

# Hemophilia B:

## Paths to Empowerment



Your Voice. Your Life.



# Foreword

The B2B (hemophilia B patient to hemophilia B patient) program began in 2005. It was created so that people who have hemophilia B could speak to others with hemophilia B, with the goal of helping each other learn how to live with this condition. The program's original mission remains the same today:

## 1. Help people with hemophilia B address their challenges

## 2. Strengthen the support system and educational network in the hemophilia B community

As part of the B2B program, books were written to educate people who have hemophilia B. The seven previous books are:

- *Young Adults and Hemophilia B*
- *Learn From Experience: A Guide for Mature Adults*
- *Navigating the Preteen Years*
- *Hemophilia B in Early Childhood*
- *Hemophilia B: Your Point of View*
- *Many Faces of Hemophilia B: Challenges and Opportunities*
- *Hemophilia B: A Family Perspective*

The books give information and tips about living with hemophilia B from people who have hemophilia B. They present personal stories by young adults, mature adults, parents of infants and toddlers, preschoolers and teenagers, and aunts and uncles. The books also include thoughts from people in the medical field who treat children and adults with hemophilia B.

This book is the eighth in the B2B series. It is called *Hemophilia B: Paths to Empowerment*. It focuses on ways you and your family can become empowered to overcome the challenges you face. Members of the hemophilia B community and our own B2B Advisory Board offer thoughts and speak about their experiences on their paths to empowerment.



On behalf of Pfizer Inc., The Coalition for Hemophilia B Inc., and the B2B Advisory Board, we would like to extend our gratitude to the members of the hemophilia B community who contributed to this book. Your time, knowledge, and personal stories about life with hemophilia B are greatly appreciated:

*Dan B., Paul B., Ian C., Wayne C., Ben D., Nina D., Melissa F., Felix G., Jeff K., Jennifer M., Edward N., Greg P., Chad S., Jared S., Matt S., Becky V., Tony V., Bobby W. and Rocky W.*

The views and opinions expressed in this book are those of an advisory board comprising patients, parents, and hemophilia care specialists within the hemophilia B community, and are not necessarily those held by Pfizer Inc.

The narratives and statements from health care professionals in this book were provided prior to its initial publication in 2016.

The information in this book should in no way replace the advice of your health care professional. Be sure to talk with your doctor, nurse, or hemophilia treatment center (HTC) staff regarding any form of medical advice or treatment.



confidence  
independence  
freedom  
knowledge



# Introduction

## What Does Empowerment Mean?

Hemophilia B is a lifelong condition that can sometimes make it seem difficult to feel in control of the circumstances. But people with hemophilia and their families can still maintain a sense of control. By becoming an active participant in their care, they can reduce the feeling of not being in control that a chronic condition can create. This is the process of empowerment.

“ I think the mental leap I needed to make was the realization that I could own my hemophilia.” – Greg P.

Living with hemophilia B can be challenging. Bleeds, pain, and damage to tissues and joints can occur, and they can interfere with the most basic activities of life: standing, walking, school, work, recreation, play, or sports.

*“Everything you consider a daily activity, I consider a challenge.” – Dan B.*

In the words of the late Renée Paper, longtime advocate and founder of the Hemophilia Foundation of Nevada, **“Do not give up on the process. It can sometimes be frustrating and scary dealing with the complexities of modern health care systems. Perseverance and active involvement will help ensure the patient becomes a partner in their health care.”**<sup>1</sup>

*“Walking is particularly difficult, so I limp in private and swagger in public.” – Paul B.*

**“ We have made hemophilia B something (our son) has and not something he is.”  
– Ian C.**

Naturally, different people travel different paths and move at different paces toward empowerment. There is no wrong way. Each family will discover ways that fit their personalities, circumstances, and each individual's condition.

*“I remind myself that I can take the steps to manage a healthy lifestyle living with hemophilia.” – Jared S.*

This is a story of many of our own B2B Advisory Board members as they describe their paths to empowerment. It reveals that empowerment and active involvement in health care creates a better chance of being healthier and spending less money on medical costs.<sup>2</sup>

*“I . . . started to see that I needed to get my head in the game and start to change my attitude. My son was 4 at the time, and I struggled even speaking to others about his hemophilia because I was so drained and depressed.”  
– Matt S.*

### **Empowerment to become involved in hemophilia care can help to:**

- Get back a sense of control
- Improve coping skills
- Manage hemophilia B better because of improved communication with health care providers (HCPs)
- Define desired goals and do what is needed do to achieve them
- Instill a sense of self-esteem and success
- Define oneself outside of hemophilia B

## Steps in the Journey Toward Empowerment

Learning about hemophilia B and how to care for it is one of the first steps patients and families can take in their journey toward empowerment. But few people can be expected to know much about the challenges of living with hemophilia B before they encounter them. There are about 20,000 people in the United States with hemophilia, and hemophilia B is four times less common than hemophilia A. About one-third of cases have no other family members with hemophilia.<sup>3</sup> Learning as much as possible about hemophilia B can help to overcome a fear of the unknown as what it means to live with this condition becomes clearer. It may also teach people with hemophilia B and their families how to live a fulfilling life in spite of hemophilia B.

**“My daughter has hemophilia B, but that certainly isn’t the most important thing I want people to know about her. We’ve worked hard to make sure to keep hemophilia in a place of balance in our lives.”  
– Becky V.**

*“My illness has not become a burden on the family. My family has always made it a part of my regular life, and I continue to manage it in this manner.” – Jared S.*

### Advocacy groups are gateways to learning about hemophilia B and to finding help and resources:

- Help locate sources of care
- Guide in the search for coverage of that care
- Provide information about living with hemophilia B at different stages of life<sup>4</sup>
- Make connections to the larger community of people with hemophilia B
- Help find opportunities to share challenges and learn from others

## “ I am intimately involved in my treatment regimen.” – Tony V.

There are many excellent resources to educate about living with hemophilia B. The Coalition for Hemophilia B ([www.hemob.org](http://www.hemob.org)), the Hemophilia Federation of America ([www.hemophiliafed.org](http://www.hemophiliafed.org)), the National Hemophilia Foundation ([www.hemophilia.org](http://www.hemophilia.org)), the World Federation of Hemophilia ([www.wfh.org](http://www.wfh.org)), and Pfizer's B2B Program ([www.B2Byourvoice.com](http://www.B2Byourvoice.com)) are excellent places to start.

*“I was expected to take charge of my own health care at a young age. So I did. I learned about my hemophilia. And thanks to NHF's HANDI library, I learned about a lot of other people's hemophilia, and HIV, and hep C. . . The more I learned, the better I felt. To this day, the same is true. Only by being independent in my care could I cope with my chronic illness.” – Felix G.*

*“Talking with other people, especially those in my support system who have chronic illnesses, helps when feeling down and alone. Staying on top of doctor appointments and my general health helps eliminate the negative emotions that can sometimes arise from dealing with a chronic illness.” – Ben D.*

As people with hemophilia and their families become more knowledgeable, they can confidently take a more active role in decisions about care.



## Treatment Team Relationships

Establishing good relationships with skilled and knowledgeable HCPs is important. These relationships lay the foundation to become and stay as healthy as possible. They enable consistent management of the condition and help maintain quality of life.

**“ It helps to know that I am surrounded by so many great people who have my best interest at heart.”  
– Tony V.**

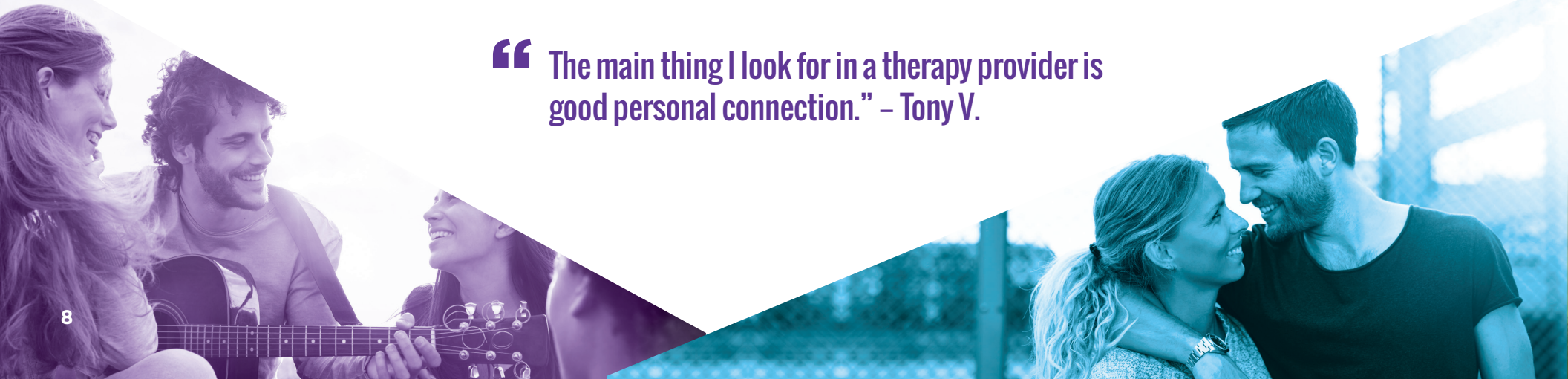
*“Be proactive, not reactive. Ask good questions of your doctors and nurses. Try to create a partnership with your caregivers.” – Jeff K.*

There are options on where to find care for hemophilia B. For example, working with a network of providers, which should include a hematologist and other HCPs who have experience treating people with hemophilia. Another option is working with a hemophilia treatment center (HTC),<sup>5</sup> which offers a comprehensive care team that provides access to the complete range of services that may be needed.

An HTC can be a lifelong resource for learning about hemophilia B, diagnosing and monitoring the severity of the condition, and developing and tracking the course of treatment. It is important to find HCPs and develop a comfortable relationship. This may help facilitate participation in the decisions about care.

To locate an HTC, visit the Center for Disease Control and Prevention (CDC) Hemophilia Treatment Center Directory at:  
[www2a.cdc.gov/ncbddd/htcweb/Dir\\_Report/Dir\\_Search.asp](http://www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp)

**“ The main thing I look for in a therapy provider is good personal connection.” – Tony V.**





For parents of children with hemophilia B, in the beginning and for years parents may be the ones who become empowered in the care of a child. Gradually, as appropriate for the child's age and personality, parents can teach children about hemophilia B. Eventually, a child may start to participate more in his or her own care. This could begin the empowerment process.

*“Elizabeth is compliant with the therapy schedule she and her doctor developed. I think she is faithful to the schedule because she had input. Her doctor listened to her needs and wants, and together they came up with a plan that both of them were happy with. Since she has ownership of the plan, she takes care of it on her own.” - Becky V.*

## Managing Hemophilia B

As much as an individual with hemophilia B learns from others, personal experience can also teach about the condition and how to cope with it. Over time, and with the medical advice of the treatment team, people with hemophilia B and their families can learn how to manage the condition on a day-to-day basis.

*“I know myself well enough to know when a bleed is going to result in greater problems.” - Ben D.*

Self-awareness and knowledge of how to care for hemophilia B may be some of the best tools throughout life with the condition. Whether it's a move to a new state, going away to school, meeting new HCPs, or walking into a new hospital, it's important to be confident in what one knows. That knowledge empowers people with hemophilia B and their families to participate in their care consistently.

**“ Who knows your body better than you do?” - Chad S.**



**action**

**possibility**

**freedom**

**independence**



## Self-infusion: A Critical Step Toward Taking Control of Hemophilia B

Self-infusion, or giving factor to oneself through a vein, is among the most beneficial and empowering steps that can be taken in the care of hemophilia B.<sup>6</sup> Learning to self-infuse allows people with hemophilia to have more control of their care. It also allows for the treatment of bleeds immediately if they occur.

**“ I’ve been self-infusing since my early 20s—relatively late in life considering how young kids are doing it now. When I was young, you had to go to the emergency room to get medicine.” – Rocky W.**

This skill can give greater control and flexibility in life with hemophilia B.

*“The freedom allowed by self-infusion made pretty much everything I’ve done possible. It gave me the ability to travel, to get an education, and to do what I enjoy.” – Dan B.*

Still, like all big steps in the journey to empowerment, self-infusion is preceded by many smaller steps that can help prepare for the process. Learning self-infusion takes time. For children, the approach may need to be sensitive and carefully thought-out.

**“ Learning to self-infuse was one of the most life-changing events ever.” – Dan B.**

## Every Child Is Different

Children learn to infuse at different paces and at different ages. Some are emotionally ready earlier. Some simply have easier veins to find. While one child might learn to self-infuse at age 9, another might not learn until 16. Still others might not learn until they must—when they are ready to leave for school or live on their own.

*“My son received encouragement from a couple of older people with hemophilia. He wanted to go to hemophilia camp, but I felt he needed to be able to self-infuse prior to attending, so we used that as a goal. Once he started, we agreed he could go to camp. Now it’s almost always by himself. My daughter was needle-phobic, so it took her many more years to learn to self-infuse. She also has difficult veins that roll. I will step in to help as needed.” – Nina D.*

Finding a vein and infusing factor in a child can be challenging, but parents can become skilled at it. When it comes time to teach their child, parents can then combine practical experience with everything they know about their own child.

**“My son is eager to learn self-infusion. We have attended some clinic days at our local pediatric hematologist’s office, so he could have one-on-one lessons. He also had some practice at summer camp.” – Melissa F.**

Parents can call on other resources too. Nurses at the HTC or hematologist’s office can help children learn how to self-infuse. In addition, hemophilia B summer camps provide the positive reinforcement of learning self-infusion alongside other children—and sometimes from another child. Children who have already taken steps toward independence by attending camp can return home proud and empowered by the progress they are making.

*“Self-infusion was a struggle, but she’s overcoming it with practice. Going to camp was the best thing ever for her! Now she is doing so well and is so much more relaxed because she is confident about her ability to find a vein and complete the infusion. . . Using her smartphone and the HemMobile® app has made it easier for her to keep a log of her infusions. She is pretty good about logging her infusion while she’s holding pressure on her infusion site. Using the phone makes it easy.” – Becky V.*



### Lessons should begin with the basics and advance as children's comfort level grows:

- Teach him or her appropriate vocabulary to communicate clearly
- Teach how to clean and sterilize the injection site
- Teach how to mix medication with sterilized water
- After finding the child's vein, allow him or her to push the butterfly needle in
- Let the child pull the butterfly needle out afterward

*Note: Be sure to follow your healthcare provider's recommendations for infusion.*

“When I went to camp, seeing other kids self-infuse was definitely a big motivator.” – Greg P.



power

preparedness

control

independence

## New Responsibility

Learning to self-infuse can also become part of empowering a child with hemophilia B to make responsible life decisions and understand the consequences of choices. There can be a positive give-and-take between parents and children about permission for new activities or responsibilities if the child learns how to self-infuse. For example, learning to self-infuse can be the requirement for participating in new sports or activities, learning to drive and getting a driver's license, going away to school, or living and working on his or her own.

*“If they don’t infuse, they don’t play. If there is a sport that they love, they will welcome the preventive care because it keeps them in the game. This will become habit and something they expect to do. I’ve explained, isn’t it better to be in the game rather than be sitting on the bench for 2 to 3 weeks waiting for a bleed or injury to heal. . . There have been times that my son reminds me that we have to infuse before we leave the house. He clearly sees the benefit and knows that the extra 10 to 15 minutes it takes to do these preparations only benefits him in his choices around being healthy and playing the sports that he loves.” – Matt S.*

**“ My parents helped me to overcome that particular barrier by making my ability to reliably self-infuse a condition of getting my driver’s license. That proved to be a good motivator.” – Greg P.**

As children learn responsibility and necessary skills like self-infusion, parents can begin to step back from being the sole supervisor and provider of care for their children. This is a step toward empowerment both parents and children. This is a time of transition for parents, too, who can then learn to let go and allow their children to become more responsible and empowered.

*“We had a port up until recently. My son hated being infused in his port. It was a constant battle for years. We had the port removed earlier this year, and he does not mind being infused anymore. No more battles! He has begun to learn self-infusions.” – Melissa F.*

## Setbacks

Setbacks can happen along the road to empowerment. The skills required for self-infusion are challenging to learn and maintain. Children may become frustrated or discouraged by the inability to find a vein or the pain of repeatedly missing one. Parents may feel sympathetic to this pain at such times. This may be an opportunity to step back and see what can be learned from the situation. Perhaps it's time to take a rest from learning self-infusion or to turn to other resources for help. There is the option to begin again when ready.

There may be setbacks when living with hemophilia B. An example could be forgetting to order syringes or gauze, or unexpectedly winding up in a situation that causes a bleed. The setback could be anything. What is important is learning how to avoid this type of setback in the future. Overcoming these setbacks can help people with hemophilia B to get back on track and take those steps toward empowerment again.

*“Our struggles have included infusing at times when he was feeling tired or rushed, which can make it more complicated. We also know it's important to infuse when he will need to be the most protected, like before sports.” – Melissa F.*

**“ We all have bad days. Relax, don't panic.” – Jeff K.**





“ What works for one, may not work for you.  
Find the best method... for you.” – Bobby W.

## Being One's Own Advocate—Transitioning Advocacy From Parent to Child

A parent is a child's first advocate. Parents teach by example, by taking the lead, by navigating the world of health care to ensure their child receives the care he or she needs—and by not appearing fearful, even at times when they may be. How they behave lays a natural path for their child to follow. Parents can lead their child to become more independent, more empowered, and eventually his or her own advocate.

**“Children will advocate for themselves if they know they'll be heard. From an early age, give them a chance to voice their concerns and talk through any concerns they have. If they know they will be listened to, they are more likely to advocate for themselves when they aren't at home.”**  
– Becky V.

Parents have worked hard to bring their child so far in the world, and this transition can be challenging. It can be easier when taken in a series of steps, and they can be proud of their child's growing independence and empowerment.

*“I find it extremely important to foster the child's identity and to make him a vital part of the family and, more importantly, an active participant in his care.”* – Ian C.

There are several ways parents can encourage and guide this transition. The growing relationship between their child and the HTC staff—or other HCPs—can empower more independence.

*“Find ways for them to become involved in the process from an early age. Give them some choice, and this will allow them to feel ownership of the process.”* – Becky V.

**“Don't be afraid to ask questions. There are never any bad questions.”**  
– Wayne C.



## Practicing Advocacy

Parents should gradually allow HCPs to address questions directly to their child. This is a role that can be practiced at home by asking the types of questions the child would hear at the medical appointment. Then together, parents and children can review way for the child to answer and ask his or her own questions.

*“One thing I have learned is to let my son be a part of his treatment plan. He feels in control. It not only helps with compliance, but he is proud of how well he helps to manage his care and the choices we make to keep a high quality of life for him.” - Melissa F.*

Parents should want their child to be a person who is not afraid to take charge of his or her own care—a person who will step up to the plate, ask important questions, and create a partnership with HCPs. By encouraging independence, children are empowered to do just that.

At times, the process may seem daunting, but it can be a process of baby steps, guided by parents’ knowledge or their child’s personality and readiness. Parents can watch their child’s confidence grow as more steps are completed in this transition.

**“ Knowledge is power and by teaching [children] step-by-step from a young age, they become empowered without realizing it—and there is a lot of self-esteem for them.” - Matt S.**

*“My husband and I consciously made an effort to gradually hand the reins for her treatment schedule over to Elizabeth. . . This has made her very responsible, and I think she really learned to listen to her body and to know when she needs to infuse.” - Becky V.*

## Being Empowered Includes Being Prepared

A bleeding event can arise out of even simple, everyday activities: a swinging door hitting an elbow, twisting an ankle in a stumble at the foot of the stairs, a strain while performing a task at work, or injury during an auto accident.

“**Something very simple can cause a bleed for me if my [factor] levels are low, so I always have to be aware of what I’m doing and what my levels are.**” – Jared S.

**People experienced with hemophilia B learn that you cannot always control what happens, but you can be prepared:**

- Wear a MedicAlert® or RoadID® pendant, bracelet, or wristband because paramedics tend to check necks and wrists. Alternatively, carry a wallet card
- Know your limits
- If it is feasible, bring factor on the job and to school
- **Be proactive:** treat a bleeding event sooner than later

*Note: Be sure to follow your HTC’s recommendations regarding staying prepared.*

*“I think Elizabeth is very prepared to care for herself or to seek appropriate care in case of an emergency. She orders her own factor and knows to make sure she always has plenty of factor on hand. I can’t think of the last time I saw her without her medical alert bracelet. She wears it 24-7. When she went to college this year, she was proactive and met with the health care team at her school during the first week of school. She had coordinated with her HTC, so the school had all of her information.” – Becky V.*

“**I do carry a card and a MedicAlert. I travel with factor when I am more than couple hours from home.**” – Chad S.

**“ I try to infuse before any strenuous activities. I hate to miss out on things, so I’m fairly good at this. I make a deal with myself to not participate if I don’t feel healthy.” – Edward N.**

## “Go Bags”

People with hemophilia B might want to keep a “go bag” or “ready bag” in their vehicle, at work, or in their locker. The bag could contain factor and sterilized water, syringes, gauze, and alcohol wipes—everything you need to infuse if something happens. Another option is to store factor at commonly visited locations: a girlfriend’s, a grandmother’s, school, or work, for example. Some people carry what they need whenever they travel overnight or anywhere where they would not feel comfortable without their factor.

*“Our HTC provides us with a list of HTCs where we are traveling. We also have a travel bag that we keep all of (our son’s) supplies and meds in for convenience.” – Matt S.*

The risk for a bleed is affected by several factors. To help reduce the risk of bleeding, people with hemophilia B should be mindful to infuse enough factor to support planned physical activities. Also, never be afraid to treat whenever and wherever necessary: even on a plane, train, or bus.

*“Be proactive! Treat sooner rather than late when bleeds arrive. Know your limits.” – Jeff K.*

*“Be prepared for all the unexpected bleeds, especially before holidays and vacations or the start of school. If you have a long day planned with extended family or other activity, bring your factor or treat in advance.” – Nina D.*

## Items to potentially include in a “Go Bag” or “Ready Bag”



Factor



Syringes



Gauze



Alcohol Wipes



Sterilized Water





## Empower Oneself by Empowering Others— Be Part of the Community

Making connections with others in the hemophilia B community forms a valuable network for learning and support.

*“The process of empowerment takes place within a context, which includes interactions with others. Positive interactions with others . . . are encouraging, strengthening, and uplifting.” – Cheryl H. Gibson, PhD, RN*

**“Through my involvement in the community—particularly through camp—I’ve been able to positively affect other people’s lives. This is very rewarding and enriching, and it’s something that has bolstered my own self-esteem.” – Rocky W.**

*“It has opened my eyes up to our community and has made me more willing to take charge of my own care.” – Wayne C.*

People with hemophilia B and families in the hemophilia B community learn from each other’s experiences. Parents can look to other families that have children who are a step ahead in age or experience for the advice and courage to take the next steps with their own children. Being active in the hemophilia B community allows children to hear what their friends are doing and how they are doing it. What they learn will help them in their lives too.

*“I have also found that attending meetings and connecting with other families have been so important. Attending hemophilia camp establishes bonds that can last for years. Nurture those connections that your child develops. They may not always want to talk to their parent.” – Nina D.*

*“I definitely felt meeting others in the hemophilia community—especially the B community—this was where I came out of my shell.” – Matt S.*

**“ To overcome my denial . . . Volunteering at camp and getting involved in chapter activities and legislative advocacy were major factors in helping me come to the acceptance that I now feel.” – Greg P.**

People with hemophilia B may face some things in life that challenge their self-esteem. Learning that others have had similar experiences can be comforting in knowing that others also face these issues.

*“... the community is really the best way to keep informed as to what is going on. I think the peer groups help because you develop friendships and realize that you are not alone and that other people have gone through the same things.” – Chad S.*

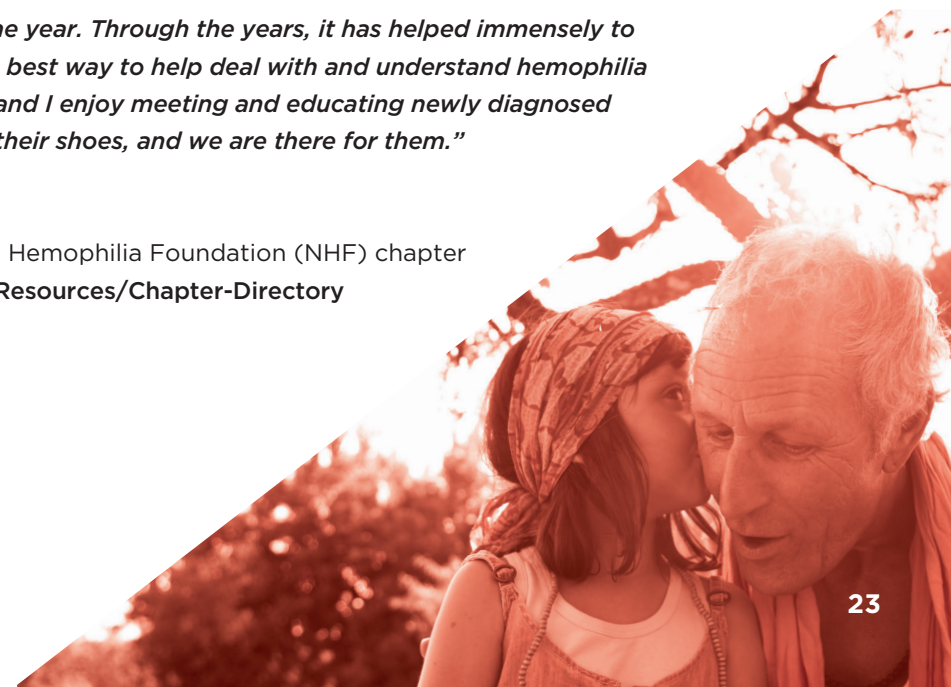
Patients who perceive themselves as taking care of their conditions may want to speak to others with similar conditions, to share their personal experiences of how they managed, and by doing so feel empowered.<sup>8</sup>

*“When I became an adult and was dealing with the emotions of chronic illness, I found self-esteem in being knowledgeable. I even had information and things to share with others. I had purpose in my life and in my community.” – Felix G.*

Volunteer at camp. Get involved in chapter activities. Become a legislative advocate. Taking action can help with acceptance of the condition. Rewarding and enriching experiences empower both people with hemophilia B and their families. It is hardly surprising that many hemophilia B community members turn to each other first for answers to serious questions in their lives.

*“We are active in our local chapter and attend many activities throughout the year. Through the years, it has helped immensely to hear others tell their stories, as well as sharing ours. We have found that the best way to help deal with and understand hemophilia is to listen to ones who have lived with it for many years. Both my husband and I enjoy meeting and educating newly diagnosed parents. I think it is important for them to understand that we were once in their shoes, and we are there for them.”  
– Jennifer M.*

To get started participating in the hemophilia community, locate a National Hemophilia Foundation (NHF) chapter by visiting the NHF Chapter Directory at: [www.hemophilia.org/Community-Resources/Chapter-Directory](http://www.hemophilia.org/Community-Resources/Chapter-Directory)



## How to Educate Others

We have explained how important it is for people with hemophilia B and their families to become educated about hemophilia B. More knowledge can create a better sense of preparedness for unforeseen events at school, work, or away from home. Educating people outside the immediate family can also be important: teachers, administrators, and health staff at schools; coworkers and managers at work.

*“I find that most people don’t know what hemophilia is or what it means, so I see it as an opportunity to educate. I just tell them about it. I answer any of the questions they have.” – Rocky W.*

For some, telling others is a sensitive topic and personal decision. Some people choose to tell friends and close coworkers because they can offer help if needed.

*“Sometimes it is a struggle to tell others—coworkers, supervisors—the reason for not being able to do some things or needing to take time off from work.” – Ben D.*

We have mentioned the role HTC and medical staff can play in the education of patients, families, and children. They can also help to assemble helpful materials and plans for school officials or coworkers.

### **There are many other excellent sources of information and educational materials:**

- The Pfizer-sponsored B2B program website offers a series of downloadable books, videos, patient stories, and more containing information and tips about several aspects of living with hemophilia B
- The Coalition for Hemophilia B, Inc. offers a newsletter, workshops, and family-oriented meetings to educate people with hemophilia and their families
- Hemophilia Federation of America, the largest patient-focused group for those with hemophilia, offers educational webinars and downloadable documents, presentations, and videos
- National Hemophilia Foundation offers a chapter directory, a national list of HTCs, information about camps and scholarships, and informative publications
- World Federation of Hemophilia offers publication and video libraries, a series of articles from young people, assessment tools, a Global Treatment Centre Directory, and the *Haemophilia* journal
- Centers for Disease Control and Prevention contributes to a better understanding of hemophilia and its complications through printable materials, data and statistics, and a directory of HTCs



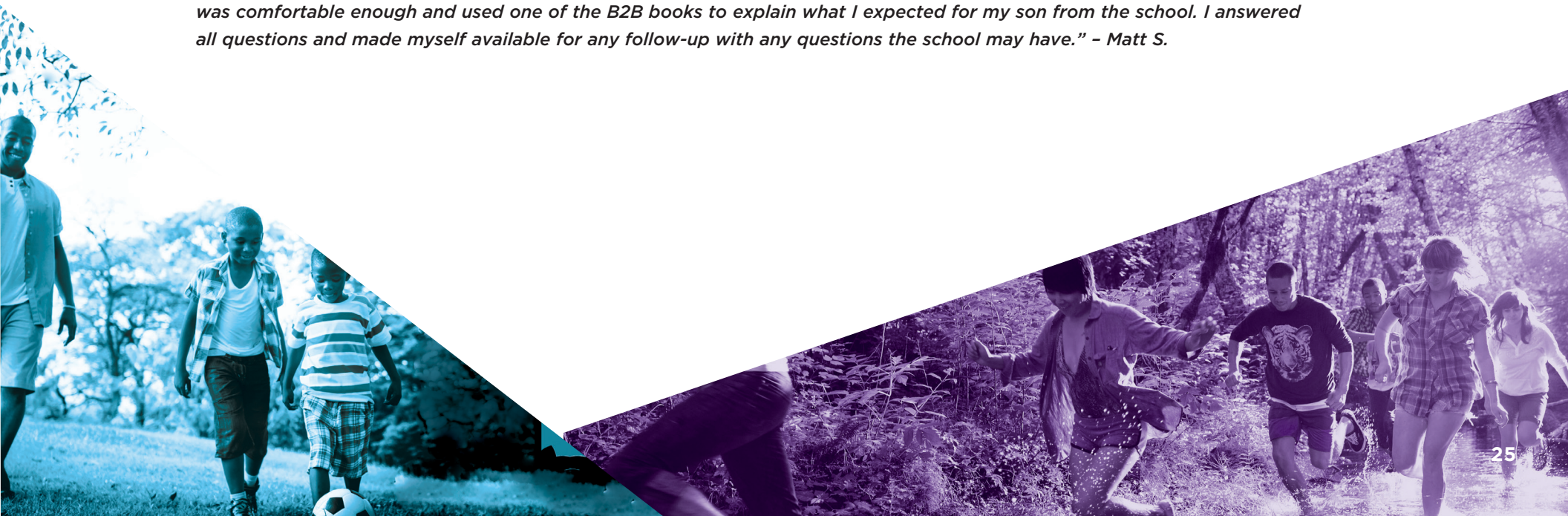


*"I do a teachers' in-service every year with the new teachers the week before school starts. It is an informal meeting. I teach them about hemophilia and give them examples of issues we have had and how we dealt with those issues. I give them an emergency care plan and a list of each of our roles: my son's, the parents', and the teachers'." – Melissa F.*

**“ I actually learned from a very early age to talk with many different kinds of people about hemophilia. Even in elementary school, I participated in presentations to my teachers.” – Greg P.**

Local or regional chapters of the national organizations offer educational materials and events. These events are also a good way to expose younger children to older individuals with hemophilia B. This can help show how others live without letting the condition control their lives. Such encounters can encourage and empower by example. The confidence gained can carry over to relationships with others at school, at work, and in life.

*"In elementary school, our HTC nurse came to the school and held a meeting with the principal, nurse, staff, his teachers, lunch staff, and gym teachers to educate them on hemophilia and how Steven needs to be taken care of. In middle school, I was comfortable enough and used one of the B2B books to explain what I expected for my son from the school. I answered all questions and made myself available for any follow-up with any questions the school may have." – Matt S.*





**“ Insurance is a must-have, be it private or government.” – Chad S.**

## Insurance

Having the knowledge, support, and resources to become an active participant in your care is essential to successful empowerment. Having insurance is a crucial step in empowerment because the annual costs of treating hemophilia B<sup>9</sup> make access to health care coverage a necessity.

Evaluating different plans is demanding and detailed work. Some people are fortunate enough to be able to call upon the assistance of larger employers' HR departments, a union, or state resources. Others can turn to insurance brokers. It may be a good idea to ask for help and guidance from your HTC staff, or consult the staff and resources of the local hemophilia chapter.

One particularly helpful tool is the “Personal Health Insurance Toolkit” on the National Hemophilia Foundation website.<sup>10</sup> The “Personal Health Insurance Toolkit” guides users step by step to make insurance selection easier. The toolkit includes fact sheets and cost worksheets, a glossary of terms, and more to help users understand coverage.

*“. . . sometimes the insurance obstacle is hard to overcome.” – Wayne C.*

**“ I am able to shop around for the insurance provider that has the best community involvement and gives back to the community.” – Bobby W.**

**options**

**personal**

**choices**

**education**





**control**

**confidence**

**happiness**

**independence**

## Summary

Being empowered can help maintain a sense of control over life with hemophilia B. One of the first steps on this path is to learn about hemophilia B. There are many resources available to teach about hemophilia B treatment and care. Being well-informed can help people with hemophilia B and their families to feel empowered to take care of themselves. With this knowledge, they can establish a partnership approach with HCPs.

New stages of life with hemophilia B lead to exploration of different steps and paths along the way to empowerment. Be sensitive to the needs and readiness on each step of the journey. There will inevitably be setbacks along the way, but it is important to understand that these are things everyone experiences. Such setbacks are opportunities to learn. Once learned, these lessons can help in the future.

The hemophilia B community provides many resources and opportunities to help empower everyone in it. This book is one more example of how the community is here for support. Engage with these resources and help to feel empowered.

*“It’s not weak to have pain or a limp, but it is weak to refuse to try and change that reality for another.” – Felix G.*

**“ There are things in the world worse than hemophilia B; if a future member of my family were to be born with hemophilia, I know from firsthand experience that they can live a full life.” – Rocky W.**

# Resources

## **Pfizer Hemophilia Connect**

We're committed to helping the hemophilia community.

For the past two decades, Pfizer has been a part of the hemophilia community. We recognize it can be difficult to understand what support is available to help families with bleeding disorders, and to help address this challenge, we created Pfizer Hemophilia Connect.

Pfizer Hemophilia Connect is a one-stop destination to access all of our resources for eligible patients.

## **Soozie Courter Hemophilia Scholarship Program**

Pfizer provides scholarships to students with hemophilia A or hemophilia B who are high school seniors, have a graduate equivalency diploma (GED), or are currently enrolled in an accredited junior college, college (undergraduate or graduate), or vocational school. Awards are based on academics, recommendations, and a personal statement from the student.

Visit [www.HemophiliaVillage.com](http://www.HemophiliaVillage.com) to download an application.

## **HemophiliaVillage.com**

The Pfizer-sponsored website, [www.HemophiliaVillage.com](http://www.HemophiliaVillage.com), provides information for the hemophilia community. Consumers and professionals alike can find product information and learn about programs and services.

## **B2Byourvoice.com**

The Pfizer B2B Consumer Advisory Board was developed to directly connect Pfizer to hemophilia B patients and caregivers in order to gain firsthand feedback from the hemophilia B community. As a result, the B2B program has created tools and resources to support the community and continues to evolve to address needs as they change. Visit [www.b2byourvoice.com](http://www.b2byourvoice.com) for more and to check out a series of books, videos, patient stories, and other resources for people living with hemophilia B.

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