

April 23, 2018

To: Nationwide Children's Complex Care Program Staff

Re: Patient/Family Experience Testimonial

I pray this note finds all who reads this encouraged by the work you do day in and out for families. I can only speak for my family but wanted to extend heartfelt thanks for your timely intervention. My son, Carl "Allan" has a dual diagnosis of Down syndrome and Autism. He's the light of our lives, yet his medical challenges require a ton of doctor's appointments, assessments, and diagnostics. It makes life extremely hectic for my husband, Carl and I as we both work full-time outside the home. We also have two beautiful daughters, so we have our hands full. Add ministry, and extra-curricular to the mix, how we manage with no immediate family locally is a miracle in and of itself.

Since a referral by the Down Syndrome Clinic (Dr. Nash) to your incredible clinic, we've seen a marked improvement for our entire family. In eight months, your team has rallied around my family with resources:

- Referral into Dermatology for his alopecia
- Referral to Autism Clinic for ABA
- Assistance with outreach to my son's County Coordinator to assist with a complex issue re: waiver status
- Referral to Dental Clinic
- Care Coordination to alleviate multiple days off work to get Allan to appointments to Pulmonary, Audiology, ENT, Dermatology, Physical Medicine, Psychiatry, Eye Clinic

You too have been invaluable with medication intervention. My son has not slept through the night in years. Nor have Carl and me as his parents. Allan would remove his clothing through the night, and we'd find ourselves in some 'unpleasant' diaper clean up situations. As you can imagine, there was lots of bills for carpet cleaning, on top of washing laundry daily, and an increasing sleep deficit for us all, which was exhausting. With the addition of melatonin, an OTC remedy, Allan's now sleeping through the night.

Your team along with our son's county coordinator has also made us knowledgeable about HealthChek, and Allan receives up to 50+ hours/week in home health now. The added support and one-on-one for Allan within three days led to a first significant milestone. At 10.5 years of age, our son now successfully uses the toilet to take a bowel movement. We thought this day would never come. Home health has provided some balance and allows Carl and me to give added



time to our girls. The partnership of A1 Home Health and their intake staff has been a dream come true, after working with other home health agencies whose lack of showing up left us feeling insecure.

Dr. Steingass' knowledge and education she provides has been helpful. She's attentive to Allan and especially to a very worried Mom like myself. Her advice is valuable to me, and we trust her. I appreciate how responsive she is to my concerns. I want to also highlight Ms. Tiffany Houpe, RN Case Manager who has been a rock for me. I cannot thank the heavens enough for her responsiveness in helping me find resources (dental, summer camp, autism-specific clothing—we found sleepwear for Allan that zips in the back to prevent night-time fecal smearing). Tiffany has also been non-judgemental, kind in tone, and listens to my concerns. Just today, I shared with her how close I am to running out of paid time off, and she partnered with Allan's other specialists to ensure I didn't have to

take any more time off until it resets without compromising Allan's appointment needs. With his adverse behaviors (scratching, smacking himself and jerking his neck to communicate his frustration), these visits can be exhausting, so I am grateful how Complex Care supports us.

I'd be incredibly remiss if I didn't highlight your amazing team of social workers. I didn't even know you existed until I found myself a mess of tears speaking to a dear friend who attends my local church. She is a social worker at your hospital and a wealth of knowledge. Your hospital is better for having Mrs. Chante Meadows on your staff. With her education, I was able to ask Dr. Nash in the Down Syndrome Clinic for her thoughts on if being referred to you was appropriate and medically necessary. I remember in tears telling Dr. Nash, "I'm policing and coordinating his care all by myself it feels like...I need help."

And for context, I am a professional patient advocate for a local company. What I do incredibly well for others, I frankly stink at doing for Allan. I don't know how to explain it other than feeling paralyzed, frozen...it's a looming mountain, and while I know what to do with all my skill set, I feel so inept. And I know that feelings aren't true indicators here because my work speaks for itself in the countless families I help daily across the US. \$500,000 in claims money saved in just the past three years with accounts I've handled. At the end of the day, I am a wife, a mother whose biggest aim and desire is to simply see Allan grow and thrive, becoming so much more than my fears and doubts. He's a lifesaver....the reason I work faithfully and passionately in healthcare now. So I cannot thank you for helping me do what I could not. Oh, I can love him, cuddle him and cheer him own, but you've helped me make sense of his medical path. You've helped clear the fog.

I praise God for each of you. The work you do is never in vain. You've probably more thankless days than most, but for this family, you've been a game changer. THANK YOU!

Eternally grateful!

Carl and Melody Bogan, Allan's #1 fans and parents

(Family Photo, includes our daughters, Vivian (9.5) and Samantha (7.5))

