Billy's Voice

Introduction

We are delighted in one sense to be able to bring you this long-awaited supplement and introduce you to Billy, but on the other hand we are perplexed that the Billy still finds himself in the same place as a few months ago…without support and the appropriate medical care he needs to sustain him with his rare condition; that would give him access to a better quality of life.

Billy suffers from a very rare form of epilepsy - the medical profession had given up hope…however, Billy has a remarkable mother who has fought at every turn to ensure that her son has the right to life…she has campaigned, motivated, appealed and been to government to get her son the right medical care…

Charlotte Caldwell lived in Chicago for 2 years so that Billy could receive innovative treatment. A special diet that is based on biblical principles was introduced with amazing results. This treatment is now available in the UK but instead of having direct access to this Charlotte finds herself again fighting for treatment. Having fought to have funding, promised it at government level, this funding was then 'snatched' cruelly away at the last moment. This gave Charlotte no choice but to pursue an avenue she didn't want to, but sometimes we have to do things we don't want to in order to save a life…

Charlotte and the 'Keep Billy Alive' campaign continues in earnest, he has proven to everyone that with the right treatment he can have a normal, stable life – this week Billy took three steps on his own. We would like you to take many more with him and support the campaign that will offer stable, uninterrupted care that every citizen ought to be entitled to…

Editor.

‘Billy Bear’

By Lorraine Wylie

With eyes the color of cornflowers and a smile to melt the heart, there’s no doubt that three year old Billy Caldwell is a born charmer. Although, it has to said, that like all little boys, Billy’s mum is his number one fan. Every morning, regardless of what’s happening on the weather front, the sight of her son sleeping peacefully adds a touch of sunshine to Charlotte’s world. Only a mother can understand that special rush of love their child evokes. The only thing to equal its intensity is its strength.

As far back as the ancient days of scripture, the power of maternal love has proved a force to be reckoned with. In Old Testament days, Rizpah may have been circumscribed by the boundaries of her culture and gender with neither power nor authority. Nevertheless, she braved the elements, fought off predators in order to preserve the bodies of her sons from desecration and taught King David a lesson in loyalty. Later, Hannah sacrificed the joy of raising her only child so that he could have the honor of serving God.

Charlotte Caldwell may be separated from her biblical predecessors by time and culture but there is no doubt, she possesses the same brand of maternal love.

Unlike Hannah, she has not had to leave young Billy to the gentle care of a man of God. Instead, it was the clinical surroundings of hospital wards that took him away from home. Neither has her love for her son forced her to battle wild life on a deserted mountain top. But she has struggled against a medical prognosis of hopelessness, governmental bureaucracy and endless hours of heartache. Fighting for son’s life has been an exhausting and painful experience.

Charlotte’s agonizing journey began when, at just eight months; her baby son was diagnosed with intractable epilepsy and sent home to die.

By this stage Billy was having dozens of major seizures per day and, despite a cocktail of toxic drugs, nothing could stop them. Suddenly, instead of a healthy baby, Charlotte cradled a fragile body that seemed more like a doll than a child. Tossed about by the storms of epilepsy, she watched helplessly as her son teetered between life and death. In the end doctors offered to write a prescription for morphine and told the young mum to take her son home for his last few weeks of life. Distraught with grief, Charlotte instinctively turned to God for help. With tears she pleaded with Him to spare her child. She also promised that if her plea was granted, she would dedicate her life to caring for the child He had placed in her care.

As is often the case, there was no immediate sign of divine intervention. While God undoubtedly hears our prayers, He sometimes expects us to use whatever earthly means are at our disposal. After all, Jesus didn’t physically roll away the stone from Lazarus’s tomb. He left the onlookers to do it while he took care of the miracle.

In Charlotte’s case it was her maternal love that was to be the chief weapon in her battle for Billy’s survival. Instead of administering morphine, Charlotte began surfing the web in a desperate bid to find someone to help. When she came across the Children’s Memorial Hospital where Dr. Nordli was a renowned expert on treating children with life threatening seizures, she knew she was on the right path. The only problem was that Dr Nordli was in Chicago while she and Billy were in Northern Ireland. When both government and the medical profession, refused to help Charlotte had only one course of action. Together with a little help from her friends, she raised enough money to get to America and begin her search for hope.

In September 2007, mother and son visited Dr Nordli in Chicago. After assessing Billy, the medical expert gave his mum an early Christmas present. When asked if he could help her child, his reply was a resounding ‘yes!’ In fact, for the first time Billy received a proper diagnosis. According to the doctor, the little boy was suffering from a condition known as Angelman Syndrome which he was certain would respond to treatment. Apart from weaning him off his cocktail of drugs and introducing more appropriate medication, the American doctor prescribed a combination of special diet and physiotherapy. The results were amazing! Instead of seizures on a daily basis, Billy’s attacks were reduced to weekly episodes and even these weren’t as violent as before.

Today, Billy has celebrated his third birthday. He and his mum, unable to afford the spiraling costs of living in America, are now based in Oxford where Charlotte has been able to source the treatment he needs. In 2008 she launched the Billy Caldwell Foundation which apart from helping Billy, is intended to provide support for families facing similar difficulties. Already several children have

followed Billy's journey to Chicago and benefited from the expertise of Dr Nordli. But, in order to help Charlotte maintain Billy's progress, more money is needed.

The devoted mum has kept her promise to God. She never leaves Billy and dedicates every waking moment to his care. Yet, when asked how she feels about the enormity of her task, she sums it up with a smile.

'Every morning when I see my son still breathing, I feel so blessed. Undoubtedly I've been given a great responsibility but it's also an amazing privilege to know a child as wonderful as my wee Billy Bear"

www.billycaldwellfoundation.com

'Against all odds' – Billy Caldwell today…

MY STORY

By

Charlotte Caldwell

My life changed forever on 26th July 2005 with the birth of my son Billy. From that day on, I began to understand the meaning of unconditional love. With it, came an enormous responsibility for this little human being.

When Billy was 4 months old, he awoke from his sleep stared wide-eyed for thirty second and then seemed to doze off. He repeated this two more times that night at thirty minute intervals. I rang the out-of-hours doctor who correctly directed me to our local general hospital, Tyrone County Hospital, Omagh, to get his stats checked out. The receiving medical staff there detained him overnight and transferred him by ambulance the next day to the Paediatric ward in the Erne Hospital, Enniskillen. On his way there, Billy had his first major convulsion. It was not to be his last.

I have never felt so frightened in all my life during this major seizure that continued for six hours. I felt totally powerless over it. I had prepared myself that Billy was going to die that day.

Between seizures, Billy was transferred to the Royal Belfast Hospital for Sick Children for further care under a specialist Neurological Paediatrician. Billy remained in the RBHSC for the next fourteen weeks. I watched as he experienced the full range of seizures; petit-mal; grand-mal; tonic-clonic; absence attacks.

Drug after drug was administered to Billy without success. These included Topramax, phenobarbitone, Sabril, medazalim, chloral hydrate, and many more. On one occasion, the specialists put Billy into a deep anaesthetic sleep in the Paediatric Intensive Care Unit, in an effort to end the seizures. This was to no avail.

I quickly had to learn a new vocabulary with terms like MRI, EEG, complex partial seizures, Limicatal, diazepam, and many more. Publications like *Your Child's Epilepsy*, *Epilepsy, The Facts* became compulsive reading for me. My little boy was reduced to a lifeless doll in my arms, no smiles and no head control, just his large blue eyes staring back at me, seeming to ask Why?

Looking back over our many difficulties, the blackest time of my life was when Billy was five month old. He was having 25 to 35 seizures throughout the day and night. I had to be vigilant 24/7. On an almost weekly basis, I had to rush Billy by ambulance to the Accident and Emergency Department during these uncontrollable major seizures (status epilepticus). This appeared to be an unending nightmare for Billy.

And then I took things into my own hands. I started to do my own research on the internet. I began to develop antibodies to the word epilepsy. I try not to use it now, if I can avoid it, because I had to googled it so many times. I had accumulated large piles of print-outs on the subject. But I was driven by the belief that I needed more knowledge of the subject to give Billy a fighting chance.

And then I opened up the website of the Childrens Memorial Hospital in Chicago and Dr. Nordli. In the US, a doctor who specialises in the care of children with seizures is termed an epitologist. We just do not have such a specialist in the UK. As I looked into his clinical facilities in Chicago, it became obvious to me that Dr. Nordli is a world-leader in his field. I felt that, at last, I could see my first road-sign on our highway to hope.

On 8th September 2007, I sat in Dr. Nordli's office in Childrens Memorial Hospital, Chicago and asked him the question that was most important to me and to Billy.

IS THERE HOPE FOR BILLY?

'ABSOLUTELY' was Dr. Nordli's clear answer, without any hesitation. Tears filled my eyes. I had been given the right to hope for the first time in Billy's short life. This never happened in Belfast.

Since that day, my hope has been justified by my increasing confidence in all the medical professionals in the team at Childrens Memorial. Dr. Nordli started Billy on the Ketogenic diet and weaned him off the more toxic drugs. He established an exact diagnosis for Billy's condition (Angelmans Syndrome).

In addition, his intensive physiotherapy with Daisy Tan and her Chicago team has proven to be very helpful to Billy's development. Over the last 9 month since then, his major seizures have been abolished. He only rarely has a minor one. He can now take 60 steps with minimal support. He can say Mum, which he uses to great effect when he wants fed or to tell me when he is tired. But most of all he can communicate best with his beautiful big blue eyes. Billy has learned how to tease me with the way he looks. But that is fine because he can reward me with his smiles, and then I know that I am privileged to by Billy's Mum. I will always be indebted to Dr. Nordli who restored my hope in Billy's future and my belief in the caring profession. Thank you, Dr. Nordli.

Latest News – Billy took three steps this week on his own!

www.billycaldwellfoundation.com

www.billycaldwellfoundation.com