

scottish  
**spina bifida**  
association



## The Vision

Scotland's voice for Spina Bifida, Hydrocephalus and related conditions



## Our Strategic Development Plan

### Summary Achievements 2005 -2006

---

Each year we examine key aspects of our development under four main headings.

**Learning & Growth** - This reflects the extent to which our organisation is consistently evaluating and reviewing its operations and supports staff, volunteers and users to have a clear vision of the needs of our client group we serve, in the context of living in Scotland in the 21st Century.

**Stakeholders:** All those who have an impact on the Association for example users, supporters, funders, central and local government and any other interested parties or external factors which may impact on the work we do.

**Internal Systems:** This looks at how we manage the organisation operationally.

**Financial and Legal:** We examine ways in which we evaluate our financial controls and systems and other areas of compliance and governance.

Over the past year our achievements can be summarised as follows:

#### Learning & Growth

- Development of New Purpose Built Unit
- Revision of Child Protection Policy

#### Stakeholders

- Implementation of new Branch Policy
- Development of proactive contact with users
- Representation on national and local committees relevant to users

#### Internal Systems

- Preparation for integrated IT infrastructure in new build
- Purchase of new database to offer Electronic Patient Record facility for all users
- Update financial and donor development software
- Develop Policy documentation matrix for ongoing evaluation and review

#### Financial & Legal

- Increase in fundraising income and promotion of Capital Build fundraising campaign
- Develop Fundraising Marketing Plan
- Review financial accounting processes in line with SORP 2005
- Contribute to consultation on Charity Accounting Regulations

## The Mission

"The Scottish Spina Bifida Association seeks to increase public awareness and understanding of individuals with Spina Bifida/Hydrocephalus and allied conditions. It aims to support all those affected to identify their needs and to empower them to make informed choices and decisions."

## Annual Report

2006 has arguably been the most significant year in the 40-year history of the Association, as we committed to a radical review of our services, which culminated in the development of a new purpose built Family Support Centre and Scottish Headquarters in Cumbernauld. This state of the art centre, designed by Cooper Cromar Architects and built by Robertson Construction Central Ltd, will provide a superb location from which to offer an enhanced range of services to our users throughout Scotland. We have been delighted by the wide ranging support from the construction industry who have rallied round to support our cause and to transform our aspirations to reality.



In tandem with this major project we continue to provide a range of direct services to over 3000 users and in addition, provide an increasing level of advice and guidance to professionals throughout Scotland.

A wider public awareness of spina bifida and hydrocephalus has been made possible not least because of the decision to appoint the Association's first Honorary Patron, celebrity chef Gordon Ramsay OBE, who has raised the profile of the organisation and its work, significantly over the past twelve months.

We are privileged to continue to campaign on the need to fortify flour with folic acid to reduce the incidence of Neural Tube Defects of which Spina Bifida is the most common and severe form. Currently, folic acid is made available as a tablet supplement to women of child rearing age, with evidence suggesting that the uptake is generally low throughout the country. The need for mandatory fortification is therefore very strong and if implemented sensitively, can still afford consumer choice.

The Family Support Service staff continue to offer individualised support for children young people and adults affected by Spina Bifida and Hydrocephalus and allied conditions through their dedicated support service and national telephone Helpline.

We also continue to encourage and support local groups of parents and users to meet, in a style which meets need and demand. This can vary from locally constituted branches of the Association, to parent and toddler and local support groups which meet the specific needs of local users in local areas.

We have continued to enjoy real partnership working with a range of organisations within the voluntary and statutory sectors. These include collaborative work with our sister organisation in England, Wales and Northern Ireland, ASBAH and the development of multi disciplinary Spina Bifida clinics in the main hospital paediatric centres in Scotland.



We reported last year that the Association had committed to support research on Hydrocephalus and Visual Impairment through a joint venture with the Royal Hospital for Sick Children, Glasgow and the Caledonian University. The project has now commenced and we look forward to its development over the coming years.

We have also been invited to serve on the Neurosciences Implementation Group on behalf of the Neurological Alliance in Scotland as a direct result of our contribution the Scottish Executive's review of NHS Services in Scotland last year.

Our major initiative over the past year was to launch our new capital build campaign, which proposed the development of a new £1m capital build in central Scotland to offer a National Centre of Excellence for children and families affected by Spina Bifida, Hydrocephalus and related conditions. Our Honorary Patron, Gordon Ramsay who generated huge media interest on the day, formally launched our "Buy A Brick" campaign at our AGM in September last year. We are delighted to confirm that the project has been completed within timescale and within budget projections and the Association is now the proud owner of a wonderful new purpose built resource to serve Scotland's children and families.

Our planned future developments are designed to further enhance and develop the service delivery arm of the Association and will include the piloting of a new telemedicine initiative using the centre's state of the art video conferencing and audio visual facility to link families direct to the major hospital centres and enable them to enjoy the benefits of a "virtual" consultation with our staff, their hospital consultant and other health professionals without the need to travel long distances and hosted within a family friendly and supportive environment.

All of these achievements would not have been possible without the continued support of donors at corporate, community and individual level. We thank you sincerely for your continued support, without which we could not develop such new and innovative services for those for whom we have a special responsibility.



Andrew H D Wynd, Chief Executive

## Dr Margo Whiteford

2005-2006 has been a very exciting year for the SSBA, starting with the launch of the 'Buy A Brick' Campaign by our Honorary Patron, Gordon Ramsay last September. We received fantastic media coverage for this and the campaign proved to be very successful, allowing our staff to move in to our new premises in Cumbernauld in April 2006. The new building is a tremendous facility and with all of our staff under one roof the Association's business can now be run much more efficiently. Of course, none of this would have happened without the hard work and dedication of our Fundraising Officer, Deborah Roe, our Chief Executive, Andy Wynd and his supporting staff, the constant support and input from David Griffin and the many companies who donated their services and provided us with materials at cost price. We are indebted to them and sincerely appreciate their efforts.



We are starting this year on a very positive note and our hope is that the SSBA will now go from strength to strength



# SSBA Staff 2006

## ADMINISTRATION

---

**Andrew H D Wynd** - Chief Executive and Company Secretary

**Gail Jones** - Association Administrator

**Caroline Kenny** - Receptionist

**Cheryl Bradshaw** - Receptionist

## THE FUNDRAISING TEAM

---

**Deborah Roe** - Fundraising & Events Manager

**Sandra Bauld** - Fundraising Administrator

## THE FAMILY SUPPORT TEAM

---

**Anne Kane** - Family Support Worker

**Diane Lowrie** - Family Support Worker

**Anne Metcalfe** - Family Support Worker



## STAFFING

As at 31st March 2006

The Staffing Complement of the Association is as follows:

(The approved establishment is shown in brackets)

|          |   |                              |
|----------|---|------------------------------|
| 1(1)     | - | Chief Executive              |
| 1(1)     | - | Association Administrator    |
| 1(2)     | - | Administrative Assistants    |
| 1(1)     | - | Fundraising & Events Manager |
| 2.7(2.7) | - | Family Support Workers       |



## The last 12 months at SSBA



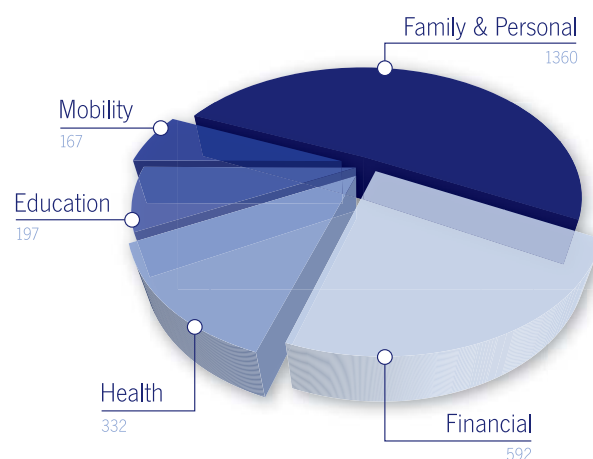
The construction of our new headquarters throughout the year took place in sun wind and rain. Ahead of schedule, on budget and exceeding expectations - the keys to The Dan Young Building, were presented to the organistaion on 31<sup>st</sup> March 2006. As a mark of appreciation to all those involved in the project a plaque was unveiled at the entrance to the new building.



### Statistical Information As at 31st March 2006

|                                                                                               |       |
|-----------------------------------------------------------------------------------------------|-------|
| Members of the Company                                                                        | 2070  |
| Number of Directors serving on the Board                                                      | 15    |
| <b>Users</b>                                                                                  |       |
| Children with Spina Bifida/Hydrocephalus or related conditions (under 18 years)               | 445   |
| Young People and Adults with Spina Bifida/Hydrocephalus or related conditions (over 18 years) | 985   |
| <b>Carers</b>                                                                                 |       |
| Parents, Partners or carers of those with Spina bifida, hydrocephalus or related conditions   | 1497  |
| <b>Donors</b>                                                                                 |       |
| Number of gifts received during the year                                                      | 3760  |
| Number of "active" donors on database (SYBUNT Report)                                         | 13764 |

### Contact Analysis Family Support Service 2005/2006





## A Personal word from our Patron

*"As Patron of the Association, I have been delighted by the public's response to the Buy a Brick appeal. £250,000 was raised in 8 months and the new Family Support Centre is a wonderful new resource for all the families in Scotland affected by spina bifida and hydrocephalus. However, the appeal is not over yet! The Association require to raise over £400,000 annually to provide all of its much needed services and as they receive little statutory funding they rely on the generosity of their supporters. This year, once again I will be leading the campaign to encourage you to support this worthy cause and help the Association to maintain and develop its specialist services throughout Scotland"*



Walls Up..

Roof on...

Nearly there

OUR NEW BUILDING



Gordon Ramsay and some families met at the "Buy a Brick" campaign launch on the site of the new building on 5th September 2005

As part of the 5<sup>th</sup> September Buy a Brick launch Gordon Ramsay was invited into the STV studios and interviewed live on the "Scotland Today" lunchtime news by Shereen Nanjani and Stephen Jardine. Clips from the interview and footage filmed in the morning at the actual launch were also shown on the Scottish News Headlines at 6.00pm and 10.00pm.

The STV evening news is watched by over 950,000 Scottishviewers.

# Summary Accounts

## Statement of Financial Activities (including Income and Expenditure Account)

Year ended 31 March 2006

|                                                        | General Fund     | Designated Fund | Restricted Fund | Total 2006     | Total 2005 (revised) |
|--------------------------------------------------------|------------------|-----------------|-----------------|----------------|----------------------|
|                                                        | £                | £               | £               | £              | £                    |
| <b>Incoming Resources</b>                              |                  |                 |                 |                |                      |
| <b>From charitable activities:</b>                     |                  |                 |                 |                |                      |
| Sales & services                                       | 35,040           | -               | -               | 35,040         | 33,319               |
| Rental income                                          | 1,320            | 5,710           | -               | 7,030          | 8,903                |
| <b>From generated funds:</b>                           |                  |                 |                 |                |                      |
| Legacies & bequests                                    | 535              | -               | 75,283          | 75,818         | 573,255              |
| Activities to generate funds                           | 274,844          | 1,010           | 92,966          | 368,820        | 243,619              |
| Investment income and interest                         | 17,694           | -               | 16,481          | 34,175         | 16,024               |
| <b>Other incoming resources:</b>                       |                  |                 |                 |                |                      |
| Miscellaneous income                                   | 6,640            | 107             | -               | 6,747          | -                    |
| Gain on sale of property                               | 84,226           | -               | -               | 84,226         | -                    |
| Gains/(losses) on sale of fixed assets                 | (2,700)          | -               | -               | (2,700)        | 1,010                |
| <b>Total incoming resources</b>                        | <b>417,599</b>   | <b>6,827</b>    | <b>184,730</b>  | <b>609,156</b> | <b>876,130</b>       |
| <b>Resources Expended</b>                              |                  |                 |                 |                |                      |
| Costs of generating funds                              | 67,800           | -               | 22,934          | 90,734         | 64,961               |
| Charitable activities                                  | 244,358          | 4,499           | 22,910          | 271,767        | 216,032              |
| Governance costs                                       | 34,024           | -               | -               | 34,024         | 26,012               |
| <b>Total resources expended</b>                        | <b>346,182</b>   | <b>4,499</b>    | <b>45,844</b>   | <b>396,525</b> | <b>307,005</b>       |
| <b>Net income before transfers</b>                     | <b>71,417</b>    | <b>2,328</b>    | <b>138,886</b>  | <b>212,631</b> | <b>569,125</b>       |
| <b>Transfers between funds</b>                         | <b>(657,481)</b> | <b>-</b>        | <b>657,481</b>  | <b>-</b>       | <b>-</b>             |
| <b>Net income for year</b>                             | <b>(586,064)</b> | <b>2,328</b>    | <b>796,367</b>  | <b>212,631</b> | <b>569,125</b>       |
| <b>Statement of Total Recognised Gains and Losses</b>  |                  |                 |                 |                |                      |
| Net income/(expenditure)                               | (586,064)        | 2,328           | 796,367         | 212,631        | 569,125              |
| Gains on revaluation of investments                    | 16,143           | -               | -               | 16,143         | 4,022                |
| <b>Total gains and losses recognised since 1 April</b> | <b>(569,921)</b> | <b>2,328</b>    | <b>796,367</b>  | <b>228,774</b> | <b>573,147</b>       |

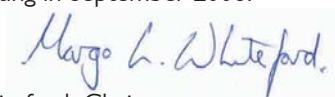
# Summary Accounts

Balance Sheet  
As at 31 March 2006

|                                                          | 2006           |                  | 2005           |                |
|----------------------------------------------------------|----------------|------------------|----------------|----------------|
|                                                          | £              | £                | £              | £              |
| <b>Fixed Assets</b>                                      |                |                  |                |                |
| Tangible fixed assets                                    |                | 788,773          |                | 48,319         |
| Investments                                              |                | 59,003           |                | 45,673         |
|                                                          |                | <b>847,776</b>   |                | <b>93,992</b>  |
| <b>Current Assets</b>                                    |                |                  |                |                |
| Debtors                                                  | 121,775        |                  | 51,828         |                |
| Cash at bank and in hand                                 | 395,183        |                  | 760,856        |                |
|                                                          | <b>516,958</b> |                  | <b>812,684</b> |                |
| <b>Creditors:</b> amounts falling due<br>within one year | 256,203        |                  | 26,919         |                |
| <b>Net Current Assets</b>                                |                | <b>260,755</b>   |                | <b>785,765</b> |
| <b>Total assets less current liabilities</b>             |                | <b>1,108,531</b> |                | <b>879,757</b> |
| Represented by:                                          |                |                  |                |                |
| Restricted fund                                          |                |                  |                |                |
| <b>New Building Fund</b>                                 |                | 796,367          |                | -              |
| Unrestricted funds                                       |                |                  |                |                |
| <b>General Fund</b>                                      |                | 247,500          |                | 817,421        |
| <b>Rebecca Cottage</b>                                   |                | 63,313           |                | 60,985         |
| <b>Research Fund</b>                                     |                | 1,351            |                | 1,351          |
|                                                          |                | <b>1,108,531</b> |                | <b>879,75</b>  |

The above statement is an abbreviated summary of the full audited accounts, copies of which are available from the Association National Office at The Dan Young Building, 6 Craighalbert Way, Cumbernauld, Glasgow G68 0LS. It should be borne in mind that this summary may not give sufficient information for a complete understanding of the Association's financial affairs.

The full accounts, which have been audited and given an unqualified audit opinion, have been approved by the Board of Directors and will be placed before the Annual General Meeting in September 2006.



Dr Margo L Whiteford, Chairman

This summary is consistent with the Associations full accounts.

Barrie Scott & Co

Chartered Accountants, Registered Auditor



# Office Bearers, Directors & Staff as at 31st March 2006

## Office Bearers

Prof D G Young - Honorary President  
Dr Margo L Whiteford - Chairman  
Andrew H D Wynd - Company Secretary

## Directors

Jonathan Best (appointed 5/9/05)  
June F Devlin  
Jean M T Dryden (resigned 5/9/05)  
Samuel P Forrest  
David Griffin  
Christine M Hudson  
Graham M Hudson  
William H Humes  
James Lawson  
Shirley A McClymont  
Vivien Morton  
Anna F Stratton  
Deyrick Smith (appointed 3/5/05)  
Dr Margo Whiteford  
Professor Daniel G Young

## National Office

Andrew H D Wynd - Cheif Executive  
Gail Jones - Association Administrator

The Dan Young Building  
6 Craighalbert Way,  
Dullatur,  
Cumbernauld,  
G68 0LS  
T: 01236 794500  
F: 01236 736435  
Email: [mail@ssba.org.uk](mailto:mail@ssba.org.uk)  
Web: [www.ssba.org.uk](http://www.ssba.org.uk)

## Family Support Service

Anne Kane - Family Support Worker  
Anne Metcalfe - Family Support Worker  
Diane Lowrie - Family Support Worker

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

LO-CALL: 0845 911 1112  
T: 01236 794516  
F: 01236 736435  
Email: [familysupport@ssba.org.uk](mailto:familysupport@ssba.org.uk)  
Web: [www.ssba.org.uk](http://www.ssba.org.uk)

## Fund Raising Office

Deborah Roe - Fundraising & Events Manager  
Sandra Bauld - Fundraising Administrator

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

Appeals Hotline: 01236 794508  
T: 01236 794500  
F: 01236 736435  
Email: [fundraising@ssba.org.uk](mailto:fundraising@ssba.org.uk)  
Web: [www.ssba.org.uk](http://www.ssba.org.uk)

# Our Supporters

Over the past year thousands of ordinary people throughout Scotland and beyond have given their time talents and money to help us provide essential services for our users. Without their support we could not continue. Thank you for making a real difference. Sponsors over the past year include.

## Local Authorities

Aberdeen City  
Angus  
Argyll & Bute  
Clackmannanshire  
East Dunbartonshire  
East Lothian  
East Renfrewshire  
Moray  
North Ayrshire  
North Lanarkshire  
Perth & Kinross  
Renfrewshire  
Shetland

---

## Trusts

Miss Marion Broughton's Charitable Trust  
The Sir Jules Thorn Charitable trust  
The Dickson Trust  
The Totara Charitable Trust  
Leith Holiday Home Association  
Forteviot Trust  
A & S Lass Charities Ltd.,  
Alexander Moncur Trust  
Edinburgh Children's Holiday Fund  
The Darroch Charitable Trust  
The Sylvia Aitken Charitable trust  
JTH Charitable Trust  
The Childwick Trust  
Four Acre Trust  
The Robertson Trust  
Templeton Goodwill Trust  
The Adamson Trust  
The Ponton House Trust  
The Nancie Massey Charitable Trust  
PF Charitable Trust  
W M Mann Foundation  
The Sir William Coxen Trust Fund  
Tesco Charity Trust  
Cruden Foundation  
The Souter Charitable Trust  
The Colin Montgomerie Charitable Foundation  
Noble Resolve and Temperance Auxiliary  
William Grant & Sons Distillers Ltd  
John Liston Scottish Charitable Trust  
The DWT Cargill Fund  
The Bellahouston Bequest Fund  
The Steel Charitable Trust  
The Hugh Fraser Foundation  
The Society of Deacons and Free Preses  
The Astor of Hever Trust  
John M Archer  
The David Solomon's Charitable Trust  
The Hugh and Mary Miller Bequest Trust

## Capital Build Trusts

Children's Aid Scotland  
W M Mann Foundation  
The Agnes H Hunters Trust  
The Clothworkers Foundation  
The James Wood Bequest Fund  
The Rank Foundation  
The Beatrice Laing Trust  
The Gannochy Trust  
The R J Larg Family Charitable Trust

---

## Capital Build Individuals/Groups

Jennifer Rankin  
Burnside Church  
Glasgow Council Credit Union  
Thurston Manor Holiday Park  
SSBA Lanarkshire Branch  
Strathbrock Parish Church  
Lagerstedt-Kranz UK Ltd  
Menzies Distribution Ltd  
John Menzies plc  
Petershill Social Club  
Crosshill Parish Church  
Kirsty McNab  
Jackie Brown  
Maybole Round Table  
Jan Johnston  
Cumbernauld United Soccer Academy  
Wylie & Lochead  
Institute of Directors  
Bothwell Philharmonic Choir  
Gordon Ramsay Holdings  
Capital Build

---

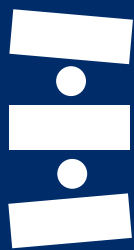
## Individual. Group Donors

Gordon McBride  
Mary Murphy  
Mr & Mrs Robert Hendrie  
Gordon Adam  
Chris Mclean  
Walter Frame  
Mr & Mrs Reilly  
Kirsty Burns & Halifax Building Society  
British Energy grou plc  
Fiona Deighan  
Lothian Buses plc  
Rockware Glass Limited

## Legacies

In addition we were privileged to receive support from individuals who had included us in their wills.

Legacies Sheena M Nicholson £1672 (final receipt)  
Bridget Hughes £74146



scottish  
**spina bifida**  
association

Scotland's voice for Spina Bifida,  
Hydrocephalus and related conditions

Scottish Spina Bifida Association  
The Dan Young Building  
6 Craighalbert Way, Dullatur  
Cumbernauld, G68 0LS  
T: 01236 794500 F: 01236 736435  
Email: [mail@ssba.org.uk](mailto:mail@ssba.org.uk)