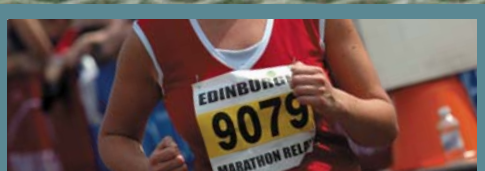
The magazine for people in Scotland with Spina Bifida and/or Hydrocephalus

talk:BACK

Issue 18 – Summer 08 Scottish Spina Bifida Association £2.10

The Family Conference Weekend 2008 – a review

page 8



Summer time brings out the best...

scottish spina bifida association

Welcome to the summer 2008 edition of *talk:BACK*, the magazine for people in Scotland with Spina Bifida and / or Hydrocephalus.

Hello, and welcome to the summer edition of the magazine – and unlike the same issue last year, it looks like we might even manage to have a proper summer this year, complete with the odd day of sunshine!

We hope that we have once more put together a strong issue of the magazine that contains a wide range of information, news, view and advice, but all with one thing in common: providing as much support and help to our readers and users as we can.

I'm confident that you will find a host of useful information in this issue, not least the latest news on the Blue Badge Scheme, changes in the Incapacity Benefit scheme and an extremely useful article on pregnancy with spina bifida and / or hydrocephalus. There is so much useful information available, and the great news is that, if handled in the right way, pregnancy needn't be any more daunting than it is for anyone else.

We also take a look back at our Family Conference in February and hear some first-hand experiences from families who were there.

We also catch up with Claire Forde and Harry Stratton who both made some remarkable achievements recently, Claire by doing exceptionally well in the BBC Radio 3 Choir of the Year Competition and Harry by appearing as a mascot during the Scotland v France rugby match!

Elsewhere you can read the obituary of Elsie Wilson MBE, a remarkable lady who played an instrumental role in the formation of SSBA as an organisation and who sadly passed away recently, but will be remembered for a long, long time by those who were lucky enough to know her.

And for those keen to make a direct contribution to support the Association, check out our Fundraising pages where you will find some fun ways of helping raise much-needed funds.

Happy reading...

> ***"Elsie Wilson was a remarkable lady who played a key role in the formation of SSBA and will be remembered for a long, long time by those who knew her."***

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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contents

Summer 08

BACKchat

New parking rules at Braehead Shopping Centre

Braehead has launched a scheme to fine drivers who park in spaces reserved for disabled people. The shopping centre brought in the new rules on Monday, March 31, which means anyone parking in one of the 387 clearly-marked disabled spaces without a valid disabled badge will be fined £60.

Update: lone parents of disabled children and signing on

You may have seen recent publicity about lone parents being made to sign on at the Job Centre once their youngest child is 12. This is due to come in from October 2008. There is now clarification on this issue and if you're a lone parent with a disabled child on middle or high rate DLA component, you will be exempt from the proposals and will not have to sign on.

Folic acid fortification delay by Ministers

Government Ministers have delayed a decision on whether to fortify UK flour with the vitamin folic acid, following the publication of a research programme in America that seemed to suggest that bowel cancer rates have risen there since flour fortification was implemented.

As a result, further expert consideration has been demanded before the Government gives formal approval for mandatory fortification to go ahead in the UK.

Many experts however believe that, far from causing cancer, folic acid has an overall preventative effect – as suggested by a study carried out last year by the Scientific Advisory Committee on Nutrition.

Incapacity Benefit changes unveiled

Many carers look after someone who receives Incapacity Benefit. Indeed some carers are disabled themselves and receive Incapacity Benefit in their own right. The government has announced changes to Incapacity Benefit and Income Support (for those who receive it because of incapacity for work) through the Welfare Reform Act 2007. The existing benefits will be simplified and replaced by the Employment Support Allowance (ESA) for all new claimants. In addition, a new personal capability assessment (PCA) will class people as having 'limited capability for work' rather than 'incapacity for work'.

The ESA will have two elements – the first one is a 'contributory' element based on National Insurance contributions and the other is a 'non-contributory' means-tested element. There will be a 13 week assessment period during which time all new claimants will receive a basic benefit equivalent to Jobseekers' Allowance. They will either have a PCA during this period or enter the 'support group' for those with a health condition which makes it unreasonable for them to attend interviews or work related activity. Those who pass the PCA will be classed as having 'limited capability for work' and they will receive a 'work-related component' of ESA on top of their basic allowance. They will still have to take part in certain work-based interviews and activities.

Existing Claimants will initially have their benefit levels protected. However, details of moving existing claimants from Incapacity Benefit to Employment Support Allowance are not formulated.

Blue Badge consultation – have your say

Proposals to increase the reach of the disabled parking scheme to more people who need it and make it easier to take action against those who steal, forge or fraudulently use a Blue Badge were put out for consultation by Transport Minister Rosie Winterton.

The consultation contains proposals to ensure parking close to essential amenities and services continues to be available to those who need it most. Proposals include:

- Extending the reach of the scheme, for example, ensuring more parents of severely disabled children are eligible for a badge;
- Giving parking attendants the power to confiscate on the spot Blue Badges that have been stolen, forged or are being fraudulently used;
- Improving the security of the badge design to stop forgeries;
- Creating a system of national data sharing, to identify Blue Badge cheats.

The consultation also asks if individual local authorities should be given the opportunity to run the scheme in a way that responds to local circumstances.

Mobilise Director of Policy and Campaigns, Helen Smith, says: ''The Blue Badge scheme desperately needs updating and I welcome these proposals. It is now so abused that I sometimes feel like more people have a Blue Badge than don't. We need to make it a scheme that really benefits the lives of disabled people. However, I do have reservations about the proposal to allow local authorities to run the scheme in a way that responds to local circumstances as it could cause a lot of confusion''.

Information

Copies of this consultation can be found at www.dft.gov.uk/consultations or you can contact Tasha Duggan on 0207 944 4780 or by email at: bluebadgeconsultations@dft.gsi.gov.uk

Claire Forde is on song with the Inverclyde Schools Training Choir

12 year old hyrdocephalus sufferer Claire Forde from Greenock sings soprano in Inverclyde School Training Choir, and has just qualified for a UK-wide event.

Inverclyde Schools Training Choir has successfully qualified for the semi-finals of BBC Radio 3's Choir of the Year competition in Liverpool, with the anticipation of going all the way to the finals, to be held in December 2008 at the Royal Festival Hall, London.

The children singing in the choir are drawn from primary schools from across the Inverclyde area with the ultimate aspiration to join the Inverclyde Schools Junior Choir.

Claire Forde, who is 12 years old, has sung with the Training Choir for the past two years and has been making huge progress..

In the two years since Claire joined the Training Choir she has even performed twice at the Royal Concert Hall, Glasgow, as guests of the celebrated Phoenix Choir.

Not only that, she shared a stage with the likes of stars such as Sydney Devine and Eve Graham of the famous New Seekers.

She also sang with the Training Choir in January 2008 as they triumphed for the second year in succession in their category at the well respected Inverclyde Music Festival.

Under the auspices of their conductor, Gemma McLean, and accompanist, Mark MacDonald, the Training Choir are carrying on a rich tradition of choral signing in the Inverclyde area – and one of which the region can be rightfully proud.

In addition to entertaining audiences at such fantastic venues as the Royal Concert Hall and the Queens Hall, Inverclyde Training Choir have performed a number of charity concerts – including ''Music for Malawi'' and the ''Ardgowan Hospice Concert'' in 2007 – as well as clocking up performances on numerous occasions at Greenock Town Hall.

They are now a permanent feature at the hugely popular Christmas Concerts series , held at St Mary's Church, and also at the Summer Concerts at the Mid Kirk in Greenock.

Claire performing at the Music for Malawi concert in Greenock and at the recent competition.

The Training Choir's biggest fan is without doubt the current Provost of Inverclyde, Michael McCormick, who never misses a performance and cannot praise them highly enough.

It should be pointed out that Claire's achievements are all the more remarkable as she has primary hydrocephalus and has a ventricular peritoneal shunt in situ, having undergone the operation when she was just a baby of 18 months old.

Amongst the typical problems Claire faced was her extreme fear of such noises as clapping, laughter, whistling and TV sound effects.

"The Training Choir's biggest fan is undoubtedly the current Provost of Inverclyde, Michael McCormick, who never misses a performance."

These noises left Claire crying hysterically and many nursery and school concerts, sports days, church services and school assemblies had unfortunately to be abandoned due to noises that were obnoxious to her.

The school bell presented particular problems and her teacher took the extraordinary step of removing the clock on the wall to stop Claire counting down, with terrified anticipation, when the bell was due to sound.

Claire has now conquered her fears over certain noises and beams broadly as she is photographed soaking up the applause after another couple of successful performances.

We would like to wish Claire all the very best with her singing in future and wish her and the rest of the Inverclyde Schools Training Choir all the very best of luck in the next stages of the Choir of the Year competition.

We hope she lets us know how she gets on.

Harry takes the field at Murrayfield!

In October last year Anne Kane, one of the SSBA Family Support Workers, discovered that Cumbernauld Rugby Club had been awarded a mascot place at the forthcoming Scotland v France rugby international at Murrayfield -- a huge honour for any rugby club to receive. Even better, Anne learned that Cumbernauld Rugby Club were giving the place to the SSBA and that everyone immediately thought of Harry Stratton as he is rugby daft.

Harry and his family eagerly accepted this once in a lifetime opportunity and over the coming months the enormity of his role slowly began to dawn on him and his family. As his mum said: ''Our wee boy was to lead the mascots out onto the pitch at Murrayfield in front of over 60,000 people!''

She tells the story.....When we arrived, Lynsey who was our point of contact at Murrayfield, took us up to the hospitality area where we met up with the other mascots. We all then had a lovely lunch and then all the mascots got changed into their Scotland kits to have a rehearsal for the event.

After the rehearsal we waited until it was time to do it for real. We were starting to get a little nervous for Harry as the enormity of his up and coming task started to sink in as the stadium steadily filled up. Before we knew it the Frattellis started to play and the flames either side of the tunnel started to shoot up towards the sky and as the mascots started to run out onto the pitch Harry took his place on the pitch. Close behind the mascots was the Scotland squad and everyone took their places to meet The Princess Royal, Princess Anne. Then the French national anthem was played and when Flower of Scotland was played we all became rather emotional. A lot of family bought tickets to the match so that they could also be a part of Harry's big day as did his Head Teacher and Deputy Head Teacher from his primary school. After the anthems the mascots left the pitch and took up their places to watch the match.

After the match the mascots went back up to the hospitality area where they were all given soup to heat them up before they went back down to the tunnel to meet the players.

Once in the tunnel the mascots all lined up ready to meet the players as they made their way out of the tunnel. Harry met virtually all of the Scotland players and they all kindly signed his autograph book and his shirt.

When Harry met Jim Hamilton he gave Harry his match shorts and socks as a momento, which was very kind of him. One of the French officials also gave him an official French hat and one of the French players – Dimitri Szarzewski – came out and gave Harry his match shorts and socks as a souvenir also.

It really was a marvellous day and the memory will stay with us all for a very, very long time indeed. Thanks to all concerned for their efforts.

Rugby mad Harry has the time of his life at Murrayfield!

Mrs Elsie Wilson M.B.E.

Little did her parents, Alexander and Elizabeth Allan, know that their daughter Elsie would make such a mark on the world at the time of her birth in 1924. Having achieved many prizes in her time at the Girls High School in Glasgow Elsie had an ambition to become a doctor. With the outbreak WWII this ambition was thwarted and Elsie found herself at 18 years in charge of a camp reception station for Italian prisoners. One of her amusing stories was of Guiseppe Delia, an Italian prisoner whose sole interest and drive was to return to Italy so that his perpetual cold would clear. It was during the war through her attachment to the RAMC that she met and subsequently married Alan Wilson. This long loving partnership lasted for over half a century.

After the war the Wilsons moved to London for some years before the call of Scotland was too strong to resist. While in London their first two children were born and soon after their return to Wishaw, Lanarkshire came their second daughter, Alison. Elsie was closely involved in community projects and in particular assisting with the setting up of Children's Hearings after contributing to the Kilbranon Report.

Some say life begins at forty but for Elsie, thirteen years after Alison's birth, a completely new challenge arrived as she was prgnant with twins.

The Wilsons were told that there was no problem with Donald but Jon might need a bit of special care. This was the start of what in retrospect was a great achievement by Elsie as not only did she successfully raise her family but also was the instigator of what became the Scottish Spina Bifida Association (SSBA). Elsie investigated what was the anomaly of spina bifida, or myelomenigocele as it was becoming known. By 12 months later she had discussed in detail the situation with her consultant John Bentley who gave her support to establish a parent's group in Lanarkshire. Subsequently, with colleagues in Glasgow, they developed this parent's movement and it became the above Association in 1966. An early and effective parent's group who focussed on the requirements of the patients who had the disorder and a potent stimulus to the National Health Service in which provision for the children was not always adequately developed. Clearly as time went by the requirements were not only associated with the medical conditions but also with educational and social aspects. SSBA has continued to develop its services to individuals and families.

Many positive developments have been achieved and these have been done by patient persistence rather than aggressive confrontation. Because of the nervous system being the controlling system of the body challenges arose in so many different aspects of life. It could be from the associated hydrocephalus for which a successful surgical procedure had been developed in that decade, from the mobility aspects where muscle power and sensation were impaired to varying degrees, or urinary problems with the deficient nerve supply causing problems such as continence, or learning problems and employment difficulties which had to be overcome.

An example of Elsie's persuasive powers is that she persuaded P & O to take a group of children off on an educational cruise on SS Uganda. She realised what a stimulus that could be and got agreement that if each child could find £50 the company would meet the rest of the cost. As a result many benefited from trips to the Baltic

For 20 years she continued her active involvement and then she said she was taking a back seat but she continued to be a strong support to the Association as she had so much experience and was blessed with a great deal of common sense. When the Honorary President was asked what was required as Elsie was retiring the answer was ''an Elsie Wilson in each of our branches which now cover all of Scotland''.

"My helping hand, my guiding light, but most of all quite simply the very best friend I will ever have."

Her many years of unpaid service helping others less fortunate than herself earned her the M.B.E. in 1987. While sometimes there may be doubts of the justice in Honours this to Elsie could not be questioned as if anyone did deserve recognition she did for all her selfless work for others.

Another interesting public appearance was Elsie and Jon appearing on the queen's Christmas broadcast with Prince Philip in the surroundings as Jon had one of the early deliveries of a motability car.

Having recently passed his test mother insisted that they took the car by train to London where he had his first experience of driving in the big city!

As Jon said at Elsie's funeral he knew that the Association and all the families say a great big thank you for her tireless and determined contribution which has resulted in the prospering Scottish Spina Bifida Association. It is there as a support and to assist families in what continues to be a very challenging world.

Elsie had that satisfaction as she retired to Comrie in her latter days where the family spent so many happy times. There she enjoyed further community work as well as enjoying her other interests which included golf, arts, books and travel especially if it was to shoot off to see a Picasso exhibition

Having given up golf she still had to go to the Comrie Golf Club on a Saturday for her soup and apple pie with custard. Her four grand children, two great grandchildren and her own family have great memories to live with but no longer have as Jon said- ''My helping hand, my guiding light, but most of all quite simply the very best friend I will ever have''.

Family Weekend Conference

8th to 10th February

SSBA's third Family Conference took place recently and *TALKback* was there to see all the action as it happened.

Our third Family Conference was held in the impressive Hilton Edinburgh Airport Hotel in February and was once again a great success, proving as it did to be extremely informative and useful for everyone who attended.

A total of 36 families took the time and made the effort to attend and had the opportunity to listen to a number of top quality presentations from a range of professionals who are specialists in their field. They were drawn from fields as diverse as health, social work, law and sports.

Full crèche facilities were provided by North Edinburgh Childcare which allowed parents to attend the talks while the children enjoyed a wide range of activities, ensuring absolutely everyone had a terrific, rewarding time!

> ***"Thanks for the great work – everything was brilliant."***

Our grateful thanks as always go to all our speakers, some of whom stayed with us with their families over the weekend which let parents discuss various problems in a more informal setting. Thanks too must also go to all the hotel staff who helped at the Conference and Helen Stoker and her team at Edinburgh Childcare.

Thank You

The Conference would not have been possible without funding from many organisations and our sincere thanks go to:

- BBC Children In Need
- Coloplast
- Jimmy Johnstone Trust
- The ARCHIE Fund, Aberdeen
- Children In Need Fund
- The Sick Kids Friends Foundation
- Yorkhill Children's Foundation
- Cumberland Building Society
- SSBA

> *We were able to speak to the Family Support Team at any time and they were always there for us.*

> *This is our first Conference – please book our place for the next one.*

> *Great Conference. We learned a lot from the speakers and from other families.*

> *Very impressed with the crèche staff and the facilities for the kids.*

Spina bifida, hydrocephalus and pregnancy

Pregnancy is always a delicate time, but this can be even more complicated for mothers with spina bifida.

The chances of women with spina bifida and hydrocephalus having straightforward pregnancies and deliveries have never been better.

This is partly due to increased knowledge and expertise amongst obstetricians and midwives, but also due to healthier, better informed and better prepared potential mothers.

Ideally, all women should see their GP for preconceptual advice: if you have spina bifida or hydrocephalus, this is essential.

Be prepared: remember Folic Acid!

If you or your partner have spina bifida or a family history of spina bifida, you have an increased risk of having a baby with spina bifida. By taking folic acid for at least a month before you start trying for a baby (and continuing until the end of the 12th week of pregnancy), you can help reduce this risk by about 70%.

For you, the folic acid tablets available at chemists or supermarkets are not enough. You need 5 mgs a day and this is only available on prescription from your doctor.

Then, before you get pregnant you should arrange to see these experts:

- **urologist:** your kidney function will be checked to ensure that your kidneys are fit for the extra work they will have to do during pregnancy; your urine will be checked for infection.
- **continence adviser:** self-catheterisation may be difficult late on in pregnancy and you need to plan how you will manage. You may be prone to constipation and may need to change your bowel medication or management. If you have a stoma, this can be affected as your abdomen gets larger – it may change shape, your ostomy products may not stick well and may leak.
- **physiotherapist:** your balance will alter as you get bigger and you may need to use a wheelchair more often. The physio will advise on exercises to help prevent swelling of your legs and feet, advise on skin care and prevention of pressure sores and help if the growing baby causes you some breathlessness.
- **neurosurgeon:** having a shunt is no contraindication to pregnancy. It will not harm the baby's growth; a pregnancy will not harm the shunt. (For more information contact Nancy Bradley on hydro woman@aol.com. She has conducted a long term study on the relationship between pregnancy and shunts.) If you haven't seen your neurosurgeon for years, now is the time to catch up with him.
- **dietician:** she will help you to keep your weight at a sensible level
- **GP:** you may be the first patient with spina bifida or hydrocephalus that your GP has cared for in pregnancy. Give your GP and the Practice Midwife time to brush up their knowledge.

When you are pregnant

Get to know your midwife really well and educate her about your disability and how it affects you (she should read 'Pregnancy and Disability', published 2007 by the Royal College of Nursing www.rcn.org.uk Tel: 0845 772 6100).

Decide where it will be best for you to have antenatal care – at home, at hospital, at the GP's surgery?

Ask about suitable antenatal classes.

Arrange a visit to the local maternity unit – look at accessibility. Are they prepared for disabled mums? Are examination couches and beds height adjustable? Will there be a cot that you can manage? What equipment will you need to take into hospital with you?

Discuss antenatal testing and scanning and decide what you are comfortable with.

Does she know of an obstetrician who has delivered babies of women with spina bifida?

Write a birth plan

Involve your partner and midwife in this. Include:

- natural birth or caesarian section? (C-section is rarely necessary for non-obstetric reasons).
- pain relief (the anaethetist will discuss the possibilities of having an epidural).
- positions for labour
- will you be able to get into (and out of) a birthing pool?
- will your partner be able to stay overnight if you rely on him to assist with your care?
- If you want to breastfeed, will there be help and encouragement?

After the birth

New parents find the first few weeks difficult and you will be no different!

Accept all help you are offered by your family and friends but don't let them take over.

See your continence adviser to get your bladder and bowel regimes re-established.

Try to rest when the baby sleeps.

Rely on your Health Visitor if you have worries or questions about your baby. Don't feel you're being a nuisance – she's there to help you.

Most women with spina bifida and/or hydrocephalus have normal pregnancies, uncomplicated deliveries and lovely babies.

With a little forethought and care, you could be one of them!

Raising awareness of the role of folic acid

In collaboration with other colleagues within the UK and Europe, SSBA has been instrumental in raising awareness of the benefits of folic acid supplementation to reduce the incidence of neural tube defects of which spina bifida is the most severe.

In recent years there has been a strong lobby to consider mandatory fortification of flour with folic acid, a proposal heartily endorsed and supported by the organisation.

The addition of this vitamin in the food chain is a safe and effective way to improve our national health and reduce the number of babies born with this complex and lifelong disability.

At long last, in 2007 the Food Standards Agency agreed to recommend to Ministers in all four countries in the UK that flour should be fortified with folic acid. There is, however, much work to be done to ensure that this recommendation is transformed into a reality. The Association will continue to raise awareness of the need for such implementation as soon as practicable.

Further information can be obtained from our website at www.ssba.org.uk.

New information guide for midwives

A new booklet, Pregnancy and Disability, has been published by the Royal College of Nursing to improve the level of care available to disabled women who are pregnant.

Midwives and nurses have welcomed the 32-page publication which will help them to provide high quality, client-led care for disabled women during pregnancy, birth and beyond.

The author, Jackie Rotheram, herself a disabled mother, writes with the authority of long experience gained in pioneering and running the first specialist midwifery service for disabled women at a large women's hospital.

With her collaborators she gives a thorough description of how others can deliver the kind of service that meets the needs of disabled women by seeing the woman first and her impairment second.

The complex issues of what it means to be disabled, with relevant statistics, are discussed in full.

The legal background to disability discrimination is well covered, highlighting the new Disability Equality Duty – all public sector organisations including the NHS are now positively required to promote equality for disabled people.

Case studies of the four broad categories of disability – physical, sensory, learning and long-term mental illness – illustrate vividly the issues for health care workers.

These will assist midwives and nurses to consider and plan in advance with disabled clients how their particular needs can be accommodated, working with other agencies and professionals where appropriate.

Rosaleen Mansfield, Chair of Trustees, Disability, Pregnancy and Parenthood International (DPPI) said: ''I warmly commend this new guide. A large proportion of the enquiries DPPI receives come from disabled women considering parenthood, or already pregnant.

''They want to be as actively prepared as anyone else. They also need extra information, possibly to help them source support and equipment. This new guide is an invaluable new resource.''

Case Study – Pregnancy and Disability

The booklet features a case study of Mary, who has spina bifida and is a long term wheelchair user. Genetic counselling and urine testing were arranged in her antenatal assessment because of fears of infection related to catheterisation, which Mary performed for herself. Other issues included breathing as her uterus enlarged, her ability to care for herself, tissue viability, pregnancy changes, antenatal care provision, type of delivery, and pain relief.

Six months later and now pregnant, Mary visited the antenatal clinic where a needs assessment was performed. Antenatal screening tests were all accepted. Referrals were made at Mary's request to professionals including a dietician, physiotherapist, health visitor and urodynamics specialist, because of repeated infections.

Mary expected no difficulty with her wheelchair and early pregnancy proceeded normally but Mary experienced some difficulties later on when bending forward became difficult. Her increased weight and reduced mobility also increased pressure on her lower back, so she was admitted at 28 weeks for rest and help with tissue viability. She had no pressure sores but her buttocks were becoming increasingly red and tender. A special mattress was provided and physiotherapists provided advice on exercises and taking regular periods of lying flat.

In preparation for the birth, appointments were made with the obstetrician to discuss the mode of delivery and a tour of the delivery suite and postnatal ward was arranged. At 34 weeks' gestation Mary's large uterus was compromising her breathing so it was decided to perform a caesarean section. Mary remained awake for the delivery and her partner stayed with her throughout the procedure and afterwards.

Mary was seen by the physiotherapist and a manual handling assessment was performed, identifying no risk issues. Her partner took responsibility for bathing the baby as bending was difficult for Mary. She concentrated her efforts on breastfeeding and a five-day hospital stay helped her to establish this and gain more confidence. The occupational therapist performed a home assessment and found that Mary and her partner had planned well.

The community midwife visited daily at first, gradually decreasing her visits until transfer on day 21 to the health visitor who Mary already knew.

Fundraising focus

Forthcoming events and activities

14th August – Charity Golf Day

Team of 4 £400. Venue: Westerwood Golf Course.

The Scottish Spina Bifida Association are holding their first Corporate Charity Golf Day on Thursday 14th August 2008. The Westerwood Golf Course in Cumbernauld will be the venue for the challenge which promises to be a fantastic networking and social event.

The Westerwood has a magnificent 18 hole, par 72 golf course which is a feast for the senses. You will be surrounded by sparkling scenery, meandering through a paradise of silver birches, firs and heathers with many holes overlooking the Kilsyth and Campsie hills.

Teams of 4 will compete on a Best 2 Score Stableford basis with full handicap allowance and the event itself will comprise of: goody bags, a light lunch, golf, hole in one challenge (with the opportunity to win a car), raffle and a 3 course dinner to finish the day.

Cost for a Team of 4: £400

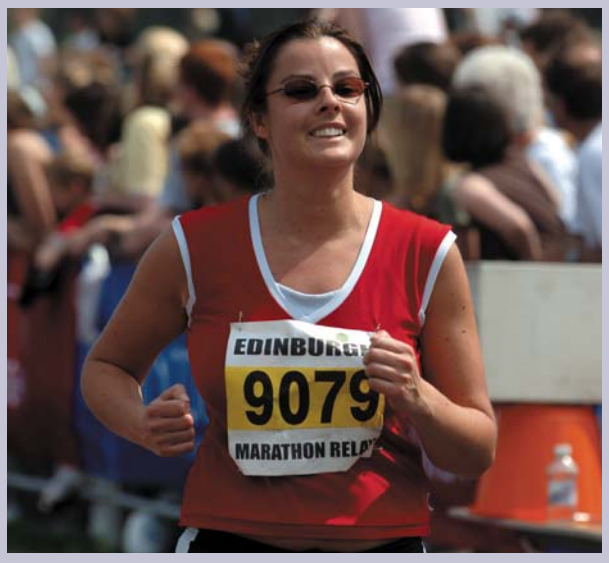
If you would like to take part in the SSBA Charity Golf Day or look at our sponsorship opportunities please contact Clare on 01236 794508 or email Clare@ssba.org.uk

10th-14th September – London to Paris Cycle Ride

You'll enjoy cycling through beautiful English villages and the stunning countryside of rural France into Paris, one of the most magical places on earth.

This trip is a fantastic challenge for anyone wanting to do something amazing for a great cause! There will be lots of like minded people on the trip all looking for the challenge of a lifetime and of course meet new friends. Some people come with frinds or family but most people come on their own – so what are you waiting for? Sign up today for a fantastic experience and the

Join in the fun and get fit at the same time!



opportunity to make life long friends.

For more information on this challenge please call 01236 794500 or email fundraising@ssba.org.uk

Other overseas challenges are available please visit www.ssba.org.uk/overseas

14th September – Cumbernauld 10k

Venue: Broadwood Stadium, Cumbernauld

Run it for Ramsay. Run this, the 2nd Cumbernauld 10k in aid of the Gordon Ramsay Appeal.

The Association has been chosen, for the second year, as the nominated charity for the Cumbernauld 10K and we are asking those who enjoy keeping fit to 'Run it for Ramsay'. Gordon Ramsay, Honorary Patron of SSBA, launched the F Word Appeal in 2006 when he asked everyone to participate in, or hold an event, to raise funds for the Scottish Spina Bifida Association.

The 10k run was set up last year, by North Lanarksire Council, to celebrate Cumbernauld's 50th anniversary and was such a success that they expect double the number of runners this year. This will be a fantastic way to keep fit and raise funds for Gordon's favourite Charity.

To Run it for Ramsay contact Deborah or Clare on 01236 794508.

Big Fun Runs – 5k's Glasgow – Saturday October 4th 2008 • Edinburgh – Sunday October 5th 2008

Run, jog or walk – it's up to you The Big 5K Fun Runs

All of the runs will be 5 Kilometers in length and will be open to Men, Women and Children of all ages. Children under 13 can enter but must WALK the course and be accompanied by a paying adult. You can enter as an individual or as part of a family or team .

Individuals will only be able to take part if they agree to raise money for a chosen charity. The Big Fun Run suggested minimum fundraising target is £50 per person.

All Big Fun Runners will receive a 'Big Fun Run' Medal and a Goodie Bag. Both routes are suitable for wheelchair users. Some sections of the courses will be on grass or have a steep elevation so the wheelchair may need to be pushed through these sections.

Glasgow Big Fun Run – Bellahouston Park – Saturday October 4th 2008

Bellahouston Park is a huge park (175 Acres) and has many features and facilities to tempt visitors and local residents to its grounds. It boasts The Walled Garden with its fine collection of ferns and daffodils. The House for the Art lover also has a less formal garden consisting of mixed shrubs and herbaceous borders. Other facilities are a 18 Hole Pitch and Putt Course, Cycling Activity Centre, Two Bowling Greens and much, much more.

Edinburgh Big Fun Run – Holyrood Park – Sunday October 5th 2008

Holyrood Park is a unique historic landscape in the heart of the city, whose dramatic geology is world renowned. The Park boasts a wealth of history and archaeology.

The 5km course will take you round the Holyrood Park and the 350 million year old Arthur's Seat. The route gives fantastic views of Edinburgh and surrounding areas.

To take part please contact Fundraising on 01236 794508 or email fundraising@ssba.org.uk

30th October 2008 – Gordon Ramsay's Gala Dinner

£500pp Venue: Stirling Castle

The most luxurious event of the year is back, hosted by Gordon Ramsay OBE. The red carpet will be rolled out and the Association will once again welcome guests from the world of television, radio and sport to this feast of entertainment. Ticket reservations being taken.

Diving with Sharks, Whitewater Rafting & Skydiving can be undertaken at anytime of year to suit you, so call 01236 794508 and book your challenge today. GREAT FOR TEAMS OR INDIVIDUALS!

How to take part – contact Fundraising

To take part in any of these activities 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: 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!

Monklands Evening Visitor Service

Free visitor transport for the people of Monklands.

What is the scheme?

NHS Lanarkshire is look at ways to improve transport links to our hospital.

As part of this a free evening visitor bus service to help people to hospital to visit their friends and family will be piloted.

The initial trial will take place in the Monklands area and if this is successful it is hoped to introduce the service in other areas in Lanarkshire.

The door-to-door service aims to help older people, people with a disability or those on a low income get to hospital for visiting times.

How do I get a place on the bus?

All you have to do is call 0845 128 4027 book your place between 2pm-4pm Monday to Thursday and 2pm-3.30pm on Fridays.

Space is limited and priority will be given to older people, and individuals either registered disabled or on benefits.

When you first call you will be asked a few questions so that you can be registered for the service. All information will be treated in the strictest confidence.

You can book transport up to one week in advance. You can also book more than one journey in a week.

How does the service work?

After you have booked your place you will receive a telephone call confirming the time you are to be picked up.

You will be picked up as near as possible to your front door.

The bus will leave Monklands Hospital after visiting hours are over and you will be dropped off at home.

Who operates the service?

NHS Lanarkshire has provided funding for Community Transport Glasgow, in partnership with Strathclyde Passenger Transport, to run the pilot scheme in Monklands.

Community Transport Glasgow has been running a similar scheme in Glasgow for the past year.

NHS commitment

NHS Lanarkshire is committed to ensuring that:

- All vehicles will be fully accessible and maintained to the highest possible standards.
- You arrive at your destination on time.
- All staff will be courteous and treat you with respect.

If you have any comments or complaints please contact us at:

Community Transport Glasgow,
PO Box 8906,
Coatbridge,
ML5 5WU.

Wheelchair skills course

Following the success of last year's event we are running a wheelchair skills course for children under 16 years of age.

It will be held in the Craighalbert Church Hall (next to our Centre) on the 14th and 15th of October.

Parents, brothers and sisters are also welcome to come along and join in.

There are a limited number of spaces for this course and if you are interested in attending please phone the Family Support Workers on 01236 794 516.

Handle with care...

Children with disabilities are "voiceless" in decisions says Commissioner

Fear of legal action, confusion over rules and a failure to include children and parents in decision making are all excluding children with disabilities from everyday activities, says new research published recently.

The report, entitled Handle With Care, was produced by Scotland's Commissioner for Children and Young People and also discovered that these same problems are causing children with disabilities stress and loss of dignity.

Handle With Care examined policy and practice in the moving and handling of children with physical disabilities and was based on a survey of all 32 Local Authorities. It involved interviews and focus groups with children and young people, parents and practitioners as well as a review of relevant law.

It concludes that there are vast differences across Scotland in moving and handling practice, staff training and the extent to which children and parents are involved in decisions about their care.

Essentially, children with physical disabilities can be victims of a 'postcode lottery' which has serious implications for their quality of life.

The report also highlights the dilemma staff face in choosing between following a policy – which may mean moving a child in a way that causes the child pain or distress – or disciplinary action by moving a child in the way he or she prefers.

Staff are also concerned about a lack of resources and the fact that moving and handling is often given a low priority by service providers.

They are also often unclear about policies and rules and may concentrate solely on limiting all risks due to a fear of litigation. Some parents and carers feel that health and safety of staff is prioritised at the expense of the rights and needs of children.

The children themselves often feel that they are treated like any other 'load' and are sometimes handled without being consulted on what method they prefer and what is comfortable.

> ***"Essentially, children with physical disabilities can be victims of a 'postcode lottery' which has serious implications for their quality of life."***

They can even end up being excluded from activities such as school trips and visits to facilities such as swimming pools.

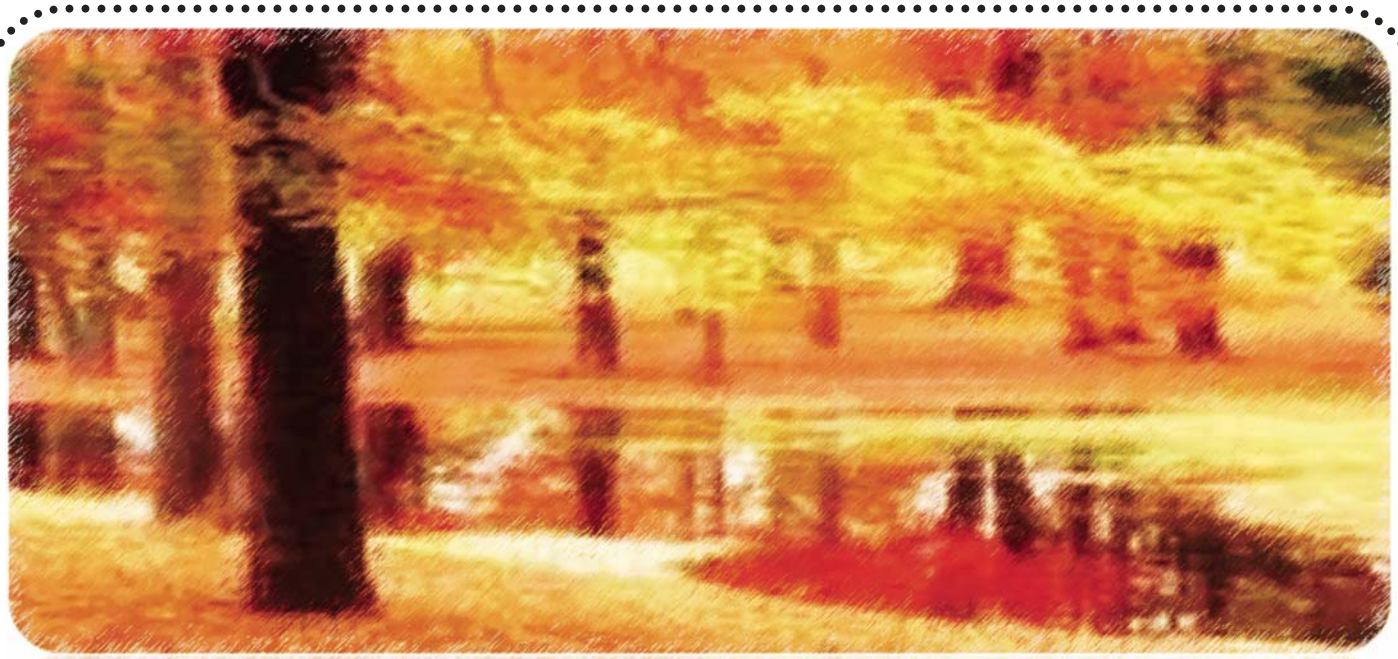
> ***"National standards are desperately needed so that, though the detail of policy may vary from council to council, there are clear guidelines that ensure the say and well-being of staff and children."***

Ultimately, their quality of life can suffer as a result.

Kathleen Marshall, Scotland's Commissioner for Children and Young People, commented: The moving and handling of children with disabilities has a real impact on their happiness, comfort and safety, but staff are understandably confused over what they can and cannot do and have to constantly juggle conflicting priorities.

''National standards are desperately needed so that, though the detail of policy may vary from council to council, there are clear guidelines that ensure the say and well-being of staff and children. The quality of life of children with disabilities should not be a postcode lottery.

''Currently there are excellent examples of Local Authorities doing much good work but too much by chance rather than design.''



4th September 2008
Continence Awareness Exhibition

We are planning to offer a one day exhibition on the 4th September 2008 at the Scottish Spina Bifida Association Family Centre – The Dan Young Building.

The exhibition will centre on improving 'Quality of Life'. We know that only a minority of people with continence problems use appropriate products to manage their condition. Fewer still investigate treatment options or seek professional help.

The exhibition will address ways in which good management can promote lifestyles (e.g. travel, social engagements and interpersonal relationships), while promoting the many products that can be used to manage or treat the condition.

- Up-to-date Information on the latest Bowel and Bladder Management
- Wide range of Continence Management Product / Demonstrations
- One to one personal consultations with Specialist Continence Advisors

To book a place please phone 01236 794516, or return the attached tear-off slip.

Name _____

Address: _____

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Please return to FREEPOST Plus, RRAE-SCGY-CSJA, SSBA, 6 Craighalbert Way, Glasgow G68 0LS.
(No stamp required. Please return completed form by 15th August.)