



SMS

SMITH-MAGENIS SYNDROME
FOUNDATION UK

Connecting Families ★ Raising Awareness ★ Building Futures

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

Early Summer 2020 Newsletter



Covid-19 Support

Nigel Over
Chief Executive Officer

Covid-19 came out of the blue and has surprised us all on how it is impacting on our lives, both today and into the future.

In November 2019 the Foundation embarked on a new phase in our journey as we looked to the future with an ambitious development strategy, bringing together a staff team, looking to invest significantly in research, identify ways to make the future of those with Smith-Magenis syndrome better, strengthening the bonds that connect families, and raising the profile of SMS within the community. Spring forward to March 2020 and the world suddenly changed overnight. Our plans for the future have been put on hold whilst we focus on community cohesion and keeping the Smith-Magenis Syndrome (SMS) Foundation UK afloat.

On 01 April 2020, our Senior Management Team came into post; an integral part of our development strategy and essential for us to be able to meet the growing demands of our SMS community. What should have been a gentle ramp up of activities shifted instantly to all hands on deck to respond to the ever changing situation. Fundraising runs and walks have all been postponed. Our fundraising strategy has taken on a totally different complexion. Social events have been postponed. A virtual community has arisen. Research has all but stopped. Revision to SMS guidance is on the backburner whilst we focus on addressing immediate needs and concerns around Covid-19. One thing that hasn't changed has been the organisational work in the background to make the Foundation a strong, robust and sustainable charity to protect our future.

In this issue of the newsletter, we will reflect on what we have done, and where we plan to go next.

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Our Vision, Our Mission

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.

Responsible Fundraising



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www.smith-magenis.org

Free for Tea at Three, Whine with Wine at Nine

From the outset of the Covid-19 restrictions, the Foundation was quick off the mark for hosting daily drop-in 'coffee breaks' through videoconferencing. Whether it is morning elevenses, free for tea at three, or whine with wine at nine these instantly proved popular for families to come together.

One mum's comment sums up the whole feeling:

"To all my SMS family, these chats are keeping me sane. It is virtually the only adult contact I get that is as close to face to face as is possible."



So popular are these chats that Nigel currently hosts eleven of them each week, has increased the duration of those in the evening and was asked to introduce new virtual drop-ins just for the parents and carers to be able to unwind together with those who simply 'just get it' with the syndrome. Fortunately, the charity is able to do just that thanks to grants from the National Lottery Community Fund and Foundation Scotland Community Response, Recovery and Resilience Fund.

The National Lottery Community Fund, Scotland Director, Neil Ritch: said: *"In these uncertain times our priority is to ensure that National Lottery money continues to flow to charities, voluntary sector organisations and grassroots groups. I would like to congratulate the Smith-Magenis Syndrome (SMS) Foundation UK on their award. Theirs is an important project which will help people get through the current crisis and a great example of how our grant holders are stepping up to support their communities."*



Guest speakers are dropping in including Ann Smith, Charity Ambassador Ciara Harvie, and co-chairs of the Scientific and Clinical Advisory Committee Dr Ashley Liew and Dr Caroline Richards. Other guests are being invited.



Regular visitor Debbie Brooks says:

"Being a special needs parent can be lonely, especially when caring for someone with Smith-Magenis Syndrome since very few people understand what you are going through. During this time of uncertainty, caring for high needs individuals with SMS without the normal supports can be challenging and emotionally draining. The SMS caregiver Zoom calls are a great way to connect with other people with similar experiences"

An SMS Parent comments:

"The calls have given me the strength to keep going."

These chats are open to all within our SMS community. All you need to do to join is click on the link provided on our Facebook Page. If you do not have Facebook, then let us know and we can send you the link by email or text.

www.facebook.com/SmithMagenisUK/

www.smith-magenis.org

<https://twitter.com/SmithMagenisUK>

Where's Genny Bear?

Our [SMS Bear Hug and Be Hugged campaign](#), which launched in May with our **Teddies to the Rescue** garden activity, has been created to help our families through the social restrictions and to help rebuild peer to peer support when re-emerging into society. Built around the phrase 'hug or be hugged', showing the affection and interaction of those who have Smith-Magenis syndrome, our teddy bear activities offer fun for all the family, bringing us together for connection and mutual support.

Our very own Genny Bear is missing. Her friends have been kidnapped by pirates. We needed our SMS families to come together to rescue the bears. There were some fantastic adventures, with a few photographs of the occasion below.



Lily rescues her teddies from her brothers



Elizabeth to the rescue



Well done Sam



Logan saves the day



Clara makes a run for it



Genny Bear is still missing, but we don't know what she looks like. Can you help us by drawing what you think Genny Bear looks like? For the next stage of our [#SMSBearHugandBeHugged](#) campaign, we want you to design your very own Genny Bear (taken from the 'geni' in honour of Ellen Magenis who gave her name to the syndrome). The winner of each category will receive a Build-a-Bear gift card. The overall competition winner will see their design inspiration become real and receive a large Genny Bear later in the summer. (open to UK participants only)

The competition closes on Saturday 13 June 2020. Entries will be independently judged by Ann Smith, Ashley Liew and Caroline Richards.

Our upcoming teddy bear activity on 20-21 June is the **Sunset, Moonlight and Sunrise picnic** – hosted on the longest day/shortest night to reflect the lack of sleep that many of our parents and carers face on a daily basis. We would absolutely love you and your families to join us for this event, raising awareness of SMS, and bringing together our community during this challenging time. Visit our website www.smith-magenis.org for more information on how you can take part and how to receive your very own teddy bear's picnic box!



Later this Summer Genny Bear will set off on her travels between SMS families, meeting new friends, and keeping a travel diary of her adventures along the way. Follow the adventures of the **Genny Bear Relay** on our Facebook page.

Genny's travels will include school activities, social media stories and press coverage raising awareness of SMS, and most importantly will encourage families to meet up with each other along the way, fostering community engagement that is so vital to the wellbeing of our SMS families.

#SMSBearHugandBeHugged

Information and Support Service Update

Having accurate information and advice has never been more important than under the current Covid-19 situation. 1 in 4 people with SMS are in the high-risk category for coronavirus. Half of those in the high-risk category had to request the shielding letter and registration. Most other families are in the vulnerable category and are shielding. Gathering member experiences has meant that we have been able to make representation to the UK Government and devolved administrations through our genetic organisations networks to provide clarity and amendments to the process.

Becoming registered within the high-risk category has been a multi-level approach. The initial list was produced from centrally held health records. Copies were sent to GPs for review and amendment. However, we were able to identify that it is often the specialist clinician who had the in depth knowledge of the patient rather than the GP, so some individuals who needed to be on the list were still being omitted. At the start of May, guidance to medical practitioners was updated bringing clarity to how to add patients. This would not have happened without the problems being highlighted by our families. There remains a slight delay on entries as the list is updated weekly on Mondays. Those not in the high-risk but considered vulnerable are able to contact their local authority for additional support. The process is constantly evolving recognising that we are in uncharted waters with Covid-19. Fortunately, our membership of Genetic Alliance UK keeps us alert to the changes as they arise, as well as giving us a voice to help influence the decisions.

As well as seeking to remain at the heart of policy and practice, we have seen a 250% increase in the number of requests into our information service since the start of the Covid-19 restrictions. This excludes the responses we provide through social media and the community drop ins. An approximate breakdown of the types of issues we are addressing would be:

- 35% medical related questions
- 20% emotional support (although this also comes into many of the other headings)
- 15% care services, respite
- 10% equipment and practical solutions
- 10% benefits advice and assistance.

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.

General enquires should be sent to info@smith-magenis.co.uk or by leaving a message on 0300 101 0034.

For urgent matters, please contact either:

Hazel Wotherspoon hazel@smith-magenis.co.uk m: 07952 047894,

Nigel Over nigel@smith-magenis.co.uk m: 07803 605739

Every family deserves the lifeline that the SMS Foundation is already providing to some. Families need to be signposted to the Foundation immediately upon diagnosis. We must grow our support and awareness so we can create a thriving future for all families living with SMS.

The enhanced Information and Support Service is a primary focus for the new management team. The project costs of delivering this service at an enhanced level will be approximately £87,000 per annum.

We want to acknowledge the grants we have received to help us deliver this vital service from the National Lottery Community Fund (£4,841) and the P F Foundation (£3,000).



P F Foundation

(London)

Our Fundraising During Coronavirus

The Coronavirus outbreak is set to have a serious and unprecedented impact on the charity sector – and will continue to do so for a long time to come. Charities are facing significant financial losses following the cancellation of key fundraising events such as the London Marathon, balls, galas, community fun runs, and all in between – and this means crucial charity services are suffering in the aftermath of the crisis.

Here at The SMS Foundation UK, our hard-working team have been coming up with ways to keep our services running to ensure every family who needs us can access vital support, information and emotional and practical guidance. We are here to make sure no one living with SMS feels isolated or alone – now more than ever. Along with the adaptation of our existing services, such as the creation of our community cohesion Zoom sessions to bring our families together, the team have been developing some community-led fundraising events to raise vital income to keep our services reaching as many people as possible. Over the last few weeks, we have had some exciting events taking place.



Our very own Nigel Over braved the shave and raised £292. Well done Nigel! We hope your head isn't too cold 😊

Nigel says "Everyone who knows me knows that I have had the same hairstyle for over 25 years. It needed a trim. How short, you decided. **Shaving Makes Smiles** – Starting at #8 for every £100 donated to the Smith-Magenis Syndrome (SMS) Foundation UK through this fundraising stream, more hair comes off."



The 2.6 Challenge (26 April 2020).

We would like to thank all of our supporters who recently took part in the 2.6 Challenge to raise money for The Smith-Magenis Syndrome Foundation UK.

A special thank you to Hazel, Ellen and Hope for the 2.6-mile circuits you did around the Falkirk Wheel.



Ciara Harvie's Songs Make Smiles Concert – our wonderful ambassador, Ciara Harvie, treated us to a stunning vocal performance via Facebook Live, singing a medley of tunes for our SMS families. Through Ciara's music, we were reminded 'What a Wonderful World' we live in, and that together as a community and family no-one should feel isolated as 'You'll Never Walk Alone'. Ciara sang songs to lift our spirits like 'A Dream is A Wish Your Heart Makes', and our fantastic audience raised £246 for the SMS Foundation via donations on the night.

Quiz Time!

Nick and Salli Hunt hosted their inaugural quiz night on 22 May, raising a brilliant £392 for the Foundation.

Families who took part had a fantastic time, and we are hoping Nick and Salli will be kind enough to make the quiz a regular feature!



Mia's Story

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.

In choosing to support the SMS Foundation, you will be helping us to support children like Mia and her family, who turned to the SMS Foundation for help and guidance following Mia's diagnosis as a small baby.

For some time, Mia's mum Katherine tried to plough on as normal with family life. *'I didn't want us as a family to be defined by Mia's condition,'* she says.

'But more recently I've started to realise we are isolated and need some support. We get judged when we're out because of Mia's behaviour. People think she's very naughty and admittedly her behaviour can be quite severe. But we know it will fuel the fire if we try to control her. So we know we're handling it the best way.'

Recently, Katherine and her husband, Mia's dad Giles, have met other families affected by SMS through the SMS Foundation. *'We were ready to meet others fighting similar battles, those who understand how hard it can be, and not to be judged.'*

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

The 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.



We need your help to continue to run our vital services. Donate now via www.smith-magenis.org and help us support vulnerable SMS families in your local community.

Sharing My Story

Have you been inspired by Mia's story?

We plan to revisit the families featured in our previous case studies and prepare new ones. These stories mean so much to our community and help us to raise awareness of what Smith-Magenis syndrome is like to us.

Do you have a story to tell?

Showing the challenges and sharing the successes are all part of bringing support and understanding to the wider community. The more stories we have, the more impact we can make. To share your story, please could us at info@smith-magenis.co.uk

The Smith-Magenis Syndrome Foundation UK has reached out for a professional experienced in media and/or journalism to volunteer with us over the summer to help us coordinate our case studies project.

Where Funds Can Go

Your fundraising is vital throughout the year, but especially now during this global crisis, when our SMS community need us more than ever. Donating a regular gift to the SMS Foundation could make a vital difference for families in isolation, helping us to provide practical guidance and emotional support and comfort at this critical time. We are here to make sure no one living with SMS feels isolated or alone. Your donation will help us to connect families, raise awareness and build futures for those living with SMS.

Start a regular gift today and make an ongoing difference to the lives of families living with and affected by SMS

£2.85

per month provides
£34.22(ish) per year
- two chromosomes,
but one deletion /
mutation.

Monthly Giving

£17.11

per month
recognises the
deletion giving rise
to Smith-Magenis
Syndrome on
chromosome 17p11

£25

per month will help
provide 1 hour of online
or telephone support for a
family living with and
affected by Smith-Magenis
Syndrome.

£10

per month will help
us to keep the
information pages on
our website updated

A little goes a long way

£11.17

per month
recognises the
mutation in Smith-
Magenis Syndrome
on chromosome
17p11

Our Donation Platforms



You shop. Amazon gives.



Donate today through www.smith-magenis.org

Future Events

At the time of writing this newsletter, we cannot be sure of when events will start up again after the measures put in place to tackle the coronavirus situation. If restrictions stay in place, we will find ways of socialising as a community even if this is as individual families.



Sunset, Moonlight, Sunrise Picnic Party

Saturday 20 June
Sunday 21 June

Gardens Everywhere

Join us for this event, raising awareness of SMS, and bringing together our community during this challenging time. Visit our website for more information on how you can take part and how to receive your very own teddy bear's picnic box!

Stay awake and party through the shortest night of the year, having fun and raising funds for the Foundation. This is what our children with SMS do with their parents every night of the year.

Contact: Leeann Stevenson, leeann@smith-magenis.co.uk



The Kiltwalk 2020

Sunday 16 August
Dundee
Sunday 13 September
Edinburgh

Kevin Bridges: *"Get your kilt, go for a walk, get some endorphins, serotonin and vitamin D... all in the name of a good cause!"*

Whether it is the Wee Wander, Big Stroll, or Mighty Stride, these walks are popular, fun with a great social element.

Contact: Nigel Over, nigel@smith-magenis.co.uk



Great North Run 2020

Sunday 13 September
Newcastle upon Tyne

2020 is going to be a very special year for the Great North Run as they celebrate their 40th year! This year, the world's biggest half marathon, starts in the centre of Newcastle and finishes at the coast in South Shields.

Contact: Emma Riddell, emma@smith-magenis.co.uk



SMS Ball at Bury

Saturday 19 September
Bury, Lancashire

A second Ball in 2020 sees us in Lancashire in September. Inspired by one of our younger children with SMS, this event is being organised by his aunt for the benefit of the Foundation. Further details will be provided in due course.

Contact: Nigel Over, nigel@smith-magenis.co.uk



Avon and Kennet Canal

Saturday 3 October
Bradford on Avon,
Wiltshire

Join the "Barbara McLellan" for a leisure boat trip along the Avon and Kennet Canal with other SMS families. The boat can take 40 people and is fitted with a hoist for getting wheelchairs on board.

Contact: Leeann Stevenson, leeann@smith-magenis.co.uk

Conference 2021



2021 SMS Conference

30 April to 3 May 2021
Solihull

We are returning to the St John's Hotel in Solihull for our next Conference from Friday 30 April to Monday 3 May 2021. Venue booked, care arranged, entertainment confirmed. Keeping to the established format, we are busy pulling our topics together for another exciting weekend.

Contact: Nick Hunt, nick@smith-magenis.co.uk

For sponsorship opportunities

Contact: Helen Hargrave, helen@smith-magenis.co.uk