



December 2016 Newsletter

The Sydenham's Chorea Association Incorporated as SCIO

In November this year, our application to become a Scottish Charitable Incorporated Organisation was accepted by the Scottish Charity Regulator (OSCR). We are delighted to have reached this point with the organisation, and Andrew and Samantha have put in a lot of work in the background to get us here.

Hopefully with our new charitable status, we will have more opportunities to tap into research programmes and funding. We are currently involved with a UK wide research project (details below), and we would like to support much more of these. A big part of our role is to help people understand Sydenham's Chorea better, and research into the condition will be key to that.

UK Sydenham's Chorea Research Project

We are currently assisting a multi-disciplinary research team with their planning for a UK wide study into the incidence of Sydenham's Chorea. We are hoping to fund part of the programme in addition to providing support to the team.

The questions and contact we receive from all of you through the website and our social media has already been helpful to the team, so we really appreciate all the emails and messages that we receive. Keep them coming!

We hope that this study will help us to identify how many people in the UK suffer from Sydenham's Chorea, if there are any geographical hotspots, and what age range are affected. It may also help us as an organisation to identify the support network available across the UK.

We will keep you posted as the programme develops.

Crookfur Primary School Raise £300



A big thank you to Nicole Strachan and the pupils at Crookfur Primary School who raised £300 for us by holding a bake sale at the school. They also sold cakes during a careers night.

Chairman Andrew went along to the school (which he used to attend himself), to meet Nicole and the other pupils, and be presented with a cheque.

A huge thank you to Nicole and everyone at Crookfur for an amazing fundraising effort.

Sydenham's Chorea Information Leaflet

The information leaflet that we developed with NHS Greater Glasgow and Clyde is available on our website under Educational Documents. We have already sent this to all the main children's hospitals in the UK and all the educational teams in Scottish Local Authorities. Our intention is to circulate it to Local Authorities across the UK, and local GP surgeries.

You might find the leaflet useful to pass to teachers etc. to help explain Sydenham's Chorea.





Fundraising Dinner 2017



Following the success of our last fundraising dinner, we are trying to finalise dates for the next event in Spring 2017. The event will again be held in Glasgow, and we will be looking for items to auction and raffle on the night.

Please keep an eye on our website and social media for further details as they become available.

Thank You Fundraisers!

A big thank you to all of the staff and customers at Paxton Chip Shop in Heysham who raised over £35 for us earlier in the year.

Another thank you to Café Crema at the Scottish Enterprise Technology Park in East Kilbride, who have raised £101 for us this year.



Royal Hospital for Children Glasgow Team Publish Research

The Sydenham's Chorea team at the Royal Hospital for Children Glasgow have successfully had their recent systematic review published in *Developmental Medicine & Child Neurology* this year. The team were looking at the psychiatric symptoms presenting in Sydenham's Chorea. Mallika Punukollu, Michael Morton, Nadine Mushet, Marisa Linney and Colm Hennessy completed the review which was published in April. For more details, or to purchase a copy of the article, [click here](#). Nadine and Dr Morton are both founding members of the Sydenham's Chorea Association.

Get Involved!

We are always looking for enthusiastic individuals to get involved with the Sydenham's Chorea Association. If you would like to help us, there are lots of ways you can contribute. Contact us on info@sydenhamschorea.org.uk if you would like to help.

- Run a local educational day for medical professionals and families
- Run a local support group or family day for patients of Sydenham's Chorea
- Help us contact patients in your local area
- Help us fundraise in your local area

The Sydenham's Chorea Association run various support and educational events throughout the year. For details of all of our events, visit the Events page of our website www.sydenhamschorea.org.uk or visit our Facebook or Twitter pages.



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