

Good things come to those who wait...

Our daughter Molly was 7 months old when we received her diagnosis of Hurler Syndrome. We were completely blind-sided. Once we came to grips with the news, we needed to move "quickly" to get her the proper treatment. We were ready to move fast, but things outside our control slowed our intentions. That's when the waiting began...

Waiting isn't easy. It involves emotions, stress, and endurance. We usually refer to "waiting" in a negative sense, because we are out of control, nervously hoping for the best, and struggling with the possibility of what will be. I've learned to look at it in a more positive light.

Our first attempt to be admitted halted after the placement of a shunt. We were sent home for a week and I was frustrated. A few days later, I saw my daughter's eyes- her entire eyes-for the first time. The shunt was working, removing excess pressure and fluid from her eyelids, and this bonus was a very special gift to me.

The second time we came in to get admitted, Molly tested positive for RSV. This setback upset us again, and we returned to our apartment with a sick little girl and our heads down. However, this wait allowed our son to visit from Chicago, the best "medicine" we could have hoped for!

The saying, "the third time's the charm" rang true for us, as we got admitted again, 45 days after arriving in Durham... and here we are, on the PBMT unit, playing the "waiting game" once more. We are prepared to wait patiently for engraftment... and a renewed health for our daughter. In the meantime, we are determined to find the blessings this newfound patience provides us.

An excerpt from a prayer sums up the lesson quite simply, it states...

" I asked God to grant me patience. God said, "No. Patience is a by-product of tribulations; it isn't granted... it is earned."

-- Jenny, Duke PBMT Parent