

SBH Scotland.

There  
for

the journey.



**Annual Report 2018**

Spina Bifida  
Hydrocephalus  
Scotland







*By far the best support  
we have in our lives.”*

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# Welcome



**Spina Bifida Hydrocephalus Scotland (SBH Scotland) provide a lifetime commitment of specialist support and information to all those affected by these lifelong, complex disabilities including family members, carers and healthcare professionals.**

Created in 1965 by parents, for parents and their children, over 50 years later we're now a national charity with individuals remaining at the heart of everything we do.

SBH Scotland's Direct Services Support Team work across Scotland to support over 4,000 individuals with a range of services including: a helpline, one-to-one support in homes and schools, combined clinics

in hospitals, support groups, financial advice, play sessions, outings and workshops.

All of our services are completely free to members and with little statutory funding we are indebted to grant making bodies, individuals and companies who allow us to support all those who ask for our help. Thank you for your support and for taking the time to find out more about us in this annual report.

# Chairperson's Report



**Each year brings with it challenges both internally and externally** however, thanks to a dedicated staff team nationwide, a committed board of trustees and the continued support of generous individuals and grant making bodies I'm proud to say that this year we have still been able to increase our level of service delivery. Thanks, in part, to a generous legacy receipt the overall income generation has also been extremely positive against budget.

We remain the only charity in Scotland dedicated to supporting spina bifida and/or hydrocephalus. As these conditions are classed as rare, with around one in every thousand pregnancies affected, they are often overlooked and therefore the provision of national health services for our members are incredibly limited. However,

the demands which each disability brings and the pressures they can put on the individual, parents and carers are very real. That is why SBH Scotland's range of services are a vital lifeline for so many and why they remain as relevant as ever.

Responding to the needs of our members is as important as ever but against a backdrop of over 20,000 registered charities in Scotland alone, the search for funding remains as difficult as ever. A big challenge for us remains time-limited funding where successful projects are launched, becoming an important part of people's lives. At the end of the funding term SBH Scotland then has to make some serious decisions about the ability to continue funding them. Over the past twelve months we have therefore made a concentrated

effort to focus our investigations on sustainability in a bid to ensure the integration of time-limited projects into core services where it is necessary. Over the next few years we hope to see those plans come into action.

Our report this year gives us the opportunity to reflect on many of the positive outcomes achieved through our extensive work and I would personally like to thank all those who have, and continue to, make those achievements possible.

**Dr Margo L Whiteford CBE**



**Chairperson**



## Stronger Links: Stronger Families





**Looking forward to another successful chapter**

In February SBH Scotland were delighted to announce that we had secured funding from the Big Lottery Fund Scotland to continue our 'Stronger Links: Stronger Families' project for the next 3 years.

This important project, covering Edinburgh, Lothian, Borders and Fife has made great strides in supporting families with children aged 0-9 since 2014 and the continued funding means we can do even more, growing the project to increase the support to children up to the age of 14 as well as covering Tayside.

# Chief Executive Summary

## Achievements

-  We continue to focus significant resource in encouraging all of our children to have the best chance in life through targeted early years and learning support. One specific area is that of bridging the attainment gap thanks to our 'Have A Go' project supported by Scottish Government through a CYPFEIF and ALEC Fund Grant.
-  Direct Services within Scotland have continued to increase with a more focused delivery within three regional teams. This has allowed more flexibility to respond to emerging regional variations in levels of demand and style of support.
-  National coverage remains constant for services including the Helpline, Clinical Support and Financial Support Services.
-  The organisation continues to be represented on national and international groups who have a particular interest in spina bifida, hydrocephalus and related conditions and to enable service user's voices to be heard in policy matters and service delivery.



## Looking forward...



In our commitment to e-health and innovation, we plan to launch an app called 'MyCarePod' for SBH Scotland members. The app offers the opportunity for members to access their own health and social care records on our electronic portal, diarise appointments and store important health and wellbeing information.



Thanks to funding from the DM Thomas Foundation we will be launching the Spiney the Diney Club to engage every one of the charity's children and siblings as well as being a wonderful resource and gift for each new born child.

**Andrew H D Wynd MBE**

**Chief Executive**



# Positive Partnerships

**Spina Bifida Hydrocephalus Scotland (SBH Scotland) work with all nursery or educational institutions that require our help.**

With so many children in every class, teacher and learning support assistants often have a mammoth task in nurturing the abilities of all the young people, especially when some of those have additional support needs.

As well as going in to schools and nurseries to provide talks for staff, SBH Scotland have spent this year growing the number of resources which are available to them. One of those resources involved working in partnership with teachers and students at Dalespark Primary in Peterhead, a school which

has an exceptional approach in working for the inclusion of those with additional support needs.

Together, we produced an educational film called **'Getting it right for me: Achieving, Included, Respected'** that offers insight into strategies which have worked well for our members.

The film follows Andrew who was born with spina bifida and hydrocephalus and has overcome many barriers during his life including the adjustment to becoming a permanent wheelchair user after sudden complications prevented him walking.





This film, along with existing SBH Scotland resources such as our Hydrocephalus and Learning booklet, will be promoted by the charity's support workers to schools across Scotland and will serve as a model of how these complex disabilities can be approached by those working in an education setting to help all children reach their full potential.

Our partnership working with Dalespark Primary saw it crowned winner of the 'Education Partnership' Award at the Scottish Power Foundation Awards in November 2017.

To view our film please visit our YouTube Channel @SBHScotland.

Grateful thanks to Big Lottery Fund and the ScottishPower Foundation for their support in the creation, production and distribution of this resource.



# Fundraising



Northern Tower  
Abseil



Cumbernauld 10K

Every year we budget annual unrestricted income based on the performance of previous years, knowledge of pending applications and service developments. Income from over 30 income streams are budgeted including trusts and foundations, special appeals, community fundraising, sponsored activities, corporate partnerships and social/corporate events. With a limited marketing budget the majority of the charity's fundraising successes were achieved via an increased use of digital opportunities, networking and personal approaches.

We made the decision to continue enhancing our use of digital from the previous year to drive online sales, promote events and most recently reduce costs from third party suppliers by the creation of our own in-house, online registration and payment system. This enhancement has not only streamlined our administration process but has also increased sponsored activity income by 22.17% in this financial year.

Similarly in events, through a combination of corporate networking, relationship building, press and digital promotions



Bungee Jump



Kiltwalk



Question of Burns

this year's Question of Burns saw an additional 125 people in attendance and an increase of 41.96% in income generation.

Additional income was also generated by the team via applications for Restricted Projects which would deliver time limited specialist services that would complement our core Family Support Services. We are also grateful to the Scottish Government for a welcome contribution of £160k to support our core activities.

Thank you to every person who

donated, attended an event, volunteered, sat on a fundraising committee, undertook a challenge or generously provided a grant to SBH Scotland in 2017/18. We still need to raise over £1million each year and we can't do it alone. Together we can make a real change for the better in Scotland – Thank you!

**Deborah Roe**

A handwritten signature in cursive script.

**Director of Fundraising**



# Did You Know



In every **£1**



we spend goes to providing our specialist support services

Our 2 Finance Support Workers were able to achieve over

**£170,000**

in benefit gains, one off payments and grants for members



*“Thank you for a fantastic baby group catch up today. It was lovely to meet new mums and babies! I always love coming through, and I’m so grateful for the support you have given.”*



Support is offered across all 32 Scottish local authority areas



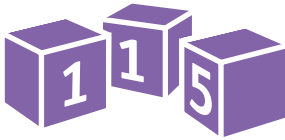
34% increase in service delivery



We provided 29 school talks across Scotland.



This year we held over



Groups and Playschemes across Scotland including trips to Lego Live, Auchengillen Outdoor Centre and a Seagull Trust Barge cruise.



*“Basically, thank you for being there for our family for the past 19 years.”*



web sessions took place on [sbhscotland.org.uk](http://sbhscotland.org.uk)

1

New Sensory Garden was built





# Meet the Super Squad – Forging Friendships

**SBH Scotland groups and playschemes are a great way for children to make new and lasting friendships.** Whether it's through musical, creative or sensory play, friendships for children

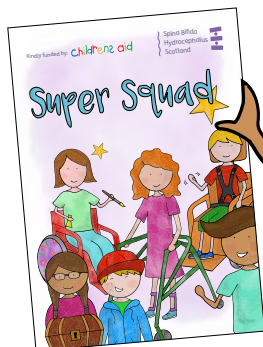
can be forged for life in seconds. Our groups also offer the opportunity for parents and carers to meet and build up a permanent network of

vital support both inside and outside of the charity.

Every child is unique with individual abilities and personalities but they may not always know how to communicate their needs or emotions. To help with this we created the Super Squad to introduce some of the conditions which children attending our groups have in the hope that children will relate and talk further about themselves to parents, siblings and new friends.



For full details on our range of groups please visit: [sbhscotland.org.uk/groups](http://sbhscotland.org.uk/groups)



Thanks to funding from Children's Aid Scotland we were able to bring the Super Squad to life through a colourful, illustrated booklet. The booklet features a variety of children each talking about a different aspect of their condition, be it spina bifida, epilepsy or hydrocephalus and we even meet one of the siblings to hear why he enjoys attending with his sister. Suitable to read in our groups or take home as an activity this exciting booklet gives our children the opportunity to reflect on their

own conditions, their similarities to others and focus on their own likes and dislikes.

We're proud to be able to provide a different range of support groups in different areas of Scotland. Ranging from Family Groups in Aberdeen and Glasgow to coffee catch ups and project outings across Edinburgh and Lothian. Groups are also available for all ages and our central belt youth group and adult social groups also continue to go from strength to strength.



Sinc

# Health Check Clinics

**When our members turn 16 they move from paediatric healthcare into the adult healthcare system.** The reality of this is that there are no more regular reviews with NHS consultants and doctors and the only time contacts are made with healthcare professionals is usually when conditions have reached crisis point. From August, thanks to the recruitment of a new Nurse Specialist, SBH Scotland has launched monthly

‘Health and Wellness’ clinics for all adults with spina bifida and/or hydrocephalus. The aim of the health checks is to support our members in developing a wide range of self-management strategies, encouraging them to be more proactive about their own conditions, treatments and care. Potential problems can often be picked up and dealt with to prevent more serious health problems developing.



# e August...

## Health Check Clinics



46

members have had face to face appointments



As a result of early feedback from initial health checks we ran a Continenence Information Day in October



10

members have had phone/skype appointments

The clinics are confidential and are carried out in a fully equipped treatment room at our centre, The Dan Young Building, in Cumbernauld. For those who can't make it to our centre, phone or webcam (through NHS Attend Anywhere) consultations (pictured) are also offered, making it an accessible option for those who live in remote and rural areas.

Many adults who are living with a long-term health condition can feel isolated or low in mood and are disinclined to go out or be involved in any social activities. Therefore, a further part of the clinic focuses on mental health and emotional wellbeing where we talk to members about how they're feeling so we can offer additional support and guidance.

Supported by



**The Hospital Saturday Fund**

# Summarised Accounts

For Year ending 31 March 2018

	Unrestricted Funds £	Restricted Funds £	Expendable Endowment £	Total Funds 2018 £	Total Funds 2017 £
<b>Income and Endowments</b>					
<b>From</b>					
Donations and legacies	777,291	-	-	777,291	282,095
<b>Charitable activities</b>					
Supporting those with spina bifida & hydrocephalus	17,802	382,356	-	400,158	458,052
Other trading activities	439,166	-	-	439,166	397,623
Investment income	2,770	4,172	-	6,942	6,429
<b>Total</b>	<b>1,237,029</b>	<b>386,528</b>	<b>-</b>	<b>1,623,557</b>	<b>1,144,199</b>
<b>Expenditure on</b>					
Raising Funds	350,846	-	-	350,846	288,461
<b>Charitable activities</b>					
Supporting those with spina bifida & hydrocephalus	491,056	439,566	40,602	971,224	976,937
<b>Total</b>	<b>841,902</b>	<b>439,566</b>	<b>40,602</b>	<b>1,322,070</b>	<b>1,265,398</b>
Net gains/(losses) on investments	(866)	(1,138)	-	(2,004)	20,578
<b>Net Income/(Expenditure)</b>	<b>394,261</b>	<b>(54,176)</b>	<b>(40,602)</b>	<b>299,483</b>	<b>(100,621)</b>
Transfers between funds	(60,081)	52,678	7,403	-	-
<b>Other recognised gains/(losses)</b>					
Actuarial gains/losses on defined benefit schemes	3,000	-	-	3,000	(12,000)
<b>Net movement in funds</b>	<b>337,180</b>	<b>(1,498)</b>	<b>(33,199)</b>	<b>302,483</b>	<b>(112,621)</b>
<b>Reconciliation Of Funds</b>					
Total funds brought forward	417,646	122,854	766,178	1,306,678	1,419,299
<b>Total Funds Carried Forward</b>	<b>754,826</b>	<b>121,356</b>	<b>732,979</b>	<b>1,609,161</b>	<b>1,306,678</b>

	2018 £	2017 £
<b>Balance Sheet - As 31 March 2018</b>		
<b>Fixed assets</b>		
Tangible assets	732,979	766,178
Investments	211,067	211,258
	<u>944,046</u>	<u>977,436</u>
<b>Current assets</b>		
Debtors	87,230	102,751
Cash at bank	985,928	685,416
	1,073,158	788,167
<b>Creditors: Amounts falling due within one year</b>	<u>(178,043)</u>	<u>(210,925)</u>
<b>Net current assets</b>	<b>895,115</b>	<b>577,242</b>
<b>Total assets less current liabilities</b>	<b>1,839,161</b>	<b>1,554,678</b>
<b>Pension Liability</b>	<b>(230,000)</b>	<b>(248,000)</b>
<b>Net assets</b>	<b>1,609,161</b>	<b>1,306,678</b>
<b>Unrestricted funds</b>	754,826	417,646
<b>Restricted funds</b>	121,356	122,854
<b>Expendable Endowment funds</b>	732,979	766,178
<b>Total Funds</b>	<b>1,609,161</b>	<b>1,306,678</b>

## Statement by the Trustees

These summarised accounts are a summary of information extracted from the full annual statutory accounts for the financial year ended 31 March 2018 which were approved on 12 July 2018 and signed by the auditor, Hardie Caldwell LLP, who gave an unqualified audit report, on 31 July 2018.

These summarised accounts may not contain sufficient information to allow for a full understanding of the financial affairs of the charity.

The full annual statutory accounts and the auditors' report on those accounts including the report of the trustees may be obtained from The Dan Young Building, 6 Craighalbert Way, Cumbernauld G68 0LS.



# Thanks

**We are continually grateful for the ever generous support of individuals, trusts, grant making bodies, companies and legacies which ensure that Spina Bifida Hydrocephalus Scotland is available to provide dedicated support to all those in Scotland who ask for our help. We would like to thank everyone who donated in the 2017/18 financial year. Due to the number we are unable to list each and every one of you but rest assured we remain incredibly thankful.**

## **Trusts**

Aberbrothock Skea Trust  
Alma & Leslie Wolfson Charitable Trust  
AMW Charitable Trust  
Ann Jane Green Trust  
Appletree Trust  
AS Lass Charities  
Bank of Scotland Foundation  
Barbara Ward Children's Foundation  
BBC Children in Need  
Bruce Wake Charitable Trust  
Cameron Whiteford Charitable Trust  
Commonweal Fund  
Cruden Foundation  
D W T Cargill Fund  
Dalziel Charitable Trust  
DM Thomas Foundation for Young People  
Dullatur Foundation  
Edinburgh Children's Holiday Fund  
Edinburgh Innovations Ltd  
Global Charities T/A Make Some Noise  
Hugh & Mary Miller Bequest  
Hugh Fraser Foundation  
IBB Trust  
James Inglis Testamentary Trust  
James Tudor Foundation  
James Weir Foundation  
James Wood Bequest Fund  
John Napier's Trust  
Joicey Trust  
JTH Charitable Trust  
Kilpatrick Fraser Charitable Trust  
Leach Family Charitable Trust  
Leith Benevolent Association Ltd  
Leng Charitable Trust  
Lynn Foundation  
Michael & Anna Wix Charitable Trust  
Miss AM Pilkington Charitable Trust  
Miss E C Hendry's Trust

Mory Wilson Trust / Rotary Club of Rutherglen  
Nancie Massey Charitable Trust  
Netherton Charitable Trust  
Nigel Bruce Charitable Trust  
Noble Resolve Gospel and Temperance Mission Auxilliary  
Northwood Charitable Trust  
PF Charitable Trust  
Radio Clyde Cash for Kids  
RKT Harris Charitable Trust  
Santander Foundation  
Scottish Children's Lottery  
Scottish Power Foundation  
Shared Care Scotland  
Sir Gerald Elliot  
Souter Charitable Trust  
Suburban Taverns Charitable Trust  
Sylvia Aitken's Charitable Trust  
Talteg Limited  
Tay Charitable Trust  
Templeton Goodwill Trust  
Tesco Bags of Help  
The Adamson Trust  
The Alliance  
The Barcapel Foundation  
The Carmella and Ronnie Pignatelli Foundation  
The Corra Foundation  
The Goldsmiths' Company  
The Martin Connell Charitable Trust  
The New Maclay Murray & Spens Charitable Trust

W M Mann Foundation  
W M Sword Charitable Trust  
Ward Family Charitable Trust  
Zurich Community Trust  
One Trust that would prefer to remain anonymous

### **Grants and Local Authority Income**

North Lanarkshire Council  
Scottish Government

### **Legacies**

Anonymous (One)  
Mr John Foley  
Mr Tom Hardie  
Mrs Jessie Collie

### **Corporate Support**

180 Advisory Solutions  
4th Consulting Ltd  
Aberdeen Beauty Clinic  
Aberdeen Exhibition & Conference Centre  
All Talent Agency  
Anchor Tool Hire  
Anderson Anderson + Brown LLP  
Antonine Hotel  
Apache North Sea Limited  
Ardival Harps  
Arnold Clark Automobiles Ltd  
Asda Bearsden  
Asda Clydebank  
Asda Dyce Superstore  
Asda Peterhead



Aviva  
AxSys Technology Ltd  
B&M Bargain Store  
Bank of Scotland  
Barclays Wealth  
Beautylicious Aberdeen  
Best Western Kings Manor Hotel  
Binnie-McKenzie Partnership  
Blair Drummond Safari Park  
Blyth and Blyth, Cornerstone  
Bryden Medical Ltd  
BTO Solicitors  
Bungee Jump Scotland  
Cala Homes (West) Ltd  
Capri  
Carr Berman Crichton Solicitors  
CBRE Ltd  
Celtic FC Foundation  
Certas Energy  
Charles Bullen Stomacare Limited  
Chisholm Hunter  
Cineworld Cinemas  
City Building  
Clydesdale Bank Plc  
Cole AD  
Coloplast Limited  
Conoco Phillips  
Cooper Cromar  
Curtis Moore Ltd  
D Millen Butchers  
Dean's of Huntly Ltd  
Designer Contracts Ltd  
Diageo PLC  
Dobbies Garden Centre  
Dougall Baillie Associates  
Douglas Park Golf Club  
Dounby Post Office  
Dress 2 Party  
Edrington  
Ennis Flint EMEA  
Ernst & Young LLP  
Excellimore Ltd  
Exterior Media  
Fairfield Energy Limited  
Fat Buzz  
Fergusons Hair Academy  
Fitzsimons Ltd  
Foremost Products  
Frasers Property  
French Duncan  
Gary Thomson Hairdressing  
Givergy  
Glasgow Climbing Centre  
Glen Ord Distillery Visitors Centre  
Gleneagles Hotel  
Glengoyne Distillery  
Go Ape Aberfoyle  
Grants Bros (Meat Cannery) Ltd  
Grosvenor Casino Aberdeen  
Hallmark Hotel  
Hamilton Park Racecourse Company  
Limited  
Headline Hairdressers  
Healthcare Environmental Group

Highland Safaris	Miller Samuel LLP
Hilton Glasgow	MR Fencing Fife
Hook Fish & Chips (Formerly Di Marcos)	MSIS Oilfield Services
HSS	Nexen Petroleum U.K. Limited
Investec Wealth & Investment Ltd	Next Plc
Isle of Skye Candle Company	Nisala
J & J Lindsay	Oran Mor
J & W Aitken	Pagazzi
James Chapman (Butchers) Ltd	Paramount Creative
James Gibb Residential Factors	Peppermint Lounge
John Adams (Coach Supplies) Ltd	Persimmon Homes
John Amabile Design	Peter Brett Associates
Just Employment Law	Peter Vardy Vauxhall
Kingfisher Systems (Scotland) Ltd	Phase Eight
Knight Frank Edinburgh Commercial	PM Solutions
Knockhill Racing Circuit Ltd	PWC
Lava Jewellery	Rab Ha Restaurant
Lifestyle Value Convenience Store	Radisson Glasgow
Liquid Academy	Rainbow Room Academy
LJF Powder Coating Ltd	Regis Banqueting Ltd
Loch Lomond Group	Resonance Capital
MacGregor Healthcare Ltd	Rettie & Co
MacGregor MacDuff	Riverpark Investment & Financial
Mackies Pharmacy	Consultants Ltd
Make Believe Parties and Events	Robertson Construction
Malmaison	Robinson Low Francis
Mar Hall Hotel	Royal Bank of Scotland
Marco's on the Shore	Savills UK
McLeod & Aitken	Scotia Homes
Mel's Food & Wine	Scottish Parliament
Mercure Glasgow City Hotel	Segton Bar
Metropolitan	Servest

Sew Good  
Sim Building Group  
Slaters  
Smartest Energy  
St Vincent's Healthcare and Public  
Sector Consulting  
Standard Life Investments Limited  
Tennent Caledonian Breweries UK Ltd  
Tesco Craigmarloch  
The Big Partnership  
The Canal Inn  
The Heritage Bar  
The Keenan Consultancy  
The Palace Hotel  
The Rangers Charity Foundation  
The Warehouse Health Club  
(Aberdeen) Limited  
The Woodcutter  
Tor-na-coille  
Towergate Insurance  
Traveltek Ltd  
Trump International Golf Links,  
Scotland  
Trump Turnberry Resort  
Turning Heads  
Two Fat Ladies at the Buttery  
UBS AG  
Venture Studios  
Vets4Pets  
Village Hotel Glasgow  
Viper Innovations  
Vision Outsourcing Limited

West Carlston Garden Centre  
Westerwood House Hotel  
Weston Tavern  
Why Not Nightclub  
William Hill  
Williamwood Dairy  
Wylie & Bisset

### **Honorary Patron**

Gordon Ramsay OBE

### **Patron**

Duncan Bannatyne OBE

### **Ambassadors**

John Amabile  
Nicola Cassells  
Meggan Dawson-Farrell

### **Chairperson**

Dr Margo L Whiteford CBE

### **Directors**

Dr Rhoda A Abel  
Jonathan R Best  
Prof Robert Carachi MBE  
Thomas A Cromar  
Kirstie Dawson  
Fraser D Falconer  
Scott Howie  
William H Humes  
P Michael Samuel  
William S Scott MBE  
Deyrick Smith  
Brenda C Wilson

## **Chief Executive and Company Secretary**

Andrew H D Wynd MBE

## **Senior Management Team**

Clare Cogan Turner

Deborah Roe

Sophie Tear

Lorraine Wilson

## **Auditors**

Hardie Caldwell LLP

Statutory Auditors

Chartered Accountants

Citypoint 2, Tyndrum Street,

Glasgow, G4 0JY

## **Bankers**

The Royal Bank of Scotland

142-144 Princes Street

Edinburgh

EH2 4EQ

## **Solicitors**

Miller Samuel Hill Brown LLP

RWF House

5 Renfield Street

Glasgow

G2 5EZ





Having a baby  
with spina bifida or hydrocephalus  
is not the end.

Just the  
beginning.

SBH Scotland.  
There for the journey.

Help  
us make a  
difference.

## Spina Bifida Hydrocephalus Scotland

The Dan Young Building,  
6 Craighalbert Way, Dullatur,  
Glasgow, G68 0LS

**Tel:** 03455 211 811

**Email:** [mail@sbhscotland.org.uk](mailto:mail@sbhscotland.org.uk)

**Web:** [www.sbhscotland.org.uk](http://www.sbhscotland.org.uk)  
[www.hydrocephalusscotland.org.uk](http://www.hydrocephalusscotland.org.uk)

Spina Bifida  
Hydrocephalus  
Scotland



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