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Annual Report

1st April 2022 – 31st March 2023

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 2022 – 31st March 2023

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 elected May 2022

Other roles

Volunteer

Deborah Ferry Facebook Moderator

Patron and Medical Advisor

Mr Mano Shanmuganathan MD FRCS, Consultant Neurosurgeon

Bankers for the period 1st April 2022 – 31st March 2023

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

Independent Examiner Colette Eklund

Annual Report for the year 1st April 2022 – 31st March 2023

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) (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 closed Syringomyelia Arnold Chiari Association Facebook page continues to grow in membership and we are able support families with our conditions and share information regularly.

Our Helpline is there for anyone who needs information and support and the SACA newsletter is 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.

Our SACA Annual General Meeting was held virtually to safeguard the health of the trustees on 25th May 2022, the majority of the trustees were still keeping their contacts low.

Chairperson Miriam Martin read her Chairs report on what has happened in SACA since the last Annual General Meeting in October 2019, especially how we adapted to the virtual world since March 2020. She passed on deepest sympathies to those who lost loved ones since we last met.

SACA Treasurer Grainne Timlin presented our Financial Accounts and Independent Examiners Report for the for the periods 1st April 2019 -31st March 2020, 1st April 2020 - 31st March 2021 and 1st April 2021 to 31st March 2022. Grainne reported income from Membership fees was down in the middle of the pandemic as we hadn't any face to face events, but we were very grateful for all the fees, donations and fundraising that was received throughout these periods.

Proposals to revamp the SACA 50% Fund to assist members, were put forward by SACA Vice Chairperson Victor Mayhew. The changes suggested were, to make the Fund more confidential and he suggested that only two of the Trustees would be involved in the

processing of applications - two trustees are required to sign off on any payments of the charity's funds. The total fund would remain at £2000, with the maximum pay-out increased from £500 per individual to £1000. The recipient would only be required to pay 20% of the claim and the charity pay the other 80%. He also suggested as we were reducing the applicants from 4 to 2, that the fund would be reviewed by trustees every six months and topped up if funds were spent and if additional funds were available. A revised name was still to be agreed. A vote was taken and passed to give trustees permission to take charge of the fund and report back at the AGM and it was agreed that the trustees would discuss the proposals at the next trustees meeting.

A suitable venue for a summer event was discussed. A new trustee Melissa Murray was elected, the remaining trustees confirmed they wished to remain for another year and were re-elected. We also welcomed two new members.

Following the AGM the SACA trustees completed the revamp of the 50% Fund, accepted Victor's proposals and changed the name to the 80 20 Fund. Members were informed.

We held our first face to face meet-up in three years at Shanes Castle, Co Antrim on 31st July 2023; we had an enjoyable day out. It was a great opportunity to welcome new members and their families and renew old friendships. The sun shone too. We also celebrated our 30th anniversary which occurred in 2020.

In January 2023 we organised two trips to the Pantomime at the Grand Opera House, Belfast to see Cinderella, on Sat 7th January and Tues 10th Jan. These trips have proved very popular with our SACA families. We entered a draw on radio station U105 sponsored by Budget Energy and won £250 towards Panto tickets which was much appreciated. Thank you to the sponsors Budget Energy.

We continued over the year to be represented and have our voices heard at online and face to face meetings with our Alliance partners, NI Neurological Charities Alliance and NI Rare Disease Partnership and had the opportunity to attend several meetings of the All Party Group in Neurology and All Party Group in Rare Diseases and thank these groups for their support.

The expenses for the running costs of our charity, is sourced from subscription fees and the fundraising efforts of our members and their families, along with donations from members and the public and we are extremely grateful for their generosity. We also wish to thank to BT Charitable Giving for matching staff donations this financial year of £60.00.

As chairperson, I want to thank all our dedicated team of trustees and volunteers who generously offer their time and services on a voluntary basis, and thank our many supporters.

Compiled by: Miriam Martin, Chairperson

Dated: 3rd November 2023