

Isle Of Wight Association of Spina Bifida and Hydrocephalus

Chair's Report to the 56th Annual General Meeting

2024 has been a year of reflection for me as the Chair and I was delighted to see so many members and supporters at our extra meeting in January. At that meeting it was very clear to me how much members value the charity and the need to explore options for how we strengthen the charity moving forward became very apparent.

I am pleased to welcome Donna Woodcock and Joost Spit as Trustees and I would like to take this time to also thank our current trustees, independent grant assessor and Rebecca Cadle our secretary for their support and assistance with the Association.

Once again it is very important to acknowledge the amazing support Donna Woodcock and her family provide to the Association through their fundraising activity. 2024 saw another fabulous year with a fundraising total of over £8,000 raised for the Association. Donna's overall fundraising total since 2016, is nearing an incredible £40,000. We are forever grateful for the work that Donna undertakes. This was recently recognised at a local award ceremony where Donna was presented with an award for her work, Well Done Donna!

Today we are recommending a further minor amendment to the Constitution objects – more details are in the enclosed papers.

Since our meeting in January, I have been exploring options of a partner organisation to work with the Association. I will provide an update on progress at the AGM. A copy of the paper we have prepared to assist the conversation with potential partners follows.

Carol Alstrom
Chair of Trustees
IWASBAH

Isle of Wight Association for Spina Bifida and Hydrocephalus

Options for Partnership Working

The Isle of Wight Association for Spina Bifida and Hydrocephalus was established in 1969 with the aim of supporting people across the Isle of Wight with these conditions.

In 2023 the long-standing chair stepped down alongside a number of Trustees and a new chair, Carol Alstrom, was appointed. Carol and the existing Treasurer Wendy Murwill have worked over the last two years to maintain the charity and during that time have recruited 3 other Trustees to support the association moving forward. They are Tony Stables, Gill Kennett and Glenn Smith. At the current time the main functions of the charity are distribution of grants to members to aid independent living where statutory services are unable to assist and provide signposting to other services who may be able to assist members with independent living.

The Association has a strong fundraising team who currently generate around £8,000 per annum. A small number of grants are also received from local grant making charities.

In January 2025 the Trustees met with members of the Association and carers/families to discuss the way forward. It was agreed that we would explore partnering with another Island based organisation to strengthen the offer. This would include potentially working with the existing members to establish what support they want, establishing how we widen the offer of the charity and attract new members with these conditions and explore what support may be available for backroom functions.

It was also agreed that we would seek to recruit some additional Trustees with a range of backgrounds including grants/fundraising, media/PR/social media and finance.

This paper provides an introduction to IWASBAH to assist potential partners in considering whether they would want to explore working with the Association.

Financial Health

The Charity has financial resources of approximately £110,000, fundraises and receives grants to around £10,000 per annum and gives a range of grants for equipment and traveling expenses for mainland healthcare to members to a similar level. More detail is available on request.

Partnership

We are looking to work with another Island based organisation to do the following:

1. Link with our existing 33 members and talk to them what they need from the Association, over and above the current offer. In the past a worker has supported members with applications for funding, shopping and other tasks, this stopped during Covid and the staff member moved onto a new role. The role was not replaced. The Board at that time were not happy with the way the worker was performing so decided not to renew the role. From this work the Association would want to understand members needs and how members feel these can be met. At that point we would want to discuss with the partner what options may be available to meet that need.
2. Undertake an exercise to establish how the Association can expand its membership and reach to people with spina bifida and/or hydrocephalus. The focus in the past has been on establishing links with the maternity unit at St Marys. This has proved unsuccessful but does not mean this couldn't be part of an approach. Most of the babies born with these conditions will be born on the mainland (predominately Southampton) and exploring links

with them would be part of the work. Alongside this consider how to extend the support of the Association to members in the community. Additionally, links to genetic services and neurological care in Southampton may also form part of the work. There is a nationally recognised centre of excellence at Chelsea and Westminster Hospital which some Isle of Wight Patients have been seen at. Refreshing the links with them will also be part of this workstream. Finally, local links through primary care services, ensuring GP's and other primary care practitioners are aware of the Association.

3. Backroom functions for the Association mean the administration of the membership database and management and payment of grants. We would be keen to establish if a partner would be willing to assist with this function.

We would welcome a discussion with potential partners on how these functions could be fulfilled and the potential costs. Further work will need to be undertaken with the Board of Trustees and the Membership to work up these options in more detail.

10th February 2025.

Isle of Wight Association for Spina Bifida and Hydrocephalus
Registered Charity No. 296313
Annual Accounts for year ending 31st December 2024

<u>Receipts & Payments 2024</u>		<u>£</u>
Total Combined Receipts		45,185.71
Total Combined Payments		(45,499.09)
	Net between receipts and (payments)	(313.38)
	Balance brought forward from 2023	4,764.69
	Balance c/f	4,451.31

<u>Receipts and Payment</u>					
<u>Receipts</u>	<u>2024</u>	<u>2023</u>	<u>Payments</u>	<u>2024</u>	<u>2023</u>
	<u>£</u>	<u>£</u>		<u>£</u>	<u>£</u>
Donations/Legacy	1,377.00	1,996.67	Members: Grants	(3,860.05)	(1,560.00)
Fundraising	8,888.20	8,668.09	Members: Equipment Repairs & Maintenance	(2,000.00)	(1,188.60)
Community Action Grants	-	23,750.00	Members: Hospital Travel & Expenses	(411.03)	(648.09)
Miscellaneous (transfer from petty cash)	101.42		Members: Community Action Grants	-	(23,864.20)
Investments Sold (funds closed)	34,819.09	4,136.66	Administration - Stationery/Ink/Postage	(187.43)	(567.75)
			IWASBAH payment to members	(9,940.00)	(1,320.00)
			Meeting Expenses (Room Hire/Taxis)	(210.00)	(123.00)
			Social Events	(200.00)	(408.00)
			Insurance	(190.58)	(96.00)
			Investments Purchased	(28,500.00)	(33,300.00)
	45,185.71	38,551.42		(45,499.09)	(63,075.64)

Reconciled Account Balances as of 31st December 2024

	<u>Bank Account</u>	<u>Petty Cash</u>	<u>Total</u>
	<u>£</u>	<u>£</u>	<u>£</u>
Balance b/f on 01/01/2024	4,764.69	101.42	4,866.11
Plus Total Receipts	45,185.71	0.00	45,185.71
Plus Transfers In			
	49,950.40	101.42	50,051.82
Less Payments	(45,499.09)	(101.42)	(45,600.51)
Less Transfers Out			
Balance c/f as 31/12/2024	4,451.31	0.00	4,451.31

Notes

Investments**£**

Investment Value as at 31/12/2023	115,934.51
Investments Sold (account closed)	(26,851.39)
Funds transferred into the investments	28,500.00
Funds transferred out of the investments	(8,050.00)
Interest	3,754.90
Appreciation	4,934.86
Investment Value as at 31/12/2024	<u>118,222.88</u>

Treasurer**Ms Wendy Murwill****Date: 17/03/2025****Accounts Independently Examined by:****Mr Matthew Green****Date: 17/03/2025**

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