



Annual Review 2010-11



*Helping sick children and young people
meet their healthcare needs*

Chair's Report - Our Golden Jubilee Year

This has been another significant year in the history of the organisation, as we celebrate the Golden Jubilee of the founding of the movement which was to spread throughout the United Kingdom and subsequently overseas. With Action for Sick Children in England we celebrated the milestone at a Jubilee lecture given by Sir Al Aynsley Green in London, where it all began. As he looked back to a time when children had very few visits, if any, from their parents, and had to endure long, lonely stays in hospital, he paid tribute to the organisation for its work over the last fifty years, but emphasised that our work must carry on as challenges remain.



Sir Al Aynsley Green with (from left) Gwen Garner ASC(S), Pam Barnes ASC, Mary O'Connor and Dymna McMahon Children in Hospital Ireland, at the Golden Jubilee celebration in London

We have continued to work to improve health care standards for all children and young people and have endeavoured to ensure that they and their families receive access to the support and care that they require. We have represented their interests in a variety of key groups, raising awareness of their needs and concerns within government, the NHS and other non-governmental organisations, whilst continuing to give support and information to families, and to influence policy and practice.

EACH Child and Young Person's Health Matters Campaign

The Campaign and our Manifesto have provided the focus of our work to **highlight children and young people's** healthcare rights based on the European Association for Children in Hospital (EACH) Charter articles. This has included the lodging of a petition with the Scottish Parliament concerning the right

to education for all children and young people at times of illness, regardless of where they live, their condition or whether they are being treated at hospital or in the community.

Our conference *Does EACH Child and Young Person's Health Matter? Asking the Difficult Questions*, held in Glasgow in September 2010, challenged Scotland to fulfill its obligations under the United Nations Convention on the Rights of the Child, to uphold the EACH Charter and to keep its promises to children and young people.

Chaired by Dr Kate McKay, National Clinical Lead for Children and Young People's Health in Scotland, the topics included *Nursing Our Future: The Policy Landscape*, *Do Babies Have Rights? How Much Should Children Count? Better Health, Better Care: Are Young People There? The Education of Children and Young People with Health Needs* and *Why do play, recreation and education matter to children and young people's health?* ASC(S) staff presented work and the conference concluded with Inspector8, a group of young people from Dumfries and Galloway, acting out a health scenario.

Projects

The Community Specialist Play Pilot Project in Forth Valley has been successfully completed and evaluated, and all our different projects, which are reported in detail within this review, have advanced our work.

Resources

We have raised awareness of the healthcare rights of children and young people through our promotion of the EACH Charter and through our publications and website, and for example have reached many families, by **distributing our 'What to expect when a child goes to hospital' booklet to 1,200 pre-school settings.**

Thanks

We are greatly indebted to our funders and fund raisers, and wish to record our grateful thanks to them. I would like to express gratitude for all the dedicated hard work of our staff team, Executive Committee and volunteers.



Gwen Garner, Chair

The Future

We anticipate being involved in the next European Association for Children in Hospital Conference which takes place in the UK in 2012, and following on from the series of surveys that we have carried out since 1985 we plan to update our Family Facilities and Access Survey of hospitals which admit children. This will establish the facilities that are available and the progress that has been achieved since our last survey in 2007.

We welcome Marjorie Gillies, Liam Campbell, and Margaret Rooney to the Executive Committee this year, and look forward with confidence to our future work of promoting and campaigning on behalf of the needs of all sick children and young people in Scotland.

Gwen Garner, Chair



In the year up to 31st March 2011 we worked with 6,265 children, young people, families, voluntary groups and health care providers

Who we are

Executive Committee 2010-11

Gwen Garner (Chair)
 Robert McFarlane (Vice-Chair)
 Duncan McEachran (Treasurer)
 Frances Barbour
 Deborah Catty
 Gwendoline Cowan (until May 2010)
 Dr Zoe Dunhill
 Marjorie Gillies (from March 2011)
 Dr Una MacFadyen
 Professor Richard Olver
 Patrisha Summers

Company Secretary/National
 Co-ordinator Elizabeth May

Staff

Fiona Bartley-Jones, *Project Officer Tayside*
 Amy L Joss, *Community Play Specialist Project Officer (until September 2010) thereafter Project Officer Stay Well Lanarkshire*
 Dagmar Kerr, *Area Co-ordinator Greater Glasgow & Clyde*
 Lysia Abercrombie, *Project Assistant Stay Well Lanarkshire (from September 2010)*
 Catherine Nelson, *Dental Project Co-ordinator*
 Anne Wilson, *Development Officer*

ASC(S) Advisers

Melanie Brown
 Jonathan Bryden, *Head of Finance, Clyde Community Health Partnerships*
 Gwendoline Cowan
 Lady Caplan
 Rory Farrelly, *Nurse Director, NHS Greater Glasgow & Clyde Acute Operating Division*
 Liz Nicol, *Play Co-ordinator/Volunteer Manager, NHS Fife*
 Jacqueline Reilly, *Discharge Co-ordinator, Royal Hospital for Sick Children Glasgow*
 Professor George Youngson

Finance Officer Alison Glass FCCA

Auditor Barstow & Millar

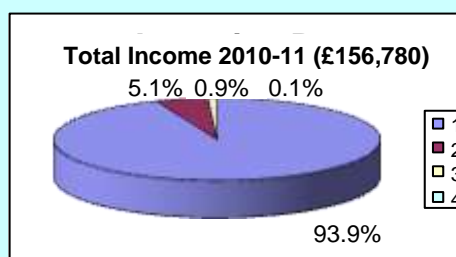
Bankers The Royal Bank of Scotland Plc

Our Supporters

Thanks to all Supporters 2010-11

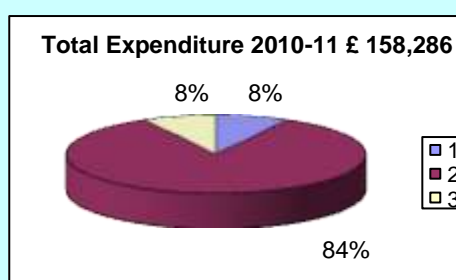
BBC Children in Need, Binks Trust, Endrick Trust, Harold Merton Adams Trust, Hugh Fraser Foundation, James Hewitt Foundation, Jenny Lowe, Jim Woodward, Lloyds TSB Foundation for Scotland, Margaret Gilbride School of Dancing, NHS Greater Glasgow & Clyde Endowment Funds, Pfizer UK Foundation, R J Larg Trust, The Robertson Trust, Scottish Community Foundation, Scottish Government Healthcare Policy & Strategy Directorate, Snowball Trust, Sophie North Charitable Trust, Soutar Charitable Trust, The Self Management Fund for Scotland, Widower's Children's Home Trust

Our Financial Year



Income April 2010 - March 2011

| | 2011 £ | 2010 £ |
|--------------------------------------|----------------|----------------|
| 1. Voluntary Income | 147,284 | 171,845 |
| 2. Activities for Generating Funds | 8,070 | 4,536 |
| 3. Investment Income | 1,404 | 2,971 |
| 4. Income from Charitable Activities | 22 | 767 |
| | <u>156,780</u> | <u>180,119</u> |

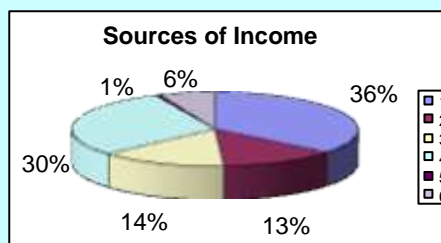


Expenditure April 2010 - March 2011

| | 2011 £ | 2010 £ |
|----------------------------------------|----------------|----------------|
| 1. Cost of Generating Voluntary Income | 12,614 | 12,312 |
| 2. Charitable Activities | 133,104 | 175,378 |
| 3. Governance | <u>12,568</u> | <u>13,512</u> |
| | <u>158,286</u> | <u>201,202</u> |

Summary Balance Sheet
 as at 31 March 2011

| | 2011 £ | 2010 £ |
|------------------------------------------|----------------|----------------|
| Fixed Assets | 1,304 | 2,002 |
| Current Assets | <u>152,655</u> | <u>153,139</u> |
| | 153,959 | 155,141 |
| Current Liabilities (creditors/accruals) | 3,887 | 3,563 |
| Deferred Income | - | - |
| Net Assets | <u>150,072</u> | <u>151,578</u> |



| | |
|-------------------------|-----|
| 1. Scottish Government | 36% |
| 2. Pfizer UK Foundation | 13% |
| 3. BBC Children in Need | 14% |
| 4. Other Trusts | 30% |
| 5. Other Donations | 1% |
| 6. Other Income | 6% |

The full audited accounts are available from the Company Secretary at the Registered Office at 22 Laurie Street, Edinburgh EH6 7AB

Manifesto for the Scottish Government, Members of the Scottish Parliament and those responsible for the formulation of healthcare policy

Action for Sick Children (Scotland) believes that every sick child or young person has the right to:

- Care by professionals with relevant training and experience in the care of sick children and young people
- Access to education whenever they are well enough to learn
- The opportunity to use play as part of their treatment when ill, and as a means of understanding their condition and its treatment
- An advocate of their choice to accompany them through times when they need support
- A parent or parent substitute to be with them at all times when in hospital, unless the child or young person confirms they do not want this
- Age and stage appropriate information and assistance in order to understand and follow treatment plans
- Holistic health care, including dental care that is designed for a child or young person's needs.

Action for Sick Children (Scotland) calls upon the Scottish Government, elected Members of the Scottish Parliament, and those responsible for the formulation of healthcare policy, to ensure that all children and young people's healthcare rights are upheld in line with the European Association for Children in Hospital (EACH) Charter, which is underpinned by the United Nations Convention on the Rights of the Child (UNCRC). Action for Sick Children (Scotland) calls upon them:

1. To ensure equity of access to education for all sick children and young people, regardless of their illness, age or where they live.

EACH Charter Article 7, UNCRC Articles 28 and 29

2. To empower and support young people to take responsibility for their own health and management of their chronic condition.

EACH Charter Articles 4 and 5, UNCRC Articles 12, 13 and 23

3. To ensure a clearly defined healthcare pathway exists from early years to adulthood for all sick and disabled children, including transition from paediatric to adult services.

EACH Charter Article 9, UNCRC Article 23

4. To ensure that children and young people who are vulnerable, by virtue of the fact that they are in care or because they have exceptional healthcare needs, are accorded the same degree of respect, understanding and privacy as we would accord to any other child or young person.

EACH Charter Article 10, UNCRC Articles 2 and 39

5. To ensure that advocacy services are available to all sick children and young people particularly those who are looked after and those with exceptional healthcare needs.

EACH Charter Article 5, UNCRC Article 12

6. To ensure that children and young people with additional and complex needs are adequately provided for in any government funded oral healthcare initiatives and services.

EACH Charter Article 4, UNCRC Article 23

7. To ensure that all healthcare facilities, where children and young people are treated, provide safe and age-appropriate play opportunities, and are maintained and organised by trained and registered Hospital Play Specialists.

EACH Charter Article 1, UNCRC Articles 7, 23, 24 and 31

8. To work with the NHS, local authorities and the voluntary sector to ensure a co-ordinated approach to the healthcare needs of all adolescent parents and their children.

EACH Charter Article 4, UNCRC Article 24



Children and Young People's Healthcare Rights

All children and young people under the age of 18 have rights. The United Nations Convention on the Rights of the Child (UNCRC) sets out the 42 rights that all children and young people are entitled to. **Article 24** talks about young people's rights in relation to health care.

You have the right to the best health possible and to medical care and information.

Action for Sick Children (Scotland) is a member of the European Association for Children in Hospital (EACH) which has produced a charter of 10 standards or rights for children and young people at times of illness. We asked young people to come up with a **young person's version of the charter and this booklet is the result.** We'd like to say thank you to all the young people and adults who gave us their ideas, suggestions and time to produce this charter.

EACH Child and Young Person's Health Matters

Education at time of illness for Children and Young People

In December 2010 ASC(S) submitted a petition to the Scottish Parliament Petitions Committee asking the Scottish Government to demonstrate how local authorities are complying with the duties imposed by Education legislation and Guidance to ensure that children and young people absent from school are provided with appropriate and equitable education provision. In February 2011 we asked the Petitions Committee to ask the Scottish Government to review the 2001 **Guidance on the 'Education of Children Absent from School through ill-health'**.

The following experiences show why ASC(S) is campaigning about this issue.

Connie had several operations on her leg. She had a metal frame on her leg for a few months and needed a wheelchair. Two months after her operation she felt well enough to go back to school, but she found that returning to school with a frame and wheelchair needed considerable planning to sort out a special desk, to carry out health and safety assessments and to arrange transport to and from school. It took seven months **before she was able to go back.** Connie's mum found out that her daughter was entitled to home tuition during recovery, but their local authority said they had no available home teachers and there was a two year waiting time. Connie lost confidence and became depressed about falling behind and not seeing her friends.



She did however eventually make a good physical recovery and returned to school. Her strength and determination helped her to catch up on most of her school work, but her mum says she is still trying to rebuild friendships. Better pathway planning would have helped her to continue her education during this period and reduced the negative impact on her confidence.

Tom A year ago Tom had to travel **outside his local authority to a children's hospital** three times a week for dialysis. His local authority would not pay for hospital teaching so whilst other patients were being taught, he could not take part. His mother contacted ASC(S). We advised her about their rights and she challenged her local authority. After discussion, and the involvement of a journalist, the local authority changed its practice and it now pays for hospital tuition for its children.



Susie was 4 years old and in her pre-school year. She had been a patient in a **children's hospital since January 2010** and several months later had still to receive education in hospital. Hospital teachers were not allowed to teach her, as the authority she lived in had refused to pay for hospital tuition. Everyone else on the ward was being taught. Provision of pre-school education needs to be given the same priority as primary or secondary education.

A young person who was repeatedly admitted to hospital told us,

*'I do think it is important for young and sick children to be given the chance of an education while in hospital. While I have been in hospital in the past I have not been given the chance to get any help with keeping up with school work. I found it hard going back to school after being in hospital as I was very far behind in all my work and had no-one to help me go through it. I think it would be beneficial to offer children the chance of help with keeping up with school work while they are **in hospital.**'*



A young adult told us about the impact of missing out on education during their illness.

'I have been in several hospitals when I was younger as I had a lot of health problems ... I was first in hospital when I was really young and was in and out on numerous occasions until I was in my teens. I was in for different time scales. I can't remember how long, but there were a few times when I was in for quite a while. At this point, as I got better, I was not offered any help or guidance with school work.'

*I have mostly been in hospital when I was ill, however even there I was not offered any help. I felt this wasn't very good as when I was well enough to go back to school, I was so far behind that **I didn't actually want to go back. I think introducing help for children with their school work while they are in hospital is a good idea, as long as they are well enough to do it, also if they want the help, as some children may not want it.'***



Our Projects

Demonstrating Best Practice in Child Health

Special Smiles

Over the year this dental project trained staff to use our dental play materials developed for children with additional and complex support needs in four schools in Renfrewshire and seven in Glasgow.



National Smile Event, Mary Russell School, 2010

Teachers have welcomed the project and told us that the playbox and playbag are very appropriate for children with additional support needs. ASC(S) developed this resource which was piloted in Tayside in 2007-09, because children with additional and complex support needs have a higher risk of dental caries and of attending hospital for dental surgery. This is because the nature of their condition can make it difficult, emotionally or physically, for them (or their carers) to look after their teeth properly. Many of these children also



Special Smiles in Cairo, Egypt

suffer dental anxiety and will not co-operate with oral health practices or dental treatment. Despite this neither **Childsmile**, the **Scottish Government's** child oral health programme nor the National Dental Inspection Programme operates in special needs schools. Our project is therefore a very valuable

resource for this vulnerable group. During the year, our Project Co-ordinator Catherine Nelson also delivered training and resources to a team of volunteers who were travelling to Egypt to work with children with additional support needs. The volunteers reported that the children really enjoyed the experience of playing with the different items and these will continue to be used. We are pleased that our resources have worked well with children and families in this different cultural setting. In the year ahead the Project will continue to work with schools in Glasgow.

Children and Young People In and Leaving Care

In the period under review the project supported children and young people in the care system in two ways.

Working in partnership with Foster Plus and City of Edinburgh Council, Project Officer Anne Wilson delivered training to carers in Livingston, Paisley, Ayr and Edinburgh. The training was designed around the toolkit produced by the project a year earlier. Topics ranged from the healthcare needs and rights of children and young people at times of illness to dental care for children with additional support needs. After taking part in the training, carers reported greater understanding of the health needs and rights of those in their care and increased confidence in their ability to support their child at times of illness and when having to access healthcare.

'The sessions focused my thinking enabling me to think about what a child would need to be prepared for. I am more aware of children's rights in hospital and have gained insight into legislation covering consent.'

The project also delivered 'Seasons for Growth' programmes to twelve children and young people. These programmes aimed to support vulnerable children and young people to cope with the impact of change and loss on their physical and mental health. The sessions took place in a Primary School, in a Foster Care and a Residential School setting.

All participants reported that, ***'they were feeling better in themselves in their head and their bodies'***, and many said that now when things were difficult they could talk to someone. Comments included:

'I liked the way the leaders delicately helped us to feel better.'
'When can we get to do another of these programmes?'

And from their parents and carers: ***'Thank you for giving both boys a chance to speak and be supported through a time of emotional pain and trauma.'***

The project will continue to deliver training to foster carers.

Tayside Child Health Rights

The project has continued to work with groups of young mothers to support them to look after their children at times of illness. Project Officer Fiona Bartley-Jones has used our DVD 'Child Health Rights, What do you know? Young Parents Speak Out', made in collaboration with young parents in Tayside, as a starting point for discussion. She has also developed workshop facilitators' notes for those working with young parents. <http://www.ascscotland.org.uk/default.asp?page=83>

The Project Officer also contributes to the NHS Tayside Sexual Health Strategy Group and has developed strong links with the new Family Nurse Partnership recently launched in the area. In recent years the project has worked hard to raise awareness of the very specific healthcare needs of young and vulnerable parents and their children so we welcome the arrival of the Partnership.



Photo: Scottish Youth Health Photography Project

Helping Children, Young People and Families

Stay Well Lanarkshire

In November the project piloted our generic self management programme to young people living with long term conditions and by the end of March delivered a further two programmes. Workshops covered the realities of illness, coping with change, healthy lives and communication and all sessions ended with fun activities such as drumming or video making. We are delighted that the young people feel that taking part has increased their confidence and ability to communicate about their condition. The project is currently funded until March 2012.

Ashley's Stay Well Story



Ashley

Before attending the Stay Well Lanarkshire Project, Ashley was **'annoyed with her situation'**. Although comfortable talking to doctors and health

professionals, her peers were teasing her and she lacked the confidence to deal with this appropriately. Through attending the full programme and returning as a peer supporter in later workshops, Ashley feels she has gained the confidence and skills which allow her to **'forget about her epilepsy and feel more normal'**. She has become more aware of **'others out there who face the same difficulties'**.

One of the most positive outcomes Ashley feels she has gained from the Project is the support group she has been able to form with others in the groups. This support network of peers who face similar difficulties and the interaction with project workers/volunteers has had a **positive impact on Ashley's ability to communicate with others in school and other aspects of her life.**

Ashley felt that the content of the workshops provided her with the correct level of information for her age range in a fun and enjoyable way. Her favourite activities included the film making and African drumming. The film making was one of her biggest challenges in the beginning and in the first workshops she

stayed behind the camera throughout. Since carrying out the film-making task again Ashley took on a more central role in front of the camera and states that she **wouldn't think twice about participating in the task again.**

Ashley feels that her confidence has grown dramatically through participation in the project. By asking her to step outside her comfort zone and take part in tasks she would not normally face she feels she now has the ability to confidently participate in other aspects of her life. Although reluctant at first to continue on in the project as a peer supporter, after further discussion and training Ashley feels that it now may be something she would be interested in doing.

Community Play Specialist Pilot

The Community Play Specialist pilot project concluded in October after working in NHS Forth Valley for two years. The project offered play specialist input in the community to children referred to tertiary centres outside the area who would not otherwise have seen a hospital play specialist. An independent evaluation showed that children benefited from access to this service so it was disappointing that funding could not be secured to continue this work. The following story shows how we helped:

'Susan had ongoing anxiety about planned procedures, especially about her cleft palate management and would not open her mouth at dental appointments. Mum felt she could 'remember' the pain of surgery she had at nine months old. Susan had an appointment with the Orthodontist so Play Specialist Amy Joss visited the child at home to prepare her for this. Play work focused on her anxiety and worry and Amy also discussed with the mum that while it was unlikely that Susan could remember the surgery at such a young age, discussing it in such a way might make her child fear future treatment. They discussed using positive language and other children's stories from books left with the family. Amy also stressed that the proposed dental work was not expected to be painful.

Mum later reported that Susan had coped very well, allowing the orthodontist to

look at her teeth. Susan had agreed to further treatment - a brace to correct tooth alignment - so Amy visited her again along with the Oral Health Education Nurse. They worked together to prepare Susan for having an impression taken of her teeth, using real equipment and play. Susan and her siblings enjoyed messy play, touching and smelling the items and seeing how it would feel in their mouths. Susan consented to the impression being taken a week later in clinic. The dental unit nurses were very happy with how compliant she was and how quickly they were able to take her impression.

Greater Glasgow & Clyde

One family got in touch with us when their baby suddenly became so seriously ill with a heart condition that they feared for her life. The grandparents helped look after the older child who was nearly two, while her parents spent most of their time in the intensive care unit with the baby. Area Co-ordinator Dagmar Kerr provided a Hospital Play Bag containing a **patient gown, a nurse's uniform, masks, stethoscope, gloves, picture books, video and hospital based games**, for the two year old. A year later, with the younger child finally on the road to recovery, the family wrote to tell us that this scaled down version of our Hospital Playbox had helped the older child to deal with what



Children role play in Glasgow Nursery with ASC(S) Hospital Playbox

she had seen and experienced. She had been upset at seeing her baby sister suddenly attached to tubes and monitors. She had seen her mum and dad very worried and she had spent a lot of time apart from her parents. At her age she **hadn't been able to talk about was going on and being able to play helped her and the family to get through this very difficult time.**

Action for Sick Children (Scotland) is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children and young people within our healthcare system

Our vision is for the best quality healthcare for children and young people in Scotland.

Our mission is to enable children and young people to meet their individual healthcare needs, in partnership with parents, carers and professionals. We do this through direct support and advice, influencing policy and campaigning for service improvement.

Our work includes:

- Working with others to ensure that health services are planned for sick children and young people in child-centred environments with appropriate ratios of trained staff
- Informing young people, parents and carers of their rights and responsibilities and empowering them to participate in decisions about the treatment and care of their child
- **Raising awareness and representing children's needs** and concerns within the Scottish Government, healthcare committees and other non-governmental organisations
- Promoting high quality healthcare services at home and in hospital, while working to obtain equality of services and access across Scotland



Action for Sick Children (Scotland) represents sick children, young people and their families on ...

Association of Paediatric Anaesthetists of Great Britain & Ireland (APAGB)

Coalition for Scotland's Disabled Children - Transition Task Group; Education Task Group

Community Child Health for the 21st Century Steering Group

Health Rights Information Scotland and Scottish Government – Resuscitation Planning Policy for Children & Young People (under 16) developed as part of the Subgroup of the Scottish Government's Living and Dying Well Strategy

Long Term Conditions Self Management Engage a Generation Project, Scottish Government

National Delivery Plan for Children & Young People's Specialist Services in Scotland Implementation Group

National Association of Hospital Play Staff

NHS Forth Valley - Child Health Forum: Maternity Services Liaison Committee (until September 2010)

National Services Division – Short life Working Group: Reimbursement Travel for Specialist Services

National Services Division – Transition Event: Make It Happen Planning Group

NHS Greater Glasgow and Clyde - **New Sick Children's Hospital Stakeholder Reference Group**; Better Together Quality & Monitoring Steering Group; Community Engagement Team – Youth Panel and Family Panel, Community Engagement

Advisory Panel (CEAP); Patients' Panel; Partners in Advocacy

NHS Lanarkshire - Child Health Services Executive Group

NHS Lothian - Royal Hospital for Sick Children Edinburgh Hospital Patient Focus Public Involvement Task Group (formerly Children, Young People & Families Advisory Board)

NHS Tayside – Engagement & Involvement with Children & Young People in Tayside; Family Nurse Partnership; Sexual Health Strategy Group

Paediatric Scottish Patient Safety Programme Steering Group

Play Scotland

Royal Hospital for Sick Children Glasgow

FILES Committee; The Rights of the Child Group; Family Support Service, Chaplaincy team; Play Service Re-design Group

Scottish Children and Young People's Palliative Care Network

National Managed Clinical Network for Children with Exceptional healthcare Needs (CEN)

Scottish Healthy Care Network

Scottish Paediatric Anaesthetists Network (SPAN))

St Andrew's Family Support Group



Action for Sick Children (Scotland) 22 Laurie Street EDINBURGH EH6 7AB
Telephone: 0131 553 6553

E-mail: enquiries@ascscotland.org.uk

Website: www.ascscotland.org.uk

A company limited by guarantee, No 100114, and a Scottish charity, OSCR No SC006016,
Registered Office 22 Laurie Street, Edinburgh EH6 7AB