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To: Joint Committee on Ways and Means, Subcommittee on Education
Subject: Written Testimony for Meeting on April 18, 2017

Co-Chairs Monroe and Smith Warner, and Members of The Committee,

I am thankful to have the opportunity to share with you today my experience receiving services from the Hemophilia Treatment Center at Oregon Health & Science University (OHSU), a program of the Child Development and Rehabilitation Center (CDRC). While I do not personally have a bleeding disorder, my son Lewis was born in 2011 with a severe Factor IX deficiency, commonly referred to as Hemophilia B

When my wife and I found out we were expecting our first child in late 2010, we were excited to be growing our family and everything that comes with that experience. While the news was certainly cause for celebration, it also served as a catalyst for uncertainty and anxiety as my wife has a family history of hemophilia and had been identified as a genetic carrier for the condition after participating in a research study earlier in her life. Were we to deliver a baby boy, there was a fifty percent chance he would be born with Hemophilia.

After finding out we were indeed having a boy, we proactively contacted the Hemophilia Treatment Center at OHSU. The staff and clinicians helped educate us on what life might look like for us, should our son have hemophilia, and were extremely supportive of us as we dealt with the emotions that followed. Perhaps most importantly, the team worked with our obstetrician and health plan to ensure a safe delivery and facilitate cord-blood testing to learn if Lewis had hemophilia. We felt very fortunate to live in a community where we had access to this type of service and support, all provided before we knew our child had hemophilia.

We learned the day after Lewis was born that he did, in fact, have hemophilia. From that day forward, the Hemophilia Treatment Center became a regular part of our life. Early on, when Lewis was an infant, this meant an annual visit and frequent phone calls to the nursing staff for signs and symptoms related to possible bleeding. As first time parents, and parents of a son with a bleeding disorder, every 'first' – whether it was crawling, climbing, or walking – was joyous and terrifying at the same time. As he grew older and became more active, our annual visits turned into weekly visits as we began to proactively treat Lewis' hemophilia by infusing medication intravenously, allowing his blood to clot to prevent serious bleeding. As you can imagine, inserting a needle into the vein of a toddler can be both physically and emotionally challenging. The Hemophilia Treatment Center staff exhibited expertise and calm during these appointments, ensuring that our son could receive his infusions.

While the staff was extremely helpful and successful with our weekly infusions at OHSU, we shared a mutual goal of getting to a point where my wife and I could independently treat and manage Lewis' disease. After over a year of weekly venous infusions that were proving difficult

even by the most skilled nursing staff, the Hemophilia Treatment Center staff provided options that might lead to easier infusion experience. We ultimately decided to have a sub-dermal port implanted in Lewis' chest that would provide easy access to administer his weekly medication. It was a difficult decision for us to make. However, the staff of the Hemophilia Treatment Center once again helped educate us on the different options that were available, ultimately helping guide us into the treatment strategy that was right for our family. They connected us with other families with similar experiences, answered countless questions, and calmed our fears. We were thankful to have the support of the Hemophilia Treatment Center team in a decision that was ultimately ours to make, but we felt much more prepared to make given our relationship with the Center.

Lewis will turn six years old this coming August, and our visits to the Hemophilia Treatment Center have returned to being annual visits and check-ups. My wife and I have been trained by the Hemophilia Treatment Center team to administer Lewis' medication on our own at home, which has given us flexibility, confidence and ultimately independence in caring for our son. In addition, the Hemophilia Treatment Center has provided us comprehensive care and support. They have provided live education to his day care provider and school, kept us involved and appraised of important research related to hemophilia, and have connected us to other families just like us. The Treatment Center has become an invaluable part of our family.

We are fortunate to have the Hemophilia Treatment Center at OHSU. While we are no longer completely dependent on them to help care for our child, knowing that there is a team available to help and support us as Lewis grows older provides us with valuable peace of mind as parents.

Thank you for continuing to support the programs of the CDRC at OHSU, including the Hemophilia Treatment Center. Your decisions have a direct impact on parents and children living within Oregon.

Kind regards,

Aaron Patnode
Submitted on behalf of Carrie, Lewis and Lydia Patnode

Lewis Patnode (5 y.o.) at the State Capitol for Bleeding Disorder Awareness Day on Monday, March 20, 2017