

# Why I'd go to any boys the

**Courageous mother Tracy tells of her endless fight against her two children's serious health problems**

STEPHANIE BELL

MUM-in-a-million Tracy McCausland cried for two hours on St Valentine's Day when her seven-year-old son Callum told her for the very first time that he loved her.

Those three little words never meant so much as when coming from the mouth of a child whose mother had battled since his birth to give him a chance to learn how to speak.

Fate dealt Belfast-mum Tracy and husband William a cruel hand when both their boys, Callum (6) and Sam (2), were born with rare and complicated medical conditions.

Callum suffers from severe Dyspraxia, a brain-to-muscle communication disorder affecting speech and coordination.

Many people will have heard about Sam, Tracy's youngest boy, who has Congenital Muscular Dystrophy, a condition for which there is no known treatment or cure.

His prognosis is frightening – over time his muscles will waste away condemning him to a wheelchair, probably before the age of 10.

In his teens he will lose the ability to swallow and breathe on his own and eventually Sam's life will be cut short, probably before he reaches his 20s.

Last year Tracy had to uproot herself and her boys for a year to take Callum to Miami, where in September he started a year's specialist treatment to develop his speech.

Living thousands of miles away from home and family is just one of the many sacrifices this amazing mum has made in her relentless battle to give both her sons every chance of a normal life.

Her remarkable story illustrates the limitless power of a mother's love.

Tracy said: "After having been told he might never speak, to hear him say, 'Mummy, I love you' clearly for the first time was a heart-stopping moment for me."

"Callum is a different wee boy, he is so much happier and more motivated and started using his voice for the first time just three weeks into the treatment. To hear him say his first words was just amazing."

It's hard to imagine the emotional rollercoaster Tracy and husband William have been through since first becoming parents six years ago. Tracy describes the feeling of learning about both of her sons' severe conditions as "like grief".

She said: "When you are pregnant you have all these hopes and dreams

for your child. When you realise that that's not the way it is going to be, it is like a punch in the gut and you go through a period of mourning for that future that will now never be."

So rare are her children's conditions that Tracy has had to embark on extensive research, communicating with parents across the world to find out what can be done to give each of them the best chance.

In Callum's case, doctors could not put a name to his condition and Tracy herself found the diagnosis after tireless research.

She said: "I was so determined to find out what his proper diagnosis was, as I always had this paralysing fear that I would find out further down the line that I had not given him the right therapies to give him the help he needed to reach his potential."

"With both my boys this is important – no-one goes to war without knowing their enemy."

"How could I help my boys fight when I didn't know what we were fighting, let alone the rules of battle?"

"The doctors kept telling me Callum was an enigma – others said he was autistic."

"Through my own research I found out about dyspraxia and felt that it was the only diagnosis which really fitted his mix of symptoms."

Sam was born in August 2006, but the couple only found out last June, after months of agonising tests, that he has Congenital Muscular Dystrophy.

Tracy said: "With CMD there is a severe lack of case histories, and it is difficult for the doctors to confidently predict the course, severity and timescales for this form of the disease."

"I can honestly say that in the months following Sam's diagnosis I went through every emotion known to man."

"Launching the charity has helped and it is important that we continue to raise funds to keep the new research going."

Almost exactly one year ago Tracy launched the charity SAM (Struggle Against Muscular Dystrophy) to fund research into the condition in the hope of finding a treatment and cure.

Her enthusiasm and drive have seen it take off and local celebrities James Nesbitt and Emma-Louise Johnston have thrown their weight behind the campaign.

In just one year SAM has raised more than £100,000, which we can reveal is set to fund a new research

# lengths to give my two chance of a normal life

FIGHTERS: Tracy with her beloved boys Callum and Sam and (right) with James Nesbitt at a fundraiser



study into CMD, as well as part-fund the setting up of the world's first MD patient database.

The research may be too late to help Sam, but Tracy is as determined as ever to give it her all to help other children unfortunate enough to be born with this frightening condition.

"Someone said to me that it might be Sam's legacy as opposed to his saviour and although those are hard words to hear, I have to balance optimism with a sense of realism," said Tracy.

The struggle is an ongoing one for Tracy, but it is selflessly driven by her unquenchable love for her

children. She said: "I do have moments of utter despair, but when I look at my boys I realise it is our job to make every day as precious and as happy as possible for them."

"I don't think you ever understand the true meaning of love until you are a mother."

"I never would have believed you could feel such an intensity of emotion as you do for your children, you just want to protect them and give them the world."

"I thank God for my two boys, they are my life."

For further information or to support SAM, log onto [www.pleasefixsam.com](http://www.pleasefixsam.com).

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