



SMS

SMITH-MAGENIS SYNDROME FOUNDATION UK

Connecting Families ★ Raising Awareness ★ Building Futures

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

Spring 2020 Newsletter



Our Foundation Our Future

Hazel Wotherspoon
Chairperson

The Smith-Magenis Syndrome (SMS) Foundation is a small UK registered charity that supports families, who have children of all ages, with Smith-Magenis Syndrome and provides information for professionals working with these families.

The Foundation was first started as a support group in 1992 by Julie Jowitt, known then as the SMS Contact Group. With the help of Contact-A-Family the group developed from an initial set of 6 families by writing to doctors all over the world who then sent information and referred families on to Julie.

By 1998 the group of families numbered 200, and they were obliged by law to form a charity. Last November we voted to change our constitutional status to that of a Charitable Incorporated Organisation (CIO).

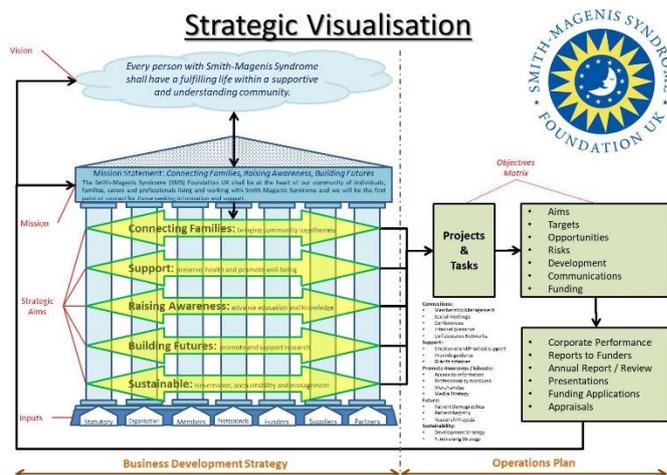
2020 marks a year of exciting changes to the Smith-Magenis Syndrome (SMS) Foundation UK. Following an extensive governance review with the help of Bruce Tait Associates, we have put in place our business development and fundraising strategies.

Having been run solely by volunteers, our Trustees, for the past 28 years, we have reached the stage where we need dedicated resource to meet the demands being asked of us. From 1st April we are employing our first members of staff to support the work of the Foundation and our members. Nigel Over and Leeann Stevenson are moving from the Board of Trustees into the roles of Chief Executive Officer and Information & Communications Manager respectively. We are further delighted to announce that Helen Hargrave joins us as our Fundraising Manager.

Inside This Issue

- Governance Matters Page 2
- Meet Your Senior Management Team Page 3
- Meet The Trustees Page 3
- Information and Support Service Page 4
- Staying Connected Page 4
- Emergency Planning Pack Page 5
- Charity Ambassador – Ciara Harvie Page 5
- Getting Medicines Approved – Slenyto® Page 6
- Connecting Families, Raising Awareness Page 7
- Future Events Page 8

Strategic Visualisation



Our Vision

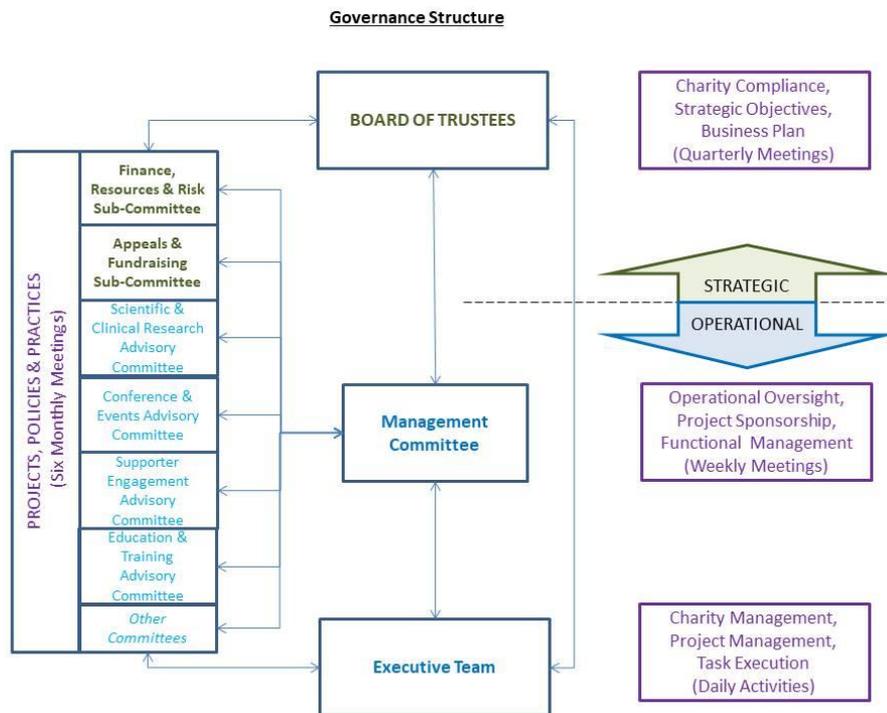
Every person with Smith-Magenis Syndrome shall have a fulfilling life within a supportive and understanding community.

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.

Governance Matters

Becoming a Charitable Incorporated Organisation and employing a staff team means that we need to change how we work. Until now, the six Trustees have collectively delivered all the activities and services of the Foundation, the regulatory and legal compliance matters, as well as planning for the future. Going forward, we are putting in place a new governance structure with greater opportunity for members to become involved.



Board of Trustees

Where day-to-day management and operations are delegated to staff or volunteers, the board remains responsible for supervising the chief executive and ensuring that the organisation is being well managed and operating within agreed policies, the law and its budget. The board considers strategic and compliance matters.

Committees

The committees advise the board on the general strategies of the charity within their respective remits and expertise. They will recommend, monitor and review policies, practices and projects. Supporting the Executive Team, the committees may assist in the development and delivery of projects and initiatives to benefit our members.

Management Committee

Comprising representatives from the Board of Trustees and the Executive Team, the Management Committee is responsible for controlling the management and administration of the charity. Duties include operational oversight; project sponsorship, monitoring and audit; management of allocated budgets.

Executive Team

Our senior members of staff responsible for delivering the services and activities of the Smith-Magenis Syndrome (SMS) Foundation UK.

How you can become involved

We are inviting nominations to those interested in joining the board and/or the committees.

Board Members

For the board members, we are particularly interested in individuals who can bring expertise and experience in the skills of HR management, finance, marketing, fundraising, as well as broader charity governance.

Committee Members

Each committee has a subject focus. We welcome nominations from individuals interested in these topics to help shape what we need to do as a charity for our members as well as bringing expertise into what we provide in terms of information, services and activities.

For further information, please contact by email or phone either Hazel Wotherspoon at hazel@smith-magenis.co.uk m:07952 047894, or Nigel Over at nigel@smith-magenis.co.uk m:07803 605739

Meet Your Senior Management Team

We are delighted to be able to introduce you to our Senior Management Team. Many of you will already know Nigel Over and Leeann Stevenson through our Smith-Magenis syndrome community and as Trustees.

Persuading Nigel to join our Board in 2012 has been one of the best moves we have made in the leadership of the charity. Nigel has led our governance and development strategic review that sees our evolution into a well-supported, sustainable charity ensuring long-term benefits for our community. Becoming our first Chief Executive Officer has been a natural progression for us. Nigel stays in Livingston with Angela and their daughter Susan. Their son Matthew (22, SMS) is settled in residential care in Musselburgh.



L-R: Helen Hargrave, Nigel Over, Leeann Stevenson

During the time Leeann has been involved in the Foundation she has used her design skills to breathe new life into the charity branding, logo, website and digital marketing platforms. She has also been responsible for the publication of our booklet, guidance literature, awareness videos, and leading the Support My Smile campaigns. It is fantastic that Leeann is now able to devote more time to the charity as she moves into the position of Communications Manager. Leeann and William have made their home in Marlborough and have three children, Lily (12, SMS), William (8) and Teddy (4)

Having worked in the charity sector since 2010, Helen Hargrave has spent the past five years in senior management fundraising positions for a variety of charitable causes, incorporating small local charities including Richard House Children's Hospice through to national organisations including Maggie's, Shelter and Diabetes UK. She joins the Smith-Magenis Syndrome (SMS) Foundation UK from her role as Director of Victim Services at Brake, the road safety charity. Helen is a supportive and passionate fundraiser who will bring valuable and wide-ranging experience to the Foundation as our Fundraising Manager as we enter this exciting time in our development. Helen and Adam live in Stockport with their son Jacob (1).

Meet The Trustees

Hazel Wotherspoon



Hazel worked as a paediatric physiotherapist for 27 years before leaving work to become a full time carer and is mum of 4 young adults, 3 of whom have significant disabilities; her daughter Ellen has SMS. Her prime aim is to support families in any way they need.

Emma Riddell



Emma is a mother of three children, Harry, Grace (SMS) and Charlie, Emma is currently a fulltime Mum and lives with her husband Mark in Birmingham. She is passionate about raising awareness and fundraising for the foundation.

Nick Hunt



Nick is an IT consultant and father of a boy and girl. Samuel his eldest child has SMS.

Nick is highly motivated and looking forward to helping to raise awareness of SMS as well as providing access to information and resources.

Mick Pearson



Mick's drive is to support families newly diagnosed with SMS and seeks to connect with them in his unique way. His son Riley was born in 2011 and diagnosed in 2014.

Information and Support Service

Smith-Magenis syndrome is complex and still poorly understood. A family is unlikely to have any personal history or understanding of the condition and will not have contemplated this diagnosis for their child. Confirmation that their child has SMS arrives as an utter shock. Compounding this, will be a tsunami of questions and fears regarding the potential negative implications that could impact their child. The medical team is likely to outline a range of scenarios for families in a clinical manner, suggesting the child may need long term care and face an array of complex medical and behavioural challenges. Inevitably the family turns to the internet where, unguided, they can find further frightening possibilities.

Afraid and overwhelmed, the family endeavours to make sense of what they have been told. Their thinking is anything but clear and they feel ill equipped for the road ahead. Such news increases the sense of isolation and despair that a family is feeling. Nobody should ever feel isolated or alone.

The SMS Foundation is already a safety net, catching families upon diagnosis and guiding and supporting them through their lives for as long as they need us. We are there for families to contact us by email or phone. In 2019, we handled 97 direct enquiries for information and support representing approximately 110 days of effort. This excludes visits to families and responding to queries and posts on social media channels.

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.

We wish to produce syndrome specific information guides on topics such as challenging behaviour, self-injury, adult residential, benefits, genetic queries, medication, sleep issues and links to UK and international organisations. Where information is not readily available then research projects may be initiated to advance our knowledge and understanding.

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.

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

Staying Connected

“Nobody should ever feel isolated or alone”

With the precautions in place for coronavirus, we want to make sure that families remain connected and as a community we are there to support each other.

The Foundation is hosting virtual chats with those who ‘just get it’ when it comes to Smith-Magenis syndrome. It could be:

- A morning coffee break / Sunday Morning Social
- Afternoons with Tea at Two / Free for Tea at Three
- Evening escapes, Whine with Wine at Nine

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.



“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. Think about joining in.”

Be Prepared – Emergency Pack

I have Smith-Magenis syndrome		I have Smith-Magenis syndrome	
	First Name: FORENAME	Typical symptoms include: Reduced sensitivity to pain and temperature Struggling to communicate Challenging behaviour (communication) Exhibiting self-injurious behaviours Meltdowns when excited or anxious	
	Last Name: SURNAME		
	NHS No: 0101201111		
In Case Of Emergency			
Contact: Parent's Name			
Contact Tel: 07000 000 000			
The Smith-Magenis Syndrome (SMS) Foundation UK www.smith-magenis.org		Support Numbers: 07952 047894 or 07803 605739	
UK Charity 1072573 / CIO 1186647 & Scottish Charity SC044841			

Going into hospital is never an easy time for anyone, but for someone with a learning disability and complex needs, it can be extremely stressful.

As the Covid-19 pandemic continues to grow it is important that we try and formulate some sort of plan should our loved-one with Smith-Magenis syndrome face staying in the hospital. With this in mind, we have prepared three documents for you to download to help explain SMS to the medical personnel and provide specific key information about the person being treated. All these can be downloaded from our website at

<https://smith-magenis.org/emergency-hospital-documents-for-download/>

SMS Alert Card

The alert card is a document the size of a credit card that carries the basic details of the person with SMS and designed to fit inside a wallet and used in the case of an emergency. The alert card can either be edited in Word or filled in by hand. The card also includes a QR code linking to our website for further information, and the contact details of Hazel Wotherspoon (Chairperson) and Nigel Over (CEO).

SMS Key Characteristics Factsheet

This document is a generic 'at-a-glance' factsheet summarising the key characteristics of the syndrome. The document is a single sheet which can be printed and includes a QR code linking directly to our website for further information about the syndrome.

SMS Hospital Passport

This document provides a framework for medical information that is specific to the person with SMS. Print out and fill in the fields.

Charity Ambassador – Ciara Harvie



Classical singer Ciara Harvie, who is a former The Voice contestant sang at a Summer Soiree for Donaldson's School in Linlithgow in 2016 and her singing had one of the five SMS pupils, Matthew Over, in tears.

Ciara said "When I first met Matthew, I was really touched by his reaction to *O Mio Babbino*. He recognised how sad and emotional the song was, even though it was sung in Italian. I had never heard of SMS before I met Matthew and now realise not many people have. I feel very honoured to have become the ambassador for the Smith-Magenis Syndrome Foundation. I really believe that music can have a positive effect on everyone, no matter their age, disability or background. I love the idea of using my talent to help people in any way I can".

As our charity ambassador, Ciara likes to spread awareness of SMS in any way she can and to help us raise funds that as a small charity we desperately need. Ciara's cover of *What A Wonderful World* plays on our Share My Smile 2019 video.

Getting Medications Approved – Slenyto®



So how does a medicine get listed for prescription?

Nigel Over explains his journey through the approvals maze for the introduction of a prolonged-release melatonin (Slenyto®) as a treatment for insomnia in children with autism spectrum disorder and/or Smith-Magenis syndrome.

After clinical development the first step is for the drug to be licenced in the UK by the Medicines and Healthcare products Regulatory Agency (**MHRA**). Where there is a licensed form of a drug, then unlicensed preparations can no longer be prescribed.

Once licenced by the MHRA, the national health agencies will decide whether to recommend the medicine for prescription. These agencies are the National Institute for Health and Care Excellence (**NICE**) in England, the Scottish Medicines Consortium (**SMC**), and the All Wales Medicine Strategy Group (**AWMSG**). At this stage, patient group representatives can be invited to make submissions, and in the case of Slenyto, this is where the input from the Smith-Magenis Syndrome Foundation was sought. If recommended, then it would be added to the Drug Tariff List supporting its use in the respective country.

After recommendation by the national agencies, each of the Clinical Commissioning Groups (**CCG**) and the local National Health Service (**NHS**) authorities will assess whether to include the drug in their schedules for prescription. This will typically be through consideration of local priorities and budgets. If accepted, then the decisions to prescribe move to clinician and General Practitioner (**GP**) level who will decide if it is in the patient's interest to receive the drug.

Last Summer, the SMC and AWMSG approached us to provide our submission concerning Melatonin. As well as the written submissions. Through the Health Technology Assessment (**HTA**), NICE had by then advised the use of Slenyto in England. There is opportunity for the pharmaceutical company to request a Patient and Clinician Engagement (**PACE**) meeting before committee assessment. Nigel attended the SMC Assessment Committee. In this case we were the only patient group to provide evidence. The committee is huge, and decisions are taken by closed ballot of its members.

The Scottish Medicines Consortium rejected the application to recommend prolonged-release melatonin (Slenyto®) as a treatment for insomnia in children with autism spectrum disorder and/or Smith-Magenis syndrome (SMS). The decision was based on uncertainty that this medicine would offer value for money to NHS Scotland. The wider implication is that the SMC are saying that prolonged-release melatonin should not normally be prescribed on the NHS in Scotland for the treatment of insomnia in children with Smith-Magenis syndrome and that other treatment options should be explored instead. Just before the Assessment Committee a decision had been taken to remove all melatonin from the Scottish Drug Tariff List. Prescriptions can be specially requested "off-label" by the healthcare professional on an individual basis.

The All Wales Medicine Strategy Group also declined to recommend the use of Slenyto as the case for cost-effectiveness had not been proven.

Neither committee were persuaded by the impact of extended sleep in Smith-Magenis syndrome; the evidence combined all clinical trials and did not differentiate SMS from autism. Nor was the ease to swallow a smaller, specially coated tablet. So, what are the costs considered in reaching these conclusions. These figures relate to the Drug Tariff price at which the NHS reimburses the community pharmacist. Clinician costs, prescription processing and dispensing fees are excluded.

Medicine	Dose	Cost per Year
Melatonin prolonged-release (Slenyto®) tablet	2mg to 10mg daily	£500 to £2,500
Melatonin immediate-release (Bio-melatonin®) tablet* ^	3mg to 12mg daily	£365 to £1,461
Melatonin prolonged-release (Circadin®) tablet#	2mg to 10mg daily	£187 to £934
Melatonin modified-release tablet*	3mg to 12mg daily	£148 to £442
Melatonin immediate-release capsules*	2mg to 10mg daily	£103 to £167

*Doses are for general comparison and do not imply therapeutic equivalence. Costs from eVadis on 3 August 2019 apart from Bio-melatonin where cost from Scottish Drug Tariff, part 7U, August 2019. *Preparations not licensed in the UK. #Use in children is 'off-label'. ^A licenced immediate-release tablet has since been introduced for jetlag in older adults that for a dose of 3mg to 12mg daily would have an annual cost of £642 to £2,567.*

Connecting Families, Raising Awareness (and Money)

We have a huge amount of support from within our community and beyond who help bring families together, raise awareness and in doing so bring in the vital donations and sponsorship needed to keep the charity going. Here we highlight just a few of activities undertaken in the past few months. Walk, Run, Cycle, Football, and Dance.

Ever since their youngest son, Toby was diagnosed with Smith-Magenis syndrome at 18 months, Clare and Evan Barker have continuously supported the Foundation.

As well as joining other events such as the UK Great Runs, the family and friends like to undertake an annual challenge walk.

Last summer the challenge was to walk the coastal path around the entire Isle of Anglesey, North Wales, starting and finishing at Llanfairpwllgwyngyllgogerychwyrndrobwlllantysiliogogoch. The feat involved walking 125 miles, climbing a total of 4,174 metres, going via 20 towns and villages, and all in five days,

Anglesey Coastal Walk

The Barker Family and Friends



London Vitality Half with Keith Maddocks



The London Vitality Half-Marathon. This was a huge challenge for me as it's my first ever half-marathon. I normally prefer 2 wheels! You ask why?

In April 2019, my son Jude was diagnosed with Smith-Magenis Syndrome. Upon receiving the diagnosis, after 7 years of trying to find help for Jude, I was shocked, uninformed and unsupported through the normal 'medical channels' because SMS is such a rare disorder. I found the Foundation through my own online research so that I could help inform GPs, teachers, and other professionals caring for Jude what it meant for him. Being able to access the Charity has changed Jude's and the rest of my family's lives. Fortunately, the Charity is available to all families that live with this condition. It provides support, both emotionally and practically. They have supported my family through understanding what the diagnosis means for Jude's future, education advice, medical recommendations, subsidised attendance to their conference, access to further Professionals globally to help understand Jude better and manage the health implications that come with SMS, as well as regional family networking days and online community groups.

Bridlington to Liverpool, 200 miles of cycling over 3 days.

"We done it. We left the toughest till last with 90 miles left on the last day. Weather warnings and tough terrain meant we left at 5.15 am and we all rolled jubilantly in together to the Liver Building to the sound of church bells (honestly) at 7.50pm. At that moment our sore legs/bums vanished, and we were thrilled to have completed this tough challenge as a team of non-cyclists of varied age and fitness.

We had a fantastic 3 days with a great set of lads, and we are blown away by the support Thank you so much to every single supporter."

Coast to Coast

Paul Donnelly and Friends



Castle Vale Town Football Club – Charity Partner



Castle Vale Town under 13s showcasing their new attire. This shows our continued support to our charity partner, the Smith-Magenis Syndrome Foundation UK, where we again showcase their logo in order to raise awareness.

It's a cliché to say but this is more than just a club and it's a club that massively understands its community responsibilities.

Dinner and Dance Fundraiser

SMS UK Ball
Saturday 14 March 2020



The first ever SMS Ball has taken place in Norwich. Organised by Lorraine Harwood and Bryony Dobson, and inspired by Lorraine's daughter, Paige (26) who has Smith-Magenis syndrome.

With 153 guests the evening was an absolute success continuing into the small hours of Sunday morning. Donations, auction bids, raffle tickets, the wine, all flowed raising almost £7,000 for the Foundation.

Our three SMSers in attendance, Paige, Leanne and Matthew endeared themselves to everyone in the room. The ice-breaker "Heads or Tails" game, where everyone puts in a pound and then you have to choose either your head or bum as the coin is tossed, was won in typical SMS fashion with Matthew keeping his hands on his head throughout and eight heads tossed in a row.

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, Our AGM, that would usually be in May is cancelled for this year, All statutory requirements can be met by the Trustees, so instead of an AGM we will provide a written report for members in the Summer. Other events we are working on are:



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



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