

# Benjamin Falcone's Story



At 5 months old Ben had a 106 fever, it was the night of Hurricane Sandy, and every month since suffers from a high fever and difficulty breathing. By the time he was 4 years old, Ben had experienced a high fever of over 107 on 14 different occasions in the hospital, unable to eat as he aspirated into his lungs due to the airway defect, and had undergone multiple procedures to help alleviate his illness and was diagnosed with failure to thrive. He also suffers from severe stomach and joint pain from the Familial Mediterranean Fever Syndrome and he now shows symptoms of neurological/cognitive dysfunction which includes involuntary hand and finger movements. Ben is now 7 years old with about half of his life consisting of trips to his medical team from CHOP to Hackensack Hospital including a GI, Infectious Disease, Immunologist, Rheumatology, Neuropsychologist, Neurologist, Pain management, Pulmonologist, Feeding Therapy and frequent visits to the Pediatrician almost weekly. In addition, securing care takers and tutors for when he is sick and falls behind in school (another challenge that we now face). As you can imagine he was extremely developmentally delayed due to his first 4 years of life being so ill.

When you have a child nothing quite prepares you for coping with an illness in which there is no cure that is extremely unpredictable. To explain what he experiences as simply as possible, his brain each month sends a signal out to his body every 30 days that there is an infection. His body responds by secreting a tremendous amount of mucus and an inflammatory response occurs throughout his body. His joints and muscles ache and he gets fevers ranging from 102 to 108 and large sores in his mouth and nose. During this time he cannot eat, throws up continuously and is at very high risk for dehydration, seizure, etc. Each month is

different as sometimes he can walk and sometimes he is bed ridden for multiple days and in constant pain. We have had over 65 hospital trips with him unable to breathe because of the weakened airway; the inflammation impacts his airway and with the mucus it is very difficult for him to breathe. Ben's body is tired and he sleeps often, and gets tired easily. His body has a hard time regulating and he overheats so summer months are vulnerable for him and during cold and flu season any illness triggers the flare up and his fevers are higher during the episode. If Ben continues to have fevers over 105 he faces a threat of kidney failure and then heart failure. There is no cure and the only medicine that may help which is colchicine he cannot tolerate; it causes his stomach to bleed as it is not for pediatrics.

We are working to balance Ben's happiness when he is in a healthy span and then keeping his fevers under control by giving him the most supportive environment possible. We were once waiting for the light at the end of the tunnel and now just accept the new normal for us. Ben now faces a new challenge, now that he is of school age the additional challenges are education – being able to learn and process. Ben began having involuntary movements of his fingers, hands and reflexes. He is still too young for an official diagnosis but based on these behaviors it is likely that he has Bacht's Syndrome which is a manifestation from the fevers. We are faced with finding the proper education environment at this point and getting him in an appropriate place where he can thrive and support the management of his disease. Life is different. Ben however knows nothing different, but now is beginning to realize that other children are not like him and asks why Daddy doesn't get the fevers or his friends. He has been diagnosed now with anxiety and depression as he is becoming more aware of his condition. We cannot reiterate how important it is for Ben to be in a suitable learning environment with the appropriate resources to keep him physically and mentally healthy and strong.

Raising a family is extremely challenging and nothing can ever prepare a family for having a child diagnosed with a chronic condition, but knowing there is a support system and others out there praying means so much! We have so much gratitude and thank everyone for your support.

