

The magazine for people in Scotland with Spina Bifida and/or Hydrocephalus

talk:BACK

Issue 17 – Spring 08

Scottish Spina Bifida Association

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Blue Badge changes p4

Christmas party! p6

World Games p8

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SAMPLE

Parking Card for
Disabled People

Parkingskort
Ka?prou ora?h?avon?
Tarjeta de estacionamiento
Parkausweis



A new year and a new approach...



It's hard to believe that we're well into 2008 already and it's looking like another exciting and challenging year – but there's plenty to look back on, and indeed to look forward to, and SSBA certainly looks forward to being there for you this year.

Welcome once more to the latest issue of *talk:BACK*, the magazine specially dedicated to people in Scotland with Spina Bifida and/or Hydrocephalus.

It really is hard to believe that 2007 is now well in the past and we're already hurtling through 2008 – and by the looks of it, it seems that this year will be another adventure-filled period with plenty to look forward to.

We hope you enjoy this issue of your magazine, and hopefully you'll find lots of interest between the covers.

Make sure you don't miss our article on the changes to the Blue Badge Scheme – the changes aren't massive but it's important that you understand them if you or someone you know takes advantage of the scheme.

Also worth a look are the reviews of both our

Wheelchair Skills Course and our Christmas Party, both of which we held at the end of last year – and both were a roaring success.

There's a fascinating article by top ten pin bowler Sarah Anderson who recently

represented Scotland at the World Games in China, and there's an equally inspiring

report from Bruce and Lisa McAusland who have just returned from a fantastic three continent trip, taking in America, Australia and Asia.

You can also find out who has been raising what for SSBA, and you can even pick up a few ideas for how you can join in the fun by raising cash for SSBA while

enjoying some amazing adventures.

Over and above all that, you'll also find the usual mix of news, views and features you expect from *talk:BACK* and we really hope that you enjoy reading this issue.

And remember, if you have anything you'd like to share with us, or with fellow *talk:BACK* readers, get in touch!



Don't miss a fascinating article by ten pin bowler Sarah Anderson who represented Scotland at the World Games.

The Editor • 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.

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Changes to Blue Badge Scheme

The Minister for Transport has announced some changes to the Blue Badge Scheme to extend it to more people and in an attempt to reduce fraud.

Anyone applying for a Blue Badge will now receive a redesigned version which incorporates a hologram (making it harder to forge) and a gender-specific serial number so that traffic wardens and police officers can identify the user more easily.

The Blue Badge has been extended to cover children under two years of age whose disability requires bulky medical equipment, opening it up to a further 12,000 children.



In addition, people with a disability in both arms who do not drive an adapted vehicle can now apply for a Blue Badge, since it has been recognised that they can have

New fraud-combatting measures announced.

difficulties in using parking meters and other parking equipment.

In related news, supermarket chain Asda has announced plans to fine people who park in disabled bays without displaying a Blue Badge.

The scheme is being trialled at stores in Merseyside and will see parking cheats landed with a £60 fine.

Shoppers who park in parent and child spaces who are not accompanied by children will also be fined, and there are plans to extend the system nationwide. Rather than catching unsuspecting motorists, Asda hopes its scheme will act as a deterrent.

Katie and Thomas McNulty design a winner in our festive Christmas Card competition!

The winners of our recent "Design a Christmas Card" competition were Katie and Thomas McNulty. Here they are with mum and dad being shown around The Scottish Parliament building by Margaret Mitchell, MSP. Margaret ran the competition and the winning entry was printed on to her Christmas Cards, and sent out to around 1,000 people.

Thomas and Katie's design is shown here too.

For this year the Association will be running our own competition for designs that we will print on to the cards we produce. We will be running an activity day at the Centre



in Cumbernauld during the school summer holidays, providing art materials. More information will

Katie and Thomas with their mum and dad and MSP Margaret Mitchell.

be sent out to all school age children nearer the time, but for anyone who wants to submit an entry and who will not be able to come to the Centre, please send in your design by post and they will be entered on the day.

Wheelchair Skills Course

A wheelchair skills course was run in the Craighalbert Church Hall for two days during the October school holidays. These courses are run by the Association of Wheelchair Children and are provided free of charge.

The courses equip children with confidence and raise their self esteem. Parents too get the opportunity to get into a wheelchair and participate – the children think this is great fun.

The feedback we got from the participants showed what a fun filled day it was, and more courses were requested. As a result we will be organising one again during the October holidays (13th-17th October, although this does vary throughout Scotland). You can intimate your interest now by phoning Family Support and requesting to put your names down, and we will then send you out the information in plenty of time.

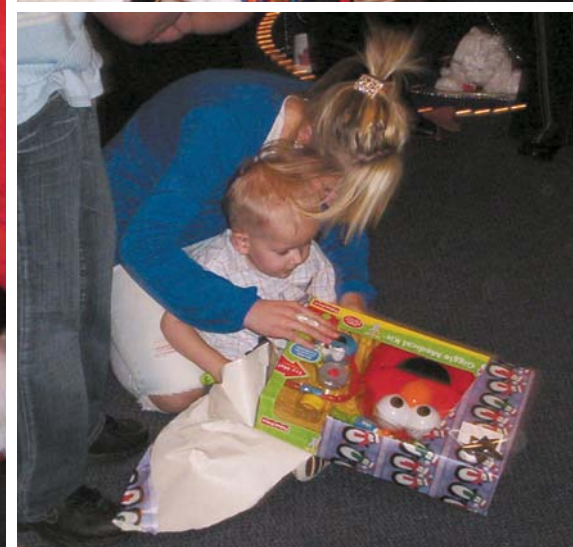




Christmas party

We held our Christmas Party at the Cumbernauld Centre on Sunday 2nd December. As you will see a great time was had by all and we had the extra fun of a visit by two footballers from Clyde Football Club. Here pictured (above) with the children are Neil McGregor (on the left) and Michael McGowan (front right).

Entertainment was provided by Mick Magic, and of course Santa arrived with the presents.



The answer is right under your nose...

A colourful new book helps young children understand and come to terms with having spina bifida.

This book is designed to help young children with spina bifida understand their condition and discover new ways to enrich their lives. Challenges facing young children with spina bifida include their movement, bathroom routines, exercise needs, diet and scars. *Right Under My Nose* addresses these topics through a novel design. These resources are interrelated to help you talk about what may be sensitive issues for your child.

The story demonstrates a young child with spina bifida leading a full life with zest, dreams, challenges and independence. It also promotes self-advocacy in children with disabilities.

Right Under My Nose



A Book for Children with Spina Bifida

 **Claire Austin, MPhil**
and Stacey Mizokawa, PhD
Illustrated by **Matthew Bates**

Put a circle around the equipment you use to move around.



There are activity pages to personalise the book for your child, and tips pages offering child-friendly answers to frequently asked questions, and activity suggestions.

The book was written by Claire Austin, MPhil, and Stacey

The book helps children learn how to approach their condition positively.

Mizokawa, PhD, of the Childrens Hospital, Los Angeles, and this does mean that there are American terms not familiar to British children (e.g. diapers for nappies) but this can be overcome. The book is free to download from www.MySpinaBifidaBook.org

Trip of a lifetime

Ten pin bowling ace **Sarah Anderson** shares her inspiring story of representing Scotland at the World Games in China.

Getting ready to leave Scotland.

My name is Sarah Anderson. I'm 19 years old from Carnoustie and took part in the World Special Olympics in Shanghai in October 2007. I first got involved in the Special Olympics in 2005 when I was still at school, I was picked to take part in the National Games in Glasgow, representing Tayside, Scotland in the Ten Pin Bowling Team, and I had lots of fun there.

The fun didn't stop there though, in 2006 I was selected to go to Rome to represent Great Britain in the European Youth Games. The Youth Games involved 1,400 Athletes from 57 countries. It also involved 400 coaches, 3,000 Family members 800 Guests 300 Media and 2000 volunteers. Before we went to Rome we had a few training weekends, we went to Runcorn, in England. Rome was a very good experience the different language, different food (they like their pasta) but all in all Rome was a lot of fun.

Then I got the trip of a lifetime when I was picked to represent Great Britain again, in China when I took part in the World Games. I felt very privileged to go because I was the only one from Scotland that was doing Ten Pin Bowling. There were more than 7,200 Athletes from 165 countries, 40,000 volunteers, 3,500 event officials, and thousands of friends, families and journalists. In order to go to China I had to get a gold medal in Glasgow which I did so I was very pleased about that. Before I went to China I went on a few training weekends to train and catch up with my team. We went to a few places such as Livingston and Runcorn. As well as training regularly I had to raise the money to get to China. I did a sponsored walk, ran a stall at the local gala and





received donations from SSBA and lots of local groups as well as joining in with group fundraising activities including a race night and a masked ball. Also before I went I was interviewed by the BBC as they were making a programme on some of the Scottish Athletes that were going. We got two made, one about the preparations before we left and one about our time there. The film crew came with us to Shanghai and filmed us all the way through. It was a good experience to see how different people lived and we got to go into a Chinese family's home and have a meal with them. Their Chinese food is very different from our Chinese takeaway and it is interesting to find out all about the different cultures. All in all I had the best experience ever. Before the games even started we got to be involved in some Chinese culture,

this was called the host town. The kind of things we were doing were visiting Yu Yuan gardens (a popular tourist attraction), and going to see the Bund which was a very famous river and the famous skyline of Pu dong. We also went to a few high schools which had different traditional Chinese acts on to entertain us. We also went to a primary school that had different kinds of sports on like Bowling, Basketball, Football, Shuttlecock, Kicking etc. Inside there were all sorts of fun things to do also, my favourite was picking up marbles with chopsticks.

We also were treated to a few meals and entertainment in the hotel on the first night and last night. We went to a flame ceremony where we had different entertainment and the Olympic Flame of Hope arrived when we were there and when the

At the Primary school.

Flame of Hope had gone everyone got to let off some steam by doing Basketball and all sorts of activities. We also went to a tea celebration, and got to try different kinds of tea.

The opening ceremony was the first time I realized just how many people were involved in The Games, there was an audience of 80,000 people cheering when we marched into the stadium country by country. Some famous people were there including Arnold Schwarzenegger, Jackie Chan and Colin Farrell. There were lots of displays and fireworks and the Flame of Hope was lit and the flag raised to mark the beginning of the Games.

At the games it was very nerve racking with a lot of people there watching you and cheering you on. My Mum and Dad came along to support me. Straight after each event it was the medal ceremony. The first competition was the team event. Anthony, John, Lucy and I all got 4th place which was good.

Each of the countries got a chill out room we could go in after our event but our team stayed to cheer each others on.

The next day was the Doubles so Lucy and I played in the morning and by the end we got a 6th place.

Then the last day was the Singles and for that I got a 4th place.

The hardest thing was not getting much time off just to relax and chill, we had to get up about 6am everyday to get to the Bowling Alley on time.

My best memories from China will be the friends I made, learning about China and how helpful the Chinese were and being part of such a big event. In every way it was a trip of a lifetime.



Lining up for the first session.

After the last competition – team, coaches and volunteers.





Speak up now!

Capability Scotland is calling on you to support its 1 in 4 Poll to help it work towards equality for disabled people

Capability Scotland is one of the country's leading disability organisations working for a just Scotland. We work with children, adults and families living with disability to support them in their everyday lives. We also work with disabled people, family members and carers to influence legislation, policy, practice and attitudes.

We need you to get involved in our work towards equality for disabled people by joining our unique **1 in 4 Poll**. The poll is made up of disabled people, or people with long term health conditions, their families and carers, and is called the **1 in 4 Poll** to highlight the proportion of Scottish households living with disability when the **Poll** was launched in 2000.

The **Poll** is managed by Scotinform Ltd, an independent research company registered under the Data Protection Act (1998). All information provided remains anonymous.

We survey our **1 in 4 Poll**

members up to four times a year on a wide range of issues. Capability Scotland uses this information to shape and support our campaigning and influencing work with politicians and decision makers. For example:

- Last Summer we asked about people's experiences of accessing social, cultural and leisure opportunities – whether they play sports regularly, go to the cinema or visit museums. This ties in with the Government's priorities around health and wellbeing, and we will be using these results to highlight what needs to be done to ensure that

disabled people also benefit from these policies.

- In 2004 we carried out a major piece of research with the Disability Rights Commission into disabled people's experience of hate crime. The information provided has been used to lobby for changes in the law, and as a result we now have a piece of legislation going through Parliament that aims to address this issue.
- One of the most enduring issues faced by disabled people is poverty and social exclusion. 'Living on the Edge', was published in 2001, updated in 2005, and showed the harsh reality facing disabled people and their families in Scotland. This has informed a great deal of our work, particularly around the government's welfare reform proposals and on fuel poverty.

You can join Capability Scotland's **1 in 4 Poll** online at our website, or by contacting Shirley Clarke on 0131 555 1104 or shirley.clarke@scotinform.co.uk to request an application form.

“ We need you to get involved in our work towards equality for disabled people or people with long term health conditions. ”

Down Under with Bruce and Lisa

Spina bifida and hydrocephalus sufferers Bruce and Lisa McAusland report back on their trip to Oz.

In the Spring 07 issues of *talkBACK* we told you about Bruce and Lisa McAusland, a couple with spina bifida and hydrocephalus, and their planned six week holiday taking in America, Asia, Australia and New Zealand. Well they have sent us in photos and an account of their trip.

In all their trip involved 13 flights from 12 different airports, and the only problems experienced were at Heathrow where their luggage and wheelchairs were lost! And on arrival in New York the hotel the holiday rep had assured them was accessible had 5 stairs to the entrance. Lesson learned – always phone the hotel yourself to check.

However, these problems were ironed out, and their trip lived up to everything they had expected. Favourite destination – Hawaii. It was possible to get wheelchairs right on to the beach as the sand is so compact. Also all public transport is

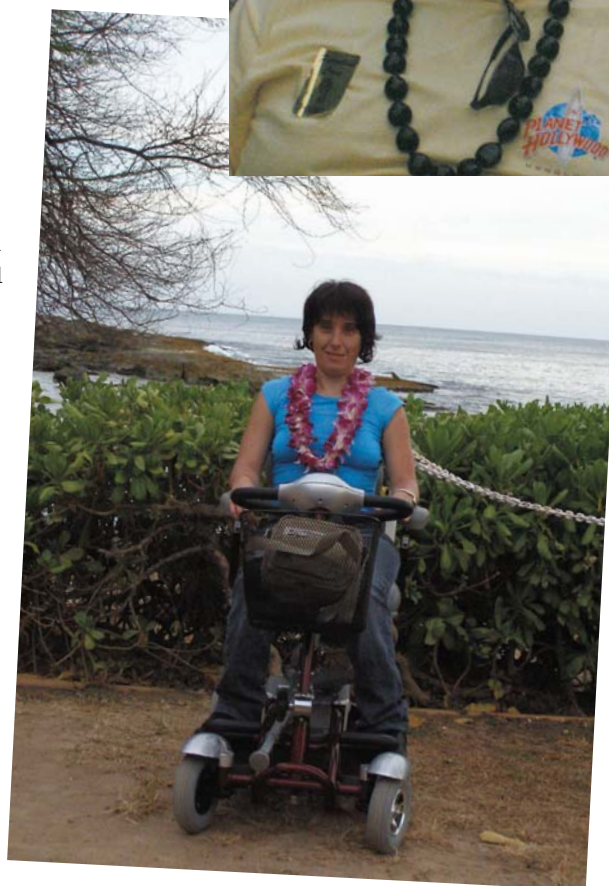


Bruce and Lisa by the sea!

and Australia were very accessible, in Bruce and Lisa's opinion America is far ahead of Britain in that respect. Least accessible, Hong Kong and Singapore.

However what they say is the trip is what you make it and to see and experience these places you should be willing to put up with some inconvenience and try to find ingenious ways of getting around them.

You can contact Bruce and Lisa to hear more about their trip, or to discuss anything else, at mcauslandbruce@hotmail.com



fitted with a tail lift. Bruce fulfilled a long held dream of snorkelling by getting out of his chair on the beach and crawling into the water, and then discovered a few days before they were about to leave that there was actually a lagoon very near that would have been easier! This means of course he has to go back again to try that.

As you might imagine America

Bruce and Lisa's Itinerary

11 Sep 07 – Glasgow – Heathrow – New York JFK – New York Hotel: Hotel Deauville Park Avenue – 4 days
 15 Sep 07 – Los Angeles – Honolulu Hawaii – Hawaii Hotel – Ohana Waikiki Malia – 6 days
 23 Sep 07 – Nadi Fiji – Auckland – 15 days
 7 Oct 07 – Auckland – Sydney – Adelaide – 15 days
 21 Oct 07 – Adelaide – Melbourne – Singapore – Singapore Hotel – Swissotel Merchant Court – 4 days
 25 Oct 07 – Singapore – Hong Kong Hong Kong Hotel – South Pacific Hotel – 4 days
 30 Oct 07 – Heathrow – Glasgow

Fundraising focus

FIRE & ICE 2008 – Saturday 23rd February 2008

Start the new year with a challenge to beat all challenges by taking part in this exhilarating event, walking over Fire and/or broken Glass. This is a great event for individuals or teams. By releasing your fears and doubts and increasing your confidence you will be unstoppable walking across 20 feet of burning embers and/or 20 feet of broken glass. Last year participants had a great time and managed to raise over £2,500 for the Association. This year the Walks are sponsored by the Round Table – Central Scotland, so

There are many ways to support SSBA while having fun!

every penny raised will come directly to the charity. This event is run by professional fire/glass walking experts from 'Blaze' – full training is provided. Don't miss out, call 01236 794508 today to reserve your place or for more information.

Great Scottish Walks Glasgow – 25th May 2008 Edinburgh – 22nd June 2008

Launched in 1998, the great Scottish walks are one of Scotland's premier fundraising events. Simultaneously supporting healthy living, these annual events offer the public the opportunity to be actively involved in beneficial health activities, community events and charitable fundraising, regardless of fitness and physical ability. Inclusivity is one of the keys to the event's continued success, promoted to all sections of the community particularly encouraging groups, teams and families to walk. In 2007 over 5,000 walkers of all ages participated, leading to the launch of a Glasgow great walk in 2008.

Walkers can choose from three distances; 1 mile, 6 miles or 12 miles.

Great Wee Scottish Walks

Dumfries – Dock Park, 13 April 08
Inverness – Bught Park, 20 April 08
Aberdeen – Duthie Park, 27 April 08
Dundee – Camperdown Park, 04 May 08
Glasgow – Glasgow Green, 11 May 2008



Perth, North
Ince, 18 May 2008
Edinburgh – Fettes College, 15 June 2008
Irvine – Galston, 03 August 2008

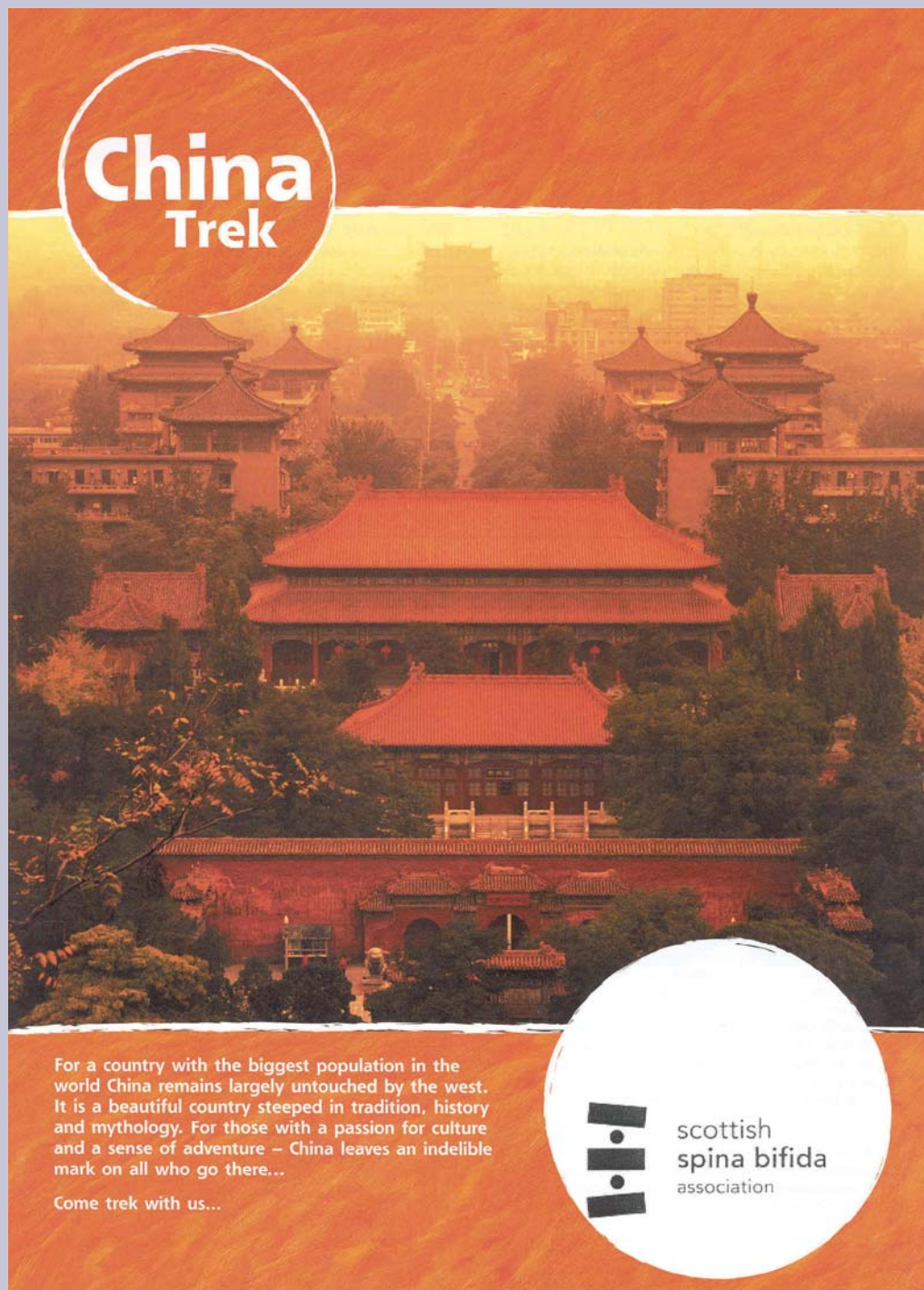
A popular family event. Suitable for tots right through to teens, the aim of the walks is to encourage children and young adults to see that walking and physical activity is fun and healthy and encourages interaction between their peer groups as well as community (younger children are welcome to bring their parent, older siblings or guardian with them along the routes).

On-line entries for all walks are now available at www.greatscottishwalk.com Alternatively call 01236 794508 or email fundraising@ssba.org.uk for an application form.

Edinburgh Marathon – 25th May 2008

The Edinburgh Marathon offers





China Trek

For a country with the biggest population in the world China remains largely untouched by the west. It is a beautiful country steeped in tradition, history and mythology. For those with a passion for culture and a sense of adventure – China leaves an indelible mark on all who go there...

Come trek with us...

 scottish spina bifida association

runners the ultimate personal challenge with a spectacularly scenic route, which takes runners past many of Edinburgh's famous landmarks and tourist attractions. The Association only has a few guaranteed places left for this race so please call Clare today on 01236 794508 for more information.

Ladies Who Give an F – 1st June 2008

The Scottish Spina Bifida Association Ladies Lunch is back for a 2nd successful year, so think glitz and glamour as you are treated to an afternoon of sumptuous food, champagne and lots of fun. This

year the event will take place in the luxurious 5 star Radisson SAS Hotel in Glasgow. Tickets are on sale now £35pp or table of 10 £350. Those who book a table of 10 before 28th February will receive 2 complementary bottles of wine for you and your guests. Call 01236 794508 or email fundraising@ssba.org.uk for further details.

Skydiving, Whitewater Rafting, Diving with Sharks and Overseas Treks

All year round sponsored activities – Call 01236 794508 for further information.

Try our China Trek if you fancy an exotic challenge.

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!



Clos-o-Mat good news

Some of our users who have, or are waiting to have, installed the very popular Clos-o-Mat automatic shower toilet, may have been worried by recent stories that the manufacturers have gone into liquidation.

However, we are reassured by the manufacturers that they are here to stay, with business going from strength to strength.

The story came about as a result of the announcement that Clos-o-Mat AG in Switzerland is in receivership. This has arisen through problems with the Swiss Aquaris toilet, however, they are continuing their customer service operation for the Clos-o-Mat Palma Vita.

The British company, Clos-o-Mat GB is a totally separate company to Clos-o-Mat AG, Switzerland. Established over 40 years ago, Clos-o-Mat GB manufactures the Clos-o-Mat Palma in the UK, and has established the shower toilet as a



proven product, supported by consistent quality of manufacture, supply, service and maintenance.

Peter Willan, Total Hygiene Chief Executive Officer (the suppliers of Clos-o-Mat), comments, "We were aware of potential problems with Clos-o-Mat AG some time ago and as a consequence have taken appropriate steps to ensure that we continue to supply and deliver quality automatic shower toilets – including the Clos-o-Mat Palma Vita – for the long term. Indeed, over the past 12 months we have invested significantly in our manufacturing and service operation to accommodate the increased activity and broadening range."

Anyone reading this who would like more details of the product can contact Family Support for a brochure.

The Clos-o-Mat has proven to be very popular.

25th Anniversary 2008 Mobility Roadshow

25th and 26th April 2008 • Royal Highland Centre, Edinburgh
Open 10 am daily • Free admission and parking

Be inspired

Latest innovations for a mobile lifestyle

Join in

Demonstrations and activities for all the family

Feel the experience

Test drive a variety of adapted and specialist vehicles, wheelchairs, powerchairs and scooters plus travel, leisure and home products

For all the event details and regular updates
www.mobilityroadshow.co.uk • Tel 0845 241 0390



The Mobility Roadshow®
the future of mobility

- Badges are locked into a rigid protector sleeve
- Flexible, sturdy lock attaches to the steering wheel
- Visible deterrent saves the mess, distress and expense of a break-in
- Single (for the badge) or double (for the badge and clock) protectors available

Special Offer for SSBA

- A national road atlas
- Urban area mapping
- Detailed street mapping of 65 city centres featuring all the parking options and facilities for blue badge drivers
- Information on tourism, accommodation and a useful directory of services.

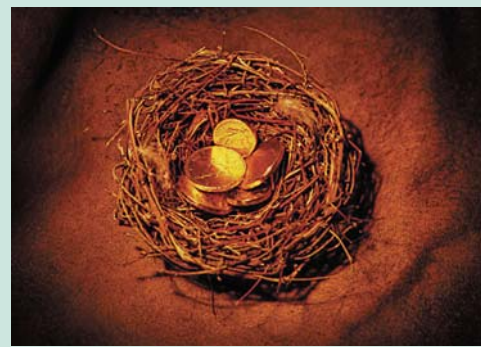
Security against theft !!



Free blue badge atlas when you order the protector

**PIE Enterprises Ltd,
The Bridge,
12-16 Clerkenwell Road,
London
EC1M 5PQ**

Financial Planning Workshop



for families of disabled children

We are planning to offer a half day workshop on 29th April on an issue of concern to many parents

“How do I secure the financial future of my child (young or adult) with a physical or learning disability?”

These issues affect everybody and we aim to cover topics that are of most concern to parents.

To enable us to plan this event would you please return this page, indicating below if you would be interested in attending and the topics you would like to see covered.

- ☐ The importance of making a will – why it is necessary
- ☐ Power of Attorney and Guardianship
- ☐ Setting up Discretionary Trusts – the value of trusts
- ☐ Tax planning issues e.g. inheritance tax
- ☐ Financial planning for the present and future
- ☐ Investment options – what are your choices?
- ☐ Gifting family assets – what are the implications?

Name: _____

Address: _____

Please return to: **FREEPOST Plus RRAE-SCGY-CSJA, SSBA, 6 Craighalbert Way, GLASGOW G68 0LS**
(NO STAMP REQUIRED. Please return completed form by 29th February.)