



info@saca.org.uk

Helpline 078 26 004 008

Annual Report

1st April 2023 – 31st March 2024

Charity Number NIC 100528

HMRC charity number XT6688

Registered Address: 4 Broughton Park, Belfast BT6 0BD

Charity Trustees/Office Bearers for the period 1st April 2023 – 31st March 2024

Miriam Martin	Chairperson and Admin
Victor Mayhew	Vice-Chairperson and Newsletter Editor
Grainne Timlin	Treasurer
Anthony Doran	Data Protection Officer & IT
Regina Maguire	Facebook Admin
Susan Mathews	Helpline, Facebook Moderator
Melissa Murray	Trustee, Facebook Moderator (resigned May 2024)

Other roles

Volunteer

Deborah Ferry	Facebook Moderator (resigned March 2024)
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Patron and Medical Advisor

Mr Mano Shanmuganathan MD FRCS, Consultant Neurosurgeon

Bankers for the period 1st April 2023 – 31st March 2024

Danske Bank,
Business Banking
P O Box 183
Donegall Square West
Belfast BT1 6JS

Independent Examiner	Colette Eklund
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Annual Report for the year 1st April 2023 – 31st March 2024

The purposes of our charity are as follows: The Association is established for the relief of sickness and to promote the benefit of sufferers of Syringomyelia, Arnold Chiari Malformation and associated conditions in the Greater Belfast and its environs of Northern Ireland without distinction of age, gender, disability, sexual orientation, nationality, ethnic identity, political or religious opinion and in particular:

(a) to foster an atmosphere of mutual support among people suffering from Syringomyelia, Arnold Chiari Malformation and associated conditions and their carers/families and to encourage them to provide mutual support to each other;

(b) to raise awareness amongst the medical profession and general public about the effects of Syringomyelia, Arnold Chiari Malformation and associated conditions, and methods of management.

In setting our objectives and planning our activities for the year the trustees have given careful consideration to the Charity Commission for Northern Ireland's guidance on public benefit to ensure that the activities have helped achieve the charity's purposes and provide a benefit to the beneficiaries.

Throughout the group activities and events any private benefit received by members of the public or group members was purely incidental to the purposes of our charity.

Our private Syringomyelia Arnold Chiari Association Facebook page continues to grow in membership. There we are able to support members and families with our conditions, we share relevant information on our Facebook page regularly.

Our SACA Helpline is also available for anyone who needs information and support by telephone. We also have a confidential email service – support@saca.org.uk

The SACA newsletter is very helpful for sharing personal stories and news, reaching all our SACA members including those who can't attend our events or aren't on social media.

Over the year we also set about our rebranding, planning a new logo and new merchandise.

We ensure at least one of our trustees represents the charity at meetings and events organised by NI Neurological Charities Alliance (NINCA) and NI Rare Disease Partnership (NIRDPA) and Neurology events organised by the Patient and Client Council. We are thankful to those organisations for their help and support.

SACA trustee Susan Mathews is a patient representative with the Department of Health's Pharmacy Personal Advisory Group.

The events that took place during this financial year were as follows:

Burrendale Hotel, Newcastle - on 12th June 2023 we arranged a meet up for a light lunch and chat with some of our past and present trustees many of whom are still SACA members. This invigorated us and then we set about organising a summer event.

Montalto Estate, Co Down - on Sunday 30th July 2023 we held our SACA summer event. We enjoyed the chat and treats from the café, some families got to the adventure playground before the showers and others took a stroll despite the rain.

Ramada Hotel, Belfast was the venue for our SACA Annual General Meeting on 5th November 2023. It was lovely having a face to face event AGM again, the first since the pandemic.

In January 2024 we held 3 trips to the Pantomime in the Grand Opera House, Belfast with a 64 seats booked, and our SACA families young and old enjoyed the fun.

We were represented at the All-Ireland Rare Disease Conference in Farmleigh House, Dublin on 29th February 2024.

Two trustees took part in the Neurology Engagement Review with the Patient Client Council and the Department of Health in March 2024. We look forward to further updates from the Department of Health.

I want to thank all our trustees and volunteers who generously offer their time and services on a voluntary basis. Also a big thank you to our fundraisers, donors and supporters for their generosity and support, which motivates us to keep going for the greater benefit of the SACA charity and it's members.

Compiled by: Miriam Martin, Chairperson
Dated: 19th October 2024