GROWING INDEPENDENT WITH A BLEEDING DISORDER
THE BENNETT BOYS: EXPANDING THEIR WORLD

Joseph and William Bennet are 19-year-old twins with severe hemophilia. But with Coram’s help, these adventurous young men travel the world. Read about Joe’s and William’s travel adventures, and learn how these experiences have shaped their characters and changed the way they see themselves and the world.

CORAM HELPS YOUNG PEOPLE GO EXPLORING

Alex Dorosh, Coram Patient Care Coordinator (PCC), helped the Bennett boys prepare to travel outside of the country. He and Coram’s team of PCCs work with any Coram bleeding disorder patients who want to travel. Learn about how, with the team’s help, nearly all that Coram patient travelers have to do is buy their tickets and pack their bags!

JOHN DOWNEY: A LAWYER IN THE MAKING

John Downey is moving from middle school to high school, a time of increasing independence for kids. At age 14, John is growing into a smart, mature young man who doesn’t let his bleeding disorder hold him back. Read about how John manages school, follows his passions for law, history, math, and politics, and faces a promising future.

KIDS CORNER
The Bennett Boys: EXPANDING THEIR WORLD

Joseph and William Bennett are 19-year-old twins with severe hemophilia. They take factor every other day. And that is the only difference between them and their peers without factor deficiency. Joe and William have never let hemophilia define who they are. Much of the credit for that goes to their parents, Alan and Sharon.

“My wife’s brother had hemophilia, so she grew up with it,” Alan says. “And when the boys were born, we were prepared for it. Our approach from the very beginning was that we didn’t want them to be limited by hemophilia. Obviously we were careful — they didn’t play Little League baseball or football. But we didn’t want them to feel restricted as long as they were careful about what they did.”

The boys played soccer and baseball when they were young, but were smart enough to stop when the play got too physical. At that point, William took a break from sports and delved into books. He began playing tennis in middle school and is now in the tennis club at Texas A&M. Joe switched his sports focus to track and cross country in middle school and continued those sports through high school.

One interest William and Joe have always pursued is involvement with their church youth groups. All of the Bennetts — including 12-year-old Stephen, who also has hemophilia, and 16-year-old Abby — are active in their church. Mission trips have taken Alan and Sharon to Guatemala and Turkey, and Alan to Turkey. They also took Abby to Namibia and England, and the twins on their own unique adventures.

Joe in front of the Eiffel Tower in Paris, France; Spring 2014.

Joe’s Experiences

Joe is pursuing a Bachelor’s degree in church music at Baylor University, as well as a minor in business administration. He is learning to use his talents to prepare for a career in music ministry or global missions.

At 19, Joe has seen more of the world than most adults. Three years ago, he went to Namibia, a small country near South Africa. He returned there on a second mission trip last year. Last spring, he traveled with the Baylor University A Cappella Choir to record an album in Paris. He has been part of two mission trips to La Grulla, Texas, a small town on the Mexican border. And he has gone on many performance tours, in the U.S. and other countries, with multiple choirs from Baylor.

“My first trip to Namibia was an eye-opening experience,” Joe says. “It made me realize that the world is a lot bigger than me and my own issues. One of the things I learned is that even though I have a pretty severe medical condition, I’m still very well-off compared to much of the world.”

Joe in front of the Eiffel Tower in Paris, France; Spring 2014.

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*Please see Glossary on page 8.
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Joe was more prepared when he returned to Namibia two years later. During that trip, his youth group went to areas devastated by AIDS. Many children there were orphans, and almost all came from homes without fathers. Joe knew about AIDS first-hand. His uncle had died of the disease in the early ’90s due to tainted blood products used by many people with hemophilia in the ’90s.

“Visiting those communities was especially meaningful. This was because of the personal connection that my family has to the HIV/AIDS epidemic,” Joe says. “Even though the kids have a different medical condition than me, I was able to tell them that there is hope and a brighter future. It was extremely humbling.”

William’s Adventures

William is majoring in chemical engineering at Texas A&M with a triple minor in math, chemistry and Spanish. At 17, William spent two weeks in a small community in the north of England. His group helped local churches and gave religious education classes in a couple of secondary schools. Earlier this year, he spent six weeks going to school in Mexico.

“It’s an immersion program where you speak only Spanish,” William explains. “I stayed with a Mexican family and attended classes at a school during the day. It’s a school for students from other countries. Every morning begins with grammar and other classes. In the afternoon, we have conversation in Spanish.”

William’s learning experience in Mexico was not confined to the classroom. The trip also made him realize just how much he took for granted living in the U.S.

“It was amazing to see how different some cultures are from our own. They have less of what we would consider ‘normal’ things in America and they do more with them. For example, most of the houses don’t have air conditioning. But they leave the windows open to catch the breeze, and the effect is the same.”

Two years ago, William went on a mission trip to England. Most people would assume that England would not be as foreign to him as Mexico was. They would be wrong.

“England has a completely different religious culture from America,” William says. “America is pretty much a Christian-dominated society. In England, Christians are a small minority.”

Gaining Their Independence

Whether in Africa or Europe, visiting foreign countries didn’t intimidate Joe and William, even with hemophilia. They have both been self-infusing since they were eight, so treatment was not an issue. Getting ready to travel was more challenging. They both worked with the customer service and pharmacy departments at Coram. Staff in these departments helped them make sure they carried enough factor to last their whole trips. Largely for insurance reasons, factor can’t be shipped out of the country in all but extreme cases. For William’s recent stay in Mexico, he carried enough factor to cover his prophylactic doses [preventive treatments] and extra doses in case of emergency.

“The most important thing for me was getting a ‘letter of medical necessity’ from my doctor,” William says. The letter explained that William needed the factor for his own treatment. “Factor is not readily available in Mexico.”

Joe has had similar concerns. When he went to Africa, his main concern was getting through airports with factor. He, too, took more than he would need for his every-other-day prophylactic treatments.

“After talking to my hematologist, I felt that I had enough factor to take care of myself if I had an emergency,” Joe says. “I knew I was going to be well taken care of. We weren’t going to be doing anything that would put me in danger.”

Pursuing Their Dreams

From an early age, the Bennett boys’ parents instilled in them the idea that hemophilia did not have to be a barrier to doing what they wanted in life. Alan and Sharon also made sure they could take advantage of chances to expand their horizons.

“One of the main reasons I’ve turned out the way I have and have had these opportunities for travel is because of my parents,” Joe says. “We don’t come from a lot of money. But when these traveling opportunities arose, they wanted it to happen. Every trip you take opens your eyes a little more. I would encourage parents to allow their kids the chance for travel if it comes up.”

Being able to experience life in different countries has been valuable to William as well. But that is just one part of his life as an emerging adult. He is also looking forward to exploring his future in chemical engineering.

“I can go into oil and gas, nuclear power plants, or pharmaceuticals. Or I could go into any chemical production or food production facility,” he explains. “Right now I am deciding what I like to do and I’ll move in that direction.”

That is the same advice he would give to his peers with hemophilia and their parents.

“Parents need to understand that just because their kid has this disorder, they are not weaker. They are not a bubble waiting to be popped,”
William says, “With all the medical advances over the past 20 years, we can have a level of normalcy.

“You have to accept that you might not be able to do everything someone else can, but you can still do many things. Some things we can do better than other people. For example, everyone I know is pretty much scared to death of needles. We’re pretty good with those,” he says with a laugh.

Again, his twin brother is on the same page.

“Hemophilia does not define who you are,” Joe says. “People should see themselves as a person with hopes and dreams and aspirations. I am not Joe Bennett whose blood doesn’t clot. I am Joe Bennett with a future, with a life and a unique personality. Hemophilia has actually done many good things for me. It has taught me about humility. Despite hemophilia, I am very well off. I think I have a greater sense of gratitude than I would have otherwise.”

At 19, William and Joseph Bennett have gained wisdom beyond their years. Their parents instilled some of that, but much of it is due to their own maturity. They have both developed a strong sense of self. And that acceptance of who they are is related to — and perhaps made stronger by — growing up with hemophilia.

*Glossary:

**Factor deficiency:** A genetic condition that causes hemophilia. Without the normal amount of factor VIII or factor IX, a person’s blood cannot clot normally.

**Letter of medical necessity:** A letter provided to hemophilia patients by their doctor. It can be shown to other doctors or other people who need to know about the patient’s care. The letter explains that the patient needs factor for treatment and prevention of bleeds.

By Valerie Hansen | Contributing Writer

Alex Dorosh, Coram Patient Care Coordinator (PCC), helped the Bennett boys prepare to travel outside of the country [see page 4]. He and the other Coram PCCs work with our bleeding disorder patients who want to travel. They make sure these patients have all the medications and supplies they need while on the road. With the team’s help, nearly all that patients have to do is buy their tickets and pack their bags!

**Planning the Details**

When helping a Coram patient plan a trip, the first thing Alex does is contact a Coram pharmacist. He asks the pharmacist to get a factor order from the patient’s hematologist. Often, if a patient is going out of the country, the factor order will differ from a standard order. For instance, Joseph and William Bennett are both on regular prophylaxis. [This means scheduled preventive factor treatments.] They infuse every other day. For their trips, their doctors wrote their regular factor orders. Then, they wrote separate orders for extra factor in case of emergency.

“Patients may normally infuse every other day. When traveling, the doctor would want them to take enough factor with them to infuse every day, just in case,” Alex explains.

“The length of the trip is probably the biggest issue we address when we prepare patients to travel. The amount of factor they need to carry clearly depends on the length of the trip.”

Once the doctor’s orders are on file, Alex contacts Coram’s Hemophilia Insurance Verification Team. This team works with the patient’s insurance company to ensure that factor is covered for the
Giving Advance Notice

William’s trip brought up another issue that Alex needed to consider: dose size. Because of William’s factor needs and the drug’s availability, each dose came in two separate vials.

“Because we had plenty of notice — about six weeks — we were able to watch the drug availability,” Alex explains. “When the single-vial dose became available, we ordered the needed quantity ahead of time. This prepared us for both William’s and Joseph’s trips.

“If a patient’s trip isn’t planned, we can always work it out. But advance notice is better. Two weeks will work, but a month’s notice is best.”

William’s factor comes in boxes that contain everything he needs for his factor dose. This includes factor, syringe, needle, alcohol swab, and tape. In addition, Coram supplies a travel-size sharps container to dispose of needles. The doses are packed in a box with ice packs and carried on the plane. The patient’s doctor or Coram can write a travel letter for the patient to take with them. The letter states that what they are carrying is a necessary drug that needs to be kept at a controlled temperature.

Additional Preparations

Alex always encourages his patients to explore the area where they will be staying. They should locate the nearest hospital or, if possible, a hemophilia treatment center.

“It’s good for the patients to search out these facilities. This prepares them in case something happens and they need help locally. Once they are out of the country, Coram is limited in how much we can help them.”

Another issue is the patient’s ability to self-infuse. Or, if the patient is young, the issue is the family’s ability to infuse.

“We educate our patients that learning to self-infuse is an important part of gaining independence,” Alex says. “Some young people are worried at first because they have always relied on a nurse to infuse them. But they learn that they can do it on their own. It’s really empowering.”

Travel itself has that element of empowerment, even if it’s with family. Venturing out of a person’s comfort zone promotes self-reliance, and thus an increase in self-confidence. Once Coram’s team of experts does its job taking care of therapy details, young people like Joseph and William Bennett can stretch their own wings and learn to fly.

Middle Ground

The transition from middle school to high school is a time of increasing independence for kids. This time of life can be tough for anyone. Adding hemophilia to the mix can make it an even bigger challenge.

In this patient profile, we visit John Downey as he moves through this sensitive time in his life. Read on to find out how he juggles his increasing maturity with the challenges of having a bleeding disorder.

By Valerie Hansen | Contributing Writer

Most of the kids that 14-year-old John Downey went to middle school with will be moving on to the same high school he will attend in the fall. His peers know he has hemophilia. He has never had an issue with explaining it to them.

“I think it’s better for them to know than to have a lot of rumors about what I have,” John says. “The other kids don’t see me as having hemophilia. They just see me as a good person. They try to see the bright side of it.”

One of those bright sides is when John and his friends go to an amusement park. Standing in one place can cause problems for John. So, he gets a special pass from customer service to go to the head of the line. His friends get to go with him, which makes having hemophilia not such a bad thing.

“Standing too long can make his blood pool and puts him in danger of getting a clot,” explains John’s mother, Marile. “He’s okay if he’s moving.”

Going to amusement parks is one of the activities the Downey family enjoys as a group. But it is just one of the side trips they make on their annual summer vacation. Every summer, the family takes an extended vacation traveling across the country in an RV (recreational vehicle). John, older brother Joseph, parents Paul and Marile, and John’s dog, Wags, travel to historic locations around the country. Through their travels, they have learned about American, African American, and Native American history. They have also learned about how people of different cultures live.

“We don’t really have a schedule,” John says. “We just go where we feel like going. This year we
went to Wisconsin and across to Washington and Oregon. Then we went down to Las Vegas, and into California. We have been in about every state in the U.S. We have also been to many historical sites, from Gettysburg to a Navajo reservation.

**FUTURE GOALS**

For John, right up there with exploring history is an interest in politics and the law. For his elective classes in high school, he chose Latin at the suggestion of his lawyer uncle. He knows his interests in math, politics and history will also affect his choices in future high school years.

“He is very interested in how governments work,” his father Paul says. “Just for his own information, he studies how governments in different countries have worked through history. He’s really a whiz kid where that is concerned. You can name about any country and he can tell you that country’s political history.”

John thinks he will probably pursue law as a career after high school. In the meantime, he is giving himself a head start.

“Actually, I’m trying to practice how to be a lawyer,” he says. “I got a lunch detention for doing practically nothing. I went to the vice principal and gave him my argument about why it was unjust. He removed the lunch detention. Then other kids gave him my argument about why it was unjust.

“I think the students liked my dedication. I think I was a great representative of my team.”

John thinks he will probably run for class president in high school. When he does, he thinks his past track record of stepping up as a councilman will speak for itself.

**SCHOOL SPORTS**

At 6’-1” and 300 pounds with size 18 feet in eighth grade, John likely would have been pressured to play sports at most schools. Although he is not a young man who bows to pressure, it is fortunate that the coaches at his middle school understood his position. John likes physical activity like swimming and biking, and he walks every evening. However, contact sports don’t tempt him.

“I am taking physical education classes in high school. But sports that have a lot of physical contact, like football, are out of the question,” he says. “I have to choose what I do carefully. I’m interested in sports; I’m just not sure what I want to do. I know that what I pick will be something I can be good at my whole life.”

Whether it’s track, wrestling, or some other sport, John will make his own decision after working it through using his usual precise thought process.

Given his size, bullying is another fact of high school that John is not too concerned about.

“In middle school there were some kids who were annoying,” he says. “But they were annoying to everyone.”

His mother shared that when John started seventh grade, there was a smaller boy who was being bullied. John stuck up for him.

“John started looking out for him, having lunch with him so he wouldn’t be bullied.”

**A SURPRISING DIAGNOSIS**

There is no history of bleeding disorders in John’s family. The first sign of a problem for John appeared when he was a month old. Marile noticed a purple bruise on his chest. She took him to the doctor, who sent them to the emergency room. From there, they went to the pediatric center to see a hematologist. There, they took John’s blood. The next day, the arm they had punctured was very swollen.

“They sent us back to pediatrics,” Marile says. “They expected a bleeding disorder but thought it was probably von Willebrand disease. [This is a bleeding disorder that is generally milder than hemophilia.] It turned out he had hemophilia.”

**TEACHING SCHOOLS ABOUT HEMOPHILIA**

When John first started going to school, it was tough. His parents were new to the disorder, and he wasn’t able to explain it either. Two preschools refused to enroll him.

But Marile and Paul researched hemophilia. Armed with information, they adjusted to life with John’s condition. They explained it to their son and learned how to explain it to teachers.

As John got older, he also learned to talk about his hemophilia. He did this not only with his peers, but with his teachers and the school as well. By the time he entered second grade, John had become his own advocate. Naturally his parents were involved in meeting with school officials. They helped explain some of the special considerations he would need in classes such as gym class. However, John himself has been at the helm of his condition from a very young age.

At 14 going on 35, John Downey is a leader among his peers. He is very clear about what is right and wrong, and is not afraid to share his opinions. He also knows his passions of law, history, math and politics will play roles in his career choices. For this sharp young man, hemophilia is just a part of life, not a barrier to a bright future.
Help Hemo-Phil-A-Saurus find his way through the Jungle Maze!
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