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# Annie's '**Big Birthday**' Fundraiser - help me change the lives of children with Transverse Myelitis

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In August this year I have a birthday with a big fat 0 at the end of it, and I am hoping for a special present from you to mark the occasion.

I live with the after effects of an auto immune attack on my spinal cord in 2004, which left me paralysed from the waist down. This rare condition is called Transverse Myelitis (TM), and there is no cure.

I've made some recovery, but can only walk with crutches and suffer from chronic fatigue amongst other problems. This happened when I'd achieved many of my life goals, but imagine it happening to a young child?

## **TM has no respect for age or gender**

Around 75 UK children and young people live with TM. The TM Society have support groups for adults and an active Facebook page, but there is nothing like that for young people. So imagine how alone they must feel?



## **Families living with rare conditions feel isolated**

Last July, the TM Society ran its first ever Family Weekend at the Calvert Trust in the Lake District. For most children it was the first time they had met another with the same condition. Siblings joined in the fun too, and parents shared information, experiences, and solutions. Everyone made new, long-lasting friendships.

On reading how much the Family Weekend meant to these families (as editor of the TM Society magazine), it was obvious that it needed to become an annual event. To prove my point, the 60 places for 2016 sold out in days.

But, all of this costs money, and this is where you come in.

## **How you can make my special birthday extra special**

The TM Society is a small, volunteer-run charity with no external funding. Last year's Family Weekend was only made possible by grants and fundraising.

So, my dear friends, to mark my special birthday I am asking you for a very special present. I'd like you to do a fundraiser or donate money to help fund a Family Weekend for our amazing TM children and families.

You could take on a sporting challenge, run a card or quiz night, have a cake sale, do a clothes swap, or whatever appeals to you. I'll happily attend any event (particularly a wine tasting) to talk about the Family Weekend project. And, thanks to the generosity of my local gym Isenhurst Country Club, I will do my bit by organising a Pilates/Pool Party on Sunday, 5 June. If you'd like to bring friends and family to enjoy a work out session and/or a swim let me know. There will lots of cake to reward you for your efforts!

## How your birthday gift will make a difference

It costs around £1250 for a family of 4 to attend the Family Weekend and I would like your help in raising £2000. This will go towards giving them a unique and unforgettable experience which will change their lives for the better.

## Let's hear from the families how your money will make such a difference

*"My name is Owen, I am 17 years old, and have been paralysed since I was 10 months old. I am a permanent wheelchair user so the chance to go to The Calvert Trust to do lots of physical outdoor activities is amazing. I made lots of new friends who I keep in touch with on Facebook. Because I have had the condition myself for nearly 17 years I was able to help other people as we all could chat about problems that we all have in common and can't talk to other people about. I took part in orienteering, abseiling, archery, canoeing and also swimming, which I haven't been in a pool for years due to having a feeding tube, catheter and scoliosis, but there I didn't feel embarrassed about how I look, and people were really nice."*



*"Our daughter was very shy and did not want to go, but she was so happy when we arrived, and was able to go horse riding, cycling, and canoeing. She is now very daring and independent. People told us even though TM is rare, we are not alone, we're in a huge TM family. We thank the camp for making us stronger"*



## Help me make dreams come true

My dream is for the Family Weekend to become an annual event. Older kids would become leaders and role models for the younger children, and real family networks would become established. Young people would continue meeting up into adulthood, and have a ready-made support network. This would help tackle the feeling of isolation that so many people with rare conditions like TM feel.

If you can help make my dream come true, please call me to chat through ideas. Meantime, a huge thank you for anything you can do to make my special birthday extra special.

Kind regards

*Annie x*

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More information:

**Just Giving page**

[www.justgiving.com/Annie-Schofield1](http://www.justgiving.com/Annie-Schofield1)

**TM Society**

[www.myeltis.org.uk](http://www.myeltis.org.uk)

**TM Society Fundraising resources and ideas**

The TM Society offers a range of support for fundraisers

[www.myelitis.org.uk/fundraising-resources.html](http://www.myelitis.org.uk/fundraising-resources.html)

**TM Society Magazine** The Spring 2016 edition has some wonderful stories and photos from the 2015 Family Weekend

[www.myelitis.org.uk/the-tms-magazine.html](http://www.myelitis.org.uk/the-tms-magazine.html)

**Calvert Trust**

[www.calvert-trust.org.uk](http://www.calvert-trust.org.uk)