

Reed

We received Reed's official BBS diagnosis at 10 months old. Our feelings about Reed's diagnosis began with disbelief and denial, then progressed into guilt, worry, despair, envy, jealousy and then more guilt. Often we felt lonely and isolated from everyone - that no one else understood the feelings we had - the worry for our child about his future. Ultimately, we asked ourselves, "Why did Reed get this?"

Once the initial shock subsided, we searched for information regarding BBS and desperately to find other families like ours. Through our search, we found a blog about a family dealing with BBS, a BBS family association and a clinic specializing in the treatment and research for BBS. Learning from other families who have gone through similar experiences helped immensely. The advice and guidance shared about early intervention services, necessary medical providers and therapies, as well as the current and ongoing research felt like a blessing.

Looking back, my advice to BBS parents is to be proactive in finding and building the village for your child. Make connections with the BBS Family Association and Marshfield. You will learn so much from them, and to know you are not alone in this journey is a huge support and comfort. Take all the help offered and don't be afraid to ask for more. Also, know it is ok to cry, to question why, to look at other children with envy, to feel frustrated and angry and all the many other emotions you will feel. We have all done it, but believe me you will get through this.



That's not to say we don't have bad days still. If we're honest, we all do. Our son has BBS, but BBS is not our son. Our son is Reed, a beautiful, witty and fun-loving boy who starts kindergarten this fall. We love every little bit of Reed with all our hearts and we always will.

- Kevin and Kat Smith



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