WINTER 2019
Quarterly Newsletter

SWAN UK
syndromes without a name

LOTTERY FUNDED

SWAN UK UPDATE

Happy New Year and welcome to our SWAN UK (syndromes without a name) quarterly newsletter!

Undiagnosed Children's Day is only three months away and we'd love you to be involved in the celebrations, so whether you're interested in fundraising for SWAN UK, sharing our social media messages, talking to your local press, getting your child's school involved or doing a talk, let us know. Turn to page nine to find out more.

Last year in numbers

- We welcomed nearly 300 new SWAN UK members
- Sent 170 balloons
- Held 79 events, which included nine Information Events, coffee meet ups, stay and play sessions, family days out and workshops
- Had around 250 members attending our information events
- Had 520 children at a SWAN UK event and 735 adults
- Welcomed our new Fundraising Officer, Amy (read more from Amy on page 10)

Parent Reps

We now have 20 Parent Reps across the UK. The areas they cover are: Newcastle, Scotland, Southampton, Bournemouth, North Wales, South Wales, West Yorkshire, North East, Shropshire, North West, Sussex, Essex, Bedford, Bristol, South Yorkshire, North Yorkshire, Northamptonshire, Nottingham, Portsmouth, Liverpool and a Parent Rep for dads.

Parent Reps get together in Birmingham

SWAN UK Parent Reps are members of SWAN UK who volunteer a few hours each week to act as a local point of contact. They help raise awareness of the support SWAN UK can offer by making links with local services and professionals and help bring parents together. They also act as an important link between the local community and the national SWAN UK community and can help to signpost families to what is available in their area. To find out more about the Parent Reps covering these areas visit our team page on our website: undiagnosed.org.uk/our-team.

Rowan judges Bake Off

Our friends at GoodStuff invited us back to their annual Great Bristish Bake Off extravaganza. After making a fantastic honorary judge last year, Rowan rose to the occasion to help put the baking finalists through their paces. He was joined by previous Great British Bake Off runner-up Steven Carter-Bailey. As well as being treated to some delicious cakes, a proportion of money raised from their raffle will also be donated to SWAN UK.

Rowan with Steven and the GoodStuff finalists

Do you write or have a blog?

We're always looking for new bloggers to share their pieces with us so if you write about your experiences of raising a child with an undiagnosed genetic condition and you'd like to have a profile on our website and are happy for us to share your writing, get in touch.

Twitter Takeovers

Every Wednesday evening we have Twitter Takeovers from SWAN UK members who share their experiences and also help get the word out about SWAN UK. You don't need to be an expert on Twitter to get involved. Let us know if you're interested and we can support you. Email: miriam.ingram@undiagnosed.org.uk.

To get in touch about anything else in this newsletter email: info@undiagnosed.org.uk.

STAY AND PLAY IN WARRINGTON

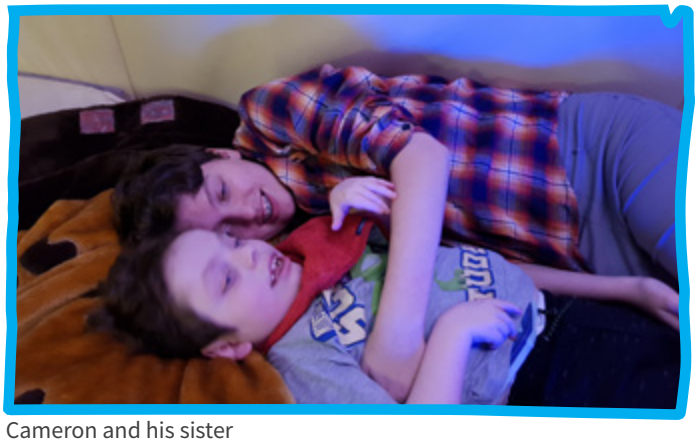
Hi, my name is Sarah and I live in Warrington with my partner Alan, and our four children. There's my eldest Jess, who is 16, my second eldest Hannah, who is 13, my youngest Catherine, who is three, and my third eldest child Cameron, who is 10, and my only swan.

Cameron was 15 days old when we discovered he had a missing corpus callosum. This connects the two hemispheres of the brain, and communicates to the rest of the body to tell it what to do. We knew his future was uncertain, but only time would tell how much this would affect him. As he grew older, it became apparent that his disabilities were quite severe, and there were many more problems within his brain that were affecting his learning and motor functions. We discovered that his missing corpus, also known as agenesis of the corpus callosum, wasn't in fact a diagnosis, but merely one of a few brain abnormalities that he had been born with. We were still none the wiser as to what had caused his genetic condition, and still don't have a diagnosis.

We've adapted in our own way to Cameron's differences, but each day throws many challenges our way, and living without a diagnosis can take its toll, especially as his future is still unknown.

Despite his many difficulties, Cameron is a happy boy, who smiles a lot and charms everyone he meets. He enjoys the company of others and loves to experience new surroundings. He loves music, and particularly likes looking at sensory lights. As a family we have attended many SWAN UK meet ups in Warrington, organised by myself, and the North West Parent Rep, and lovely staff at SWAN UK. We meet once a month at the Warrington Play and Sensory Centre along with other SWAN UK members and their families. The centre was set up a few years ago to help disabled children and adults, as well as their families, by giving them somewhere to go and enjoy refreshments, chat with other families in similar situations, play in their purpose built soft play area, experience the light and sound room, and attend regular events put on by the centre themselves.

The venue was a perfect choice when looking for a place for SWAN UK members in the North West to meet up and get to know each other. It has become the highlight of our month, and something our whole family look forward to. There aren't many things we can enjoy as a family that can easily include Cameron. Often, it's difficult to leave the house, as we don't always know what will be available when we arrive at a venue, but we never have to worry when this event comes around. The meet up offers us a perfect opportunity to talk to other parents, and our children have other swan siblings they can spend time with, without anyone feeling judged, or having to explain ourselves to others who may not understand what we go through.



Cameron and his sister

We can relax knowing there is somewhere to change Cameron with dignity and privacy, we can give medication and administer pump feeds without stares or questions, because everyone is in the same boat. We can be sure that everyone's needs are met, that no one feels left out, and we don't have to worry about any of the problems mentioned above. Cameron loves the meet ups, he enjoys the sensory room; the atmosphere is calm, and because everyone there is dealing with similar life experiences, we all feel at ease, like we're part of a community, instead of being stared at, or feeling like we're in the way. Without these events I feel we would become isolated, hardly ever leave the house, and not have anything to look forward to.

As a SWAN UK member I'm part of a wonderful community of supportive people. It's great to have so many people to turn to when you need advice, and to not feel so alone any more. The online forum is great for chatting to like-minded people and sharing your stories, and the little achievements that mean so much to us. The meet ups though are invaluable, to be able to chat to the members in person, to feel included and be able to go somewhere without all the usual worries that our families have to face, makes a world of difference.

Stay up-to-date with our family events by reading our monthly E-News and following us on social media.

INTRODUCING LEXI

My name is Lexi and I am 16. I live with my sister Lilith who is 19, my mam and my step-dad. I also live with my dogs: Kim who is 15, and Daisy who is seven. The rest of my family includes my dad and step-mum, grandparents, and lots of others.

My dogs are really important to me. I started college recently and I am studying how to look after animals. I also like Lego and steam trains. I think I have been a member of SWAN UK since I was eight years old, so half of my life.

SWAN UK is important to me because I get to meet people who are like me.

I don't remember when I found out I had an undiagnosed genetic condition, because I was too little to understand. When I was little I knew there was an extra bit in my blood that makes things tricky. My mum says when I was little I needed a lot of tests because I found things difficult. One of the tests showed I had an extra chromosome. My mum said it was years before the testing showed it was part of chromosome four, but not linked to any known condition, so I am still a swan.

At first I was really confused about being undiagnosed, but now I am happy with who I am. Even though it makes things hard for me, I am proud of being unique.

My mum says because we live in the north east I got really good genetic testing at the Centre for Life. I didn't like going there because I always wanted to go to the fun exhibitions not the boring NHS bit.

Lexi and his dogs, Kim and Daisy

Being undiagnosed means I need extra help at school; I get very tired, there are things I can't do, and that sometimes makes me upset and angry. When I'm upset I like to get hugs with my dogs and when I'm angry I like to break things. My mum keeps cracked plates for me to smash on bad days.

It's tough for my family because they need to help me deal with it. They put me first and it sometimes stops them doing what they want to do. But I always know that they have my back. My mum has spent a lot of time on meetings and appointments, and she worries about me a lot. All my family worry about me because life can be hard for disabled people. I find it hardest when people point out that I'm different, especially because some people are jerks about me being different. I am glad the police take hate crime seriously, and that I have friends who always look out for me. There are people in the world who think disabled people don't belong. But there are more caring people than mean people. The best thing is knowing that I have so many people who always have my back.

One thing that I would change would be either that all undiagnosed people were famous and got the support we need, or that I could have more dogs! A diagnosis would mean it would be easier for me to get the support I need to deal with my disabilities a bit better. I feel good about my future. College is going well and my dream is to work with dogs.

Before SWAN UK I didn't know anyone else who was undiagnosed. Now I know lots of people like me. We are all different, but all equal and special. My friends at SWAN UK have been my light in dark hours, like sending me balloons when something bad happens and playing with me in the ball pool on trips (you're never too old for a ball pool). With SWAN UK I've been on many trips, and met loads of new friends.

SWAN UK means that I get to share my world with other people like me, and our families. It makes me feel proud of being unique instead of sad at being different, and I would not be as confident as I am now if it wasn't for SWAN UK.

If you would like to share your story and help raise awareness of undiagnosed genetic conditions email: info@undiagnosed.org.uk.

INTRODUCING TINA

Hi, my name is Tina and I am the SWAN UK Parent Rep for Shropshire. I live in Telford with my son Oliver, who is six years old and my menagerie of pets.

Oliver was born in Coventry by emergency caesarean at 33 weeks as I had developed HELLP syndrome (a life-threatening pregnancy complication usually considered to be a variant of pre-eclampsia). Oliver spent seven months moving from hospital to hospital because he kept turning blue and over the months he had too many tests to remember, many intensive care stays, consultants for every part of his body, constant oxygen and had to be fed through a tube. At one point it was discovered that he had four fractured ribs and rickets.

Oliver was diagnosed with a multitude of issues including vocal chords palsy meaning he can't have liquids or lumpy food and only has pureed food and is PEG fed. He has global developmental delay, bilateral squint, chronic lung disease, enlarged tongue, chromosome condition dysmorphic features, floppy larynx, restricted airway and constipation but no overall diagnosis. He left hospital on full oxygen, tube feeds every two hours and 16 lots of medication per day.

Tina and Oliver

Over the years we have had almost daily consultant or medical visits, a gastrostomy (PEG) allowing Oliver to be fed more easily, oxygen reduced to being given at night and during illnesses, a reduction in medication. It has been discovered that Oliver also has autism; he is non-verbal and has sensory processing disorder but still no overall diagnosis has been found. The 100,000 Genomes Project didn't find a syndrome after four years.

He is still complex and has life limiting conditions but Oliver has always been the happiest child. He is so brave and strong and inspires me every day despite having an uncertain future.

Oliver

After finding out about SWAN UK at an exhibition I attended, I realised that Oliver had a syndrome without a name and joined up. In the years since this I have found that being a member of SWAN UK is like being part of a huge and much needed support system and I don't feel alone. It feels like Oliver fits somewhere instead of fitting everywhere and nowhere because of his many conditions. I regularly attended trips organised by Parent Reps but nothing was local to me in Telford and I realised that there was a need for a Parent Rep within Shropshire so I took on the role.

I am highly involved with various charities and groups relating to disabled children and have attended the Hidden Disabilities and Illnesses Exhibition in Telford. I hope to try to ensure that parents know that just because their child doesn't have a diagnosis it doesn't mean that they are alone. I hope to promote SWAN UK throughout Shropshire and to provide coffee meetings, stay and plays, trips and a support network. Joining SWAN UK has helped me feel less isolated and I've made lots of new friends and want to let other parents know that they aren't alone in this lonely and uncertain time.

If you'd like to get in touch with Tina email: shropshire@undiagnosed.org.uk or find her on or find her on Facebook: bit.ly/parentreptinalowe.

DADS' UPDATE

Hi dads and people who have to put up with them! I thought I'd do a quick roundup of what happened this year and what's coming up.

So, what have we done this year as a dad's group in the SWAN UK community? Well we've broken the 100 dads mark, which I thought was a good start – that's what one percentage-ish of the dads out there?

I still think there are loads of barriers to joining and I'm not totally sure what they are (do we look like we bite? or might sit in circles singing 'Kum-Ba-Ya'? #hint none of these things happen). I dunno, if you do, or you've got any ideas, then please let me know. Better than the number of dads is how awesome they've been at chatting and being there when things have been grim. This year for the first time we had a dad's summit. A group of us met up in Birmingham and did some talking about what dads might need and talked and talked into the night. Out of that came a survey of as many swan dads as we could find so we could find out confidentially what was going on for dads. You can read a summary of the dads survey results on pages six and seven of our last quarterly newsletter: bit.ly/swanukautumnnewsletter18.

What's next then?
– The second dads' summit will be 16-17 March. Ping me on the email below for more details.
– We're also planning a dads' fundraiser amd will bring you details in the New Year, but it'll hopefully try and include some more dads around the country that we can get out to.
– We want to reach out to more swan dads next year. If you know one, get them to ping me or someone at SWAN UK and if they're on Facebook we'll get them in the dads' Facebook group (if you're not on Facebook you can still be involved). We can't wave a magic wand but we can let everyone know they're not in this alone.

To get in touch email: dads@undiagnosed.org.uk.

NEWS FROM SCOTLAND

Hi, I'm Dr Wendy Inglis-Humphrey, Project Manager of the Scottish Genomes Partnership and I'm going to give you an update on genetics in Scotland.

The Scottish Government's recent announcement of extra funding for genetics and genomics is welcome news for families in Scotland hoping that information about gene changes might provide them with much-needed new information about the cause of their undiagnosed condition. On 10 September, the First Minister announced that as part of the 2018-19 Programme for Government, £4.2m would be invested in Scotland over the next two years to continue to develop our understanding of the role of genes and genetic variation in causing disease, with the aim of offering the possibility of more rapid and complete diagnoses. She also highlighted the hope that information learned about the genetic causes of disease through such work would lead to better treatments in the future.

This exciting announcement builds on recent UK-wide research studies like Deciphering Developmental Disorders (DDD) and the 100,000 Genomes Project.

Research like this is giving scientists new information on the role of specific genes in development and maintenance of our body systems, as well as the DNA sequences on our genome that control these genes. The DDD study has identified more than 30 new genes for developmental disorders and studied more than 13,000 families with these conditions. Research will continue on the data until 2021. Diagnoses are also being made through the 100,000 Genomes Project. Some patients with a rare condition may get a genetic diagnosis for the first time. Others may not, but scientists expect to keep getting new information through deep analysis across the whole dataset over the next few years.

In Scotland, the Scottish Genomes Partnership (SGP) was established with a core aim of providing evidence to inform the future delivery of NHS Scotland genetics services and to ensure that the learning from genome-based science can be applied within NHS clinical services in Scotland. It is through SGP that Scotland has been participating in the 100,000 Genomes Project; recruitment is now complete with 395 families taking part. Early in 2018, knowing that this study was coming to an end, the National Services Division of NHS Scotland working with the Scottish Genetics Laboratories Consortium (SGLC) submitted a proposal

to Scottish Government for new investment to make sure NHS Scotland could continue to offer state-of-the-art genomic tests in the genetics clinic where there was clinical need.

The funding awarded will make sure the NHS can continue to develop Scotland's genomic medicine service: a mixed portfolio of the most appropriate genetic and genomic tests will be made available to patients in Scotland over the next two years using the latest genomic technologies.

While some of these tests will be offered as part of core NHS Scotland genetic services, whole genome testing will continue as a research programme for now, to build firm evidence for when this test can be most effective within NHS services. The new funding will also ensure Scotland has a central facility for storing genomic data, which will allow more efficient sharing and analysis for clinical diagnoses and valuable future research.

To find out more about the Scottish Genomes Partnership visit: scottishgenomespartnership.org.

NEWS FROM WALES

Hi, I'm Emma, Genetic Alliance UK's Policy and Engagement Manager for Wales and I'm going to update you on what we've been up to recently and what we have coming up.

SiGNAL project

In October, the Welsh Rare Disease Patient Network came together for its annual meeting. The event included a number of presentations from patients, carers, health professionals and researchers from across the field of rare diseases. Dr Ian Tully, Clinical Geneticist from the All Wales Medical Genetics Service spoke about the SiGNAL project which had been recruiting SWAN families in Wales to sequence their exome in order to try and find a diagnosis. Approximately a third of patients recruited to the project received a diagnosis.
Some of these patients and families attended the meeting and were able to hear feedback from Dr Tully about how the project went as well as having the opportunity to meet other patients affected by rare conditions and support groups who were exhibiting at the meeting. The feedback from those in attendance has been extremely positive.

Opportunities for you in 2019

In 2019, we are planning to organise a number of workshops across Wales to engage with patients and families affected by rare and undiagnosed genetic conditions.

The purpose of the workshops will be to develop a Welsh specific toolkit as part of the Rare Resources project of information resources for families in Wales who have received a diagnosis of a rare, genetic condition or who have an undiagnosed condition. The toolkit is a flexible resource with information and signposting to support services.

We will be sending out further information about the workshops in the New Year but we would welcome input from SWAN families who would like to get involved with the project.

The 100,000 Genomes Project

The 100,000 Genomes Project in Wales completed recruitment of patients in September. As part of the Welsh Genomics for Precision Medicine Strategy, there has been a lot of work going on throughout the Local Health Boards in Wales to engage healthcare professionals about genomics and how it is going to be moving from within the genetics service to other mainstream specialities within the NHS. There is a lot of work happening to upskill the health professional workforce with the end goal being to improve patients' experience when coming into the service. An organisation called Genomics Partnership Wales has been set up to bring together all the organisations working to support the delivery of genomics services and education across the region. We are working with them to develop a Patient and Public Involvement panel.

This is another opportunity where we would welcome contributions from the SWAN UK community – your experiences will be key to identifying the current problems within the service and helping develop ways to improve them.

If you are interested in joining the Welsh Rare Disease Patient Network or would like to register an interest in being part of the upcoming workshops or part of the Patient and Public Involvement panel, please get in touch with Emma: emma.hughes@geneticalliance.org.uk.

EUROPEAN REFERENCE NETWORKS SAVE LIVES

Hi, I'm Farhana, Public Affairs Manager for Genetic Alliance UK.

Did you know that Genetic Alliance UK, the charity that runs SWAN UK, is running a campaign to ensure UK hospitals can continue to be part of networks across Europe working to treat those affected by rare and complex conditions?

These connected hospitals are known as European Reference Networks (ERNs). ERNs were developed by the EU to work together to tackle rare and complex conditions.

Not only do they help provide diagnosis and treatment, they can facilitate large clinical studies to improve our understanding of rare conditions. They can help with the development of new medicines and medical devices, and provide training and knowledge exchange.

Each ERN is grouped to cover a range of conditions, for example, EpiCARE is the ERN that diagnoses, treats and cares for those affected by rare and complex epilepsies. This ERN brings together 28 expert hospitals in 13 European countries. It offers individuals and families the best care and expertise available.

Most people don't realise that their hospital is part of one, or more, ERN(s). In fact, many of the major children's hospitals in the UK are connected to ERNs.

Great Ormond Street Hospital is a founding member of the EpiCARE ERN, coordinating all the hospitals in the network – some as close as France, others as far as Finland. You can see how the EpiCARE ERN helped a four-year-old boy with a rare epilepsy condition here: youtu.be/_nxis0PIE3A.

Brexit

The UK is leaving the EU and this means that UK hospitals may no longer be able to take part in ERNs. Currently there are 24 ERNs and the UK is involved in 23. Until recently, the UK was leading six of these networks, however, in preparation for the UK's departure the EU asked these hospitals to step down from their roles by 14 November 2018. In the case of the EpiCARE ERN, Great Ormond Street Hospital is no longer the coordinating hospital.

This is a huge blow to the hospital and staff who worked so hard to make the EpiCARE ERN an outstanding network.

Protect ERNs

We're already seeing negative effects from the UK's withdrawal from the EU – and we haven't even left yet. That's why Genetic Alliance UK is running the Protect ERNs campaign – to make sure that families affected by rare and undiagnosed conditions are not disadvantaged.

Louise James, SWAN UK Parent Rep for Bristol, explains why ERNs are so important to her family and her son Scott who is affected by an undiagnosed condition: bit.ly/protecternsscot. Louise knows that sharing rare disease health data is crucial to improving our understanding of these conditions, and asks:

'What happens if we don't have access to this information? If these networks break down? What good is all this amazing research if it doesn't get shared?'

A breakdown in European Reference Networks would cost lives. Please show your support and add your name to the Protect ERNs campaign here: protect-erns.eu.

Every single name helps to make our voice stronger so that we can put pressure on the Government and EU to prioritise ERNs in their negotiations to agree our future relationship with the EU. Over 1,400 people have signed up. Please can you help us to get to 2,000?

If you have any questions or want to share your story about why collaboration is important, please email: farhana.ali@geneticalliance.org.uk. Find out more about ERNs in this short video: europa.eu/!Np48ym.

UNDIAGNOSED CHILDREN'S DAY #ROARSOME

Undiagnosed Children's Day is coming up on Friday 26 April 2019 and we'd love for you to get involved and celebrate the day with us!

Our Big Lottery funding comes to an end in October so your help is crucial in helping us to provide support to families affected by undiagnosed genetic conditions.

Bravery

This year our theme for Undiagnosed Children's Day is bravery. We want to hear about your child's achievements, however big or small. We would love to share your stories, videos, quotes and photos about what makes your child brave. We'd also like to hear from siblings and see your best lion photos.

Get involved online

Keep an eye on our social media pages and website about ways you can get involved leading up to Undiagnosed Children's Day and on the day. You'll be able to:

- Change your social media profile pictures
- Retweet our social media messages
- Use the hashtag #roarsome on Twitter
- Share your quotes and family stories with us
- Film and share your videos of your children doing their best roars
- Share your lion photos with us
- Get involved in our Undiagnosed Children's Day Twitter Takeover

Be brave

We are asking you to do something brave to raise money for SWAN UK. Whether that's learning a new skill, reaching a personal achievement, holding a tarantula, skydiving or climbing a mountain, get yourself out of your comfort zone and raise money for SWAN UK this Undiagnosed Children's Day!

Get your schools or community group involved

We're looking for primary schools that would like to get involved in supporting SWAN UK on the day such as by having a fancy dress day, bake sale or assembly. Please get in touch if you think your children's school might be interested.

Fundraising activities

There will be plenty of other fundraising activities running in April that you can get involved in. Due to the success of the Virtual Marathon last year we'll be rerunning this. It's a great way for the whole family to get involved. Read about the Davey family's experience of taking part last year: **bit.ly/marathoninamonth**.

We're also looking forward to helping you organise some fun-filled quizzes and a readathon to celebrate Undiagnosed Children's Day. Look out for our Just Giving Campaign Page for Undiagnosed Children's Day.

For fundraising enquiries email amy.conochie@geneticalliance.org.uk. For everything else email miriam.ingram@undiagnosed.org.uk.

FUNDRAISING IN 2019

Hi I'm Amy and I recently joined the SWAN UK team as the Fundraising Officer. I am excited to be working on new fundraising ideas for 2019, in particular for Undiagnosed Children's Day coming up on 26 April.

If you are thinking about fundraising or planning an event or a challenge then please get in touch, I'm here to support you and excited to hear your ideas. We are producing a shiny new fundraising pack with tips and advice on how to raise money for SWAN UK. If you'd like a copy please let me know.

Are you up for a challenge?

It's the New Year and we all know what that means, time to run off those mince pies! If you are the adventurous type then why not sign up for a challenge event in 2019 to raise money for SWAN UK. Half marathons, Tough Mudders, Wolf Runs, Inflatable Obstacle Races or Family Fun Runs are all great ways to get people to donate for your efforts and raise awareness about SWAN UK and what it means to have an undiagnosed genetic condition. Please get in touch if you are up to the challenge.

Amy, our new Fundraising Officer

Tips for easy fundraising

If running is not your thing then here are some easy online fundraising ideas:

- Amazon Smile – Amazon donates while you shop
- Set up a Facebook Donate button
- Order a collection box from us online and start a collection at work, in a local shop or community centre, or use it as a swear box at home!
- Or simply set up a regular monthly donation to SWAN UK by clicking here: **undiagnosed.org.uk/donate**

SISTERS CLIMB FOR SWAN UK

Natasha and I are sisters and we both work at SmartSearch on the Account Management team. Our main event was the Yorkshire Three Peaks but in the six month build up we had a variety of different fundraisers at our place of work, including a cake sale, silly hat competition, a putting challenge and Pie the Managing Director.

What inspired you to take on this challenge?

I am a determined person and about a year ago, I decided I wanted to challenge myself physically. I knew that the Three Peaks was something that would push me to my limit but was also meant to be an amazing experience. Once we had decided to do this, I opened the invite to my team and other colleagues (and their partners) within SmartSearch. The team came together and comprised of Collette Allen and Paul Smith, Bethan Hubbard and Alex Bond, Andriana Gunadi, Ben Wholley, Joe Henson and Charlie Catley, Natasha Viney, Lucy Banks, Georgia Dolan, Bryn Morgan-Hughes and Carl Chadwick.

Had you done anything like this before?

As a company, we have raised money in the past for mainstream charities, but I had never arranged anything as big and challenging as this.

Why did you choose to raise money for SWAN UK?

As I was organising this, I wanted to choose an organisation that not only I, but the people who would sponsor us could connect to. Natasha and I both knew Vanessa because she grew up on the same street as us and I was in Vanessa's year at school. Since then, through social media I saw her family grow and then the struggles that Eden Rose and her family had to face. It was this that made me look into SWAN UK and what they do.

After speaking to Vanessa and doing some research, I saw how much our fundraising would benefit SWAN UK and the families they help.

How much did you raise?

We decided that if were going to do such a big challenge, that we should try to raise as much money as we could, so we set our target at £2,500. To help us raise money, we arranged events at our place of work before the actual walk. We kicked off our fundraising activities on SWAN UK's Undiagnosed Children's Day with a bake sale. Colleagues from all areas of the business contributed baked goodies, as well as donating, and we raised an amazing £746!

The next activity we had was our silly hat day. Again, it was great to see so many people getting involved and we all had the privilege of meeting Eden Rose as she came to judge our hats.

It was so lovely to be able to meet Eden, she was such a sassy little lady who didn't let the fact she was struggling with various health issues get her down. It really motivated all the team doing the walk meeting Vanessa and Eden.

SmartSearch having a silly hat day

Our final fundraiser was Pie the Managing Director! Our Managing Director, Martin Cheek, was such a good sport and willingly allowed anyone within SmartSearch to throw custard and cream pies at him!

He really committed to the cause, encouraging everyone to throw at least one pie at him! Not only that, Martin generously decided to match the £500 we raised on the day!

Because of that and the other events, we not only hit our target before our walk but exceeded it by £650 meaning we raised a total of £3,150.

Pie the Managing Director

How much training was involved?

I enjoy outdoor activity especially walking but we knew that it would be a bit more than a stroll in the country. My partner Paul and I regularly walked with Natasha joining us when she could. We did two out the three peaks but left the last one until the day! Not only that, Natasha and I spent several hours at the gym with the treadmill at the maximum incline. On the day, the feeling was so good! As a team, we were so excited and had planned to try to stay together. That proved more difficult than we anticipated. For the first peak, we were all still together but after that, it was agreed that we should all go at our own pace.

What was the best moment?

For me, it was knowing that not only had I completed a great personal challenge, but that I had helped SWAN UK to be able to support families of children with undiagnosed conditions. As strange as it sounds there was nothing better than being cold, wet and tired knowing we had accomplished something great.

Collette climbing the three peaks

Would you recommend it to others?

Absolutely, I would recommend both the walk and the fundraising. The sense of achievement and joy at the end overrides the pain we felt throughout the challenge.

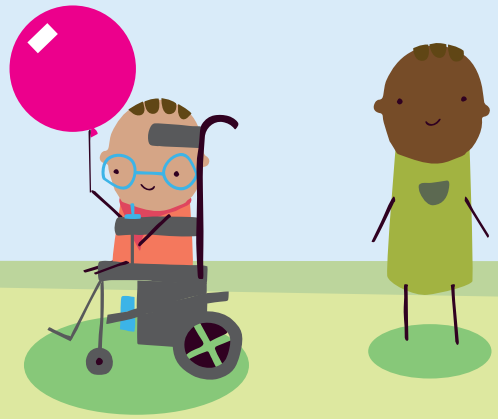
If you'd like to organise a work fundraiser email: amy.conochie@geneticalliance.org.uk.

SWAN UK (syndromes without a name) is a support network run by Genetic Alliance UK offering information and support to families of children and young adults with undiagnosed genetic conditions.

Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 200 patient organisations.

Rare Disease UK is a multi-stakeholder campaign run by Genetic Alliance UK, working with the rare disease community and the UK's health departments to effectively implement the UK Strategy for Rare Diseases.

Genetic Alliance UK
Registered charity numbers: 1114195 & SC039299
Registered company number: 05772999



+44 (0) 20 7831 0883
info@undiagnosed.org.uk
undiagnosed.org.uk

SWANchildrenUK
SWAN_UK
SWANchildrenUK
SWANchildrenUK

LOTTERY FUNDED