



4th Chromosome 18 Europe Family Conference Rome Marriott Park August 5-7, 2016



Photograph by Catherine Underhill

Families travelled from all over Europe, Australia and United States to come together for a weekend full of learning and laughter (and the odd tear) for our conference. For some, it was the first time they had ever met another family who knows the challenges their affected child or adult faces. For some parents, they were able to get a glimpse of what the future may hold for them and their small child, and it wasn't as scary as they thought it might be. Doctors from Poland, Italy and the US met and made connections, and therapists were able to show ways of helping communication for some of our most profoundly affected children and adults.

It was awesome.

The staff of the Rome Marriott Park Hotel did all they could to help make the conference run smoothly. Sarah Russotti and the staff did a wonderful job in the run up to the conference, with the conference room alongside the creche room, and just along from that, we ate our meals together in a huge room. As always, there are things we can and will do better next time: thank you to all who gave us the all-important feedback forms.

Presentations at the conference:

Drs Cody and Hale

<http://www.chromosome18.org/research-resources/>

Go to the website to see more presentations from the conference at

<http://www.chromosome18eur.org/conference/saturday/>

Check out the Gallery of photographs taken by Catherine Underhill which Steve has put on the website
<http://www.chromosome18eur.org/conference/gallery/>

One of the joys of our Chromosome 18 Europe conferences is meeting families with young children who make the often difficult journey to get to their first conference. When the Sarosi family arrived in Milan in 2012, their lovely daughter was a baby, and the email Dora sent me afterwards set me on a mission to find a self advocate affected by Tetrasomy 18p. We rely on our self advocates (and everyone else) to fund their own way to the conference, and so our panel is made up of those people who can make the journey. My prayers were answered when the marvelous Meloni Brothers travelled from Sardinia to join us in Manchester, and I was thrilled that their parents made it to Rome, too. I so wish I had a video of the moment Michelle Moon from California met David Meloni in the foyer of the Marriott Rome Park...it was wonderful. Dora and Peter made it from Hungary to join us, and I'm glad these two fantastic self advocates affected by Tetrasomy 18p were there for them to meet.

Sarah Hunt from Canada ran our first Siblings programme in Manchester, and was happy to come to Rome 3 days early to train Mattia Meloni from Italy and Jonathan Rugman from the UK to run our full programme for sibs. Phillip Moore was an integral part of the team of adult sibs who were there to facilitate activities for siblings aged from 8 up. **The Sibs4Sibs panel** which resulted from the collaboration of these amazing youngsters on Sunday was one of many conference highlights for me. As a parent I have no idea what went on: I just know that it worked.

What's your highlight? Please let me know!



Chris and Doris travelled with their two little children from Austria to join us in Rome. When I asked Doris if I could have a short piece about their experience of their first Chromosome 18 Europe conference, I was delighted with what I got back...

Veni, vidi, vici by Juli(us)a SPECKMOSER

I came; I saw; I was conquered by the feeling that my one year old brother Manuel, my beloved mom and dad do not know who I am. I am Julia, 3 years old from Austria. I have distal 18q- as a mosaic. Nature tried to create a new and better human being by using the method of "Try and Error". Try; I miss about 91 genes on chromosome 18 on the longer "q" arm including the TCF4 gene, which says; I live with the Pitt Hopkins Syndrome. Error; I am now 38 month of age and cannot walk or speak, I find it hard to communicate with my family and sometimes when I like to say it is enough, I bite.

And then came Rome, the entire city with all her history and the will to create a new and better world. Here we took part at the "Chromosome 18 Europe conference", which was brilliant organised (including my potty on the room) and was very useful to my family. Manuel and I spend good times at the crèche, while mom and dad were listening to the lectures of the conference. All four of us had lots of fun staying at the pool, swimming and meeting all the other families. I guess, the most powerful moment to mom and dad was the part, when the young adults told about their lives and their experiences. That was the kick; mom and dad needed to understand who I am and who I will be. We also visited places in Rome where lots of sweating people, took lots of pictures of really old stones and buildings. I speak in the name of mom, dad and Manuel, when I say; THANK YOU SO MUCH FOR ALL YOU GAVE TO US. The team of Chromosome 18 Europe made it happen. And thanks to the research team in San Antonio, Texas - you made it happen that our blood is part of your research.

See you all in Birmingham!***

*****The Management Committee are already investigating venues for the next big Chromosome 18 Europe Conference in 2018. It will come back to the UK. Top of the list of must haves is a POOL! Watch this space...**

Several families have asked for a contact list of the people who attended the conference in Rome. This is standard practice following many conferences, and I have the information necessary to put such a list together for distribution to the people who were able to make it. If you would rather NOT share your email address with other families who went to Rome, please get in touch with me by November 5, 2016.

Emily and Matt Sutton's family is part of the very active group of Tetrasomy 18p families in the UK. She and Matt hosted a get together for Tetra 18p families in 2015, and they are planning to do it again with help from their circle of friends and families

Tetra-get-together 2017 2 June 2017-4 June 2017 · Maureen's!

Read more on Emily's lovely blog

<https://tetraspecial.com/2015/08/05/we-are-family/>

Watch this space for more information, and let me know if you would like to get together with families living close to you. Let us know if you and other families in the region would like to get together: doesn't have to be syndrome specific, nor does it need speakers. A picnic in a park, or lunch in a club...

Chromosome 18 Europe would like to help!

Save the date!!!!

**Birmingham Childrens' Hospital Rare Disease Unit
Family Fun Day for families affected by Chromosome 18 disorders
April 1, 2017**

Following a very happy meeting with Drs Cody and Hale and the Rare Disease Team after the conference in Rome, Dr Larissa Kerecuk and her team are working to set up a family day for Chromosome 18 families. We settled on a Saturday, April 1, and decided that that would be a happy time for our first event together. I learned that families anywhere in the UK can request an appointment at the unit. For more information about BCH Rare Disease Unit, go to <http://www.bch.nhs.uk/clinical/rare-diseases>

Dr Cody may be back in the UK at the end of February, and if all goes well, we'll set up a family day. Watch this space!



Important message from Jeni Morrison, Membership Secretary

We currently have 156 active members from all over Europe. These are members who have an active membership with Chromosome 18 Europe and therefore Chromosome 18 Registry. In the last 12 months we have lost 22 members due to no response to renewal requests. Active membership gains you access to the Chromosome 18 worldwide registry, including the syndrome only Facebook pages, Chromosome 18 Europe Facebook pages and the Care Givers Notice Board which allows you to read and ask questions regarding any syndrome related issue to not only families within your own country, but families worldwide. You will also receive regular newsletters from not just the Chromosome 18 Europe community but also from the Chromosome 18 Registry in San Antonio. For this to happen, we need to sync the information required for the worldwide Chromosome 18 Registry and Research Society.

How it works:

I send out reminders 1 month prior to annual membership renewal date. Prompt response ensures that you remain active for another 12 months from the anniversary of your membership. When you respond directly to the email sent from ch18eurmembership@gmail.com, make sure that you include Names and Dates of Birth of all family members who want to be registered and have access to the above services. Each family member can get our emails to their own address eg. Siblings, self advocates as well as parents. I need to have their email address for that to happen! If I don't receive a response to that email, I then send up to 3 reminder emails and 1 postal reminder. This costs Chromosome 18 Europe extra money! If you choose not to renew or I don't receive a reply, then your membership will cease on the exact date of your membership anniversary and you will lose access to all of the above services of support and information. And we really, really don't want that!!!

CHARITY REGULAR GIVING DIRECT DEBIT AND GIFT AID FORM

Carol Russell, our treasurer, has put together a form for those people who have asked how to make a regular monthly donation to Chromosome 18 Registry and Research Society (Europe). You'll find the form on the website at

http://www.chromosome18eur.org/newsite/wp-content/uploads/ch18eur_gift_aid_form.pdf

One dad told me that his monthly donation cost less than the price of a Starbucks every week.

Fundraising ideas for EVERYBODY! With the festive season now on our minds, you can earn pence and pounds when you shop from your favourite suppliers through

Give as you Live:

Raise funds when you shop online by registering to support Chromosome 18 Europe

<https://www.giveasyoulive.com/howitworks>

When I order from Amazon, Tesco, John Lewis and Domino Pizza (and many, many more companies), pennies rack up for our charity!

Easyfundraising.org.uk

<http://www.easyfundraising.org.uk/causes/chromosome18eur/?t=Easyfundraising-li&u=VWWZ7P>

Chromosome 18 Europe has 12 supporters registered with this website, too! Purely by clicking through with this portal, the charity has gained £118.76.

Calling all fundraisers: we are setting up a Working Group with the aim of supporting fundraisers with whatever they may need. Left to me, I'm sad to say that I haven't always been able to get information out at the right time, and don't always know when events have been held or how much money has been raised. I've made a lovely 'thank you' certificate to send out to any and all fundraisers, and I'd love to send yours to you asap. Jeni Morrison, our very efficient membership secretary, is helping to create a spreadsheet which will help us follow your progress. What can we do to help you? Can you give us your ideas and suggestions so that we can share them with everyone else in the group?

**And then there are the Chromosome 18 fundraisers who are already out there!
Looking forward to reading more about any events and exploits you have planned...**

Eve Rushmer, one of our amazing Self Advocates, celebrated her birthday by doing a Skydive in aid of Chromosome 18 Europe! She wrote :

Hi Bonnie,

I was so nervous at first to jump out off a plane but it was the best thing I have done in my life!! I raised over £870 pounds in the end and I would like to thank everyone who donated and supported me throughout the skydive!!

Thank you xx



Jen O'Neill, Nathaniel's aunt, climbed Everest to raise funds for research into Tetrasomy 18p!

Published on Aug 4, 2016

In April of 2016 Jen O'Neill climbed to Everest Base Camp to raise money for her 2 year old disabled nephew Nathaniel. He has a rare genetic condition called tetrasomy 18p. Nathaniel cannot walk, speak, or eat solid food because his muscles have not developed normally. He also requires 24/7 care. Much of his condition is still undiscovered and requires further research.

To see Jen's journey, go to

<https://www.youtube.com/watch?v=w9rZtmcp8RY&feature=youtu.be>

It never ceases to amaze me to learn of the lengths families and friends will go to in their fundraising challenges to support Chromosome 18 – Thank you, Jen x

Claire Grieves wrote to me in April:

Hi Bonnie

I hope you are well, I haven't been in touch for a while but hopefully you received the last lot of fundraising money I sent through late last year after the marathon? I just wanted to check if you have been offered any charity places for any forthcoming events as I am yet to book myself into any events this year and thought I would check if you have been offered any challenges I could take up?

Claire has raised £766 for us over the past year – how fantastic is that???



Bournemouth Bay Half Marathon, April 2016

On Sunday 3rd April, three daddies and one honorary uncle took part in the Bournemouth Bay Half Marathon. We made a weekend of it with families coming from Bristol and London, plus some extended family members joining in the fun.

There was a mixture of nerves and excitement leading up to the start but the four runners gave a sterling performance and clocked some great times. Especially considering that three of the four were doubtful contenders due to serious injury and health problems. We are so proud of them for overcoming their difficulties and struggling on with their training, and getting such a commendable result.

The atmosphere down at Bournemouth Pier was superb and the most exciting part was watching the joy on our kids' faces as their daddies ran past and through the finish line. There were some teary eyes – mostly the dads I might add!

Our personalised superman '18' logo T-shirts drew quite a bit of attention, and with the mums and kids also sporting their own pink and blue versions, we were a stand-out group!

The beer was flowing and the deep-heat was blazing after the event as the men were on an endorphin high with their success!

It really was a wonderful weekend of fun, families and togetherness. We are so pleased that we were able to have such a great time raising money for this worthy cause and the weekend was another reminder of how incredibly lucky we all are to be part of this marvellous 'tetra' family.

A huge thank you to all the families that came to stay; Emily and Matt are so grateful for how easy and stress-free you made the whole weekend and it was a pleasure to spend the weekend together. As always we really advocate for any families that want to explore the option of arranging a family get together; this is our second now on the South Coast and it was another mammoth success!

The total raised after gift aid was £1,426. Well done to Matt Sutton, Greg Ross-Sampson, Chris Vance and Andy Reeves and a massive THANK YOU to all donors!

We're looking for ways to support fundraisers – let us know how we can help you to help us

Hung Out to CRY!



Hung out to Cry!

Colleagues from Commercial Finance Systems take part in a truly scary fundraising challenge and help to raise over £3000 for Chromosome 18.

Last week, a group of colleagues (made up from Commercial Finance Systems, Client Coverage and MITIE) took on the Ve-locity challenge at Zip World in Bethesda. This is Europe's longest Zip Wire, and more notably... the World's Fastest!

If you would like to donate, please follow the link below

<http://www.virginmoneygiving.com/team/HungOutToCry>

Matt James of Commercial Finance Systems takes up the story.....

"We arrived early in Bethesda, and soaked up the glorious sunshine as we all gradually become more nervous about what lay ahead of us. The staff kindly waived the need for us to wear their standard-issue boiler suits, and fitted the heavy duty wearable harnesses over our summer clothes.

By 11 am we were more than ready to go (or get it out the way at least!). The day involved two separate zip wires. The first is classed as the Little Zipper but it definitely didn't look that way from the top! It's still the 5th big-gest in Europe too. We went in pairs, each of us being attached to parallel lines, effectively setting up a mini-race where we had little control over speed other than the effect of gravity, and stretching your arms out towards the end to increase air resistance. With a mix of hilarity, denial and some very choice language, we all made it safely to the bottom. Everyone loved the experience and we were keen to get on with the real deal.

The journey up the mountain was interesting. An open-sided bus with cast iron seats. Not a very comfy proposition with the track up is consistently rocky and takes over 15 mins. Queue more profanities and hilarity and we were bounced around all over the place.

The views from the top were stunning and were worth the drive up alone. We managed to pose for a team photo (attached) and then got on with what we came to do.

This wire looked ridiculously long. We were told that you can reach speeds of up to 119mph. It was again a case of pairing u and with a mix of anguish, excitement and more profanities we all got on with it. I can't explain the feeling but I expect it's as close to the feeling of actually flying solo that I'll ever have. At the bottom we were all overwhelmed with the delight of having done it."

The colleagues who took part were:

Commercial Finance Systems: Matt James, Aidan Burrows, Michael Jackson, Cath Yates, Tracey Merry-weather, Erin Humphreys, Georgie Stoker, Paul McCann, Steve Bolton, Mike Ruthven; **Client Coverage:** Mer-rall Shoreman, **MITIE:** Bryonie Lyons, **Lloyds Retail Banking:** Amina Islam

It would be great if you could join us in the Fundraising Working group, or in any of the other working groups Apostolis has suggested to help us to help more families get the support they need.

Proposed Working Groups:

1. Security and Conference Law
2. Technology, Website and Computer Applications
3. Media and representation of the Society
4. Conferences
5. Fundraising
6. Siblings groups
7. National/ Shared Language Groups
8. International Organizations eg Eurordis and Rare Connect
9. Contacts and Travels
10. Newsletters
11. Submission of any kind of proposal that can be financially supported from a bigger organization
12. Christmas and planning of social activities

Several of the working groups are already beaver away, but it would be great to have input and help from anyone and everyone who has a little time to help.

Family Fund is a UK grant giving charity for families raising disabled or seriously ill children. Family Fund provides a huge and diverse range of grants to families, accommodating their different circumstances. Last year they helped 72,043 families with over £33 million awarded in grants and services.

To request an application pack or find out more about Family Fund, their grants and the impact this support has on other families, please go to <https://www.familyfund.org.uk/> or call 01904 621115.

You can apply for a grant from Family Fund every 12 months, families are encouraged to reapply. The application form is easy to read and has instructions throughout explaining how to fill it in.

Eve Seall posted on Facebook:

We recently applied for funding for a specialist trike for Ellie from a charitable trust who give grants for equipment disabled children. We found out yesterday we were successful so I thought I'd share the details with you all in case you want to apply for funding for anything. It was an easy form to fill in and then made the decision in about 10 days which is much quicker than a lot of the more well known charities. The grants aren't means tested, which a lot are, but you do need to declare your income and outgoings but they don't necessarily use that to make their decision. We had assessments from three trike companies for Ellie to make sure we got the right one. The quotes varied from £1400 to £2600, which explains why we applied for the funding! We went with the cheapest and got it funded in full. Anyway here is the link to the website. Hope that's of help to some of you.

Boparan

Website for the Boparan Charitable Trust
WWW.THEBOPARANCHARITABLETRUST.COM

We'd really LOVE to help families in UK and Europe get together close to home...please get in touch if you have any ideas for events and venues. Jeni and I are ready to get something in the north going: get back to us if you'd like to take part, and where!

Phew! This has been a marathon of a newsletter to prepare and get out to you all!
Thanks to Jeni for sending it out

Bonnie McKerracher, Secretary

Please contact me at bonnie18qmum@btinternet.com if you have any contributions, questions or comments.