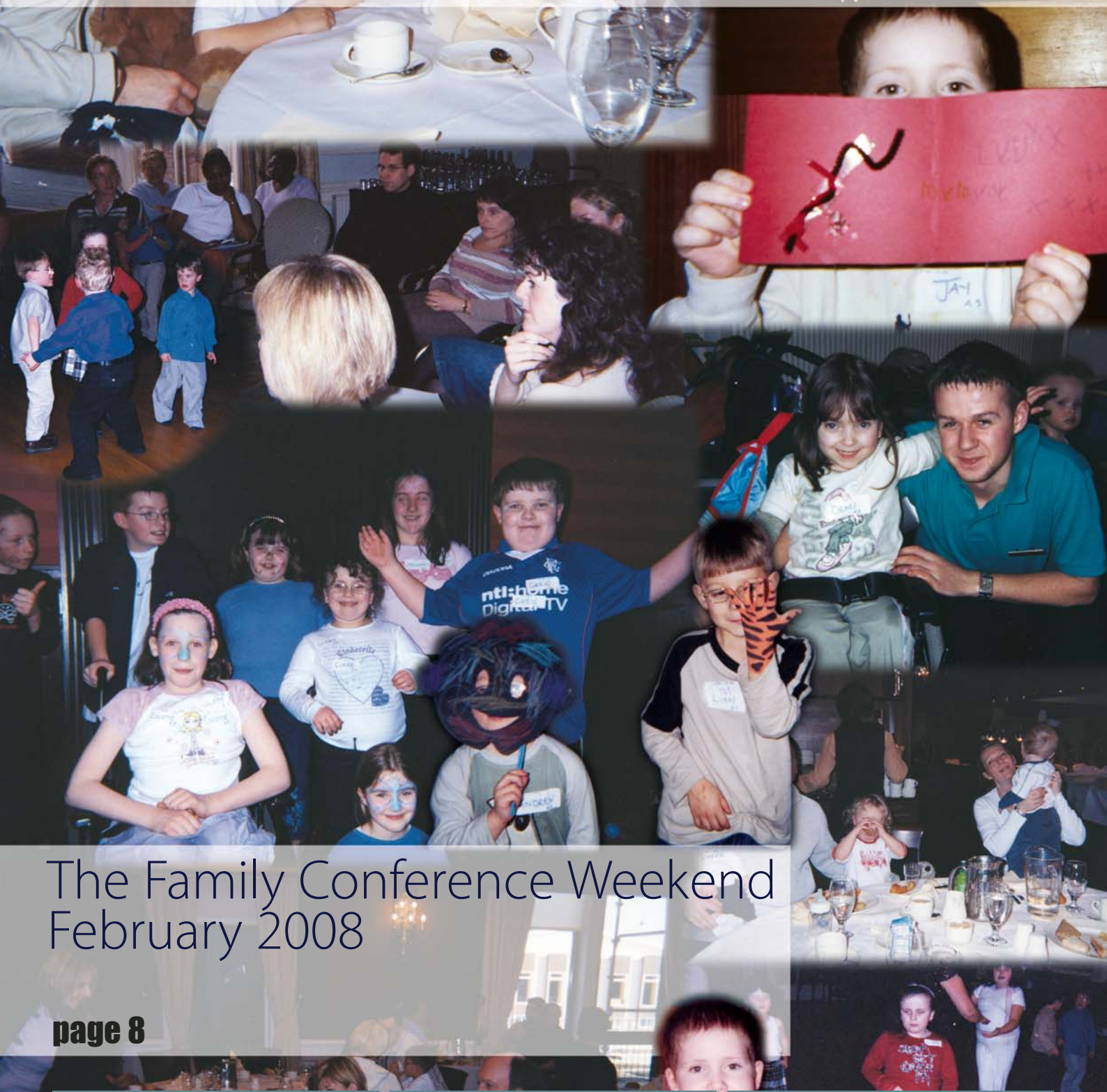


talk:BACK

Issue 16 – Summer 07

Scottish Spina Bifida Association

£2.10



The Family Conference Weekend
February 2008

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Positive changes ahead?



With a new Prime Minister at Number 10 SSBA Chief Executive **Andrew Wynd** wonders whether it will mean any positive changes to the law concerning disabled people.

Welcome to the latest issue of *talk:BACK*! It seems like only yesterday that we were working on bringing you the last issue, but since then there has been a few big changes, most notably, a new face at Number 10.

So, in this issue a few key figures in the world of disability give us their thoughts on what a new Prime Minister would mean for disabled people and whether they thought

that we would see some positive changes to the law. Turn to page 5 to find out what they said.

On the path to employment

We take a look at a new scheme in Edinburgh and the surrounding area, which has seen Jobcentre Plus and the NHS join forces in a bid to help disabled people get on the path to employment (page 6).

presentations from consultants, lawyers and other professionals about issues affecting those with Spina Bifida and Hydrocephalus.

If you've never attended the weekend then turn to page 8 for more details.

Fundraising Focus

Turn to page 13 to find out how you can help raise some money for people with Spina Bifida and Hydrocephalus. There's plenty to join in with and while you'll be helping a good cause you'll also be having some fun too.



It's a family affair

Also in this month's issue are details of next year's Family Conference Weekend, taking place in February.

The weekend is a great opportunity to attend

Deborah Roe

Speaking of fundraising, we would like to congratulate fundraiser Deborah Roe who has been awarded Best Up and Coming Fundraiser at this year's National Awards.

The weekend is a great opportunity to attend presentations from consultants, lawyers and other professionals.

Andrew H D Wynd • Chief Executive, Scottish Spina Bifida Association

talk:BACK is the official magazine of The Scottish Spina Bifida Association. Our aim is 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.

Scottish Spina Bifida Association
The Dan Young Building
6 Craighalbert Way • Cumbernauld G68 0LS
Tel: 01236 794 500 • Lo Call: 0845 9 11 11 12
Website: www.ssba.org.uk

Andrew H D Wynd: Chief Executive
Julie Snaddon: Head of Administration
Lorraine Wilson: Bookkeeper/Administrator
Caroline Kenny: Receptionist
Cheryl Bradshaw: Receptionist
email: mail@ssba.org.uk

Services and Development Manager

Mark Lees

Tel: 01236 794515
email: mark@ssba.org.uk

Family Support Service

Anne Kane
Anne Metcalfe
Diane Lowrie

Tel: 01236 794516
email: familysupport@ssba.org.uk

Fundraising

Deborah Roe: Head of Fundraising
Clare Cogan Turner: Fundraising Officer
Sandra Bauld: Fundraising Administrator

Tel: 01236 794508
email: fundraising@ssba.org.uk

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talk:BACK



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summer 07

BACKchat

School's back!

We can provide training, information and leaflets on spina bifida and hydrocephalus to Teachers and Support for Learning Assistants throughout Scotland – just contact the Family Support Service.



£1m – is it enough?

According to Capability Scotland, wheelchair services in Scotland need long-term funding commitments if they are to meet the needs of users. The claims followed the Scottish Executive's announcement of a £1m increase for wheelchair and seating services, despite a review published last June that recommended funding should be doubled from £14.2m to £30m.

Sheila Williams, head of disability initiatives at Capability Scotland, welcomed the commitment, but added: "However, we are concerned that money will not go far enough to provide a service that meets the needs of disabled people across Scotland.



Fire Safety Guide launched

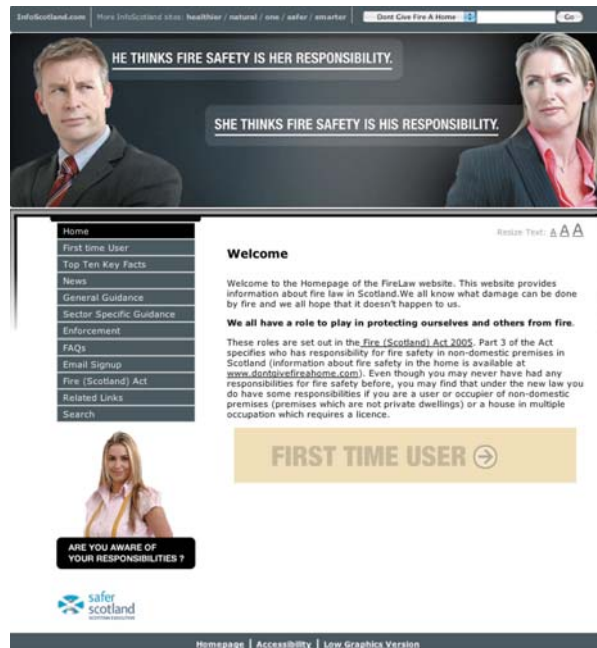
A guide for the emergency evacuation of disabled people from buildings was launched on July 5 by the Scottish Executive with the support of the Disability Rights Commission.

The guide provides practical advice on pre-planning for the evacuation of disabled people in the event of a fire.

It highlights the types of issues that employers and others with fire safety responsibilities should consider in their plans.

The 40 page document also outlines the relevant legislation – fire safety, health and safety, and disability discrimination law.

The guide is the first bespoke guidance for evacuation of disabled people to be issued by the Scottish Executive and complements a series of sector-specific guides on new fire safety legislation.



The fire safety guide's site.

The fire safety guide can be viewed online at www.infoscotland.com/firelaw

Adult Literacy and Numeracy in North Lanarkshire

The Adult Literacy and Numeracy Team has bases in several locations throughout North Lanarkshire and aims to help those with limited initial education, particularly young adults, and those with a health problem or disability affecting learning, speech sight or hearing. Wherever possible, learners have access to IT suites in which they can use computers as a

tool for learning or to acquire basic computer literacy. Learners can meet in a variety of locations during the day or evening and the programme of learning is centred around their own interests and life experiences working at their own pace and to an agreed plan.

Contact Family Support if you're interested.



Our Edinburgh Family Group enjoyed their summer outing at East Links Park.

A new face at No. 10

As Gordon Brown takes over the reins at number 10 some of the key figures in the world of disability shared their opinions on what it means for disabled people.

David Morris, senior policy advisor to the Mayor of London (Disability), comments: "There is great potential for a radical and positive change in our lives, and Gordon Brown has the opportunity to make this a reality. Under Blair's governance we saw the creation of the Office for Disability Issues and the public sector duty to promote disability equality. The move towards individualised budgets for people using personal assistance has also been very welcome.

"However, there is no room for complacency. The Discrimination Law Review Green Paper for the new Commission for Equality and Human Rights looks set to alarmingly dilute the rights of disabled people. And worryingly, across the UK, local disability services are being threatened with further budget cuts and closures. In my opinion, Gordon Brown has the chance to act on this and deliver a legacy of equality for disabled and deaf people if he prioritises the following issues:

- Supporting legislative rights for independent living and inclusive education.
- Providing legal status for British Sign Language.
- Delivering a network of Centres for Independent Living.
- Actively engaging with disabled and deaf people to guarantee our rights to equal citizenship and independence.

"As a disabled person, I rightly have high expectations of our new Prime Minister. By working together, we can make sure disability equality doesn't slip off the government's agenda."

Anne Begg, MP for Aberdeen South, says: "If we want to know what difference Gordon Brown as Prime Minister will make to the lives of disabled people then we will do well to look at what his priorities



were as Chancellor.

"He has been keen to end poverty, both at home and abroad. Such policies will have a benefit for disabled people because we know that families who have a disabled child or adult are more likely to suffer poverty. In the 2006 Budget, Gordon Brown set up a review into services for children. As a result, Ed Balls MP recently announced £340m of new investment for disabled children for the next three years.

"Gordon himself is blind in one eye and his son was recently diagnosed with cystic fibrosis; this knowledge of disability will give him a perspective that few other politicians have."

Simone Aspis, Parliamentary and Campaigns worker, United Kingdom Disabled People's Council, adds: "Brown at the helm – business as usual! Can we expect him to identify as a disabled person and relate to the issues which many of us face? Can we expect policies which ensure we can equally participate in political, civil and social life as he has done throughout his life? Can we expect that disabled people will enjoy the benefits of their paid labour as he has done and financial

There are high expectations of Gordon Brown.

security for those unable to undertake paid work? Will disabled people enjoy the mainstream education he clearly benefited from? And will disabled people be able to enjoy the same degree of autonomy and independence he has taken for granted? We will have to wait and see. We hope so."

Imelda Redmond, chief executive of Carers UK, says: "During the last 10 years this government has introduced several pieces of legislation which have helped carers and their families, most recently the Work and Families Act. But, too many carers still suffer ill health, poverty and discrimination. They feel the contribution they make to society isn't recognised. Gordon Brown has an immediate opportunity to tackle this through the review of the National Strategy for Carers, which is currently underway. My number one request to him is to review carers' benefits which are unfair, do not support carers to work and leave many living in poverty."

Sir Bert Massie, chairman of the DRC, comments: "Gordon Brown's biggest priority must be to tackle the crisis in social care. The situation facing disabled and older people and the army of women and child carers is now desperate. It can only be tackled by ensuring more choice, control and dignity for disabled people and their families. This will have social as well as economic benefits by creating a society where disabled people play their full part as active citizens, and by bringing considerable return to the economy.

"The new administration must also be bolder in its proposals for anti-discrimination law reform. Without more effective laws, entrenched inequalities – such as the employment gap for disabled people – will simply never shift in our lifetimes."

Get on the path to employment

Jobcentre Plus and the NHS in East Central Scotland have joined forces to help disabled people and others with long-term health conditions get on the path to employment.

Disabled people in Edinburgh and the surrounding area can now access a scheme which combines the expertise of NHS professionals with the support of Jobcentre Plus staff in order to help them into work.

Participants on the Working Towards Health programme, who may have been on benefits such as Income Support and Incapacity Benefit for many years, are given specialist support and advice tailored to their needs.

Working Towards Health provides between six and eight entirely

Get specialist support and advice with the Working Towards Health programme.

confidential one-to-one sessions with NHS health professionals. The health advisers, who include district nurses and occupational therapists, are on secondment for a year from the NHS and have been specially trained by Jobcentre staff.

Anna Riva, Leith branch of Jobcentre Plus, explains: "Sometimes a person has made the decision to move forward into work but needs that extra bit of support. The aim of Working Towards Health is really to give the person a better understanding of their health condition and to try and see if they have tapped into the healthcare that's available through the NHS so they can manage their position in employment."

The one-to-one sessions involve discussions with the health adviser to ensure that the customer is taking the right steps on the path to work and to investigate whether or not there are any health-related barriers to achieving their future goals. The sessions use techniques from a form of counselling known as Cognitive Behavioural Therapy in order to help people change their negative ways of thinking and improve the likelihood of them becoming successfully employed.

Customers going through the Working Towards Health programme can be reassured that they're receiving high quality help from fully trained healthcare experts whose main aim is "to improve the customer's quality of life and to try

and let the person regain control over their lives and achieve their ambitions".

Barrier-free

One of the great things about the Working Towards Health programme is that it's not mandatory – participants can drop out at any time if they feel it's not for them, with no effect on their benefits.

Anna comments: "There are no restrictions, which is great. The way we work is very informal and we have a fast referral process. If the person is in the Jobcentre and a health adviser is available, they'll come down and have a quick chat."

Customers can refer themselves to the programme or alternatively Jobcentre Plus staff might encourage them to consider participating. As Anna says: "We don't want to put too many barriers in a person's way, we want it to be as easy and accessible as possible."

Employment organisations working with people with long-term health conditions and disabilities, such as Shaw Trust and Remploy, can also refer their clients.

When it was launched in August 2006, the project was open solely to disabled people and people with long-term health conditions who are out of work. However, it has since been extended to include any job seekers who think they would benefit from the advice available. Many people have health



complaints which they feel may hold them back from being successfully employed, and the extension of the eligibility criteria for Working Towards Health is allowing Jobcentres in Edinburgh, East Lothian and Midlothian to provide this useful service to as many people as possible.

An opportunity to find out more

Potential beneficiaries had the opportunity to learn more about the Working Towards Health programme in January at an event held in Edinburgh. Here they could speak to employment advice organisations, disability organisations such as Capability Scotland and the RNIB, and employers who are positive about employing disabled people – those present at the event included Marks & Spencer and the City of Edinburgh Council. Representatives from Edinburgh Leisure (which runs sports and leisure facilities for the Council) were also present, helping to promote the benefits of good health and the links between exercise and positive mental wellbeing.

Lynn Ritchie, who is helping to oversee the whole programme, says: "There might be a client sitting at home unsure where they can get help, wondering where they should start. We're trying to bring together all the services that are available – sometimes there can seem to be such a myriad of different things."

Lisa Thomson was present at the Edinburgh event. She is a recruitment section co-ordinator at Marks & Spencer and was there to meet unemployed people, find out their concerns around employment and let them know about the Marks & Start programme. This is a work placement scheme which gives people from socially excluded groups (for instance disabled people, lone parents and young



unemployed people) the chance to spend two or four weeks on a placement in a store, in order to enhance their skills.

Lisa explains that Marks & Spencer is keen to take on disabled people. "We believe everybody is an individual and everybody has different skills. We're looking for people's strong points and we work together to see where we can put people in our organisation to benefit both our customer and the employee themselves, so they're in a comfortable environment where they feel they can achieve their full potential with the company."

Companies like Marks & Spencer are working with Edinburgh Jobcentres to support the Working Towards Health scheme and take it to people who will really benefit from it.

Plenty of people have already benefited from the programme: 275 individuals have taken part in

Working Towards Health so far and some of them are already having interviews for potential jobs.

Anna Riva says: "My customers have found it really worthwhile. Just

Pathways to work

The Working Towards Health programme is based on a similar scheme known as the Condition Management programme, which is part of the government's Pathways to Work scheme.

Pathways to Work is running in a number of pilot areas, offering person-centred interviews to help people who have been on benefits for a long time to get back on the path to employment. This involves a series of meetings between a trained adviser and the customer, who will be supported in identifying future life and work goals. By working together, the adviser and their client will look at any barriers which might be stopping the customer achieving their aspirations, and the adviser will help them to find solutions to overcome any obstacles.

Since Pathways to Work started, more than 25,000 people have benefited, and the scheme now covers 40% of the country. Because they are not based within the Pathways to Work pilot area, Jobcentres in East Central Scotland have developed their own scheme in the form of Working Towards Health, so that customers in the region can take advantage of similar support.

getting that extra level of support from professionals means they have a better understanding of how to manage their situation – they feel really reassured."

With an estimated 2.7m people claiming benefits related to their incapacity and the vast majority of disabled people wanting to work, innovative programmes such as Working Towards Health are making a big difference to the lives of many.

“Companies like Marks & Spencer are working with Edinburgh Jobcentres to support the Working Towards Health scheme and take it to people who will really benefit.”

Family Conference

The Family Conference Weekend is back, giving families from all over Scotland the opportunity to meet each other. So if you haven't been before, read on to find out how...

Our very popular Family Conference Weekend is being held once again in February 2008.

This will be open to all families throughout Scotland with a child of 10 years and under with spina bifida and/or hydrocephalus.

The Conference runs from Friday until Sunday and is attended by parents/carers, brothers and sisters. Presentations will include medical management, education law and provide the opportunity to speak to people who have grown up with spina bifida and hydrocephalus.

The children are looked after by specialised creche staff enabling parents and carers to attend the presentations.

This event is funded by BBC Children In Need and Edinburgh Sick Kids Friends Foundation. There will be a small charge for families.

Those who have not attended a Conference in the past will be given priority.

If you are interested in attending the weekend please fill in your details on the tear off slip below and return it to us.



Name: _____

Address: _____

Postcode: _____

Number of children: _____ Ages of children: _____

Please return to: **Family Support Workers, Scottish Spina Bifida Association, The Dan Young Building, 6 Craighalbert Way, Cumbernauld, G68 0LS** or phone: 01236 794516.



Alison Cloudsley attends the Nationwide Awards Scheme

Before I left school the Deputy Head of Greenock Academy asked me if he could enter me into the Nationwide Awards Scheme for Voluntary Endeavour for the Under 18 Individual Award Category.

This was because of my work within the school, and also at Yorkhill Children's Hospital in Glasgow. I am secretary of Yorkhill Youth Voices, which I do voluntarily. Youth Voices is a group for teenagers, set up so that teenagers had a say in what was being done in the current hospital. This includes the choice of food on the wards, the way in which we are treated by staff, and helping to make hospital stays easier for other teenagers.

I am also a member of the Youth Panel for the new Children's Hospital, which is to be built in 2012 at the Southern General Hospital. The Youth Panel was set up to help with the planning of the new hospital and to give the views that teenagers would like to put across, for example, the way the hospital will look and the name it will be given.

Also within the school I was a



Alison Cloudsley receiving her award.

Befriender to a class from the junior section of the school for two years and a Senior Pupil Helper for one year when I was in sixth year. When I was a Befriender I would go to a junior class and help them each week if they were having any problems with bullying or if they were having problems with their schoolwork. As a Senior Pupil Helper I went into junior

pupils classes and helped them with their work between my own classes.

Following my conversation with my head of year, I made up a folder of the work that I had done as secretary of Yorkhill Youth Voices. This included a report that I wrote following a trip to Aberdeen Children's Hospital and copies of e-mails that I had sent to everyone in the group to organise meetings.

On Monday July 23, 2007, I was, therefore invited to an awards ceremony by the Nationwide Building Society. The ceremony was held in a suite at the Marriott Hotel in Edinburgh. The ceremony lasted for half an hour, where I was presented with a medal and £50 worth of dining out vouchers. I really enjoyed the event, as it was nice to meet the other regional winners from the other categories, which were quite varied.

Congratulations

Finally, all of us here at **talk:BACK** would like to congratulate Alison on passing her driving test.

Tax relief



Many disabled people and their families need a little extra help with money, so this issue provides advice on the Tax Credits system.

In April 2003, the government introduced Tax Credits, to top up the pay packets of families and workers on low incomes.

There is also additional support for workers with a disability, or families where parents or their children are disabled.

There are two types of Tax Credit: Child Tax Credit and Working Tax Credit.

Supporting your family

Child Tax Credit is paid to families based on their income, regardless of whether or not they are working.

Families earning up to £58,000 are entitled to some tax credit, and if they have a child under a year old the threshold is up to £66,000. This amount is paid up until the child turns 16, or up to 20 in certain circumstances.

If your child is under one year old or has a disability, then the amount of Child Tax Credit you can receive will be higher.

Child Tax Credit is different to Child Benefit. It is paid directly to the main carer for all the children in the family, so if you are a single parent, it will be paid to you, and if you are part of a couple, you will need to tell HM Revenue & Customs which of you is the main carer for the children.

You can choose whether to receive payments weekly or every four weeks.

You may get a disabled child element for each child or young person you are responsible for, if you receive Disability Living Allowance (DLA) for them, or the child or young person is registered blind.

You may get a severely disabled child element for each child or young person you are responsible for if you receive DLA (Highest Rate Care Component) for them.

Supporting you in work

Working Tax Credit tops up the incomes of people who are on low wages.

Working Tax Credit is a payment to top up the earnings of low paid working people (whether employed or self-employed) including those who do not have children.

Working Tax Credit contains several elements, including additional amounts for:

- Working people with a disability
- People with a severe disability
- The costs of registered or approved childcare

You need to be aged over 25 and work at least 30 hours per week, or aged over 16 and work at least 16 hours per week if you are disabled or responsible for a child.

There are extra amounts for people who are disabled. If your child or children are in registered childcare, the Working Tax Credit



will pay up to 80% of the weekly cost, up to a certain limit depending on how many children you have.

How do I qualify?

You may receive the disabled worker element of Working Tax Credit if you work at least 16 hours a week and you have a physical or mental disability which puts you at a disadvantage in getting a job and you satisfy either the 'qualifying benefit' test or the special 'fast-track' rules, which are outlined below.

If you are claiming as a couple and your partner is also working for 16 hours or more a week, and is entitled to disability element, you may receive two disability elements.

Disabilities which put someone at a disadvantage in getting a job might include:

- Visual impairments
- Hearing impairments
- Problems with communication
- Difficulty getting around
- Mobility impairments
- Mental disabilities
- Exhaustion and pain

To pass the 'qualifying benefit' test, you must be receiving one of the following benefits:

- Disability Living Allowance
- Attendance Allowance
- Industrial Injuries Disablement Benefit (with Constant Attendance Allowance or Mobility Supplement for you)
- War Disablement Pension (with Constant Attendance Allowance or Mobility Supplement for you)
- A vehicle provided under the Invalid Vehicle Scheme

Alternatively, you must have received one of the following benefits in the last six months:

- Incapacity Benefit at the short-term higher rate or the long-term rate

- Income-based Jobseeker's Allowance, with a Disability Premium or Higher Pensioner Premium for you
- Income Support, with a Disability Premium or Higher Pensioner Premium for you
- Severe Disablement Allowance
- Council Tax Benefit, with a Disability Premium or Higher Pensioner Premium for you
- Housing Benefit, with a Disability Premium or Higher Pensioner Premium for you

You may be able to get more Working Tax Credit to help with the cost of registered or approved childcare. This is the childcare element of Working Tax Credit.

Full Speed Ahead

The 'fast-track' rules help if you are finding it hard to stay in work because of a disability. If your disability means that after a period of sickness, you have to change to work with lower pay or reduce your hours in your current job, you then qualify for the disability element earlier. The same applies if you are self-employed. To qualify for the disability element of Working Tax Credit via the 'fast-track' rules, you must have been getting one or more of the following for 20 weeks or more:

- Statutory Sick Pay
- Occupational Sick Pay
- Incapacity Benefit at the short-term lower rate
- Income Support paid because of incapacity for work
- National Insurance credits awarded because of incapacity for work

The 20 weeks can be made up of any time that you received the benefits or National Insurance credits which are separated by eight weeks or less – they don't have to be 20 consecutive weeks. These times may be 'linked', that is, added together to see whether you satisfy the 20 week condition.

You must have a disability that puts you at a disadvantage in getting a job. In addition, your gross earning (before tax and National Insurance contributions are deducted) must be at least 20% less than they were before you had the disability, with a minimum reduction of £15 a week.

If you or your partner (if you are claiming as a couple) get Disability Living Allowance (Highest Rate Care Component) or Attendance Allowance (Higher Rate), you can get the severe disability element. You do not have to be working to qualify for the severe disability element as long as your partner does. If you both qualify, you will get two severe disability elements.

Paying for childcare

You may be able to get more Working Tax Credit to help with the cost of registered or approved childcare. This is the childcare element of Working Tax Credit. The childcare element can help with up to 80% of your childcare costs up to a maximum cost of £175 a week for one child and £300 a week for two or more children. This means that the childcare element is worth up to an extra £140.00 a week (£175 x 80%) for families with one child, and £240.00 a week (£300 x 80%) for families with two or more children.

To claim Tax Credits or for more information, telephone 0845 300 3900 or visit your local HMRC Enquiry Centre or Jobcentre Plus.

Moving house? Getting married? Changing your contact details?

If your contact details have changed, make sure you let us know. Not only will you be able to continue receiving *talk:BACK* free of charge, you'll also stay on our database to let us keep in touch with you in the future. Let us have your new details by post, email or phone.

Scottish Spina Bifida Association, The Dan Young Building, 6 Craighalbert Way, Cumbernauld G68 0LS. Tel: 01236 794 516 • Email: familysupport@ssba.org.uk

SCOTTISH DISABILITY SPORT

SDS is the governing and co-ordinating body of all sports for all people of all ages and abilities with a physical, sensory or learning disability in Scotland, with the vision of leading the development of sport and physical recreation. **SDS** recently launched its new national strategy which will lead the work of the association through to the Olympics in London in 2012. **SDS** considers among its major partners **sportscotland**, Scottish governing bodies of sport and Scotland's Local Authorities.

SDS has 16 branches that cover the whole of Scotland ranging from the Highlands to the Scottish Borders. **SDS** has a small team of dedicated staff but prides itself on the number of volunteers and athlete members who play a major part in the running of the Association.

SDS members have featured prominently in GB teams that have been highly successful at the past five Paralympic Games including the most recent in Torino in March 2006 when

Scottish curlers as part of the GB wheelchair curling team returned home with the silver medal. Scottish athletes and teams also enjoy considerable success on the international stage. Scotland's cerebral palsy football team recently competed in the European Championships in Ireland and Scottish swimmers at the IPC World Swimming Championships in South Africa returned home with 9 medals. **SDS** organises a national events programme in

bowls, athletics, football, swimming, archery, boccia, wheelchair curling, cross country, etc. There is also a parallel programme of squad training and festivals geared to promoting new sports and developing the full potential of individual members, in particular children and young people.

SDS is committed to widening physical activity opportunities for individuals with a disability, particularly juniors. Participation at Paralympic level is the goal of many Scots sports people with a disability and **SDS** is there to offer support and advice when appropriate.

Anyone wishing to find out more about sport for people with a disability in Scotland should contact the **SDS** office on 0131 3171130 or alternatively, view the **SDS** website at www.scottishdisabilitysport.com.



Fundraising focus



26th November 2007 – Gordon Ramsay's St Andrews Day Gala Ball at Stirling Castle

This is a unique opportunity to be one of only 250 people to experience the magic of this Saint Andrew's Evening. Venue: Stirling Castle. Tickets are £500 per person.

Win 2 tickets to Gordon's Gala Dinner at Stirling Castle (including accommodation and travel)

To enter text GORDON to 86633.

You could be 1 of only 250 people at Gordon Ramsay's Saint Andrew's Day Gala Dinner.

Texts cost £1.50 per text plus network charges. Entrants must be 18 years of age. 84p from each text goes directly to the Scottish Spina Bifida Association.

For full terms and conditions and more information on the competition go to www.ssba.org.uk/competition

Xmas Raffle Draw

The SSBA are hoping to make this a record breaking year for raffle ticket sales so please contact Clare or Deborah today on 01236 794508 for tickets.

Christmas Cards

SSBA has a fantastic range of Christmas Cards for sale this year. Please call 01236 794508 or email fundraising@ssba.org.uk for our card information.

30th November 2007 – Saint Andrews Day Dinner & Ceilidh

Hosted by Cumbernauld College. Award winning French Patisserie chef and his students combine with Cumbernauld's finest catering students for a great evening of food and dance. Venue: Cumbernauld College. Tickets are £25 per person.

23 February 2008 – Fire & Ice Event

It's back even bigger and better than last year. This year you can walk on fire or glass or both and with sponsorship from the Scottish Round Table Area 51, every penny raised by you goes directly to the charity. This is an inspirational and motivational event and one not to be missed.

The evening includes superb motivational training followed by the exhilarating walk across fire and/or glass.

Venue: SSBA Centre in Cumbernauld. Apply today!

25th May 2008

Edinburgh Marathon
SSBA have a limited number of guaranteed places for this event. Don't miss out on one of the top marathons in the UK. Please contact Clare in Fundraising for more information and application forms

Thank You

The Scottish Spina Bifida Association would like to say a big thank you to all those who have taken part in or have held events for them over the past few months. Your support is very much appreciated.

Gordon Ramsay's St Andrews Day Gala Ball takes place at Stirling Castle.

How to take part – contact Fundraising

To take part in any of these activities please email fundraising@ssba.org.uk or call 01236 794500 and they will be able to give you further information or send you application and sponsorship forms.

Don't have time to collect – Justgiving.com

If you don't have the time to get people to sponsor you and collect sponsorship money later, we have teamed up with justgiving.com, a website which allows our runners & event participants to raise money quickly and easily online with their own personalised web pages.

Friends and family will be able to donate online with a credit or debit card – so no more running around with paper sponsorship forms, or chasing cheques and cash after your event. To set up your page today, please visit the website at: www.justgiving.com/ssba/raisemoney

Everyclick.com

The search engine with a heart, Everyclick.com donates half of its revenue to charities. So forget Google – make www.everyclick.com your homepage. By choosing Scottish Spina Bifida Association as your chosen charity, the Association will receive a donation from Everyclick every time you do a search for anything! There is no catch, you don't pay anything – it's just an easy way for you to support us. Donating has never been this easy. The more people that join the better, so spread the word!



Leaflet List



Please tick ☐ for leaflet(s) required.

- | | |
|---|--|
| ☐ Activities for Fine Motor Development | ☐ Latex Allergy |
| ☐ Adults with Hydrocephalus | ☐ Learning Difficulties |
| ☐ Anal Plug | ☐ Living with a Shunt |
| ☐ Anencephaly | ☐ Mitrofanoff Stoma |
| ☐ Antegrade Colonic Enema | ☐ Normal Pressure Hydrocephalus |
| ☐ Baby with Spina Bifida (Book) | ☐ Orthopaedic Aspects |
| ☐ Bladder Augmentation & Incontinence Surgery | ☐ Precocious (or early) Puberty |
| ☐ Choosing a Car | ☐ Pregnancy & Spina Bifida |
| ☐ Clean Intermittent Catheterisation | ☐ Pressure Area Care |
| ☐ Constipation and Diet | ☐ Scoliosis in Spina Bifida |
| ☐ Early Positioning, Stimulation & Exercises for Babies & Pre-School Children with Hydrocephalus | ☐ Shunt Alert Card |
| ☐ Genetic Counselling | ☐ Shunt Malfunction
(A guide to symptoms & suggested action for employers) |
| ☐ Hydrocephalus – What is? | ☐ Shunt Malfunction
(A guide to symptoms & suggested action for schools) |
| ☐ Hydrocephalus and/or Spina Bifida
(Guidelines for the Classroom Assistant) | ☐ Signs & Symptoms of a Blocked Shunt |
| ☐ Hydrocephalus & Behaviour
(for Parents) | ☐ Slit Ventricle Syndrome |
| ☐ Hydrocephalus & Behaviour
(for Teachers) | ☐ Spina Bifida – What is? |
| ☐ Hydrocephalus & Literacy & Thinking Skills
(for Parents) | ☐ Spina Bifida Occulta |
| ☐ Hydrocephalus & Mathematics
(for Teachers) | ☐ Stoma Care |
| ☐ Hydrocephalus & Numeracy
(for Parents) | ☐ Toilet Training & Spina Bifida |
| ☐ Hydrocephalus & Physical Abilities
(Motor skills & co-ordination) for Teachers | ☐ Urinary Investigations |
| | ☐ Vitamin Supplementation in the Prevention of Neural Tube Defect |

Name:

Address:

Postcode:

If you have any questions or would like further information, please do not hesitate to contact the Family Support Workers at:
Scottish SPINA BIFIDA Association • Family Support Service The Dan Young Building 6 Craighalbert Way Cumbernauld
G68 0LS • Tel: 0141 5867111 • Fax: 01415867222 • LO-CALL 0845911 11 12
E-mail: familysupport@ssba.org.uk • Web: www.ssba.org.uk

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Scottish Spina Bifida Fundraiser wins National Award for best up and coming Fundraiser

Scottish Spina Bifida Fundraiser Deborah Roe has been awarded the Best Up and Coming Fundraiser Award at the Institute of Fundraising National Awards 2007 – designed for Fundraisers by Fundraisers. Hosted by BBC Breakfast's Chris Hollins at the Hilton London Metropole on Monday 9 July 2007, the Awards were presented by a selection of influential people in fundraising.

The National Awards celebrate the achievements of professional and volunteer fundraisers, winners have been drawn from across the voluntary sector, representing a wide variety of campaigns and causes. Each category is reviewed against the best practice standards for UK fundraisers; the Codes of Fundraising Practice.

Deborah Roe was recognised as showing aptitude, ability and success beyond her experience.

Lindsay Boswell, chief executive of the Institute of Fundraising, said: "This winning individual joined her current organisation with no previous fundraising experience, and almost immediately found her overall target doubled to £500,000.

"In less than three years she has helped build the relationship with a celebrity Patron, designed her Organisation's website and secured bill board space across Scotland, to name just three achievements."

Deborah Roe, head of fundraising at the Scottish Spina Bifida Association, said: "Fundraising can be extremely challenging and I am delighted to have my efforts recognised by the Institute of Fundraising. Winning this award demonstrates that smaller Scottish charities can be recognised for their achievements at a national level".



Deborah Roe and her fundraising award.

Swimming a problem? No need to worry... we have the solution

Hi Line Ltd manufacture a fantastic range of Continence swimwear for both children and adults without the need for pads.

All styles of our Continence Swimwear range have a unique waterproof integrated pant, which has a polyurethane nylon coating that is rustle free and completely impermeable to water. Our construction combines a snug fit around the legs and waist, along with a silicone seal to the waistband. This combination offers the best protection and containment available for you or your child, without the use of a modern disposable nappy.

Our swimwear is fully washable, lightweight, and in a range of fabulous colours and patterns. The range included Bikinis, Tankini, Swimsuits and Trunks.

We can also offer a bespoke service – this is ideal for users that do not fall into the universal sizing chart. Therefore if measurements are submitted to us then we will make a bespoke swimsuit – at an extra cost.

If you need any further information on our Special Swimwear, please call our Customer Care Team on 0845 6018341

You can view the entire range on www.ostomartstore.co.uk



Direct Payments for children – the way forward

Direct Payments are a way of getting services that allows you more choice and control over how your child's needs are met. However, many parents in Scotland are confused about what Direct Payments are and how they work in practice.

What is a Direct Payment?

A Direct Payment is money from your local council, allowing you to buy care for your child instead of having that care organised by the Social Work department.

You can use a Direct Payment to buy services from a private care agency, a voluntary organisation, another local authority or if you prefer you can make arrangements to employ someone yourself.

How can I get a Direct Payment?

You can ask for a Direct Payment if you are already getting services from Social Work.

If you don't get services already then you will first need to ask the Social Work Department for an assessment of your child's care needs.

How much will I get as a Direct Payment?

You must be given a payment that is sufficient to allow you to buy in the amount of care that your child has been assessed as needing.

If your council charges for children's services, they are likely to deduct from your Direct Payment the same amount as would have been charged if they had organised the care package.

Are there any restrictions on using a Direct Payment?

A Direct Payment cannot simply be spent on whatever you choose. Instead it must be used to buy services that meet your child's assessed needs.

In addition it is not currently possible to use a Direct Payment to pay a close relative who lives in the same household as the child.

In exceptional circumstances your local council may agree to allow you to pay a close relative who lives elsewhere or to pay someone who shares your house who is not a close relative.

If you have any specific questions about Direct Payments please telephone Family Support.

Book now for self catering holiday accommodation at super rates!

Top of our holiday accommodation list is a week's stay at the Association's own fully adapted Cottage in Carnoustie.

Please phone now on 01236 794 500 and book your holiday by credit/debit card. It's that simple!

Alternatively you can take advantage of our new deal in caravan accommodation. In partnership with British Holidays we are now able to offer greatly reduced rates on any of their caravans featured in the latest British Holidays Brochure. You can order a brochure now by phoning 0870 2425500 or visit www.british-holidays.co.uk.

Our sponsored pricing structure is based on the actual cost to the Association and therefore is variable throughout the season with the most expensive generally being during public holiday and school holiday times. In order to compensate for this we have introduced a higher subsidy for families with a child under 16.

All wheelchair accessible caravans comfortably sleep 5.



Rebecca Cottage, Carnoustie (near Dundee), is a four bedroom detached cottage set on the sea front of the Angus coast with a porch looking out to sea.

Three stages to success!

- Check brochure and decide on the holiday you are interested in.
- Phone us on 01236 794 500 to check availability of sponsored price.
- Have your credit/debit card ready to secure booking.