



SMS

SMITH-MAGENIS SYNDROME FOUNDATION UK

Connecting Families ★ Raising Awareness ★ Building Futures

Registered UK Charity 1072573 & CIO 1186647. Registered Scottish Charity SC044841

December 2020 Newsletter



Introducing Your Regional Representatives

Connecting Families – Regional Representatives

A network of regional representative to be there for families, who just 'get it' from lived experience of Smith-Magenis syndrome.

Staying connected and having a friend to turn to during these challenging times is something to be welcomed. Whether it is a phone call, video chat, meeting up for a coffee, or coming together at social event, we can never underestimate the support we get from just being with other local SMS families. We have set up our regional representatives' programme with 16 parents stepping forward to ensure we have someone in every region across the UK.

Scotland

North: Claire Woo
West: Hazel Wotherspoon
East: Lisa Gray

England

North West: Jo Martland
Yorkshire & NE: Richard & Dawn Arnold
Midlands: Emma Riddell
East: Lorraine & Darrin Harwood, Anand Kakad
London: Anna Middleton
South West: Jade May
South East: Mick Pearson

Wales

North: Clare Barker
South: Natalie Hughes

Northern Ireland

Andrea Docherty

Each regional representative has their own email. However, in the first instance please contact us at regionalreps@smith-magenis.co.uk

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Our Vision

Every person with Smith-Magenis Syndrome shall have a fulfilling life within a supportive and understanding community.

Our Mission

The Smith-Magenis Syndrome (SMS) Foundation UK shall be at the heart of our community of individuals, families, carers and professionals living and working with Smith-Magenis Syndrome and we will be the first point of contact for those seeking information and support. Nobody should ever feel isolated or alone. We value every person affected by this genetic disorder and shall empower them to reach their full potential as respected members of society.

Staff Matters

Its six months since our senior management team were appointed. Having spent 2019 working on our growth and development strategy, the appearance of COVID-19 dramatically changed expectations. However, how we had planned to work is exactly what has been needed. We are committed to an agile, fully flexible family friendly work from home culture. What does this really mean?

Agile working is interpreted in many ways. In the true sense this is about retaining the focus on our core aims of connecting families, raising awareness, and building futures. As long as we are moving towards our vision, then we are travelling in the right direction. We listen and observe to what our members need, and adapt our approach and services to deliver on these.

Fully flexible, family friendly. We have no fixed hours of work. Hours are flexible and completed over a rolling eight-week period at the times that suit for the team and the needs of the charity. So, if we are sitting with our child at 3am on a Sunday morning and decide to crack on with a project for the Foundation, then that is what we can do. If we have had a rough night with frequent awakening, then taking a 'duvet day' is perfectly acceptable. It also means that we are flexible to be available for members outside normal office hours. How else would we deliver Wine with Wine at Nine? Work-life balance is core to our culture which is why the team are all part-time. Nigel as CEO should be working the equivalent of 3 days a week (he does a lot more!), Leeann is two days a week, and Helen is three days a week. All are committed to seeing the Smith-Magenis Syndrome (SMS) Foundation UK succeed.

Work from home is now an accepted new normal as a response to COVID-19. For us, this was our planned intention from day one. Whilst other charities and organisations are coming to terms with what this means, we were set up with home office and remote working equipment from the start. We have no office building, so do not have these overheads to contend with. Our focus and finances can therefore be directed on delivering the needs of the charity. It's not without challenges; there are some fundraising platforms that ask for utility bills in the Foundation's name for our registered address. Obviously, since we have no business premises, we do not have utility bills in the name of the charity.



Helen Hargrave, Nigel Over, Leeann Stevenson

Natasha Craven



Natasha Craven joined us at the start of October 2020 on a part-time basis as our Research and Admin Assistant.

Over the Summer Natasha joined the Smith-Magenis Syndrome (SMS) Foundation UK through the University of Keele Internship Programme, supported by Santander University Bank. Natasha impressed us during her Summer internship on the UK SMS Demographics project gaining positive feedback from our international community of clinicians, geneticists, researchers, and families. Natasha's knowledge, experience, and adaptability to deliver innovative solutions naturally fits with our culture and vision. We are delighted to welcome Natasha to our team as our part-time Research and Admin Assistant whilst she completes her degree in Biomedical Sciences.

The success of the Summer internships has now led us to revise our strategy and incorporate student placements and employment as a mutually beneficial opportunity within our development and core to our vision. We were Highly Commended in Cultivating Talent at the Breaking the Mould Awards.



"As one of the students taking part in this wonderful internship opportunity, I can firmly say it was one of the best experiences I have had whilst studying at Keele University. Should the Smith-Magenis Syndrome Foundation be offering any more internships, I would advise students to grab the opportunity with both hands and treasure it. For me it has not only been a phenomenal experience but has also opened up many doors for when it comes to applying for Masters and PhD courses."



Congratulations to Nigel Over who won the Terrific Trustee category at this year's SCVO Scottish Charity Awards. Nigel was nominated for his dedication to the Smith-Magenis Syndrome (SMS) Foundation UK as a Trustee before stepping across to become our Chief Executive Officer.

UK SMS Demographics Study

The priority of the Smith-Magenis Syndrome (SMS) Foundation UK has been to establish a definitive demographic profile of syndrome diagnosis across the UK by area and age, to assist with planning of support services and activities. This was to be done through Freedom of Information requests to genetic clinics, health authorities and local authorities. The virtual 100-hour internship offered from Keele University provided us with two students, Xheni Prebibaj and Natasha Craven for the Summer to progress this study.



Geographical distribution of known individuals with SMS



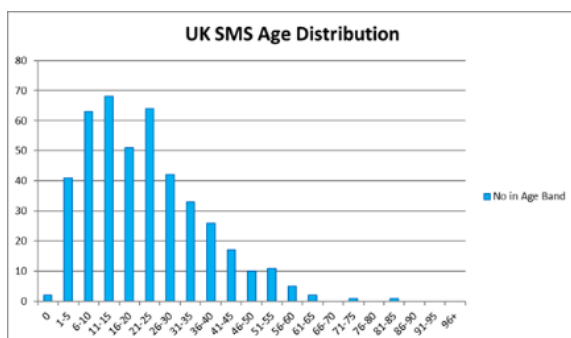
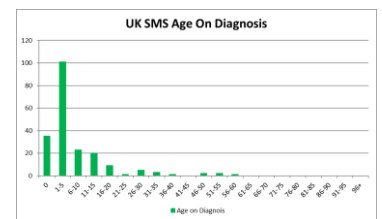
This study mainly aimed to create a profile of Smith-Magenis syndrome (SMS) across the UK, by age and area and by doing so to identify geographical areas for support services and activities. It also aimed to validate the 1 in 15-25,000 incident rate. The research was done remotely as all the information could be found online. Freedom of information requests (FOI) were written and prepared. Contact information of all the local authorities and Health Authorities, Genetics Laboratories/Clinics and Clinical Commissioning Groups in the UK were retrieved online.

Some positive responses were received that allowed the Foundation to determine that 526 individuals are known to have SMS compared to the starting point of 303 known individuals.

The Manchester Clinical Commissioning group responded positively. When the original data was combined with the newly gathered data, 69 individuals with SMS were known to be in Manchester which when calculated against their population gives a prevalence rate of 1:9,750. The data gathered indicates an underreported prevalence rate of SMS.

Another major discovery was that the local authorities do not hold the data for people with SMS, which makes it difficult to organize locally oriented support services. We can target know hotspots to reach those diagnosed who we are not in contact with, whilst also being able to talk with authority, confidence and evidence on the broader profile of the syndrome with particular relevance to justifying future grant funding.

The age demographic results identified that 50% of all diagnosed are pre-school. 80% of the known SMS population received their diagnosis as a child; meaning that less than 20% are diagnosed as adults. This gives us a clear priority on when and what support newly diagnosed families would be seeking from us. The oldest known person with SMS was born in 1919 and lived to 88 years, this might indicate that an SMS diagnosis does not interfere with life expectancy.



It is likely that this skew is due to the advancement of cytogenetics and in youth genetics testing and the increased availability of the chromosome microarray which has the capacity to pick up 90% of the incidences. Additionally, it is probable that the older people with SMS have gone undiagnosed for many years and so the age demographic data may show a bias due to this. With test advances from around 1990, and a focus on children, our age demographic would suggest that those first diagnosed with SMS would now be 35 and 55 years old. The population is split evenly between males and females.

This demographic study now allows us to target resources and effort to maximising impact as we seek to connect families and raise awareness of Smith-Magenis Syndrome. <https://smith-magenis.org/uk-demographics-study/>

SMS UK Conference – 1st & 2nd May 2021

A UK family conference like no other.

Yes, we are still planning to hold an in-person conference in May 2021, subject to the easing of COVID-19 restrictions and receiving the necessary permissions for it to go ahead. We are expecting that there will be strict protocols required for the conference to be able to go ahead.



The biggest difference this time is that the conference will be run over two days. The conference will start on the Saturday morning and conclude on the Sunday afternoon. There will be a single venue for presentations, the full Park Suite. How we present will also be a little different.

Saturday will focus on our UK SMS community. What we have learnt from our demographics study has helped us plan our regional programme. We have also been investigating how we engage with our supporters in the way you want us to, especially through digital or online platforms. So, for Saturday, we will be having this regional, peer-to-peer supporting theme, with an emphasis on our parent and carer health and well-being. We also want to cover future planning with guest speakers presenting on education plans, transitions, court of deputyship and guardianship orders, trust funds, and wills.

Sunday is intended to cover topics at the heart of Smith-Magenis syndrome. Run in shorter segments we are looking to invite speakers to present short subject overviews before becoming a discussion panel. This should be a quickfire appraisal of topics such as the genes of chromosome 17p11, sleep matters, what we know of behaviours, diet and weight, etc. A lot will depend on the speakers who are available, although we do hope to have key presenters join us through videoconferencing.

We are hoping to be able to set aside areas for kerbside chats with our speakers separate to the main presentations for individual bookable discussions.

Tables in the conference room will be allocated. On Saturday we hope to do this by where you live. On Sunday, we'll do this by age of your SMSer.

Catering and the Saturday Night



Breakfast will be by allocated time slots in the restaurant with table service rather than buffet. Lunch will be in the restaurant in two sittings. We will make these age related and run a discussion programme in the Park Suite for split audiences.

Saturday evening will be an at table service event in the main Park Suite, with cabaret style entertainment hopefully from Justin Perks, Magical Mayhem and Ciara Harvie.



Creche and Care

Tinies are returning to provide creche and care, although numbers will be more restrictive and the trips out for brothers and sisters will not happen. We are still working out room allocations and capacity. There will be a priority booking sequence determined.

SMS UK Conference – 1st & 2nd May 2021

Booking Priorities

The Park Suite capacity is what determines the number of attendees. With current distancing rules we are limited to 28 tables of 4, although there is the potential to accommodate families of 5 or 6 around one table. This gives us a working capacity of 112 attendees. The maximum family group booking size will be six people.

Booking will be based on a package covering the Saturday and Sunday presentations, Saturday night bed and breakfast accommodation the Saturday night ball. Presently we will not be offering day delegate options. Additional nights bed and breakfast for Friday and Sunday will be available for staying at the hotel.

The opportunity to book for the conference will be phased by groups. Notifications of bookings opening will be sent to current members as they happen. Expressions of interest can be emailed to conference@smith-magenis.co.uk

Booking opportunities for the conference and creche will be offered in the following priorities:

1. Families where the diagnosis was received in 2019, 2020 or 2021 with parents, the person with SMS and their siblings all eligible to attend.
2. Families who have been part of our community for a while, but who have not yet made it to one of our conferences.
3. SMS member families. If we are seeing high demand then we may have to make the hard decision of restricting the spaces to one parent with their SMSer, with discretion for siblings if no other support is available.
4. SMS families who are not current members of the Smith-Magenis Syndrome (SMS) Foundation UK.
5. Professionals working in or with Smith-Magenis syndrome.
6. Extended family.

A waiting list will be kept for anyone who would like to attend but missed out on being able to book places.

We are intending to record and stream the main sessions for anyone who cannot attend in person.

Pricing

We plan to retain our existing pricing structure whereby the charges to families are the costs to us for the bedrooms and delegate day rates. We want to keep it free for those with SMS to attend. Details of pricing will be released as soon as we have confirmation from the hotel.

We want to keep the conference as safe as possible. Anyone who tests positive, has COVID-19 symptoms and waiting for a test, or has been alerted to self-isolate, will be given a full refund.

For those travelling longer distances (over 150 miles) within the UK, we hope to be able to offer a travel bursary to help with the costs of attending if necessary. Provisions within our small grants scheme may also be applicable to help with conference costs.

Conference Preparation

Although smaller in nature, the planning required for May 2021 is more complex than ever. We would welcome support from members in helping with the organisation of the conference, particular from those who have experience in running activities under COVID-19, health and safety planning, those in the entertainment sector, and anyone experienced in virtual conferences and webinars.

Sponsorship and Donations

Conference sponsorship and corporate donations are more important than ever. Our venue costs will still be consistent with previous years, yet we will have fewer people in attendance. We would welcome any leads on companies we can approach to help with these costs.

Further Information

Email: conference@smith-magenis.co.uk

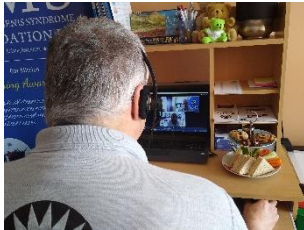
Webpage: www.smith-magenis.org/sms-conference-2021/

Full conference planned for Friday 29th April to Monday 2nd May 2022

Our Fundraising During Coronavirus

Since our last update, the team here at the SMS Foundation UK have been working very hard to maintain fundraising and income for the charity during the ongoing pandemic. Continued local and national lockdowns have significantly impacted our ability to deliver in-person fundraising events and community activities, with many of our annual events postponed until at least spring 2021.

Community Cohesion



Through your generous support, and emergency grant funding, we have already been able to meet some of the Foundation's immediate needs such as our community cohesion Zoom drop in sessions, that provide an online space for families to talk to other families with SMS, receiving both emotional and practical guidance and support. These sessions are vital for our families who are isolated and vulnerable at this time.

202 Zoom Community Cohesion Drop-Ins giving a total of 252 hours

53 Enquiries since April, equivalent to 26 days of support

We also created our SMS Bear Hug and Be Hugged campaign which saw families taking part in a Teddies to the Rescue pirate activity, our Design A Bear competition and our Teddy Bears Picnic. Thank you so much to everyone who took part in these events. Thank you to the Co-op for donating gift cards to help with our picnics.



We were incredibly lucky to receive support from a group of active hikers led by Matt Sutton who took part in the Yorkshire Three Peaks challenge in August. A whopping £14,453 was raised by Matt, friend Craig Thomas, and a host of 30 of their friends, all of whom took on the gruelling challenge in order to support Matt's family and others living with SMS. Thank you so much to everyone who took part and made this event so special – we are incredibly grateful for your support.

Yorkshire Three Peaks



We have some exciting community engagement activities planned over the next few months, including our November awareness month daily videos.



Our Christmas card design competition winners are Chloe Woo and Lauren Rose Docherty. The cards will be available to order for your SMSer at the start of December.

<https://smith-magenis.org/shop/>

The Christmas activity pack for kids is still available. Look out for more information on our website!

The Foundation has received funding from grant providers including the National Lottery, and the Wellbeing Fund. Grant funding received has been necessary to fill part of the sudden drop in income for the short term due to our fundraising events being cancelled for a large part of the year.



How We Are Continuing To Care

The SMS Foundation UK is a lifeline for hundreds of families, and they need us now more than ever. We remain uncertain of what the future holds and are continuing to look to our local community for support.

We urgently need you to continue supporting the Foundation in whatever way you can as we cope with the current crisis and the difficult times that will follow. Our families need you now more than ever so we can be here for the future.

Your fundraising is vital throughout the year, but especially now during this global crisis, when our SMS community need us more than ever. We have been thinking hard of new ways to respond to the current climate, and to ensure our services remain intact and our funding does not diminish further.

SMS 1711 Circle



One of the ways we are tackling this issue is the development of our new regular giving club, the **SMS 1711 Circle**, a group of our most dedicated supporters who donate monthly or quarterly to our cause. A regular donation could help us to pay for the future of our services, and help us connect families, raise awareness and build futures for everyone living with SMS.

We have chosen the symbolic 1711 to represent the 17p11.2 gene, referring to the specific piece of genetic material missing from chromosome 17 that leads to an SMS diagnosis. We ask our donors to commit to each £7.11, £11.17 or £17.11 to symbolise our fight in funding better research for the syndrome and supporting our cause to ensure every person with SMS shall have a fulfilling life within a supportive and understanding community.

Signing up for the club could not be easier – simply visit <https://smith-magenis.org/get-involved/circle-1711/> and follow the easy steps to set up your regular gift.

Our Fundraising Platforms



When setting up for donations / fundraising in Facebook, JustGiving, or Amazon Smile, please ensure that you select as your chosen cause:

THE SMITH-MAGENIS SYNDROME (SMS) FOUNDATION UK CIO

Donations: smith-magenis.org/get-involved/donate

SMS 1711 Circle: smith-magenis.org/get-involved/circle-1711

Fundraising: smith-magenis.org/get-involved/fundraising-resources



Genny Bear



Genny Bear was missing.

In May her friends had been kidnapped by pirates, so we send in the teddies to the rescue. Our families did fantastically well, building their boats and saving the bears. But Genny Bear was not there, and we needed to know what she looked like. At the midsummer's night picnic, we found out Genny Bear appearance and our quest to find her went on.

Then on 17th November, who should appear, but Genny Bear herself. After a long journey, she arrived with Hazel Wotherspoon, where she is self-isolating due to COVID-19. We know that Genny Bear will soon be restless and will soon be wanting to move on.

Like her cousin, Genny Smith, she will want to travel on to meet as many of our SMS families as she can. It is over eight years since Genny Smith was on her travels and what adventures did she have! Here's some of the pictures from when Genny Smith visited our UK SMS families.



Where will Genny Bear go and what adventures will she have? You, our SMS families, will decide. Her journey around the UK and maybe further afield starts in 2021.