

## Ben Deininger, Age 13 [Swimming & Baseball]

### Full of Energy

Ben doesn't remember a time that he wasn't active. When he was just five, his HTC doctor, Steve Pipe, MD, suggested he give swimming a try. Ben loved it so much, it has been his primary sport for the last 8 years. He also plays baseball and basketball at his middle school and runs track and cross-country.

Ben's family has always been active; with dad, Pete, running triathlons and biking, and mom, Christina and sisters also enjoy physical activity. Being inactive was never an option.

### Benefits of Exercise

Ben might not have appreciated the physical benefits of building strong muscles to protect his joints from bleeds. However, like most 13 year olds, he does love the social aspect of playing sports. He gets to be with his friends and have fun. Christina knows her kids are healthier and happier when they are active. Both parents also notice a big boost in mood after the kids engage in physical activity.

### Play it Safe

Ben treats his hemophilia with factor infused prophylactically every other day. Ben and his parents are very punctual with his treatments, and can remember only two or three occasions when they were unable to infuse Ben on time. Having "factor on board" helps them feel comfortable with his activities.

*"If done safely, the benefits of physical activity far outweigh the risks."*

Christina Deininger,  
Ben's Mom



Ben Deininger  
Severe Hemophilia A

Additionally, protective sports equipment is crucial. Ben wears a helmet when bicycling or playing baseball. Fortunately, swimming is Ben's favorite sport and it's one of the safest.

### Taking a Break

Five years ago Ben had a few bleeds in his elbows and knees. His left elbow, in particular, was causing enough difficulty that it required rehabilitation with a physical therapist. The family believes this may have been caused by the breast stroke and over-use of the arm. From that experience, they learned to step back and take a break when necessary.

## The Deininger's Advice



Christina, Ben, and Pete Deininger

- 1 Let your kids try a wide range of sports until they find one they enjoy. If they like what they are playing, they will continue.
- 2 Give kids an occasional break. Don't participate in year-round sports.
- 3 If you are nervous about an activity, ask your HTC for advice. They can ease your mind and help your child participate in sports safely.



517 West William Street  
Ann Arbor, MI 48103

Hours: M-F 9:00 am - 5:00 pm  
Available for after hours emergencies

Phone: 734-996-3300  
800-996-2575  
Fax: 734-996-5566

www.CascadeHC.org  
info@CascadeHC.org



Cascade's Limited English Proficiency Language Assistance Services  
Language assistance services are available free of charge. Call: 1-800-996-2575

## A Trusted Partner in Your Circle of Care Cascade...

## Cascade Hemophilia Consortium

### Cascade Compliance Officer, Joanna Pangilinan



Dear Readers,

You may have wondered, "Why all the paperwork?"

As you know, healthcare businesses are required to follow rules and regulations. At Cascade, we do not take these responsibilities lightly. We are required to document compliance with laws pertaining to pharmacy practice, insurance billing, human resource management, HIPAA (patient privacy law), and more. Constant attention to these requirements also helps us maintain accreditation with ACHC (Accreditation Commission for Health Care) which shows that we demonstrate a higher level of performance and patient care.

Your help is critical for us to meet these high regulatory standards and we greatly appreciate all you do to help us maintain current and accurate

documentation. Because this is an ongoing process, please be on the lookout for our requests. Thank you!

If you have any questions, please feel free to contact me at 734-996-3300 or 800-996-2575.

### Getting and Staying Fit - Finding Your Sweet Spot

When Sherry Herman-Hilker, PT, MS hired on as a physical therapist with the University of Michigan HTC twenty years ago, she never could have predicted how quickly medical advancements would improve the lives of people with bleeding disorders. "Because of advancements in products and adherence to prophylactic treatment, some people are finding they can drastically change their physical circumstances. They may have less pain, and actually want to move more. It's life changing."

We all agree that being active is good for our physical and emotional health. The benefits of physical activity include improvements in joint, bone, and muscle health. However, it can be challenging to find the right activity for your interests, physical capabilities, and bleeding disorder. Finding something you enjoy is most important.

Collaborate with your HTC team to find out what is right for you. If you are interested in a sport or find you are experiencing injuries from a particular sport, talk it out with your medical team. They may find ways to make it safer.

Older individuals with joint pain can get suggestions on how to start moving, even if they haven't done so in many years.

Your physical therapist will work on a progressive plan that fits your individual needs.

According to a 2010 study, after 6 weeks of supervised physical activity, significant improvements occurred in joint motion, strength and distance a person could walk in 6 minutes. Interestingly, the greatest gains were among the individuals with the most severe joint damage and coexisting illness.

There are many benefits to physical activity. Find your inspiration!



Sherry Herman-Hilker, PT, MS  
University of Michigan

### Cascade Staff

Stephanie Raymond, BA  
Executive Director

Michael Altese, PharmD  
Pharmacy Manager

Ted BeimeI, PharmD  
Pharmacist

Devin Bromley, BS  
Pharmacy Technician

Susan Carlini, BSA  
Senior Accountant

Anne Dimitry, PharmD  
Pharmacist

Colleen Joiner, LMSW  
Social Worker

Amy Luczak, PharmD  
Pharmacist

Mary McClure  
Office Manager

Joanna Pangilinan, PharmD, BCOP  
Compliance Officer

Rudra Patel, BS  
Accounting/Administrative Assistant

Jordan Burkey, BS  
Pharmacy Technician

Chelsea Seal, BA  
Business Manager

Debbie Whelan, LMSW  
Social Worker

### Volunteer Board of Directors Officers

Steve Pokoj, JD (President)

Randi Clites (Vice President)

Rosanne Ososki, MSN, APRN (Secretary)

Michelle Sumerix, CRSP (Treasurer)

Amy Hepper, MD (HFM)  
(Executive Committee Member)

### Directors

Judith Andersen, MD

Mike Callaghan, MD

Laura Carlson, RN

Susan Lerch (HFM)

Danna Merritt (HFM)

Megan Procaro (HFM)

Stephanie Raymond  
Executive Director, Cascade



## Ken Martin, Aged 50

### [Hunting, Fishing, & Outdoorsman]

#### The Early Years

Ken grew up in the 70s long before scientific research existed regarding safe physical activity for kids with bleeding disorders. In many ways, he was just a kid growing up with all of the other neighborhood boys, playing baseball in the street. Later as a teen, he loved to ride his bike 10-12 miles a few days a week, stopping along the way to visit a friend or get a Coke. He tried volleyball and even go-carts until his knee would not bend enough to get into the car.

Throughout his youth Ken did his best to play it safe. In the winter when his friends were on skates, he wore golf cleats in order to stay upright on the ice. At a young age, he learned what his body could and could not handle. By experimenting and modifying his physical activity he was able to minimize bleeds. Some activities caused automatic bleeds, and he instinctively knew what to avoid and what was safe for him.

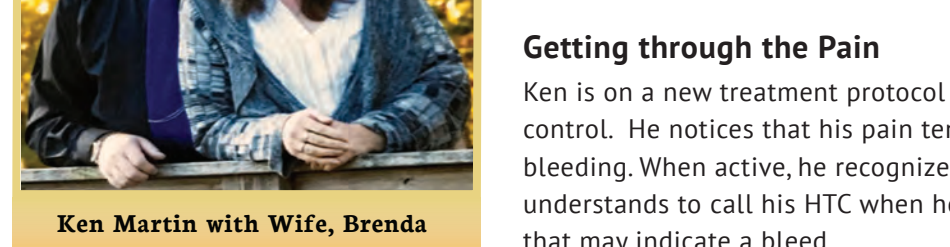


Ken Martin  
Severe Hemophilia A

#### Keep on Moving

Infrequent exercise and complications of his hemophilia resulted in decreased muscle mass and serious joint issues by the time he was in his late twenties.

While Ken was growing up, prophylactic treatment wasn't an option. Later, Ken didn't treat prophylactically because it didn't seem to work like it did for others. He was diagnosed with an inhibitor in 1972.



Ken Martin with Wife, Brenda

At work, Ken walks the ½ mile it takes to get to the cafeteria and back. He hunts with family and friends, and has been involved in boy scouts with his son. Ken is thankful for the ability to do those things and doesn't plan on stopping!

## Ken's Advice:

- 1 Don't ignore pain. Learn to know your OWN limits. Learn to understand the difference between arthritic pain and a bleed.
- 2 Get up every morning and do something to get your body moving. It doesn't have to be elaborate. Just move as your body allows.
- 3 Don't be afraid to try something new. Go fishing or boating, or do the things you'd like to do. Do what you can to modify the activity so that it is safe for you to do.

## Table of Activity Ratings

1 Low Risk		1.5 Low to Moderate Risk		2 Moderate Risk		2.5 Moderate to High Risk		3 High Risk	
Activity		Rating		Activity		Rating			
Aquatics		1		Mountain Biking		2.5			
Archery		1		Pilates		1.5 - 2			
Baseball		1.5 - 2.5		Power Lifting				3	
Basketball		1.5 - 2.5		Racquetball				2.5	
Bicycling		1.5 - 3		Rock Climbing, Indoor, Challenge/Ropes Course		1.5 - 2			
Body Sculpting Class		1.5		Rock Climbing Outdoor				2 - 3	
Boot Camp Workout Class		2		Rowing		1.5			
Bounce Houses				Rowing Machine (Training Equipment)		1.5			
Bowling		2		Running/Jogging		2			
Canoeing		1.5 - 2.5		Scooters, Motorized				2 - 2.5	
Cardio Kickboxing Class		2		Scooters, Nonmotorized		1.5 - 2.5			
Cheerleading		1.5 - 2.5		Scuba Diving				2 - 2.5	
Circuit Training		1.5		Skateboarding		1.5 - 2.5			
Dance		1 - 3		Skating, Ice		1.5 - 2.5			
Diving, Competitive				Skating, Inline and Roller		1.5 - 2.5			
Diving, Recreational		2		Skiing, Cross-country		2			
Elliptical Machine (Training Equipment)		1		Skiing, Downhill				2.5	
Fishing		1 - 2		Skiing, Water				2 - 2.5	
Football, Flag or Touch		2		Snorkeling		1			
Football, Tackle				Snowboarding				2.5	
Frisbee®		1 - 1.5		Snowmobiling				3	
Frisbee®, Golf		1.5 - 2		Soccer				2 - 3	
Frisbee®, Ultimate		2 - 2.5		Softball		1.5 - 2.5			
Golf		1		Stationary Bike (Training Equipment)		1			
Gymnastics				Stepper (Training Equipment)		1 - 1.5			
High Intensity Training (Incl. Crossfit®) Class				Strength or Resistance Training/ Weight Lifting		1.5			
Hiking		1 - 1.5		Swimming		1			
Hockey, Field/Ice/Street				Tee-Ball		1.5			
Horseback Riding		1.5 - 2.5		Tennis				2	
Indoor Cycling Class		1.5 - 2		Track and Field				2 - 2.5	
Jet-Ski® (Personal Watercraft, PWC)				Trampoline				2.5 - 3	
Jumping Rope		2		Treadmill (Training Equipment)		1.5			
Kayaking		1.5 - 2.5		Volleyball				2 - 2.5	
Lacrosse				Walking		1			
Martial Arts, Tai Chi		1		Wrestling				3	
Martial Arts, Traditional & Mixed				Yoga		1.5 - 2			
Motorcycle/Motorcross (ATV, Dirt Bikes)				Zumba® Class		1.5 - 2			

Written with permission from NHF. StepsForLiving.Hemophilia.org for details

## Jenny Maywood, Aged 32

### [Bodybuilding & Running]

#### Getting Motivated!

Jenny doesn't remember what first motivated her to join a gym; she had never been very active. Once she began going to exercise classes, she found her motivation. They provided instruction on how to train safely and effectively and made exercise fun and social. "The fun and social aspect of it helped me to keep showing up. Your buddies expect to see you there!"

Jenny recognizes the importance of setting small goals in the beginning. "One of my first goals was to be able to do one pull up! After that I did a few 5K and 10K runs."

Jenny eventually became a certified trainer. Learning that exercise keeps your body strong, and helps you maintain independence, has been a big motivator for Jenny. "If I am lucky enough to live until I'm 80, I want to be able to have enough muscle for activities such as going up the stairs, carrying my groceries and laundry, and getting off the toilet seat!"

A few years later, Jenny took it to another level.

#### Finding the Right Fit!

Jenny became interested in bodybuilding in 2010. She competed in her first show in 2011, and knew she had found her passion. Competing in bodybuilding takes a lot of will power and dedication. "Getting your training in everyday and eating a very specific diet means that at social gatherings you are probably bringing your own meal."

Bodybuilding is a sport that people of all ages participate in. Jenny has seen young adults to people in their 70s or 80s compete. Competition isn't for everyone. As long as you are not "power" lifting, and you are working with a trainer, lifting weights safely can be a benefit in and of itself.



Jenny Maywood & Family

#### Keeping Active as a New Parent

As a new mom, it can be difficult to find the time and energy to be active. With approval from her physician, Jenny began running and strength training at home. Jenny tries to get a bit of activity in while her 3-month-old naps and when she goes back to work she will be able to use the gym during lunch.

Jenny is already teaching the importance of physical activity to her kids. Her son, who has severe Hemophilia A, is on prophylactic treatment and wears a helmet and knee pads, so she doesn't limit his activity much. He joins in with Jenny when she is stretching and exercising around the house. She wants to set a good example, "I want his muscles to develop and be strong to support his body, and this can only happen if he is active."

## Jenny's Advice

- 1 Start slow! Doing too much too fast can result in injury and also may seem overwhelming. If you currently are very sedentary, start out by walking. Get 30 mins of walking in most days of the week. If you can't do 30 minutes, break it up into 2 or 3 sessions.
- 2 Start with something you enjoy and if you're limited for time, do what you can.
- 3 If you decide to start strength training, hire a personal trainer or go to group exercise classes. They will teach you proper form to reduce any injuries and give you safety cues to follow. But first talk with your HTC team or physical therapist as well to ensure that this is a safe sport for YOU.