

Syringomyelia Arnold Chiari Association

Northern Ireland · Charity number 100528

Details

Known as SACA

Status Received

Registered 2014-08-12

Register [View on the Charity Commission for Northern Ireland register](#)

Contact

Address 4 Broughton Park
Belfast
Bt6 0bd
BT6 0BD

Phone 02890800948

Email info@saca.org.uk

Activities

Purposes: The Association is established for the relief of sickness and to promote the benefit of sufferers of Syringomyelia, Arnold Chiari Malformation and associated conditions (hereinafter called the "beneficiaries") in the Greater Belfast and its environs of Northern Ireland (hereinafter called the "area of benefit") 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.

What the charity does: The advancement of education, The advancement of health or the saving of lives, The relief of those in need by reason of youth, age, ill-health, disability, financial hardship or other disadvantage

How the charity works:

Advice/advocacy/information, Counselling/support, Disability, Education/training, Medical/health/sickness

Who the charity helps: General public, Physical disabilities

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£4,539	£1,831	£0	0

Trustees

Name	Role	Appointed
Elaine Curry		
Grainne Timlin		
Miriam Martin		
Regina Maguire		
Susan Mathews		
Tony Doran		
Victor Mayhew		

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Accounts

Syringomyelia Arnold Chiari Association				
Reporting Period 1/4/2024 to 31/3/2025				
Charity Number 100528				
Statement of Receipts and Payments				
	Unrestricted Funds	Restricted Funds	24/25 Total Funds	23/24 Total Funds
	£	£		
Receipts				
Voluntary Receipts				
Donations	2680.53		2680.53	504.32
Fundraising	1279.91		1279.91	157.94
Interest Building Society Savings account	51.99		51.99	19.25
Interest Building Society 1 Yr Savings Bond	53.01		53.01	34.52
Interest Building Society 2 Yr Savings Bond	23.37		23.37	22.54
From Charitable Activities				
Membership Fees	272		272	392
Merchandise	178		178	
Outing to Panto	N/A		N/A	925
Total Receipts	4538.81		4538.81	2055.57
Payments				
Cost of charitable activities - events & activities	779.5		779.5	2882.21
General Expenses	568.75		568.75	939.34
Travel Fund	45		45	45
Charity Insurance	398.56		398.56	381.56
Bank Fees	39.48		39.48	39.09
Total Payments	1831.29		1831.29	4287.2
Net Receipts/Payments	2707.52		2707.52	-2231.63
Syringomyelia Arnold Chiari Association				
From 01/04/2024 to 31/3/2025				
Charity No 100528				
Statement of Balances				
	24/25		24/25	23/24
	Unrestricted Funds	Restricted Funds	Total Funds	Last Year
	£	£	£	£
Cash Funds				
Cash at bank and in hand	5614.37		5614.37	3035.22
Savings Account	2215.02		2215.02	2163.03
Total Cash Funds	7829.39		7829.39	5198.25
Investment Assets				
2 yr Bond	1061.91		1061.91	1038.64
1 Year Bond	1113.74		1113.74	1060.73
Total	10005.04		10005.04	7297.52

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Accounts

Syringomyelia Arnold Chiari Association				
Reporting Period 1/4/2023 to 31/3/2024				
Charity Number 100528				
Statement of Receipts and Payments				
	Unrestricted Funds	Restricted Funds	23/24 Total Funds	22/23 Total Funds
	£	£	£	£
Receipts				
Voluntary Receipts				
Donations	504.32		504.32	835.96
Fundraising	157.94		157.94	546
Interest Building Society Savings account	19.25		19.25	4.64
Interest Building Society 1 Yr Savings Bond	34.52		34.52	12.28
Interest Building Society 2 Yr Savings Bond	22.54		22.54	6.06
From Charitable Activities				
Membership Fees	392		392	428
Outing to Panto	925		925	795
Refund 50% Fund				200
Total Receipts	2055.57		2055.57	2827.94
Payments				
Cost of charitable activities - events & activities	2882.21		2882.21	2298.25
Cost of charitable activities - 50% Fund for members				440
General Expenses	939.34		939.34	99.88
Travel Fund	45		45	38
Charity Insurance	381.56		381.56	357.47
Bank Fees	39.09		39.09	41.12
Total Payments	4287.2		4287.2	3274.72
Net Receipts/Payments	-2231.63		-2231.63	-446.78
Syringomyelia Arnold Chiari Association				
From 01/04/2023 to 31/3/2024				
Charity No 100528				
Statement of Balances				
	23/24		23/24	22/23
	Unrestricted Funds	Restricted Funds	Total Funds	Last Year
	£	£	£	£
Cash Funds				
Cash at bank and in hand	3035.22		3035.22	3343.16
Savings Account	2163.03		2163.03	2143.78
Total Cash Funds	5198.25		5198.25	5486.94
Investment Assets				
2 yr Bond	1060.73		1060.73	1016
1 Year Bond	1038.54		1038.54	3026.21
Total	7297.52		7297.52	9529.15

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Annual report



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

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Annual return

Independent examiner's report to the charity trustees of Syringomyelia Arnold Chiari Association

I report on the accounts of Syringomyelia Arnold Chiari Association for the year ended 31st March 2024.

Respective responsibilities of charity trustees and examiner

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the Charities Act (Northern Ireland) 2008.

It is my responsibility to:

examine the accounts under section 65 of the Charities Act

- follow the procedures laid down in the general Directions given by the Commission under section 65(9)(b) of the Charities Act

state whether particular matters have come to my attention.

Basis of independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters have come to my attention giving me cause to believe:

1. That accounting records were not kept in accordance with section 63 of the Charities Act
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirements of the Charities Act
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Dated: 19/10/2024

Colette Eklund

Independent Examiner

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Accounts

Syringomyelia Arnold Chiari Association				
Reporting Period 1/4/2022 to 31/3/2023				
Charity Number 100528				
Statement of Receipts and Payments				
	Unrestricted Funds	Restricted Funds	22/23 Total Funds	21/22 Total Funds
	£	£	£	£
Receipts				
Voluntary Receipts				
Donations	835.96		835.96	1216.48
Fundraising	546.00		546.00	99.73
Bank Interest				0.52
Interest Building Society Savings account	4.64		4.64	3.43
Interest Building Society 1 Yr Savings Bond	12.28		12.28	13.93
Interest Building Society 2 Yr Savings Bond	6.06		6.06	9.94
From Charitable Activities				
Membership Fees	428.00		428.00	136.00
Outing to Panto	795.00		795.00	
Refund 50% Fund	200.00		200.00	
Total Receipts	2827.94		2827.94	1480.03
Payments				
Cost of charitable activities - events & activities	2298.25		2298.25	678.78
Cost of charitable activities - 50% Fund for members	440.00		440.00	128.50
General Expenses	99.88		99.88	14.39
Travel Fund	38.00		38.00	

Charity Insurance	357.47		357.47	340.69
Bank Fees	41.12		41.12	28.50
Total Payments	3274.72		3274.72	1190.86
Net Receipts/Payments	-446.78		-446.78	289.17

Syringomyelia Arnold Chiari Association				
From 01/04/2022 to 31/3/2023				
Charity No 100528				
Statement of Balances				
	22/23		22/23	21/22
	Unrestricted Funds	Restricted Funds	Total Funds	Last Year
	£	£	£	£
Cash Funds				
Cash at bank and in hand	3343.16		3343.16	1312.92
Savings Account	2143.78		2143.78	4639.14
Total Cash Funds	5486.94		5486.94	5952.06
Investment Assets				
2 yr Bond	1016.00		1016.00	1009.94
1 Year Bond	3026.21		3026.21	3013.93
Total	9529.15		9529.15	9975.93

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Annual report



info@saca.org.uk

Helpline 078 26 004 008

Annual Report

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HMRC charity number XT6688

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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

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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

Syringomyelia Arnold Chiari Association

Northern Ireland - Charity number 100528

Annual return

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Independent examiner's statement

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Dated:

4 November 2023

Signed:

Colette Eklund

Colette Eklund

Independent Examiner