

Treacher Collins Family Support Group AGM Saturday 9th October 2021 held at Twycross Zoo

Present: Sue Moore, Mark and Sandra Ellis, Simon and Vicky Moore, Philip and Kerry Tamlyn, Alan Hird, Gay and Tony Dixon, Neil Dixon, Emma Pringle, Julian and Jackie Pringle, Shelley Bale

Apologies: Luke Moore, Hazel Ellis

The minutes from the last AGM were signed by Sue Moore as a true record. There were no matters arising from the minutes. The minutes from the 2019 AGM were also signed as a true copy as we were unable to sign this due to the last AGM being held virtually.

Chair's Report

It has been another quiet year as we still recover from COVID, we have held our meetings virtually. We had hoped that this would have been another Family weekend with speakers on a variety of subjects, but we will keep that on hold until we are confident we can go ahead without COVID restrictions and worries. You will hear from our Treasure, that despite COVID we have still had wonderful people raising money for us.

There was an interesting request from The Association of British Dispensing Opticians (ABDO) who are working with NHS England on a Special Schools Project to deliver vital eye health care and high quality dispensing to children in special schools. They were looking for volunteer children of different ages, ethnicities and with certain medical conditions to allow us to create model heads, which are anatomically correct, and can therefore be used to train eye care professionals in delivering this vital service. We posted this request on our Face Book page, we hope that someone with TC may have volunteered.

This will be the last report I make for the Group and my last time on committee after 35 years I think it's about time I make way for the younger generation.

I hope you will allow me a couple of moments to reminisce. It all started in 1987 when a friend who worked for the National Deaf Children's society, mentioned to Carlo Laurenzi who also worked there that I and my new son had TCS. Carlo had recently received enquiries from a couple of other families with TC and so asked if I would be interested in a meeting together. That meeting resulted in us setting up the Group. Amongst those first families were the Dixons and the Hirds. I volunteered to become secretary which I did for many years and was then honoured to become Chair for the last few years.

I have really enjoyed my time with the group, I am extremely proud of what we have achieved together over the years and it's been a privilege to have been a part of it. I think we have been able to raise awareness of TC and hopefully show how having the syndrome is not the end of the world and not as scary as you think when you first get that diagnosis.

The Conferences we held in those early years were so informative. The family weekends were opportunities for families to meet others with TC for the very first time and I know lifelong friendships have been made. The first one was in Hope near Sheffield (where you were all very small children) I am proud that as a group we campaigned for the BAHA to be provided on the National Health and to have been part of finding the gene that causes TC.

I know that we have really raised the profile of TC, when I started no one had really heard of it, but now most of the hospitals do! I know that we have supported lots of families either by being there at the end of the phone for a friendly chat to providing grants and providing opportunities to meet each other. I know I leave the group in very good hands and I look forward to coming to events in the future and seeing how you continue to grow and support families.

And finally I want to thank the Committee and everyone who has worked so hard for the group.

Treasurer's Report

From 1st April 2020 – 31st March 2021

Financial year 2020 - 2021		
	Starting 1 st April 2020	Ending 31 st March 2021
Current account	£2,581.99	£4,626.18
Savings account	£15,725.14	£15,733.00
Total funds	£18,307.13	£20,359.18

Due to the COVID-19 pandemic, our spending has been considerably less this year as we have been unable to hold any events in person.

The committee agreed to purchase a 'Zoom' subscription so that we could hold events and meetings online.

Christina Antoniou has also raised funds for the group doing an 'Action Challenge'. This was postponed due to the pandemic but will now take place in 2022. At present Christina has raised over £550 for the group.

In August 2020 we received £210 from Dorothy Price for Gary Price 40th birthday fundraiser.

We received £10.47 from charity cards.

In March 2021 we received donations from Eileen Kelly-Moynihan for her birthday fundraiser, just over £281.27

Money received from Paypal giving was £499.52

Money raised through Virgin money giving £554.92

Hugh and Ailsa Tamlyn also donated £100 to the group

Other donations were from group members

P Connelly-Smith also donated an additional £90

Arti Patel also donated an additional £100

The accounts have been audited by Sarah Bunce and the reports sent to Sue and Shelley.

If anyone has any fundraising ideas, then please let one of the committee members know.

Updated report from April 2021 – September 2021

Financial year 2021 - 2022		
	Starting 1 st April 2021	Ending 29 th September 2021
Current account	£4,626.18	£4,097.61
Savings account	£15,733.00	£15,740.86
Total funds	£20,359.18	£19,838.61

The committee agreed to purchase another year subscription for 'Zoom' in order to hold online events and for our meetings.

Sadly, in May, we heard of the passing of Stuart Dolton's father, Stuart Roy Thomas Dolton, aged 89. Stuart's wish was that any donations were to be given to the group in his memory. The group are very thankful for the support during a difficult time and our condolences were sent to the family. The total funds raised was £497.58

We also received an email from Lorraine Elliot who saw the film 'Wonder'. She kindly donated £50 to the group after seeing the film. She also suggested that we contact the TV companies, so that when the film is shown, we could have an advert detailing our group after the film. I will look into this.

Neil has also run a huge marathon in October and we are still waiting for funds to come in from this challenge. Well done Neil!

The 'Virgin Money Giving' platform is also closing at the end of November, so I will look into another online donation platform for the group.

Shelley also confirmed that the card and order of service from Stuart Dolton Snr's funeral that accompanied the donation were displayed for viewing should anyone wish to see them.

Membership Report

We finished the year receiving a total of £576 in membership donations by a total of 21 families.

Within this year, 7 families altogether have been taken off our list. We had 2 families request to leave and also and 5 families due to the 3yr rule.

At the end of the year we had a total of 35 families on the list.

2021-2022

(Current Year)

The renewals were sent out a couple of months late, but so far we have received a total of £321 in membership donations by 19 families overall. Renewals reminders will be sent out shortly.

As it stands we will be looking at losing 1 family due to the 3yr rule.

Election of Committee

Lorraine Ryan has decided to step down from the committee, this is effective from July 2021. Sue Moore stepped down from the committee and her position as chair. Neil Dixon was elected Chair and this was proposed by Sandra Ellis and seconded by Simon Moore. Arti Patel had contacted us confirming that she wished to rejoin the committee. This was proposed by Mark Ellis and seconded by Alan Hird. Neil confirmed the members of the committee and confirmed that he is happy to continue to manage the memberships.

Alan Hird expressed that when the charity began, it was a very different environment and that we now have a younger committee to continue to make more use of the internet and social platforms.

Other Business

Neil confirmed that we had been contacted by a primary school asking us to partake in a Q&A session with classes as they were reading the book "Wonder". Neil did this and found this to be a good experience. He confirmed that one of the questions he was asked was what the best thing about having TC was and they also enquired about the charity.

Sue was presented with gifts to thank her for her hard work and dedication. Neil and Emma expressed that words were not enough to thank her and that the charity had been a comfort for Emma knowing that she was not alone.