arthritis, target joints, etc.)
- The difficulty in managing the care
- The needs imposed by having severe hemophilia
- How it affects children
- The stress it can put on a family

Hemophiliacs Lead Normal Lives – 11%

- Explain how they can participate in any activity
- These are normal kids/people with dreams
- Treat people equal
- Patients can live normal lives with proper treatment

Lack of Awareness in the Medical Community – 11%

- The need for education of health care professionals
- How little the medical community knows about this
- Need more hospitals to be equipped
- Need more doctors to be informed

Ways to Donate – 8%

- We can help
- Need for increased monetary support
- What people can do to assist

Prevalence – 8%

- A large number of the population is affected
- More common than people realize
- The scope of the community affected

Hope and a Cure – 8%

- The hope that exists for people with bleeding disorders
- Hope for a cure
- Research

The Seriousness of the Disorders – 6%

- The seriousness of the disease
- How serious this disorder can be

Recent Developments – 6%

- Not as dangerous as it once was
- Info on the medicines or development

Other Answers

- Security of funding
- Not contagious
- It costs all of us one way or the other
- We have a strong community with many members ready to help

15. Question: Which method do you prefer we use to communicate with you?

- US Postal Mail – 17 (47%)
- E-mail – 15 (42%)
- Telephone – 0 (0%)
- Facebook – 3 (8%)
- Did Not Answer – 1 (3%)

16. Question: When is the most convenient time for your family to attend an event?

- Weekdays – 4 (11%)
- Weeknights – 8 (22%)
- Weekends – 22 (61%)
- Did Not Answer – 2 (6%)

17. Question: Additional comments you want the Central Ohio Chapter of NHF to consider as it creates a strategic plan for the next three to five years?

- Focus on adding seminars to health care professionals either by classes at work (hospitals) or by adding it to curriculum.
- Focus on teaching school nurses signs & symptoms and how to care for a child with a bleeding disorder while that child is in school.
- I think education should be provided in high schools, libraries, and community centers.