



### **BJ's Life Story and the Navy**

“Oh look, Mama! That little boy has two legs and he’s walking,” said my almost three-year old innocent little girl, who all her life thought all boys were born with only one leg like her brother. I froze when I realized what Jessica had just said and wished again that things were very different for BJ.

Looking at him in the hospital nursery shortly after he was born, all wrapped up in a colorful blanket, BJ looked no different from all the other babies. He was probably the tiniest but also the loudest of them all. But unwrapping him from the swaddling blankets revealed his 4.1 lb body, his short and everted left foot, the total absence of a right lower extremity, and his short, malformed right hand. As the days and weeks passed, we began our search for the best physicians and most promising medical interventions for our son. We refused to give up hope.

Finding the right doctor and the right medical support team for BJ was incredibly challenging. We needed to find the right people who would not only provide the comprehensive care and treatment he needed, but who would also support him and us throughout the difficult journey lying ahead. When my husband came home with the paperwork for the Exceptional Family Member Program (EFMP), I didn’t know what it was all about. I was so focused on nurturing my son who was struggling to gain weight and stay alive. We knew that if BJ survived, he would need long-term physical and occupational therapy sessions and perhaps future surgeries. I was also so worried that my husband would be assigned somewhere else and not be there when I needed him most.

We were so fortunate to enroll in the EFMP. Through the program, BJ receives the medical attention he so desperately needs, the quality of life he deserves, and the best educational support available. The staff members at facilities became our support network, helping us navigate the medical, educational, and other issues that arose for BJ and for our family. Just a month after his birth, he started seeing his physical therapist through the Early Infant Intervention Program who continues to work with him on a weekly basis.

BJ's school life started when he was just about two and half years old. After a comprehensive assessment, he was found eligible to receive services under an Individualized Education Program (IEP). When he began school, he had already learned how to maneuver his wheelchair but hadn't learned how to walk with his first prosthesis and walker or his lofstrand crutches. The school therapist and I were in tears when we saw him walking for the first time using his prosthesis. He so wanted to walk, but it took so much energy and concentration. He looked both proud and focused, showing such mixed emotions. In due time, he learned how hop, skip, and even run with his prosthesis.

When BJ was six, we had another in a long line of huge decisions to make. Instead of having his left foot amputated, we went to Sinai Hospital to see a renowned limb preservation doctor who did the rotation plasty of his leg and syndactyl release and pollicization of his thumb. The EMFP allowed my husband to stay in the area with much flexibility at work. He was able to be there when our son needed him for things like major surgeries and also for unexpected visits to the emergency rooms when BJ's asthma got so bad that he couldn't breathe. My husband and I were able to make countless visits together to the Neurodevelopment clinic for BJ's health needs, for medical durable equipment, and also to extend the educational support BJ receives from the clinic's occupational therapist, educational advocate, and psychologist. We are able to fight together to push for the treatments, therapies, and resources that BJ so desperately needs and deserves.

Through the EFMP, we also had the opportunity to celebrate with other EFMP families, enjoying a day at a local area amusement park. The ability to connect with other families who understand our struggles, our sorrows, and our joys helps keep us going, reminding us that we are not alone. We have also been invited to be part of family panels for two DoD/Joint Service EFMP Conferences. At the second conference in Jacksonville, Florida, BJ had the great honor of singing the National Anthem to start the event.

BJ is now an incredible ten year old boy. He never lets anything stop him from doing what other kids his age can do. He remains competitive academically, takes piano, cornet, and karate lessons, and sings in two church junior choir ensembles. He also volunteers at our local Christian soup kitchen a few times each year.

BJ's positive outlook in life and his contagious smile affirm that he will not be held back or defeated. He has a life just like ours and rises to any challenge that comes his way. He continues to inspire us and always will.