

PRESIDENTSCORNER

The Importance of Pointing People Toward HTC's

As an individual with a bleeding disorder, I know how important it is to network within our community, share information, and seek out the best resources for ourselves and our peers. Unfortunately, that is a lesson I had to learn the hard way. Some of you may have heard this story, but it bears repeating because it can be used as a lesson to people in the bleeding disorders community.

Within the last couple years I had to have prostate surgery, which at the time didn't seem like a scary notion. Up until that point I had never had a serious surgery. I had my wisdom teeth out under the care of a hematologist who I would later consult for my prostate surgery and would come to find out, was not qualified and informed enough to treat me as an individual with Hemophilia B.

He had my best interest at heart as a hematologist knowing about my Factor IX, right?

Because I had no knowledge of our local HTC's, I thought that, because he was a Hematologist, he had worked with people just like me. But in reality, he had never worked with a Factor IX patient and was not board certified.

The lesson that I learned is still affecting me. What I didn't know hurt me and now I have lingering medical conditions as a result of my former Hematologist not properly administering my factor during prostate surgery and not communicating important information to both the surgeon and my personal physician.

After my prostate surgery I bled for a month. I didn't know when the bleeding would stop or if it ever would. I was scared for my health and my life so I quickly went to seek a second opinion from a different Hematologist.

This doctor had the humility to look at my case and tell me he honestly couldn't treat me because he wasn't informed to the level he felt comfortable. Luckily, he was able to refer me to a doctor he had done rounds with named Dr. Eric Kraut. Dr. Kraut helped me after my surgery and is there to consult my general physician and other medical staff at the Ohio State University Medical Center on all medical decisions regarding my body and my health.

Unfortunately I had to go through a lot of concern and pain in order to have a total awakening regarding my medical condition and what the proper standard of care should be for every bleeding disorders patient.

What is the lesson here? I would tell any local bleeding disorders patient that there might be a lot of Hematologists and Oncologists, but the standard of care that you both need and deserve can only be found at our two award winning HTC's, Nationwide Children's Hospital and the OSU Medical Center.

As patients who need special care and consideration we have to be informed, be our own advocates, and know that we are putting ourselves in the hands of medical professionals who know us, our disorders, and what we have to face every single day as bleeding disorders patients. If you can point someone in the right direction, do it. Tell them about the HTC's, our chapter of NHF, and all the other amazing resources that are out there. If someone had pointed me in the right direction when I needed it most I wouldn't need to share this story with you today. We all have the chance to seek out the people within our community that need informed, that need our help. Let's seize this opportunity because I truly believe we can help change peoples' lives.



A handwritten signature in blue ink that reads "Jim".

Jim Wasserstrom
President of the Board of Directors

*"Learning from Experience
is Often Painful, and the
More It Hurts the More
You Learn"*

Ralph Banks

