
TM Society Family Weekend - Summary

About the Family Weekend

The TM Society Family Weekend took place 10-13 July 2015 at the [Calvert Trust](#) on the shores of Bassenthwaite Lake, in the heart of the Lake District National Park. It was the first time such a weekend for children and young people living with TM, ADEM and NMO and their families took place outside the USA. It brought families together to share, support one another, learn, and develop friendships.

The TM Society chose the Calvert Trust as their mission is to *"...enable people with disabilities to achieve their potential through the challenge of adventurous activities in the countryside in order for them to develop, change perceptions and make positive and lasting changes to their lives."* This is what the TM Society wants for its children and young people who live with TM, ADEM, NMO or ON, and their families.

The Calvert Trust offers accessible residential accommodation and a wide variety of outdoor activities both onsite and elsewhere in the local vicinity. It has over 35 years' experience delivering challenging outdoor adventure events for people with disabilities.

Who attended?

9 families took part totalling 39 people. There were 58 places available and 17 places went unused due to cancellations in the six weeks leading up to the event. However, other charities who run similar events for their members said having 9 families was excellent and a real achievement for the first time in running such an event.

8 paediatric medical professionals took part: 2 neurologists, 1 consultant in neuro-disability, 2 nurses, 1 occupational therapist, 1 neuro-physiotherapist, and 1 urologist. They were from The Walton Centre, Birmingham Children's Hospital, Addenbrookes, and Evelina Children's Hospital at St. Thomas'.

An employee from the [Backup Trust](#), a charity which provides support to children, young people and adults with spinal cord injuries, also attended.

What did we do?

After the dinner and ice-breaker activity on the Friday evening, the outdoor activities took place on the Saturday, Sunday and Monday morning. They included orienteering, bushcraft, canoeing, zip wire, rock and rope (swinging, climbing, abseiling), riding horses, trap driving, archery, and cycling. Evening activities included playing pool, chatting and having a disco in the games rooms. Amy Rachel Curtis, who got TM aged 13 and now is an adult, came with her husband and child to speak to the children and their parents about her TM journey and what she is doing now.

Educational sessions for parents gave them the opportunity to obtain more information about TM, ADEM and/or NMO and what else they can be doing for their child from medical and healthcare professionals who are experienced in treating these conditions. It was also an opportunity for the parents to share information and advice with one another.

What we all learned and the stories

From the beginning, the children played very well together, older children helping and playing with younger children, and just having fun.

Several children remarked to their parents that they were no longer the only child with TM.

One child made a full rotation when cycling, something this child had not been able to do since the condition's onset.

Another child was able to ride a bike by using a hand powered bike. This was the first time the child had ridden a bike since the condition's onset and they were really happy.

Abseiling in one's wheelchair was a popular activity.

Some children were so tired at the end of the day, they were asking their parents to put them to bed and the parents kept saying, 'Wait a minute, I'm speaking to... (another parent).'

The Calvert Trust handed out iPads to the parents during Monday morning's activity to complete feedback forms. Once the parents were finished, the iPads were soon appropriated by the children to watch videos and film and take pictures of people swinging. The batteries on several of the iPads were drained by the end.

The educational sessions were an opportunity for two-way learning.

- The medical professionals learned that temperature regulation is an ongoing issue for children with TM and ADEM, something they were not aware of.
- As a result of the discussion around bladder issues, further research/work may be done in this area using data from the PUDDLES study.
- The paediatric urologist said children should avoid blackcurrant, fizzy drinks, and caffeine if they have an overactive bladder. When a child is older, their bodies may be able to process blackcurrant better but the age at when this happens is different for every child and for some it may not change. One family found that not giving their child tomatoes, berries and chocolate has helped the child's bladder issues.
- Children experiencing behavioural issues after ADEM's onset is not uncommon and the behaviours may make one think of autism, ADHD or Aspergers, but it is not true autism, etc. The consultant in neuro-disability recommended neuro-psychological assessments for these children to help them, their parents and teachers understand what is going on and give them learning and coping strategies.

How much did it cost?

£25,713 was budgeted for the event and it cost £21,699.72. This is due to not using the entire contingency fund, reimbursements from external providers for services not used, and several medical professionals not claiming travel expenses and paying for their meals and drinks at the hotel they stayed at.

If all 58 places had been taken, it would have costed £374.13 per person for the weekend. As 39 places were taken, the cost went up to £556.40 per person. The cost of the 17 unused places at the Calvert Trust was £336 per person, in total £5,712.

Total money raised for the TM Society Family Weekend in fundraising activities and donations where known was £19,047, which means £2,652.67 came from the TM Society's general funds.

Feedback

The Calvert Trust instructors said the TM Society was a lovely group to work with and the children were very well behaved.

Many children asked if the TM Society can organise the weekend next year. But due to resource levels within the charity, it is not known whether this will happen.

Parents said it was great speaking to other parents.

All the parents remarked at how well the weekend was organised and thanked the TM Society for the opportunity.

Having a talk from an adult in their 20's who got TM as a child or teenager and can talk about what it was like to grow up with it and what they are doing now worked very well. The talk was well attended by all the families. Several parents remarked on how inspirational they found it and it provided children the opportunity to ask questions.

Parents enjoyed the second educational session more because it was a relaxed and informal Q&A rather than presentation, which the neurologists gave the day before. Parents found the opportunity to interact with the medical professionals very good.

The majority of medical professionals also took part in the outdoor activities while they were with us and this gave parents additional opportunities to ask them questions. It also allowed the medical professionals to see the children in a non-clinical setting.