

# I helped my son beat autism by making him give up Weetabix

(AND EVEN BULLIED GORDON BROWN INTO SUPPORTING ME)

Devoted: Polly Tommey with her autistic son Billy

Picture: JASON BUCKNER

A FEW weeks ago, a one-woman campaign culminated in Polly Tommey meeting the Prime Minister to improve support for the families of children with autism. She was fighting for the sake of thousands of other parents around the country, having become an unofficial 'Good Samaritan' for the desperate parents of autistic children. Here, Polly, 42, the mother of an autistic child, tells her extraordinary story...

By SALLY BECK

ONE OF the most harrowing memories I have of dealing with the parents of autistic children is the day I took a call from a man driving his car around the M25. He was really distressed because he had a two-year-old child whom he felt powerless to help.

Sounding utterly desperate, he told me: 'My son can't speak and doesn't know he's got a mother. He's uncontrollable and I can't cope. I'm going to drive through the central reservation into the path of the oncoming traffic. Please tell my wife I love her.'

I started saying anything to bring him back from the brink. I told him that if he committed suicide, it would make everything worse. For an hour, I just threw anything at him to try to calm him down, which he did eventually. Then he just put the phone down.

I had no idea what had happened to him until two years later, when he came up to me at a conference and said: 'Remember me?' He explained who he was and said he'd phoned me because he subscribed to my magazine, *The Autism File*, and had nowhere else to turn.

Most people have no idea how unrelentingly hard it is looking after autistic children. My own autistic son, Billy, who is nearly 13, has done some terrible things without having a clue what he's done.

Billy has an older sister, Bella, 14, and a younger brother, Toby, 11, who are both 'normal' children. When Toby was six months old, and Billy was two, I took Bella to a tennis lesson. I left Billy in the car, with Toby strapped in his car seat, while I talked to the tennis instructor.

I was gone for only about three minutes, but when I came back, Billy had pulled every hair out of Toby's head. It was horrific. Toby was screaming and his head was all bloody — but Billy was just laughing.

Life before Billy was so different for my husband Jon and me. We met 20 years ago when Jon was managing a health club. He became a personal trainer with clients such as actor Anthony Hopkins, model Marie Helvin and photographer Terry O'Neill. I worked as an actress and life was fun. Our flat in the Fulham Road, West London, was always full of people. We lived life to the full.

We married in 1993 and Bella was born two years later, followed by Billy nearly two years after that.

BILLY is a typical regressive autistic child. He was developing normally until he was 18 months, then he had a convulsion in his cot. We took him to hospital and he was stabilised — but after that, all eye contact stopped, he didn't recognise us, and he stopped talking, sleeping and eating properly.

We got the diagnosis from Kingston Hospital when he was two-and-a-half. Jon and I cried every night. For six weeks, I lay on one side of the bed crying, and Jon lay on the other side of the bed crying, and we both cried until we fell asleep.

Like lots of mothers of regressive autistic children, I was desperate to get my child back. I would have done anything for a smile or a cuddle, or to hear him say: 'I love you, Mum.'

People don't realise that a large proportion of autistic children have terrible gut problems, and for 18

months that was the case with Billy. Any normal child would have been taken to A&E at some point and given a battery of tests, but with autistic children doctors say it's just part of their autism.

Billy stopped eating most things, and eventually all that was left in his diet was cow's milk and Weetabix. He was so skinny his hair started falling out, and he had sores all over his lips and up his arms.

Then, one day, a leaflet dropped through my door explaining how a wheat and dairy-free diet could help autistic children. Jon was sceptical, but I thought it was worth a try.

I replaced cow's milk with rice milk and began baking gluten-free biscuits, which I gave him instead of Weetabix. Billy starved himself for a few days then began eating the biscuits — and, amazingly, his gut problems started to get better.

That really woke Jon up, because he thought if Billy could improve just by making a change to his diet, what else could be done? He found an organisation called Allergy Induced Autism, and through them we met other people who were doing things to help autistic children.

Jon flew to the States for a Defeat Autism Now! (DAN!) conference and

learned how biomedical intervention could help. He threw himself into finding help for Billy and re-trained as a clinical nutritionist.

At the time, Jon was David Liddiment's personal trainer. David was head of LWT (London Weekend Television) then, and during a run one day, Jon told him that we were going to try treating Billy with the hormone secretin, which stimulates the pancreas.

Billy still suffered terrible constipation, and we thought it would help regulate his gut. It worked and Billy's behaviour improved.

That was ten years ago and as Billy was the first British child to try secretin, David suggested that Trevor McDonald follow his progress on the *Trevor McDonald Tonight* show.

We set up a website for anyone who wanted to know more about secretin. It got 150,000 hits, the computer crashed and LWT couldn't cope with all the inquiries.

We'd thought that by doing the programme, we'd find other people who knew of other treatments that could help Billy. Instead, we were inundated with people asking us for help.

It frightened me, because I thought if people were asking me, then there really wasn't any help out there.

People did contact us with interesting information, though, so I wrote to them and said I'd put it together in the form of a magazine, so that we could all share it and start a debate.

The *Autism File* was born — and ten years on, we run it from our bedroom and dressing room in our house in Hampton, Middlesex.

The magazine's circulation is now 44,000 and it's on sale nationally for £4.95. We get around 50 calls a day from parents, and the phone can ring until 1am with people calling from the States.

THERE are four of us, including Jon, who answer the calls, and no one gets paid any more than expenses — but I do make the helpers lunch and I sometimes manage to draw a small wage.

We get calls from fathers who can't cope with the stress. One father told how every week, without fail, his 22-year-old son, who has Asperger's — a form of autism — gets beaten up.

Mothers are distraught because their husbands have left them or have had affairs. Another father couldn't take his son to the supermarket because every time they go, he pees on the fruit and vegetables.

We get calls from Asperger's sufferers who have little or no support — three have committed suicide. Two mothers have committed suicide with their autistic children because they couldn't cope.

It's desperate and I am not trained to deal with any of this. All I can do is listen and advise where I can.

Just before Christmas, I took a call from a mother who couldn't find a school for her autistic son. He was constipated, she had no money and her husband had left her. The only way she could sleep at night was to drink a bottle of wine.

I was on the phone for over an hour, and when I put the phone down I felt so angry on her behalf that I just felt we had to do something.

We sat down and decided that people needed to know what the families of autistic children have to go through: how little support there is for autistic children and families.

We also want people to know that the mothers aren't downtrodden, ill-educated women who somehow deserve to have an autistic child — so we hit on the idea of a photo of the glamorous mothers we know.

Jon called Terry O'Neill and asked if he would take the photo. He said that of course he would. I called Peter

Mead, the creative director of the ad agency AMV DDBO, which has clients such as BT and Walkers Crisps and where I had worked as a temp, and he too said he would help.

The project snowballed and we had a £500,000 national advertising campaign which appeared on around 4,000 billboards and posters. Everyone involved has donated their time and skills free.

The main campaign was a series of 'Dear Gordon Brown' letters, asking the Prime Minister to contact me so we could discuss a way forward.

We finally met earlier this month and I told him about the Autism Trust — the charity we've set up.

There is so much misinformation out there, and so little understanding from health professionals, emergency services and the authorities that it makes caring ten times harder.

One mother, who had a 40-year-old autistic son, managed to get him a job working at the local library for two hours a day. He was fine as long as he got on and off the bus in the same place and followed the same routine. He had some independence and his mother had some respite.

Then, on the way home one day, a baby on the bus started crying. Lots of autistic people are incredibly sensitive to noise, so this man stood up, covered his ears and started screaming to block out the noise. The bus driver called the police and the man was taken away and sectioned.

HIS mother didn't see him for six months and by the time she got him back he was pumped full of drugs and could only sit rocking backwards and forwards in his bedroom. All her hard work had been destroyed.

The cost of life care for an autistic person is around £2.9 million, but we think that with the right help that could be massively reduced.

It would cost £10 million to set up an autism centre where we could educate the police, magistrates, teachers and anyone else who comes into contact with autism.

It would also be a drop-in centre for parents to get advice on education and treatment for their children.

There are amazing things being done to help autistic kids, particularly with biomedical intervention — detoxifying children through supplements and probiotics, diet, speech therapy and behaviour analysis.

Some children respond so well they are taken off the autistic spectrum and can return to mainstream school.

But very little of this help is available on the NHS, or through the local education authority.

I mentioned all this to Gordon Brown when I met him, and he was incredibly supportive. In fact, our meeting couldn't have been better. He loved the billboard campaign and said it was genius.

Gordon wants me to work with his wife Sarah to bring all the autistic organisations together so that we can work for a common cause. He wants there to be more understanding towards autistics, and for them to be more included in society.

For that to happen, the public sector needs educating, so he wants his representatives to attend a conference that our charity, The Autism Trust, is running in October. We want doctors, scientists and the public sector to learn more about dealing with autistic people.

As for Billy, he has done incredibly well. Jon and I have spent £45,000 helping him (we have debts and loans of around £30,000) and he has really thrived. He talks, he has no bowel problems, and we have a great relationship with him.

Billy is now a weekly boarder at a new residential school in Brighton, called Hassocks, where he'll learn essential life skills. Jon is the resident nutritionist there and the kids will really get the kind of help they need.

But the fact is, for many families there is still a long way to go.

I saw an advert recently asking for people to care for autistic children. It said: 'No experience necessary. English as a first language not essential.'

It made my heart sink because these children are being treated like cabbages. Our message is very simple: 'We can do better than that.'