

As everyone was filing in to get a cup of tea at the last national meeting at the Hilton, Northampton, I turned to my mum and I whispered “look what you’ve done”. She turned to me, surprised and said “what?” I told her that all the people in the room were only there because of her and because of what she had done. When she looked up again her eyes were full of tears.

If my mum had ever realised the enormity of what she did for families of children with Wolf Syndrome, she probably couldn’t have done it. The group started because of the way my mum saw life. She would say you have to make the best of everything and get on day-by-day doing the best you can. As I understand it, when Steven was born there was hardly any information available on Wolf Syndrome. Once my mum had eventually come into contact with two or three other parents over a number of years, she realised families could support each other. Mum knew families could offer each other practical information if only they knew about each other. So she set to work ensuring that every UK hospital had her address and that any family told their child had Wolf Syndrome could be given my mum’s details so they could get in touch if they felt they needed help. Initially the group stayed together through personal letters to my mum and to each other. Eventually improvements in science meant more children were being diagnosed which in turn meant a lot more phone calls and letters. It was then my mum decided to start the newsletter and a dedicated phone line was put in to ensure families could always get in touch or leave a message.

When I was little the newsletter was a family affair. My mum would compile it, my dad would print it and bind it, Katie would put it in envelopes and I would stick address labels on. Steven would be the foreman overseeing every step, of course. Over the years the group expanded, became a charity, started to host national meetings, take part in research and more and more families got in touch from across the world.

There were many more plans for the future my mum wanted for the group. I know the committee is already involved in several of these plans and through them her work will continue. But the main way my mum’s work can continue is through each and every family. Through everyone staying in touch and supporting each other, by taking time to meet up, join the national meetings, submit something to the newsletter.

I want to thank you all for your kind words, your cards and emails. You all wrote such lovely things about my mum and I know she will be missed by you all. We were her immediate family but the Wolf Syndrome Group was her extended family and that’s how I know she made you feel.

Susan

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Mum died on November 24th 2007. She was diagnosed with an inoperable brain tumour just three weeks before.