



# "Look for the helpers."

## I found them at the NF Network.

### Meet Max

It's difficult to know where to begin when discussing my son Max's diagnosis of NF2. I know that it started with a heart-shaped birthmark smack dab in the center of his forehead. Light-pink against his soft skin. His mother and I took it for a blessing, but his pediatrician frowned and told us to keep an eye on it.

We got the official diagnosis of NF2 in the autumn of 2018 when Max was 8 years old, in between little league seasons. I know the minute the rain started: a game of catch on the sidewalk, and he was slinging the ball in there. My little southpaw was starting to throw hard, really hard, strike after strike, but when I would toss the ball back to him, easy tosses he'd have caught the summer before, his glove would fall off. Come on Max, put your hand out like a stop sign. He couldn't do it. I said, "come on, kid, straighten out those fingers." He said, "I can't." You can," I said. "I really can't," he said urgently, a panicked look in his eyes. I crouched down and held his hand in mine. Is this new? The middle and ring finger refused to move.

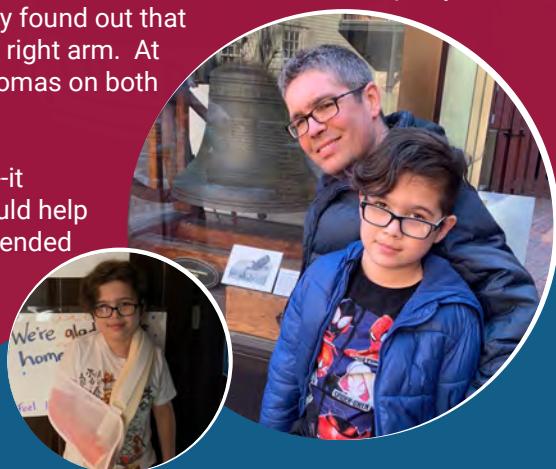
That's how NF2 works. It's slow at times, patient, attacking the body from the inside out, until one day it shows up on the surface. Winter now, and he had no control of those fingers at all. In Spring, the entire hand seemed to wilt—no wrist function, no pinky. Medicine can also be slow—we saw many doctors, but got no clear answers. We finally found out that Max had a large tumor in his brachial plexus that was sapping all nerve function to his right arm. At the same time, the telltale sign of NF2 reared its head on the MRI: vestibular schwannomas on both audial canals. Genetic testing confirmed it.

I called the NF Network—I want to say on a whim, but whim isn't exactly the right word—it showed up on my browser at the exact moment it needed to. I called to see if they could help me with insurance problems. Insurance denied the chemotherapy one doctor recommended for Max, and on my table was a bill for around 33,000 dollars. How did we get here?

I spoke with Deb on the phone who must have been overwhelmed as I told my story—where to begin? She put me in contact with John Manth, Kim Bischoff, and others in the network.

**The late great Fred Rogers famously said, "Look for the helpers."** I found them at the NF Network. I learned more about NF2 in an hour long conversation with John than I had in the last year, but perhaps more importantly, I learned that there are wonderful people out there who will help you carry the water when it's too heavy, and that you can't care for something as complex and precious as a child with NF2 without support.

They say it takes a village to raise a child, and I didn't know where the village was until I connected with the NF Network.



### Help us continue to be the helpers for the next NF family that calls.

In 2020, the NF Network touched the lives of over **1,600 individuals** affected by NF. Your gift assists us in accelerating the search for treatments and a cure for neurofibromatosis while offering hope and support to those living with NF. Donate today, and together we can make an impact.