

Tracy McCausland

If There Were Medals For Mothers

Supermum Tracy McCausland tells us about being the devoted mother of two beautiful little boys, and her never faltering quest to aid drug research into treatment for Muscular Dystrophy

She has raised over £250k in 18 months to aid drug research and clinical trials for the treatment of Muscular Dystrophy, yes, Tracy McCausland is a force to be reckoned with. They say a mother's love is the strongest sentiment, which would explain Tracy's non-stop, unrelenting mission to raise much needed funds into the research of Muscular Dystrophy; it doesn't explain, however, where she gets her seemingly never-ending energy, resolve and determination.

Tracy and her husband William have two of the most gorgeous and adorable little boys, Callum, aged seven, and Sam, aged three. Callum has severe Apraxia and is having therapy in Miami and Sam has Muscular Dystrophy. Tracy lives in Hillsborough, Co Down and spends her days looking after her children and tirelessly running the charity SAM-Struggle Against Muscular Dystrophy, which aims to raise funds for research that will work towards a treatment for CMD. She is also the hostess with the mostess as her now famous Emerald Balls, have raised thousands for the charity. This is her story ...

Callum

"Our first little boy, Callum, was born in September 2002, and had problems which were evident from birth. He was a very floppy wee baby, and slow to feed. His first year was



Tracy and Sam with brother, Callum

dogged by one concern after another; he missed all the baby milestones, there were concerns that he may be visually impaired, and as I watched all the other little babies who were born at the same time as Callum, I had a sinking feeling that he would not simply 'catch up in his own time.' After a while people stopped trying to still my growing concerns by telling me that all babies develop at their own rate. Test after test for one condition after another served to rule a lot of things out but did not really tell us what was wrong with our beautiful little boy. 'He's an enigma', was about the closest we got! Every night as I put him to bed I would pray that in the morning we would all wake up and he would be fine.

"Callum didn't walk until he was two; couldn't



Sam McCausland age 3, with his mum, Tracy

get transition between sitting and standing without help, and could not even hold a chubby crayon in his little hand as his fine motor skills were so poor and his muscle tone so low.”

Dyspraxia

Tracy spent hours on the internet talking to other parents from around the world, before learning about Dyspraxia (also referred to as Apraxia or Developmental Co-Ordination Disorder). “It seemed to be the only thing that really fitted his unusual mix of symptoms,” said Tracy.

Many children have dyspraxia, but most are only mildly affected by the condition, perhaps being a little bit clumsy with poor handwriting or minor problems with articulation. Callum, however, has a very severe form of dyspraxia which affects his gross motor, fine-motor, oro-motor and verbal capabilities. Callum receives innovative treatment in Miami and Tracy said: “He is, despite the worst predictions of many of his doctors, doing really well thanks to intensive therapy, and we are hopeful that his future will be brighter than predicted.”

Sam

“While we were still struggling to come to terms with Callum’s problems our second child, Sam, arrived. Sam was born happy and healthy on 24th August 2006 — a perfect little cherub to complete our family and a little brother for Callum who was just about to celebrate his fourth birthday.” Sam contracted Meningitis but amazingly survived with no long term effects. “Eight months later, however, we began to worry,” remembers Tracy, “as although he was hitting all his other milestones, Sam seemed to be lagging behind physically (slow to crawl, not putting weight on his feet and not pulling up to stand). Aged 13 months, his consultant at the Royal suggested we run some tests — to ‘rule a few things out.’ Two hours later our world was rocked to the core when we received a phone call to tell us that a very high concentration of a particular enzyme in Sam’s blood meant that it was almost certain that he had Muscular Dystrophy.”

Despairing Times

“The next few months are a blur; we barely functioned as the pain was just too great.



Tracy's boys - Callum and Sam



Tracy and William

Every time I looked into Sam's big blue eyes I wept tears of despair. When we received the phone call from the neurologist I fell to the floor and howled like an animal; it felt like the world had just ground to a halt. The months that followed were difficult for us as a family — trying to get our heads around the facts of the disease; I spent literally hours every night researching on the internet, talking to other parents across the world.”

Muscular Dystrophy

“The facts relating to the disease are blunt and terrible — tiny errors in DNA mean that the body lacks the ability to produce a vital protein (in Sam's case Merosin) meaning that over time the muscles waste away, leaving children unable to bear their weight. In time they lose the ability to swallow and have to be fed through a tube, and the disease also affects the lungs leading to an eventual need for ventilation. The spine becomes twisted, muscles develop painful contractures and eventually the disease takes its toll on the heart muscles. I just could not bear it — looking at my wee man, and imagining the horror and pain that his future would hold. The prognosis is grim, and the doctors shrugged off any hope of Sam having the kind of life we all take for granted. What is even worse is that there is no treatment for MD — and that we are still a long way off finding a cure.”

Letter of Love

“Our lives were completely shattered by this news, and I could not even look into Sam's big blue eyes without feeling desperation and hopelessness. Then one day I sat down and wrote a letter to my son. In the letter I described all the hopes and dreams I had for him, and how much I love him. I made a decision that day that I would do whatever I could to make those hopes and dreams come true. I resolved to do everything possible to give Sam the chance of a better future than the one predicted for him by the doctors.”

SAM Was Born

Struggle Against Muscular Dystrophy was set up in April 2008 “It rapidly became apparent that, because this is a rare genetic disorder, there is very little investment in research which might help find a treatment or a cure,” explained Tracy. “There is no government funding, no big research lab, no multi-national pharmaceutical company just waiting for the nod; and I knew then what a battle we would have to fight even to raise people's awareness of CMD, let alone move us along the path towards finding a cure.”

The Emerald Ball

Tracy began her crusade and the second SAM Emerald Ball took place in March this year at the fabulous Europa Hotel. The event

raised a truly staggering £86,000 which is already being put to use in funding the development of a promising drug candidate for the treatment of CMD. Northern Ireland's celebrities and glitterati turned out in force to join the event's hosts — actor James Nesbitt and local media personality Emma-Louise Johnston, for an evening of top-notch entertainment.

Finding a Treatment

“So far people have been extremely supportive,” said Tracy. “We have already raised a significant amount of money which has enabled us to kick off FOUR research projects. Research is expensive and we have set ourselves a very aggressive target. Time is critical. I want to find a treatment before it is too late for my little boy. I want this to be his saviour — not his legacy.”

Funding Clinical Trials

SAM is a 'zero cost charity- no money whatsoever is deducted from donations to cover salaries, administration or overheads; every penny of every pound goes towards funding research projects. The charity raised an incredible £250,000 in just over 18 months and recently announced grant funding totalling over £175,000 to evaluate three promising CMD drug candidates in 2010, and a separate effort to identify disease biomarkers. This is a tremendous step forward and SAM has also funded the entire set-up and year one running costs for a Global Patient Registry — a vital prerequisite for future clinical trials.

Following the success of the recent Emerald Ball, the charity is set to announce funding of \$100,000 to pharmaceutical research company Prothelia to support the development of their lead therapeutic, Laminin-111.

A Mother's Hope

Tracy said: “The work we are doing in raising money to fund research through the SAM charity gives me hope. There is great cause for optimism that within the next five years we will at least have an effective treatment to slow the rate at which the muscles are wasting. This will potentially buy us a little

more time for the scientists to find a cure and that dream ignites and sustains the passion I have for raising the vital funds that will help maintain the research. I dream that Sam and all the other children who suffer from CMD will have a real chance of having a brighter future than the one currently predicted for them.”

So what's Tracy's advice to other mums out there? “Never ever give up,” urges Tracy. “When a child has special needs it is our role to advocate for them; to ensure that we fight for them to have access to the therapies and interventions which will help them to have the best chance of a normal life. I have never taken 'no' for an answer, and every step of the way my children have proven the very best doctors wrong. Stay positive, believe in your children, love them unconditionally and be strong for them. Hope that tomorrow will be a better day.”

To find out more about SAM and how to donate, visit www.helpsam.info.



Tracy and her boys

www.helpsam.info:

Watch out for details of forthcoming events including a sponsored abseil, charity bike ride, and the Hillsborough Oyster Festival, and helpful tips on running your own events to raise money for SAM. People can also donate via the site!