



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 within our healthcare system. 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; empowering them to participate in decisions about treatment and care

Raising awareness and representing children's needs and concerns within government, healthcare committees and other non-governmental organisations

Promoting high quality of health care services at home and in hospital, while working to obtain equality of services and access across Scotland

Action for Sick Children (Scotland)

Newsletter Autumn 2008

Children and Young People's Healthcare Rights Resource Pack launched



Project Officers Amy, Sheila and Karen

Our Big Lottery project launched its Children and Young People's Healthcare Rights Resource Pack on 19th June at the Voluntary Sector Gathering in the SECC, Glasgow. Over 40 people attended, including some of the young people who were the stars of the 'Know Your Rights' DVD, which was shown during the session and is included in the Pack. The following week, members of the team

introduced the Pack to a further 42 workshop guests attending the NHS Scotland event, 'Better Health, Better Care'. We were delighted to take part in this workshop on 'Involving Children and Young People' together with the Young People's Health Advisory Group at NHS Education for Scotland.

Our Healthcare Rights Resource Pack includes Session Plans, the EACH (European Association of Children in Hospital) Charter and two examples of using the Charter, in DVD film and animation, both aimed at raising awareness about the rights of sick children, young people and their families and how to access health services. The resource is designed to be used by those working in a variety of settings with children and young people from early years to Secondary six.

For more information contact ASC(S) on

0131 553 6553 or see www.ascscotland.org.uk.

Special Smiles in Perth School

The 'Special Smiles' Dental Project was officially launched on 28 May at Fairview School in Perth. Fairview School is the brand new specialist local authority provision for children with complex and multiple additional support needs in Perth and Kinross. The date coincided not only with National Smile Month, but also with an awareness-raising week

for the School, so it was an ideal time for all concerned.

Those attending included representatives from Education and Dental Health, Schools, the Voluntary Sector and of course Action for Sick Children (Scotland) (ASC(S)). On arrival guests were welcomed by Head Teacher, Coral Bell. ASC(S) Chair Gwen Garner introduced the project and then Martyn Merrett, Consultant in Dental Public Health NHS Tayside, gave a short address and spoke about his support for our work.



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Helping sick children and young people meet their healthcare needs,
in partnership with parents, carers and professionals

Allergic Disorders in Children and Young People

In 2007 Professor Jürgen Schwarze moved from Imperial College London and St Mary's Hospital to the University of Edinburgh and Royal Hospital for Sick Children Edinburgh to take up the post of Edward Clark Chair of Child Life and Health. Professor Schwarze trained as a paediatrician and a clinical scientist in Germany and the United States. He specialises in allergy and in respiratory medicine and as a researcher he focuses on the immunology of respiratory viral infections and allergy.

We were delighted to welcome the Professor to his new post and to hear about paediatric allergy services in Scotland. He gave us an insight into the nature of allergic disorders in children and young people, outlined his concerns about current provision and set out his vision for allergy services in Scotland.

The nature of the problem

Allergic disorders including anaphylaxis, allergies to foods, latex, insect venom and drugs, allergic rhinitis, allergic asthma and atopic eczema, have increased dramatically in prevalence over the last three to four decades. At present about 30% of children and 25% of adults in Scotland suffer from allergies. While in the majority of children affected, symptoms are mild to moderate and can be managed in primary care and by GPs, there is a considerable group of patients with severe allergic disease. In these children, allergy is a multi-system disorder typically affecting several organs in the same patient. Full allergy evaluation and effective management of these patients requires the specialist knowledge of a paediatric allergist, who also has an important role in co-ordinating treatments by other health professionals in a multi-disciplinary approach to allergy management. A specialist paediatric allergy service will usually be able to identify the offending allergens and can provide advice on allergy prevention, allergen / trigger avoidance, lifestyle modifications, emergency treatment measures and on medication to help relieve or prevent chronic allergy symptoms. It monitors chronic allergic disease and identifies disease progression or its resolution. In addition, a specialist paediatric allergy service should offer



Professor Jürgen Schwarze FRCPCH

disease modifying treatments such as immunotherapy, where appropriate. In combination with primary care, allergy specialists can help to ensure accurate and appropriate sharing of information with other interested bodies such as schools.

Current concerns

Clearly, there is a national under-provision of specialist paediatric allergy services despite the high numbers of children affected. This has recently been identified as the case for most parts of the UK by a House of Lords report (2007). The paediatric allergy services currently available in Scotland are provided by paediatric specialists in respiratory medicine, gastroenterology and in infectious diseases, by general paediatricians, GPs, nurses or dieticians interested in allergy.

What is needed

We need a network of Allergy Centres in Scotland which would provide specialist paediatric allergy services based in the four major teaching hospitals in Glasgow, Edinburgh, Aberdeen and Dundee. These Allergy Centres should lead clinical allergy services in their region, but also share experiences and expertise across Scotland. A Managed Clinical Network (MCN) in Paediatric Allergy would help to integrate service delivery, quality control, education and training in paediatric allergy throughout Scotland. Such Allergy Centres and a supporting MCN would allow the development of important clinical services currently not available in Scotland such as immunotherapy clinics both for established indications such as hay fever and also for promising emerging areas

such as peanut and aspirin allergy, in-patient rush desensitisation for insect allergies, a specialised drug allergy service and a transition service for adolescents.

The Allergy Centres would provide allergy training, not only for the next generation of paediatric allergy specialists, but also for general paediatricians, GPs, nurses and dieticians interested in allergy. In addition, a network of Allergy Centres would help to establish Scotland as an internationally leading centre for allergy research, adding to the already internationally-recognised allergy research at Scottish Universities that comprises research in epidemiology, education, service delivery, and clinical and basic immunology of allergy. Paediatrician-led Allergy Centres could also be a catalyst for the development of more widely available specialist allergy services for adults in Scotland.

Scottish Paediatric Allergy Group

Together with Dr. Rosie Hague of Yorkhill Hospital, Glasgow, Professor Schwarze has recently set up the Scottish Paediatric Allergy Group as an initial step to promote service development in paediatric allergy in Scotland. This informal group has members from all four Scottish regions, so far including paediatric allergists, consultant paediatricians, paediatricians in training, GPs, dieticians, nurses and allergy researchers. The Scottish Paediatric Allergy group is open to all health professionals interested in paediatric allergy, representatives of charities active in this field and to representatives of parents with children suffering from allergies.

The aim of the group is to encourage best clinical practice, to contribute to continuous professional education and to promote service and research development in paediatric allergy. The senior members of the Scottish Paediatric Allergy Group have very good relationships with colleagues south of the border and throughout Europe, ensuring that paediatric allergy in Scotland will be part of new developments taking place in other parts of the UK and Europe.

Prof. Jürgen Schwarze can be contacted at: Child Life and Health, The University of Edinburgh, The Royal Hospital for Sick Children Edinburgh, Tel: 0131 5360801

e-mail: jurgen.schwarze@ed.ac.uk

Living with a Long Term Condition – A Young Person's Experience

Is it possible to say a bit about the condition you have?

I have asthma and anaphylaxis. The anaphylaxis I've had for 14 years though as a baby there was no clue of it. I've been much better over the last two to three years with different drugs. The asthma was dormant till I was seven and first appeared when I was playing football and doing PE and I would have to sit down and catch my breath. At first the doctor thought it was a problem with my lungs but after they gave me the peak flow tests and stuff, they realised it was asthma.

How long have you had it - how does it affect your daily life?

The first time it appeared was nightmarish for Mum and Dad, as I had been taken up to Gran's overnight when I was six months old and they gave me a wee drop egg. My breathing went all laboured and I started going blue. Then when I was two they gave me some peanut butter on bread and I went into shock immediately. Luckily, I was given prednisolone which we had in the house by that time. That helped but when it started to wear off, I had to get rushed to A and E. We just had to avoid certain foods after that. Now in Secondary things are much better. I have two pens in ma school bag an inhalers and ventolin and a tablet pack. Now I'm in the senior football team, ah just put the box into ma kit bag –like a grab bag. Ah'm in a routine now just like brushing your teeth in the morning, you take it for granted.

In Primary school it was different, I really didn't have any friends cos the other children were quite wary of you and you'd have the support assistant shadowing you all the time so the others didn't want to play with you. It was socially isolating, quite depressing really and harder the older I got. Primary 5-7 was the worst. After I got into Secondary 1 and 2, the support assistant was there for others too and so the focus wasn't just on me. Socially, now I've got the Scouts, that's ma second life – I love it! And then I've got one or two really close friends with other long term conditions and they are really considerate to me (I'm probably the worst case I know) cos we know what we can and can't do. We're just more aware of each others' needs – so we'll say, 'Let's not have peanut M and M's!' I think though there's a fear amongst those who are not affected by something like diabetes or that and they make a big fuss!

Are there things which help and things which don't?

I suppose it wasn't just as simple as avoiding certain things cos one time when I was about five Dad was having lentil soup. I picked up the spoon he had licked, it wasn't like I had any of the soup or anything... then I remember we were in a restaurant and they must have been frying an egg and I got set off by the smell. So some of the things which affected me really badly were barley, hops, oats, eggs, nuts obviously and lentils. Probably the worst ever time was when we were in Rothesay. I was seven or eight, McCains chips had a new recipe with paprika or cayenne or something and I was really close to death. The local hospital gave me hydrocortisone but I had to get helicoptered to the mainland and then a nurse breathed on me and ah got stuck there for three days! Then about two or three years ago they were testing a new drug in the USA, Loratadine, and ah felt a difference in three or four months an ah'll tell you how I knew, we were going on holiday to Turkey and it was a morning flight and they were doing breakfasts an it turned out fine. Then the next step was frying

eggs in the house - me at one end and the eggs at the other! An then six or seven months ago, I tried pancake – bingo! Ah'm a hundred times better!

How has the family been affected?

Well my sister is a vegetarian and that makes it a bit easier except for sesame oil. My Dad is more laid back than Mum cos she's quite wary and she'll say, 'Oh, Jack remember you've got to do this and that.' Sally, she takes it all on the chin. One thing, one of my parents always had to not drink in case I had to be rushed to hospital but Mum has a medical condition anyway which means she can't drink. They both do, so they have to restrict their own diets in a way. So it does not seem like they're making that many adjustments 'n if we go out to a restaurant we just work it out each time there's a new situation.

How are you now and what do you want for yourself?

I just think at least am not dead! I suppose I've had a restricted friends network but not so much in Secondary I it's much better.

Where do you get most help? What helps most?

I can email ma Consultant and I get help from ma GP. Then there's the internet – an NHS site for allergies for young people there's a shop an a blog. An you can sign up for a free newspaper so if foods change or they put different things in, they tell you.

What advice would you give to other families at this time in their Young Person's life?

If the person is 12+ then let them get on with it! Don't fuss, or discriminate or stop me doing things. Keep it all 100% true - don't change the story. Some people use poetic licence or they muddle it and make it like worse than it was. See in Secondary 1 science class, they changed the syllabus and everything for you. 'No, ah didn't tell you to,' so they changed it back. If it's not safe for me to do something then ah just won't do it. Ah'll tell you what really helped – we made a presentation and showed it at the school assembly and it showed that they weren't allowed to deny you rights to do something. It was worse in Home Economics – you couldn't do stuff but we found the Disability Discrimination Acts say they can't do that so we told them.

Any advice for other young people with a condition?

For younger children up to 10, my advice is make a book – like this is me, an it tells you what ah can and can't have, contacts an smells. Also here's what ah can do and there was a recipe book at the back focusing on what ah can have an a contacts page. The whole of Rothesay had a copy – well everybody knew me!

What's most important for Health Professionals to remember when treating a Young Person?

They should keep the appointment and not muck you about – like the time they waited till we got there then said it was off! Sometimes if you get a lot of different people the right hand doesn't know what the left is doing and they can even make mistakes that way. But the main thing is if the young person is older then the Doctors need to give it to them straight - no dancing about the bush!



Photo: posed by model

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Project Officer Gill Sutherland, displayed the results of the 'Two minute challenge', a competition for Fairview pupils on the National Smile month theme of 'Brush for Health' and presented goody bags to the pupils, containing toothbrushes, two minute timers, pencils, erasers, stickers and balloons. Catherine Nelson Project Coordinator, wound up proceedings by thanking those who contributed to the event and inviting guests to take a look at and discuss the new *Special Smiles* resources.

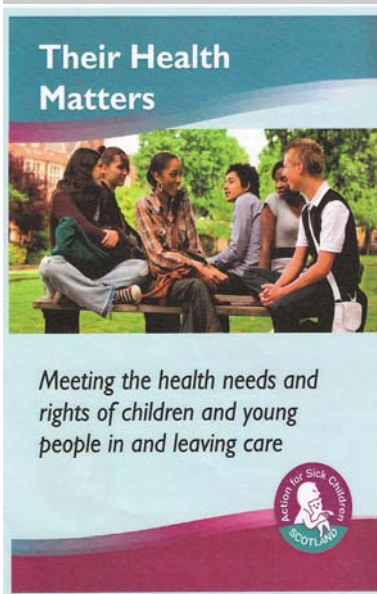
There was an enthusiastic reception for the project. Coral Bell, spoke about the wonderful start '*Special Smiles*' gave them as a Health Promoting School and said, 'the good thing about it is that we don't have to adapt anything.' Martyn Merrett expressed delight that the project has been launched in his Health Authority and saw it as 'another string to his bow' in his work in dental public health. The Dundee Courier and the Perthshire Advertiser both covered the event with a photograph and short article.

The '*Special Smiles*' Dental Project is now well underway with nine schools in Perth and Kinross - nursery, primary and secondary - agreeing to participate in the first phase of the project. Meetings have taken place with staff at all these schools, and to date, six of the schools have the resources in place. Training courses have taken place at three of the schools, with dates set for others after the summer holidays. Meanwhile, project staff have been moving into Dundee and Angus and establishing key contacts there in the fields of Health and Education.

Thanks to Standard Life plc
for printing this
Newsletter

We Can and Must Do Better

Looked After and Accommodated Children and Young People



If you work with this vulnerable group, contact Development Officer Anne Wilson about our LAAC project and for information and support on:

Children and young people's healthcare rights

Living with long term conditions

Who's who in health/other sources of help

Clinic appointments

What to expect in hospital

Dental treatment

Coping with needles and immunisations

Coping with pain.

We are delighted that Anne has now been appointed on to the Scottish Healthy Care Network Management Committee.

Have Your Say!

Health Rights Information Scotland (HRIS) is about to launch a new leaflet to help young people in Scotland have more say about their health care and treatment. The leaflet, '**Have your Say!**' is the third in a series that includes '**Confidentiality**' and '**Consent for under 16s**'.

'Have your say!' encourages young people to let the NHS know how they're being treated. It also explains how to make a complaint about the NHS if they feel they have been treated unfairly. The leaflet makes it clear that NHS staff have a duty to take the needs of children and young people seriously, whether they are making a suggestion or a complaint. It goes on to explain:

- the rights of young people
- who to speak to if they have a suggestion or complaint
- how the NHS deals with complaints and
- who can help them have their say.

Action for Sick Children (Scotland) has worked in partnership with HRIS in the development of this leaflet since the drawing board stage last year and is delighted to be featured in the **Help to have your say** section. To find out how

to get copies in your area please contact HRIS at hris@scotconsumer.org.uk, tel: 0141 226 5261 or ourselves as we will be carrying a supply in our national office.

Young Mums Tayside Project

Many of you will have read in the media recently of the alarming statistics associated with teenage pregnancy and sexually transmitted infections. This means that the safer sex message is still not getting across to young people. In a bid to combat this, the ASC(S) Teenage Mums Project in Dundee is currently trying to negotiate with various bodies in Tayside to examine the possibility of producing a multi-functional DVD that may be used in schools to get the message across that babies are hard work, expensive and effectively put an end to dreams and ambitions for teenagers.

Sadly a number of groups for teenage mothers in Dundee have folded recently, leading to a further gap in resources and services. However, a concerned and dedicated group of professionals have formed a rolling programme of classes to travel around Dundee in a bid to plug this gap. Obviously, we hope this will be very successful in meeting the needs of this very vulnerable group of young people.