By Ellis Neufeld, MD, PhD

Last November, after much planning with Dr. Sudhir Mehta at SMS Medical College in Jaipur, India, our pediatric nurse practitioner, Loren D’Angelo, MSN, PNP, physical therapist Amanda Boyer, DPT, and I traveled to Jaipur. During our four-day trip, we visited SMS Medical College, the RRC Rehabilitation hospital and the JK Lone Children’s Hospital, and we met with families and leaders of the Hemophilia Federation of India, Jaipur Chapter. We also visited the Advanced Hematology lab/Coagulation lab at SMS.

Formal meetings included discussions with Dr. Nepalia, the Principal (Dean) of SMS Medical College, and Dr. Sharma, Principal of the Children’s Hospital. We had the opportunity to present in several forums and were able to share our medical expertise with staff and trainees.

Our trip was supported in part by a four-year grant from the World Federation of Hemophilia.

In collaborating with the Jaipur Patient Group, we learned about the issues facing families in Rajasthan, India’s largest state, particularly the difficulty patients have in receiving factor close to home. With its burgeoning economic development over the past two decades, India is moving—and Rajasthan has already moved—from the lowest tier of availability for hemophilia factor to a middle-tier situation. (This is based on a scale maintained by the World Federation of Hemophilia.) Some patients are able to get prophylactic treatment and some patients have been able to receive immune tolerance therapy for inhibitors.

On last day in Jaipur, we participated in a family social and educational event for the bleeding disorders community. This event was a grand success. We met many families and kids and had the chance to do focused, age-appropriate teaching and socializing. We left having identified some specific goals for 2015.

1. The laboratory in Jaipur is challenged by inability to do some advanced procedures presently. Although the laboratory team is well trained, ready and willing to do the assays appropriately, it will require some assay kits and a freezer colder than its present -20C model to store specialized reagents and standards.

2. Patients in Rajasthan and surrounding states may live very far from Jaipur—up to hundreds of kilometers. They can travel for special events or occasional visits, but not for ongoing standard treatment. Clearly, getting treatment to the distant patients will mean better therapy in the district health centers. We believe we can contribute to progress in this regard. The factor in Rajasthan is provided under a contract with the state government by Baxter. One very encouraging fact is that for poor patients, the state government covers the cost of factor. But the supply chain for this valuable medicine needs to be made robust and secure—something we take for granted in the United States.

3. Even though the Jaipur hemophilia team has made great strides, factor procurement and distribution policies in Rajasthan state are not optimal. In part, this reflects the medical infrastructure in India. We hope to leverage our experience in the United States, our relationships with Baxter and the Jaipur team and our connections to the factor company to improve these procedures.

Three physicians from Jaipur will visit the Boston Hemophilia Center from August 2 to 5 and we will continue to work together to enhance the care for patients in Jaipur and the state of Rajasthan. We also will plan a World Hemophilia Day celebration while they are here, admittedly a little later than the April 15 official day!
In 2008, I became the projects director of the Boston Hemophilia Center (BHC) after a decade of working as the BHC adult and pediatric social worker. As the projects director, I oversee our website, Facebook page and Twinning Program. I help develop our patient education and social programs, produce our Centerpoints, newsletter and do various other projects as defined by the center. I have also written two “Gift of Experience” books based on oral histories of our patients and families.

The first book, “The Gift of Experience,” started as an oral history project that was conducted from 2004 to 2007. The book, edited by Christine Chamberlain and me, is a compilation of excerpts extracted from the oral history interviews, along with stories from caregivers who treated people with hemophilia during the 1970s and 1980s.

Twenty-one men with hemophilia, all born before 1965 and treated at BHC, talked about what it was like to have the disease in the early years without factor replacement therapy. Their histories reflect the dramatic lifestyle changes that happened once factor became available. They also reveal the heartbreaking challenges that many of them faced due to long-term joint damage and the HIV and hepatitis C viruses they contracted from contaminated blood during factor infusions.

The research project resulted in tapes and transcriptions that were gifted to Harvard Medical School’s Countway Library.

“The Gift of Experience II” was co-edited by me and two mothers, Ziva Mann and Allie Boutin, who each have boys being treated at the center. This book is for families with newly diagnosed children with hemophilia. It is a compilation of conversations with 19 parents from our center who shared their experiences raising their children from the time they were born to age 6.

These books have been well received by the bleeding disorders community and provide unique insight into the lives and care of people with hemophilia. The books are available through the pediatric center and on Amazon.

Finally, I want to let you know that I will be retiring from BCH on July 3, 2015. I am excited to move onto our family’s boat for eight months. My husband, Roger, and I are going to set sail with no real plan other than to follow the winds. I have loved working with so many of you and wish you all well.

Lessons From a Trip to the NHF Conference

By Rafael Buckentin

Even though it was back in September that I was chosen to go to the National Hemophilia Foundation’s 66th Annual Meeting in Washington, D.C., it seems like it was just last week. But before I go on about all of the wonderful things that happened there, I would like to thank the Boston Hemophilia Center for sponsoring the trip from me and my girlfriend, Kirsten. We really enjoyed it and we both learned a lot. I had forgotten how great it is to interact with other people with hemophilia. Before the convention, I hadn’t done it in years.

I promise I’ll give you all of the details I can about the convention! But first I would also like to quickly tell you a little about myself. My name is Rafael Buckentin. I’m 23 years old. I was born in Rio de Janeiro, Brazil, and I have severe Hemophilia A. My parents and I moved here when I was 7 because there were much better treatment options in the United States. I’ve always been very grateful for the opportunity to live life as much like regular kid as possible, without having to spend so much time in the hospital, like I did in Brazil.

Now on to the good part. The Annual Meeting was a blast. The theme was “Nothing About Us Without Us” and was based on the idea that active involvement and participation of individuals make a stronger community, which I thought was a powerful message. The decorations and the booths were so well done and everyone was tremendously friendly. There were thousands of people at the Washington Marriott Wardman Park, including healthcare providers, consumers and their families and members of the industry, and there was something for everyone. The three days were packed full of

>>> continued on page 4
504 plans, IEPs and IHPs: How to Help Children Succeed at School

By Kate Quint, LICSW

Understanding your rights as a parent in order to ensure your child’s academic success is important, especially if your child was born with a chronic illness. Children with bleeding disorders, particularly hemophilia, may have special medical needs or considerations at one time or another during the school years. For example, they may need to miss school as a result of having a bleed or an injury that needs prolonged treatment.

Knowing what accommodations your child may be entitled to is an essential part of putting them on the right path to educational success. There are three interventions that parents should know about:

504 plan

• Legally binding agreement between parent and school district.
• Part of the Americans with Disabilities Act and a federal civil rights law that stops discrimination against people with disabilities.
• Appropriate for children with a medical issue that significantly impairs their ability to attend or navigate school on a regular basis.
• Provides children with special accommodations or modifications to their learning environment, allowing them to have the same opportunities as their peers.
• Examples: If a child needs crutches or is confined to a wheelchair while recovering from a bleed, the school would allow additional time for her to get to class or have access to the elevator. If carrying a backpack filled with heavy textbooks strains a child’s joints or muscles, she may be allowed to have an extra set of books to keep at home. Or if a child needs an infusion during school hours, school personnel would make special arrangements for this to happen.
• Tutoring may be available if a child has been absent from school for several days.

IEP (Individualized Education Plan)

• Comes under The Individuals with Disabilities Education Act.
• Tailored to a child who has one or more documented learning disabilities interfering with his ability to process and learn school material. The disability must affect the child’s ability to succeed in the general education curriculum.
• The child needs an independent educational evaluation to identify areas of difficulty. There are strict legal requirements that accompany the IEP and a specific team is designated, including the parents, to design it.
• Examples: An IEP can provide modifications to the curriculum and classroom assignments and include extra time to complete tests, including standardized tests. The student also might qualify for extra tutoring or qualify to participate in a smaller classroom settings.

IHP (Individualized Health Plan)

• A written plan outlining a child’s physical impairment or medical issue and how staff and parents should respond in an emergency. The medical issue does not interfere with the child’s ability to learn the curriculum.
• A centralized but not standardized document explaining the children’s medical needs and how school staff should prepare and intervene, if needed.
• Recommended for any child who has a health issue or physical impairment.

If you have any questions, please feel free to contact the Hemophilia Treatment Center BHC pediatric social worker, Kate Quint, MSW, LICSW, at 617-355-0794

References:

activities, starting with a Fit ‘N’ Fun Walk outdoors at 8 a.m., continuing with events and workshops throughout the day and ending with the Afterglow Lounge at 11 p.m.

Kirsten and I decided to attend some sessions together. They varied greatly, from studies in half-life to a discussion about how comic books can be a useful tool for children with hemophilia. All of the information was very enlightening, especially for Kirsten. She learned a lot about what it means to have hemophilia and I think she really enjoyed the education.

I know I am part of a privileged group of people with hemophilia. I am particularly lucky to have been born at a time when the products I’ve been using for treatment are available (unlike other countries) and extremely safe (unlike other times). Therefore, I it was important to me to be at Celebrating 20 Years of Blood Safety and the Ricky Ray Act. It gave a powerful historical perspective on the many advocating efforts that led to passing the Ricky Ray Act, as well as accounts of survivors from that time. It made me feel even more grateful for what I have today!

The final night party was at the Smithsonian National Air and Space Museum, an incredible setting and home to the largest collection of historic aircraft and spacecraft in the world. On our way back to Boston, we were tired and overwhelmed, in a good way, with the intense program and the amount of information we collected during three days. It was an experience we won’t ever forget.

Trip to the NHF Conference

<<< continued from page 2

Upcoming Events

July 13 – Peg Geary will be joining the BHC as the new Projects Manager to replace Laura Gray
August 2 – World Hemophilia Day: Twinning with SMS Medical College in Jaipur, India Taj-Boston
August 23 – Red Sox/Kansas City Royals game