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- News round-up
- Education, education, education!

LINK

The magazine for people with hydrocephalus and spina bifida

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Driving For Perfection

Peter Farrall writes

As I sit writing this introduction on the hottest July day for 40 years, I can hardly believe that we're already more than half way through the year.

2006 has certainly been a hectic time for ASBAH... a year of reflection and celebration as we mark our 40th anniversary.

We held a Service of Thanksgiving at Peterborough Cathedral on June 10, and invited people from the past and present involved with the organisation (pages 4 and 5).

Of course there is plenty other news apart from the anniversary updates. Our fundraising section is bursting at the seams as we report on just some of the fantastic ways people have collected cash for ASBAH.

In this issue we focus on education issues and meet the three new education advisers who are working to help your children reach their full potential at school and college (pages 26 and 27).

You can also read about a new website for teenagers in Merseyside (page 24), Cathy Lunn's write-up about her time at the recent International Federation conference (page 23) and read about how bladder botoxing helped a lady with spina bifida occulta (page 25).

So as usual plenty to read about as you sit back in your deckchair, long cool drink in hand. Enjoy!

Peter Farrall
Assistant Director
(Marketing and Communications)
peterf@asbah.org

*Best wishes,
Peter*

Patron:

HRH The Duchess of Gloucester GCVO

President: Jeffrey Tate CBE

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life

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Man with a mission: John Naudé (see p 30)





ROYAL VISIT MARKS 40th anniversary celebrations



ASBAH's royal Patron the Duchess of Gloucester joined the 40th birthday celebrations which were held in the splendour of Peterborough Cathedral.

More than 160 guests attended the Service of Thanksgiving on Saturday 10 June to reflect on four decades of invaluable work... and to look forward to the future.

The multi-faith service, attended by trustees, staff, services users, parents and supporters, began with a warm welcome from the Archdeacon of Oakham, David Painter. Readings were given by HRH The Duchess of Gloucester GCVO, ASBAH's Royal Patron; Dr. Jeffrey Tate CBE, President of ASBAH and Richard Astle, ASBAH's Chairman.

Three speakers were chosen to reflect the diversity of ASBAH, with Amar Dugal, from the Your Voice Committee; Sarah Coates, parent and Trustee, and The Revd John Naudé, a former ASBAH mobility advisor who gave the address.

Peter Farrall, Assistant Director (Marketing & Communications) said:

"We wanted to ensure that the service gave a true reflection of ASBAH, which is an organisation that is accessible to all, whatever race, faith or age.

"We were limited to the number of guests, so we tried to get as wide a representation of ASBAH as possible."

Following the service guests enjoyed the summer sunshine in the cathedral gardens where the Duchess chatted to many of the guests.

ASBAH's Chief Executive Andrew Russell said: "It was great to see so many guests together celebrating four decades of progress and friendship in ASBAH.

"All the generations were there from founder members to young children, as well as donors, supporters and distinguished colleagues. I hope we can achieve as much in the next 40 years"



“We wanted to ensure that the service gave a true reflection of ASBAH, which is an organisation that is accessible to all, whatever race, faith or age.”



40th year messages of support

I have been a Paediatric Surgeon in Belfast for almost 30 years. We had around 150 new cases of Spina Bifida born in Northern Ireland each year. As you might imagine, the affected children and their families required an enormous amount of practical and emotional support, a need which has continued as these people have matured into adults. In those early years, ASBAH was mainly a support organisation for the families of affected children and there was a major commitment in my part of the UK, providing advisors and advocates who made life more than a little easier to bear..... an experience which can be retold again and again by affected families throughout the land.

Fortunately, the incidence of the condition has decreased markedly since those early years. This is not least because of the research sponsored by ASBAH over the years which has assisted enormously in our understanding of the causes and the consequences of Spina Bifida and Hydrocephalus.

The organisation is currently lobbying government to introduce folate supplementation of flour, which in other parts of the world has been shown to reduce the incidence of Spina Bifida. Thanks to ASBAH, there appears at last to be "light at the end of the tunnel" in this endeavour, which until now has been resisted by parliament.

Hydrocephalus has increased in frequency during this last 30 years. This is mainly related to increasing numbers of premature babies being born. Here too ASBAH has played a leading role in supporting families and leading research into the causes and treatment of this condition.

Without ASBAH most patients who have Spina Bifida and/or Hydrocephalus and their families would have had a more difficult journey into adult life. I would like to record my personal gratitude to all those in the organisation, from field workers to the administrative staff in head quarters, for all of the hard work and dedication over the years which has made ASBAH such an enormous success since it was conceived 40 years ago.

Mr VE Boston MD FRCS Chair of the Medical Advisory Committee to ASBAH



Dear ASBAH, congratulations on 40 years of significant contribution to support of families, both directly and through the encouragement and support of research as well as through influence on legislators.

From my own point of view as a longstanding researcher in this field (I was the first ASBAH Research Fellow many years ago) the support for research has borne fruit of direct benefit to those with hydrocephalus and/or spina bifida, in improving treatment and prevention, and reducing complications. In addition, I and fellow members of the Medical Advisory Committee are well aware of the unrelenting efforts by ASBAH to influence government policy, a recent important example being the move towards folic acid fortification. I wish ASBAH well for the next 40 years, and beyond.

**Dr Roger Bayston MMedSci FRCPath
Associate Professor, University of Nottingham Medical School**

"It's good to know that ASBAH is continuing to move forward on all fronts to achieve its aims. The support, information, fundraising and campaigning work are all essential parts of what ASBAH does for our service users, and I send you very warm wishes in our 40th Anniversary Year."

Peter Cottingham, Chairman, 1998 -2002

Congratulations and best wishes on the occasion of the 40th Anniversary of the founding of ASBAH.

The association has done amazing and useful work during its four decades and its achievements soar beyond anything that could have been imagined when it was first formed, which is a fine achievement indeed.

Through the leadership of its professional staff and the adept use of its resources, ASBAH has provided an important service to families and professionals alike. As one who has profited by your work, I congratulate you on your magnificent efforts.

ASBAH has done pioneering work in aiming to make the issues surrounding spina bifida and hydrocephalus more visible, and has played a unique role in bringing together people from a variety of professions who can contribute vastly to the well-being of families.

You have my best wishes for continued growth and progress.

**Paul D Griffiths, Professor of Radiology,
University of Sheffield**

I warmly congratulate the Association for Spina Bifida and Hydrocephalus for 40 years of sterling work.

ASBAH has an outstanding reputation for helping and advising individuals and families affected by Spina Bifida and Hydrocephalus.

When people argue we are no longer a caring society I would simply remind them of ASBAH, those who serve the organisation today, and the many who have given a commitment over these past four decades.

Well done ASBAH and long may you continue with your wonderful contribution towards seeking to assist in the lives of so many.

**Rt. Hon. Tom Clarke MP,
Former Shadow Cabinet Minister for
Disabled Persons Rights**

The 40th Anniversary is really a monument to the imaginative and sustainable work by ASBAH. It has played an important role and its efforts are widely appreciated.

Rt. Hon. Lord Ashley of Stoke, C.H.

As ASBAH continues to celebrate its 40th anniversary year, *Link* looks back to the late 1960's and early 1970's, when it appointed its first director Mary Oughtred.

Ambitious beginnings

From the moment she stepped into the modest London office one cold, snowy morning in 1969, Mary Oughtred had great ambitions to help ASBAH move forward and succeed in achieving its objectives. These were to build up the national association including the coordination of local work and to foster research into the causes and treatment of spina bifida and hydrocephalus.

Four decades on, as we celebrate 40 years of the Association, we can look back to those humble beginnings and chart a fascinating journey of dedication, determination and positive developments – developments set into motion by those early supporters encouraged by Mary, that have contributed towards positioning ASBAH as the UK's leading Association for supporting those with spina bifida and hydrocephalus and researching the causes, management and prevention.

Mary, who is now in her early nineties, remains a lifelong supporter of ASBAH and clearly remembers what she wanted to achieve back in those formative years. She explains: "I came to work as General Secretary for ASBAH via Doctor John Lorber, colleague of co-founder Professor Robert Zachary – I was involved in the running of the Association of Youth Clubs in Sheffield at the time and was asked to consider joining ASBAH on two separate occasions. I took on the role, with the remit of raising public awareness and helping those who were affected by spina bifida and hydrocephalus and finding funds for research.

What struck me during those early years was how much support families needed

– doctors were busy and didn't always have enough time to discuss important issues with patients, most of those affected were children and babies, and treatment was stressful and frightening for them and their parents, especially as surgery for spina bifida was quite a new thing.

In fact, someone once asked me, if I could wish for one thing, what would that be? I replied that I wished that we could discover the causes of spina bifida and hydrocephalus. Looking at the Association now, I feel we have made excellent progress in searching for those reasons and unravelling the mystery behind spina bifida and the wonderful thing is that the success of the charity today means that the resources are there for the work to continue.

I took on the role, with the remit of raising public awareness and helping those who were affected by spina bifida and hydrocephalus and finding funds for research.

– a significant development as the likelihood of having a subsequent child with spina bifida had become clear. I recollect many heart rending conversations with parents who already had a child affected by spina bifida, seeking advice on screening procedures.

We certainly raised the profile of the Association during those formative years – first we had the support of actress Wendy Craig, then the Duchess of Gloucester graciously consented to become the charity's patron



Mary Oughtred (left) meets HRH The Duchess of Gloucester

and then we were involved in a Christmas television appeal with the ITV children's television programme *Magpie*. For me this marked a turning point in the quest to maximise public awareness. We wanted to let people know that these conditions were treatable and, after the programmes were watched by thousands of children, their parents and grandparents, we were inundated with letters of support raising in total, around £80,000.

Another significant milestone during the early life of ASBAH was the ten year anniversary party held at Stoke Mandeville Sports Stadium. It was a fine day and the atmosphere was amazing, as over 1,000 members came together to show their support. We held a meeting, a commemorative cake was cut, youngsters enjoyed pony rides and HRH the Duchess of Gloucester was able to meet many children, including those who were severely disabled."

Mary remembers *Link* magazine too from the 60's and 70's.

"I always thought the name *Link* was highly appropriate – as the editor described, it linked member to member and doctor to doctor, with a mix of medical and self help articles and progress updates on fundraising activities and research. It's more modern now, with wonderful visuals, but it still offers the same support and information provided in the early issues. Here's to the future of ASBAH – happy 40th anniversary."



Wendy Craig

A marathon effort

Congratulations to the ASBAH A Team who completed the gruelling London Marathon in April.

The team of four men, who all live in France, decided to put their best feet forward to mark ASBAH's 40th anniversary celebrations.

As *Link* went to press, the team – all in their forties – had raised an impressive £888.

Andrew Corrigan, who led the group, completed the course in 4 hours 5 minutes. Brothers Christian and Serge Dussuyer notched up times of 3 hours 11 minutes and 3 hours 35 minutes, respectively. Team coach Philippe Renault finished in 4 hours 4 minutes.

Andrew said: "We all completed the course and feel privileged to have participated in such an inspiring event.

"None of us have ever experienced anything like the exceptional atmosphere that we encountered along every foot of this race – the crowd literally carried the runners along. We would like to thank everyone for their contributions and encouragement."



Jonathan's marathon achievement

As the ASBAH A Team limbered up at their London Marathon starting line, 23 miles further down the route a small group of youngsters were preparing for a race of their own.

Children aged between 11 and 17 years took part in the Adidas Mini London Wheelchair Marathon – and ASBAH's Jonathan Smith was among the competitors.

Jonathan, whose mother Sarah belongs to Surrey ASBAH, took part in the 2.5-mile race, which began at Upper Thames Street and finished in the Mall.

Jonathan told *Link*: "It was a fantastic day. It rained slightly but that helped because it cooled everyone down. The crowd was very noisy and incredibly supportive of all competitors, which really helped to keep me going."

He added: "It was a very tough race and I was on my own for a lot of it because those people in front were far away and so were the people behind.

"I managed to get 5th overall and 4th in my category. My time was 18.04 minutes which I was very pleased with."

Zoe runs up £6,000 for ASBAH

In a moment of madness Zoe Burnay signed herself up to run the British 10K London Run for ASBAH.

With just five weeks to train for the gruelling course and to find sponsorship, the busy mother of three wondered what she'd let herself in for.

But Zoe, whose youngest daughter Hattie, 4, has spina bifida and hydrocephalus, was determined to last the course and raise cash for ASBAH.

Zoe, from Finsbury Park, told *Link*: "I read about the London 10K run in *Link* and saw that ASBAH had a few places left. I'd had a couple of glasses of wine so I was feeling relaxed and thought "why not?"

"I called ASBAH the following day and there was just one place remaining, so I signed up.

"But, when I really thought about it, I wondered what on earth I'd let myself in for," she laughed. "But I was keen to help ASBAH and as I was 40 in March, and ASBAH was 40 this year too, I thought it would be a great challenge

"I tapped everyone I could think of, from the many contacts I have at work to friends and family. Everyone was so generous - the cash is still coming in.

Zoe joined around 20,000 other runners taking

part on Sunday 2 July in sweltering conditions, as temperatures peaked at 34 degrees. She completed the course in 1 hour 10 minutes, cheered on by friends and family, including husband Tom and children Hattie, Polly, 8 and Louis, 5.

She said: "I was overwhelmed by the number of people and I did wonder whether I was really up to it. I felt quite intimidated to begin with, but at the same time hugely challenged.

"The first few km's were the hardest but once past 5k it really did whizz past.

You definitely do break the pain barrier. Everyone gets so caught up in the atmosphere of the day it doesn't seem that far.

"I was quite pleased with my time," Zoe added. "I always go to the gym a couple of times a week but I haven't done any running so I felt it was a great achievement."

Congratulations and many thanks to the other eight

ASBAH runners who took part in the British 10K London Run. So far we have had feedback from three of them.

Their times were as follows:

Rani Bains – 1hr 3mins

Bally Bains – 59 mins

Parmod Athi – 49 mins





Thanks to funding from
The Roald Dahl Foundation,
families have learned more
about Hydrocephalus

FOUNDATION

Last year the charity, which has supported many individual service users over the years, awarded ASBAH a generous £8,210 grant to fund a series of hydrocephalus workshops

The donation, made under the Foundation's neurology programme, came as very welcome news to ASBAH's fundraising department.

Amanda Conquy Director of the Roald Dahl Foundation, told *Link*: "Roald Dahl knew at first hand the terrible impact acquired brain injury and hydrocephalus had on a child and their family.

"The Foundation is particularly pleased to make this grant to enable ASBAH to provide much needed information and support to the families of children with hydrocephalus."

Three of the five one-day workshops have already been held, providing valuable information and support for parents who have children with hydrocephalus.

The seminars, which kicked off in Darlington in last September, are a varied mix of presentations and practical workshops, with plenty of time allowed for questions from the audience.

Parents have been lavish in their praise for both the speakers and the practical sessions and said the workshops were both informative and helpful.

Helen Dow, project co-ordinator (fundraising) said: "ASBAH is immensely grateful for the support it has received from the Roald Dahl Foundation.

"The three days held so far have been very successful, with more people than expected attending. They have all given very positive feedback. Without the Foundation's support, these workshops would not have been able to take place."



Roald Dahl © RDNL

The two remaining workshops are planned for this autumn in Northern Ireland and February 2007 in the south east region.

The Roald Dahl Foundation

As well as being a great storyteller, Roald Dahl was also a man who gave generously of his time and money to help people in need, especially children.

Following his death in 1990, his widow, Felicity, set up the Roald Dahl Foundation to continue his valuable work.

Since then the Foundation has given more than £5 million offering practical help to children and young people in three areas that were particularly important to Roald Dahl during his lifetime - literacy, neurology and haematology.

The Foundation makes grants to hospitals and charities, as well as to individuals and their families.

It is funded in part through endowment, as well as through additional fundraising. The Foundation also benefits from the popular Revolving Recipes series of cookbooks.

Roald Dahl and Hydrocephalus

It's a little-known fact that Roald Dahl was involved in the development of what became known as the Wade-Dahl-Till (WDT) shunt used in the treatment of hydrocephalus.

Roald's only son Theo, developed hydrocephalus after being involved in an accident at the age of three months old, when a car hit his pram.

Theo, who was treated in the US, had a Holter shunt fitted, but the valve kept blocking, causing a build-up of fluid on his brain.

In 1961, the family moved back to England and Theo's care was taken over by neurosurgeon Kenneth Till at Great Ormond Street Hospital.

He identified the silicone rubber slit valves of the Holter valve as the cause of the trouble - they became too easily clogged with the debris that can accumulate in the hydrocephalic ventricles, particularly when (as in Theo's case) there had been bleeding in the brain.

Dahl, with the help of Kenneth Till and Dahl's friend Stanley Wade, a hydraulic engineer, spent months devising a valve for draining fluid from the brain to enable Theo to live independent of machines. The Wade-Dahl-Till valve is still in use today.

Roald Dahl Day

2006 would have been Roald Dahl's 90th birthday year and the Foundation has received a steady stream of enquiries from fans around the world asking just how they can mark the very special birthday.

After some long and hard thought, it became clear that a massive talent requires a fittingly massive birthday party.

A number of exciting events will be held throughout the UK on Wednesday 13 September and Saturday 16 September to celebrate every aspect of Roald Dahl's legacy - from his unforgettable writing to his lesser known commitment to charity.

For more information to see what's happening in your area log on to www.roalddahlday.info

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Danny on par at Charity Golf Day

Danny Mills took time out of his busy schedule to help boost the ASBAH Helpline and Information Service

Appeal at a charity golf day.

The event, organised by Coventry-based Touchstone Housing Association, was held at Kings Norton Golf Club on 9 May. Golfers and their supporters raised £18,500, which was divided between ASBAH, Entrust Care and the Heart of England Community Foundation.

Danny did such a good job as the auctioneer at last year's event that he was invited back to polish his powers of persuasion – with great success. He helped to raise more than £3200 towards the day's total.

ASBAH's own superheroes

Good luck to Superman and his superhero friends who will be pounding the streets of Portsmouth for a second time in the Great South Run.

The 22 runners – including local adviser Caroline Cashman - are all friends of four-year-old Lewis Hine, who has hydrocephalus resulting from a brain tumour.

Lewis is becoming a familiar face in *Link* through his dedicated fundraising work for ASBAH. Already the determined youngster has helped to raise more than £5,500.

He asked his Mum Emma, friends and family to run for a second year running in the 10-mile race which takes place on 22 October.

For more information about Lewis and his fundraising work visit his website at www.lewishine.co.uk



Charity ride boosts ASBAH's funds

The 13th annual Megacycle proved lucky for ASBAH attracting around 80 riders who are expected to raise more than £4,000.

The 24-hour event, which kicked off at noon on Saturday 15 July, followed the usual safe eight-mile circuit of cycle paths through Peterborough's Ferry Meadows Country Park.

Several ASBAH staff were among those dusting down their bikes for the popular event, which has raised well over £27,000 since its launch.

Organiser Ian Morley, is no longer able to take part in the Megacycle due to failing eyesight, but was on hand to cheer on the cyclists along the route.

Ian said: "It was incredibly hot over the weekend and a lot of people did suffer from the heat. Fortunately we provided as much hot and cold drink as the riders wanted, making sure they were all well hydrated."

Despite the weather, spirits remained high and as each team rider finished their lap, other team members gave them a good cheer over the line. Jon Kelly, who organised one of the ten teams taking part, said: "The Megacycle is a fantastic event which we enjoyed more than ever. We had quite a few new faces this year in the team and everyone had a great time."

A huge thank you goes to everyone who took part and raised funds for ASBAH and also to a small group of heroes behind the scenes.

Ian told *Link*: "My dad and mum, Eric and Christine Morley spend the whole 24-hours on site and without them, the event could not take place."

Wife Val is another stalwart on hand to make drinks and stamp cards... when she isn't riding laps as part of a relay team.

Ian added: "Final thanks go to George and Doreen, our superb first aiders, if we had to pay for this service it would drastically reduce the income from the event."

The 80 riders who took part during the weekend covered an incredible total of 1,796 miles between them.

Congratulations to everyone involved.



Helpline & Information Service takes off

ASBAH's long-awaited Helpline and Information Service is up and running.

The service was launched on 1 June thanks to a £224,000 grant from the Big Lottery Fund.

Helpline manager Linda Lewis and operators Annie Kilsby and Dawn Stilwell have been taken on to handle the huge variety of calls, providing support on all aspects of spina bifida and hydrocephalus.

Some of the operator's work is expected to be sign posting – using ASBAH's team of specialist advisers for education and medical related issues.

Referrals for ongoing support will be passed to the area advisers where they are available. An extensive database will provide callers with contact details of other organisations both voluntary and statutory, which may be able to help.

The volume of calls is expected to increase as more people become aware of the new service following an extensive publicity campaign.

In July 23,000 hospitals and health centres were mailed to ensure that details of ASBAH's services are present at every point of diagnosis of either spina bifida or hydrocephalus.

This includes a huge range of healthcare departments – from ante-natal clinics and maternity wards to neurosurgery clinics and district hospitals.

Press releases have also been mailed out across the country to national and local press, and healthcare magazines.

Mary Malcolm, (Assistant Director) Services, said: "It is a very exciting time for ASBAH. The Helpline is a fantastic addition to the wide range of services we already offer.

"The team are young and vibrant, and bring to the Helpline and Information service a wealth of experience and abilities."





Spina Bifida & Hydrocephalus

HELPLINE

0845 450 7755

Meet Linda, the Helpline manager

Linda Lewis is the lady with the task of getting ASBAH's new Helpline and Information Service up and running.



It is a challenge that she relishes and is keen to ensure that callers receive the best possible service.

Linda has a wealth of experience in the field after implementing and developing a call centre team for the Law Society, which dealt with individuals complaining about poor service or conduct they had received from solicitors.

She also worked with Consumer Direct, a legal advice centre, where she was responsible for developing a new call centre.

Linda, who took up the position in June, said: "I was looking for a new challenge and I hoped to find a position working in the care sector. When I saw the vacancy for Helpline manager I thought it would be perfect.

"The new Helpline will provide a vital service and I am delighted to be involved with the project from the launch".

"I love a new challenge," she added, "and although I have a lot to learn on the medical side, it is something I'm looking forward to.

"ASBAH have put a terrific amount of work in setting the Helpline Service up. Now it is really a case of waiting to discover what the volume of calls is likely to be and the sort of questions callers ask.

"It is impossible to predict just what demand will be like, so initially we have two operators employed on a job share basis. We will obviously re-assess the situation to ensure that we are accommodating callers' needs."

Meet the operators...



Dawn Stilwell

Helpline operator Dawn Stilwell has considerable call centre experience after working in the customer care department for tour operator Thomas Cook for several years.



Dawn spoke to *Link* just days before she took up her new appointment with ASBAH.

She said: "I am really looking forward to joining the team and getting on with the job.

"The launch of the Helpline and Information Service is very exciting and I am thrilled to be involved with it from the very beginning.

"It is such a valuable service and I hope to be able to help callers and make life easier for them in some way.

"It will be very rewarding work and I'm looking forward to learning about a new area after dealing with package holidays and flights since leaving school!"

Annie Kilsby

Annie Kilsby was delighted to be offered the position of operator with ASBAH's new Helpline and Information Service.



"The Helpline is such a worthwhile service," she said. "We will be the first port of call for many people, many of whom will probably still be in a state of shock.

"Hopefully we will be able to provide a sympathetic ear and also some useful information and advice.

"The position demands a mixture of skills which I have gained during my time with a support line and also at a charity which helped children with special needs."

Annie, who lives near Stamford, Lincs, added: "It is very exciting to be involved with the project from the beginning, and it will be interesting to discover what the volume of calls will be like as the Helpline receives more publicity."

Southampton signs up

Southampton & District is the latest local association to sign up to the Compact, taking the total number to 22.

The Compact, launched in 2005, is an agreement designed to bring all local associations together.

It is aimed at improving communication standards both at ASBAH and within the local associations, to benefit everyone involved, particularly those with spina bifida or hydrocephalus, their families and carers.

Stanley Fitzgerald, Chairman of the Southampton & District association, said: "Southampton and District have always been affiliated to ASBAH and we felt that we needed to retain that relationship.

"ASBAH has always been a great help to us and it is important that we stay united to achieve the best for our members."



Stanley, who took over the role as Chairman on a temporary basis 30 years ago, explained that the Southampton group now covers a much wider area following the closure of the Bournemouth and Portsmouth associations three years ago.

"We don't do much fund-raising these days because we simply don't have enough people to help out," he said, "but we are very active in other ways.

"We are always there to provide help and support for families and individuals, and we organise several events each year, such as parties for the children and young adults."

Support is also given to a local wheelchair dance group and basketball team.

Stanley added: "As I think is the case with many local associations, the committee members are getting older and we need more young people to come forward. But we plod along and do everything we can to help our members and we are lucky in that we have a local adviser in the area."

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Registered charity no. 249338



Meet Geoffrey Kerr - ASBAH's Northern Ireland Manager

With a background of over twenty years in the charitable sector, Geoff joined ASBAH in March and is enjoying the role and the challenges he has faced so far.

Geoff told *Link*; "I'm really enjoying my role as manager of ASBAH Northern Ireland. My youngest son has Downs Syndrome, and I find that regardless of the disability, carers and service users have common issues and worries surrounding that disability.

"Our aim in Northern Ireland is to provide information and support to individual families and carers throughout the province on a wide range of issues from health matters and education through to benefits and independent living."

Geoff added: "It is great to be in a position to help families, individuals and carers and provide them with the information and support they require."

TRIBUTE:

Steve James

Bristol local association has suffered the loss of long time Chairman Steve James, 59 who passed away suddenly on 23 July 2006. Husband to Ann and father to Angela, Richard and Trevor who has spina bifida, Steve had worked tirelessly for the association since 1969, first as a supporter, then in 1982 as a committee member and from 1990 taking on the role of Chairman. Described by members of the association as "a gentleman, always ready to help others", Steve was very involved in the group's activities and, after taking early retirement, spent much of his recent time channelling his energies into helping people with spina bifida in a local residential home. ASBAH would like to offer their condolences to his family and all those who were touched by his kindness and generosity.



Project supported by the
**EU Programme
for Peace and Reconciliation**

£120,000 funding for Cross Border Initiative

Young people with spina bifida and hydrocephalus from both sides of the Irish border will benefit from a unique new scheme, thanks to European funding worth £120,000.

Alan Money Penny, a consultant fundraiser from Northern Ireland ASBAH, helped to submit ASBAH's bid to the Special European Programmes Body PEACE II programme, which is dedicated to Northern Ireland and the six border counties in the Republic of Ireland.

The grant will fund the Cross Border project aimed at helping young people primarily aged 18 - 25 with spina bifida and hydrocephalus, from Inishowen, County Donegal and the districts of Derry, Limavady and Coleraine.

It will primarily provide training, leading to qualifications and developing life skills and self esteem through hands on workshops and sessions.

As a partnership between ASBAH Northern Ireland, Irish ASBAH and Inishowen Rural Development, the project will employ a Project Manager and a Development Worker who will work towards delivering the project over the next two years.

It is hoped the project will bring together as many as 50 young people from both sides of the border, along with their families and peers, to engage them in fostering cross community and cross border relations.

Alan said: "It was a real team effort to prepare the bid so it was great to hear we had been awarded the funding.

"Now things have come to fruition I hope that the project will deliver everything it set out to achieve and that we will be able to secure further funding in the future."

Colin Power, Interim CEO of Irish ASBAH, said: "We're delighted to be a part of this Cross Border project and would like to see it improve the services for people with spina bifida and hydrocephalus across the whole of Ireland."



"Up until recent years, people with disabilities were sometimes made to feel unwanted in employment situations, but with changes to the law and improved access, a whole new world of career opportunities has opened up for service users.

"The Cross Border project will overturn the lack of confidence many individuals feel, teaching them that 'they can do it' - the sky's the limit!"

**Mike McKernan
ASBAH trustee,
Northern Ireland**

Biker's Shunt

Dave Myers (left) with Si King

Dave Myers, one of the Hairy Biker chefs from the popular BBC series, had a shunt fitted eight years ago to drain fluid from a cyst on his brain.



In an interview with *Link* he talks about the circumstances surrounding the emergency surgery which saved his life and about an unexpected, but most welcome side effect.

Dave, 48, had alopecia from the age of eight. During the course of three weeks most of his hair fell out, to be later followed by his eyelashes and eyebrows.

Although small patches grew back, he found it easier to shave his head completely.

But after having his shunt fitted in 1998, Dave, from Barrow-in-Furness, grew a full head of hair.

Here he talks about his experiences...

"During my thirties, when I was working as a make-up artist in

TV and films, I began getting bad migraines. To begin with I just took painkillers and thought nothing of it, but they kept getting worse.

The world is massive and the more you explore it, the more it unfolds

One day I started forgetting the names of everyday objects. My handwriting deteriorated too until it was almost illegible.

In the summer of 1998 I was working on a film in Luxembourg. I arrived on set one day not remembering how I got there. People started to panic and I was taken to hospital.

At first everyone was talking German and being quite mean to me. After the doctors saw the scans they changed their attitude. At this point I thought, "Hang on, this doesn't look good."

Why are shunts needed?

Cerebro-spinal fluid (CSF) is produced constantly inside the four spaces (ventricles) inside the brain.

The CSF normally flows through the narrow pathways from one ventricle to another, then out over the outside of the brain and down the spinal cord. It is then absorbed into the bloodstream and re-circulates.

Hydrocephalus occurs if the drainage pathways become blocked and the CSF accumulates in the ventricles inside the brain, causing them to swell and compress surrounding tissue.

A shunt is simply a device which diverts the accumulated fluid around the obstructed pathways and returns it to the bloodstream.

It consists of a system of tubes with a valve to control the rate of drainage and prevent back flow.

There are many reasons why hydrocephalus can occur:

Congenital Hydrocephalus

This is when the hydrocephalus is present at birth. Often the exact cause cannot be determined.

Prematurity

Babies born prematurely are at risk of developing hydrocephalus and their brain is more vulnerable than that of a baby which has reached full term.

Spina Bifida

Most babies born with spina bifida have hydrocephalus. In addition to the lesion in the spinal cord there are abnormalities in the structure of certain parts of the brain which develop before birth.

Brain Haemorrhage

Other forms of brain haemorrhage including those occurring in adults ('stroke') can result in this type of post-haemorrhagic hydrocephalus.

Meningitis

This is an infection of the membranes covering the brain. The inflammation and debris from this infection block the drainage pathways resulting in hydrocephalus.

Cysts within the brain

There is a particular group of disorders involving the formation of fluid-filled cysts in the CSF systems. In these cases hydrocephalus is often due to pressure on the surrounding tissues by the enlarging cyst.

Tumours

Tumours of the brain cause compression and swelling of surrounding tissues, resulting in poor drainage of CSF. In the treatment of brain tumours it is often necessary to control hydrocephalus which may be only temporary.

Normal Pressure Hydrocephalus

Seen in older adults and characterised by dementia, decreased mobility and urinary incontinence.

Genetic

In very rare circumstances, hydrocephalus is due to hereditary factors which might affect future generations.

Codman - Working in partnership with ASBAH

The doctors had found a shadow on my brain about the size of an apple. I thought my time was up. I was flown home and taken to the Aberdeen Royal Infirmary where the surgeon told me the shadow was an arachnoid cyst, which I had been born with. It's like a piece of pitta bread in the brain apparently, but it isn't a problem until it starts filling with fluid.

"I was so relieved that it wasn't a tumour but then I was told that I could still die if it was drained too quickly. Brilliant!

"I had the shunt fitted and had to lie completely flat for 48 hours. On successive days I was raised slightly until I could sit up completely.

"Even though I was quite uncomfortable for the first few days, I had a wonderful sense of well being and I generally felt healthier and with more energy. My memory improved immediately and within a couple of months my handwriting returned to normal.

But because of the stitches in my head I couldn't shave it as normal, and to my amazement, I grew back a full head of hair. It was incredible. My theory is that the cyst must have been pressing on a bit that affects hair growth, although the doctors won't confirm it.



"Thankfully I haven't had any problems with my shunt at all since it was fitted.

I noticed early on that if I drink red wine I get a localised pain around the shunt, but that's easy to deal with. I only drink white wine now!

Activity wise, I am quite responsible and tell the doctors what I'm up to. I made sure I got the all clear before taking flying lessons - I passed my private pilot's licence a few years ago and fly micro lights."

But Dave, who spent 2005 riding halfway round the world with fellow Hairy Biker Si King, came off his motorbike in a collision with a lorry on the Isle of Man.

Dave, who broke his wrist in two places, added: "I rode thousands of miles last year with no problems, then I crash into a lorry coming back from getting a crab sandwich."

Dave added. "We're really excited about the third series of Hairy Bikers. Every series is a wonderful adventure. The world is massive and the more you explore it, the more it unfolds."

But for Dave, one of the best parts associated with his hit BBC show was a visit to a famous hairdresser in Kensington before filming began.

He explained: "She told me that I'd got some pretty bad split ends. I felt like saying, "Spilt ends! Split ends! Do you know how much I used to dream of having split ends?"

**Edward Lamb
UK Country Manager, Codman**



1. What was your previous position?

I spent 12 years in pharmaceuticals, working for Roche as Sales Manager, selling to the primary and secondary care markets. During that time I was involved with the team responsible for medication for patients with Parkinson's disease, which involved close liaison with hospital consultants and gave me a good understanding of neurological conditions.

2. When did you join Codman?

I joined Codman as UK Country Manager back in March this year, following a year spent at Cranfield University in Bedfordshire gaining an MBA.

3. What does your role involve?

I lead the Codman UK team and liaise in providing products and services for all of our customers including medical professionals, patients and their families.

4. What is Codman's position in the UK and International market?

Codman is part of Johnson and Johnson and is a leading manufacturer in the neurosurgical marketplace, both in the UK and globally. Being a global organisation we have the ability to research and develop new products and procedures worldwide that will benefit patients, and bring them to healthcare professionals.

5. What are the main challenges facing you?

One of the main challenges facing me is getting to grips with the world of neurosurgery – it's similar to pharmaceuticals in many ways but there are lots of differences too. The neurological market is a constantly changing arena so identifying new equipment and procedures is the key challenge. This will then improve the support we can offer to patients.

6. Is there any such thing as a 'typical day' for you?

At the moment it's fair to say that a typical day is still a learning process, as I build relationships with customers and get to know the neurological marketplace inside out. My remit is to manage the implementation of Codman's corporate plan, encouraging the greater uptake of certain neurological procedures, so that more patients are correctly diagnosed and treated.

7. What do you find enjoyable about your job?

I like the fact that the products manufactured by Codman actually help people, and, in doing so, can change people's lives. It's exciting to see the future developments in neurosurgery unfolding, as surgery moves to become minimally invasive – meaning less discomfort for patients, a shorter stay in hospital and a faster recovery period.

8. What do you do to relax?

I am a keen sportsman and due to play rugby with London Scottish this winter. I'm skipper of a sailing team taking part in yacht races this summer. Sport replenishes my mental stamina and helps me rest and recharge my batteries ready for another working week.



Linda's line

Everyone seems to have a claim to fame these days, so here's mine - I once saw Jeffrey Tate (world famous conductor and President of ASBAH) outside the opera house in Covent Garden.

I dithered about trying to decide whether or not to ask for his autograph, and while I was prating about on the pavement, he got into his car and left. He was probably trying to avoid the chorus of bystanders hailing him from the other side of the car park railings and

I'm sure he didn't need me to join in, but I regretted it afterwards.

I suppose that being famous can actually be quite annoying at times: people following you around, staring inappropriately or asking nousey questions – a bit like being disabled really, only with better perks! As I put up with all that annoying paraphernalia already, perhaps I could do a celebrity swap with someone like Keira Knightley – I'll have the gorgeous dresses and private limo, and she can have my blue parking badge for a few weeks.

These days you can be famous for all sorts of things, other than just looking glamorous; for example Harry Potter, albeit a fictional character, is famous for his legendary scar. However, I cannot say in all honesty that my life has changed significantly since I let it be known that I also have one (or several actually, not wishing to boast), but perhaps that's

because I got mine from an orthopaedic surgeon rather than a high ranking wizard. That should not be downplayed though, as he was top of his field at the time (Mr Sharrard I mean, not Lord Voldemort).

Of course Harry Potter has the sartorial advantage that his scar is a sort of Z-shaped affair that looks like he has come off worst from a skirmish with Zorro, whereas Mr Sharrard's several inches of irregular stitching isn't quite in the same league, and would definitely not have passed muster in Mrs Parker's needlework classes. (To be fair, neither did mine, but that was because I was usually too busy talking!)

Perhaps when I had my last operation I should have asked if there were any choices on the finishing before signing the consent form? Does anyone know if you have to pay extra for designer stitching? It's probably a bit late for me, but you never know, it might catch on....



See the next Link for a report on the Your Voice 'Be a sport for leisure and pleasure' weekend.



Your Voice presents

To work or not to work? That is the question.

BOOK NOW!
Come and have all your questions answered

**Friday 29 September -
Sunday 1st October**

**Novotel Hotel
4 Whitehall, Whitehall Quay
Leeds LS1 4HR**

£80 weekend delegate rate

£30 day delegate rate

Please note that there are a limited number of places at this hotel and the majority of rooms are twin occupancy.

Details of the precise list of topics are currently being finalised.

Topics include:

-  **Support in Employment**
-  **Employment Rights**
-  **Making your CV work**
-  **Benefits**
-  **Confidence Building and Training Opportunities**

Open to all adults – young and old (aged 18 and over)

To book your place, please contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbarar@asbah.org
Telephone: 01733 555988



Look online for educational toys

Parents searching for educational toys for special needs children will find a good selection at Little Nut Tree Toys.

It's an exciting online store bursting with a wide range of educational toys ranging from puzzles to outdoor playthings.

The company recently joined forces with Hilary Tiede, a Consultant Paediatric Occupational Therapist who offers Little Nut Tree Toys her expertise in special needs and educational play.

Director Jo Nicholson told *Link*: "We have worked with Hilary to ensure that where applicable, toys are identified as 'Special Needs Friendly'.

"We felt that parents and carers of special needs children were often given a raw deal, quite often having to pay highly inflated prices for toys that can be sourced for a lot less money."

As well as the exciting range of toys, Little Nut Tree Toys is also a great resource for parents and carers of children.

The website has a play ideas and advice area, with hints and tips for activities to keep children entertained. There's also a community chat area where you can talk to other parents and make new friends.

If you are looking for special need toys, log onto www.littlenuttree.co.uk Type 'special needs' in the search box - underneath the product categories - and the site will pull up all the relevant 'identified' special needs toys.



Online help

A new online resource has been launched to help parents learn more about communication development and disability.

Parent Point and Talking Links are two new exciting developments on the I Can website, the charity which helps children to communicate.

It has plenty of information and ideas to develop your child's communication, plus details of how to get the best support for your child if they have a communication disability.

The site includes an interactive message board, downloadable songs and rhymes, fact sheets and links to several charities, including ASBAH.

Check out the site at www.talkingpoint.org.uk/parentpoint



Monday Lottery funds Family Weekend

ASBAH's proceeds from the first draw in the new Monday online lottery will complete the funding for the first Family Weekend held for several years.

Monday, which is operated by Chariot Lottery, helps five charities each week and netted more than £13,000 for ASBAH after the first of five draws this year.

Up to 20 families will be invited to the Family Weekend where parents and children will have the chance to get-together and learn new skills in a relaxed environment.

Parents will receive in-depth training and support from ASBAH's medical and other specialist advisers.

Their disabled children and their siblings will spend the weekend meeting other children and learning through play.

Andrew Russell, ASBAH's Chief Executive, said: "We're delighted with the

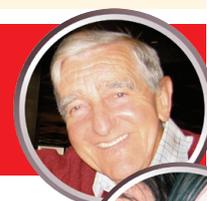
results of our first draw. Like every charity we have to balance what activities we would like to do with the funds available.

"The funds from Monday's first draw will make a transforming difference to 20 families throughout the UK, providing much-needed training and information for all the family members."

Monday, which was launched in April, and allows the online lottery players to choose which of the featured registered charity which should be benefiting from their lottery ticket purchases.

Andrew added: "We are very grateful to Monday, the Charities Lottery, for its support and wish it every success in involving many more players who want to help make a real difference to so many UK charities."

If you want to play Monday the Charities lottery visit www.playmonday.com to register.



monday
THE CHARITIES LOTTERY

ASBAH'S NEXT DRAWS
AUGUST 22ND - AUGUST 28TH &
NOVEMBER 21ST - NOVEMBER 27TH
DON'T FORGET TO PLAY!

Following on from *Link 216*, *Link* celebrates more landmark birthdays including Gwyneth reaching 80 (our first double 40...unless you know better!)

Celebr

Jason Clark

Looking back over his life, Jason Clark, who turned 40 this year, wouldn't want to change a thing.

Like many of us, Jason, from Stratford in east London, has experienced both the high's and lows of life but firmly believes it's these moments which have shaped him into the man he is today.

Jason, who has hydrocephalus, said: "Growing up with hydrocephalus was hard at times. I was in and out of hospital and suffered from black outs and fits, luckily these never happened at school but it made things difficult none-the-less.

"School was enjoyable at first, I attended a special needs school and later a main-stream primary school. I had a lot of girl friends and things were good but that all changed when I started secondary education at an all-boys school. I was singled out and bullied

School life left me frustrated and my mood swings impacted on my relationship with my father who didn't understand me, or hydrocephalus

much of the time and as a result my attendance suffered in the early years but I managed to leave with three grade three CSEs.

"I remember looking forward to going into hospital, the operations were

tough, but it gave me a break from family and school life, that I was used to and I enjoyed my visits from my mum



and Nan.

"School life left me frustrated and my mood swings impacted on my relationship with my father who didn't understand me, or hydrocephalus. As the years past it got to the point when I knew I had to do things for myself."

Nowadays Jason works with special needs children both on a voluntary and part-time basis. He added: "I wanted to treat children in a way I wished I had been - show them respect but let them know they can't get away with things.

"Working with young people is a rewarding experience and I have made many friends along the way, not least my late wife who I met through my hospital volunteer work.

"It was a huge blow when she died, and life's disappointments do set me back, but she remains a positive influence in my life and the reason I do what I do today.

"My future plans are much the same as many people's, I hope to settle down again one day, have children, continue my work with special needs children and put the bad things behind me."

Happy 80th - Gwyneth's Double 40th!

When she was born, doctors told Gwyneth Bishop's parents that she would never walk. Gwyneth had other ideas though, and recently celebrated her 80th birthday in style with her family and friends.

It was a birthday celebration to remember, as her family had arranged a big surprise – a stretch limo to take them all out to dinner!

"My daughter told me that she had arranged some catering for us to have at my home so we could have a small celebration" Gwyneth, from Pontypridd, told *Link*.

"She called me over to the window and it was a huge shock to see the limo arriving! I'd never been in a limo before so it was a real treat - we laughed the whole way to the restaurant! It really was a birthday I'll never forget."

Gwyneth's determination has allowed her to achieve many things in her life – despite the doctor's negative prognosis all those years ago.

She learnt to walk when she was one, and later she learnt to ride a bike. Gwyneth also learnt how to drive in her fifties.

Throughout her life, she has had to endure many painful operations to correct problems she had with her feet,



ations all round!



which resulted in her having to wear orthopaedic shoes and a calliper on her right leg from the age of 35.

As a teenager she became terrified of having further operations and had nightmares about having to go back to hospital, not because of the pain, but because of the anesthetic used in those days... chloroform on cotton wool. She still has nightmares about that today, 65 years on.

But a new GP convinced Gwyneth to have another series of operations when she was 19. The operations were a success and allowed her to wear normal shoes for a few years, before some of the problems recurred.

Today Gwyneth still shows the same determination she has shown throughout her life.

As she is not as mobile these days, she has got herself a computer so she can order her groceries online, and is an e-mail whiz! Gwyneth is a member of the Newport support group, and has many hobbies - and six grandchildren - which keep her busy.

Keith's milestone

Turning 40 is a huge achievement in any person's life – but for Keith Little, from Bexley Heath, who celebrated his 40th on August 8, it has been a difficult journey to reach this milestone birthday.

When he was ten days old, Keith was diagnosed with meningitis and he was fitted with a shunt. The operation was successful and he had very little problem with his shunt until he was 18.

Growing up, Keith was often pushed out by the other kids at school, as he was hyperactive and they didn't understand what he was going through. At 16 he left school and he went to a resource centre. The staff at the centre didn't know how to handle him though, and he was asked to leave for causing trouble.

At 18, Keith had a lot of problems with his shunt – which took three years to resolve. The tube to the shunt had split, and that was causing the problem.

Keith's behaviour was a problem though, and he had to be assessed at a psychiatric hospital.

His father, Ken, told *Link* that there were some difficult times as Keith was growing up; "The trouble with Keith is that he is a character, like a Del Boy – he'll wind up people for the sake of winding them



Keith Little (left) with his brother Neil

up, and people don't understand that sometimes – the other problem is he doesn't know danger.

"We used to go to watch Charlton play on a Saturday, and one time there were two policemen outside the ground, one was

huge, and the other one smaller – Keith went up and tapped the larger one on the back – who then spun round to see who had done it, and didn't see Keith – so we were laughing, the other policeman was laughing and all the other fans were laughing as we all knew who had done it. In

the end the policeman saw the funny side!

Now age 40, Keith lives independently in supported accommodation only two miles away from where his parents live. Although his parents didn't want him to go, they knew it was for the best that he live there. There are two flats together – with a shared kitchen and living room, and a private bedroom and sitting room. Although he cannot do many things for himself, he gets all the support he needs with his accommodation.

Keith is a real character, like a Del Boy – he'll wind up people for the sake of winding them up, and people don't understand that sometimes.

When Alan and Nicolette Davies moved to Japan last March, their lives seemed idyllic. New jobs in a new country and most exciting of all, their first baby on its way.

The routine scans were normal so nothing had prepared them for Alex's birth on 25 August when doctor's diagnosed spina bifida and hydrocephalus.

The family live in Kobe, near to Osaka and Kyoto, where the couple work for a multinational consumer products company which designs hair care products.

Despite the first class attention they were receiving from doctors in Japan, they contacted ASBAH, and its support has proved a lifeline.

As well as medical advice and practical information, ASBAH put the couple in touch with Sam Copeland, whose baby daughter also has spina bifida and hydrocephalus.

Here Alan and Nicolette talk about how they dealt with the Alex's diagnosis and how ASBAH has proved a lifeline.



ASBAH's helping hand stretches round the globe

What was your immediate reaction when you first heard?

Shock. Nicolette was in labour for 30 hours before Alex was finally delivered by c-section. It was a very difficult time since our family was in UK and the Netherlands.

We felt intense loneliness when Alex was born; giving birth in a foreign country to our first child was difficult enough, without our parents and friends around. This supposedly happy event turned into a very worrying and stressful situation.

How did you both deal with the news?

At first we just got on with dealing with the situation. We have made good friends in Japan who rallied around and helped us a lot. Our family flew out to Kobe to help and provide some moral support.

Can you describe the medical treatment Alex received when he was born?

Alex was diagnosed with Open MMC. He had a five hour operation at 20 hours old to close his back. He had a VP shunt fitted at 2 weeks old, thankfully without complication.

At what stage did you get in touch with ASBAH?

When Alex was about one week old, we called ASBAH in the UK, having first read all the information available on the web-site. We have also used many of their books, and the hospital staff has

also been interested in the wide range of support materials that ASBAH provides.

How useful was ASBAH?

Talking with ASBAH was simply the single best thing that happened since we heard Alex's diagnosis. The medical adviser was such a sympathetic listener and full of practical advice.

How helpful was it to speak to Sam Copeland?

Very helpful especially since Sam and her family are very positive people who are really enjoying life with their daughter, Beth. Sam gave us really good perspective on how to enjoy life and not to be absorbed with worry about your child's health condition.

Are you happy with the medical service you have received in Japan?

We can't stress enough how wonderful the staff at Kobe Children Hospital have



been - Dr. Nakashima is a well-known neurosurgeon, very knowledgeable & kind and involved us in decision making and spent a lot of time explaining what he would do. There are parent/child support groups here in Japan, but we don't speak Japanese well enough to join these.

Health wise how is Alex today?

Fortunately very good. He has frequent check-ups every 2 months at the Children's hospital to ensure his bladder function remains good, and that he has no problems with his shunt.

How are you and Nicolette coping with having a child with a disability?

Most days we don't even think about it. We don't worry about the future - we just love and enjoy Alex for the fun of each day that we share with him. He is really a very happy baby, with a big smile.

Do you enjoy life in Japan?

We absolutely love it. This is a wonderful country and the culture is fascinating, both ultra modern and yet deeply reserved at once.

What do you miss about England?

Friends and family of course, Sunday newspapers, riding our bikes along the Thames river path - the mountains here make cycling into a real work-out rather than a relaxing leisure pursuit



INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS



Helsinki hosts IF conference

Two members of ASBAH's Your Voice users group, Cathy Lunn and Amar Dugal, attended the 17th International Federation for Spina Bifida and Hydrocephalus Conference in Helsinki in July.

Here Cathy talks about her experiences of the event....

My journey to Helsinki started from Manchester airport. It didn't occur to me until I got there that I had never travelled alone by air before. Anyway, I enjoyed myself but I kept my wits about me as I couldn't just follow the crowd.

When I arrived in Helsinki I jumped into a taxi to get to the hotel as I felt slightly bemused by all the strange place names and language. The first familiar face I saw was Lisa, another member of Your Voice.

On the first evening we went out to sample the local cuisine. I didn't imagine that reindeer would be on the menu, but it was, although I gave it a miss.

The following day the conference began in earnest. Pirjo Moilanen, Chairman of SB and H of Finland welcomed everyone and talked about this year's theme – Access.

State Secretary, Terttu Savolainen, spoke about the policies that are in place in Finland to help disabled people have

access to education, medical care and housing.

The day was packed with a variety of speakers ranging from surgeons and nurses, who talked about medical issues, to Graham Webb MBE (see *Link* 216) who gave a moving account of his life.

Pierres Merten, President of IF, Belgium, talked about the transition from childhood to adulthood and stressed that it is vital that disabled people have access to the right information and support.

Members of the IF panel were introduced and asked to explain what access meant to them.

The day ended with a buffet reception at Helsinki City Hall. A tour of the city followed, but unfortunately I got on the wrong bus and was treated to a very informative tour... in a foreign language!

One of my favourite parts of Saturday's conference was a presentation by

Angela Wilson, from Australia. She talked about the importance of learning through laughter, play, art and drama.

Another very strong presentation was by clergyman, Klaus Seidenstucker, who spoke up for the right of the unborn child. He questioned the ethics of doctors and nurses who ought to be promoting life, not taking it.



Amar Dugal



Cathy Lunn

Pregnant women, he said, are not given enough accurate information about spina bifida and hydrocephalus and what advice is given is usually negative.

Two mothers of young adults with spina bifida and hydrocephalus talked about their children's transition from childhood to adulthood. In Sweden clinics have been

set up to give young disabled people as much information as possible about benefits, housing, education and medical care.

On Sunday, all adults with spina bifida and hydrocephalus, were invited to attend a workshop where we took turns to introduce ourselves and speak about our experiences

about accessing benefits, suitable housing, education and work.

The morning flew by and after lunch it was time to say goodbye.

My overall view of the conference? Fantastic - if only we could hold more of them. It really does help to know that you are not alone with your problems, and that people do understand.

My overall view of the conference? Fantastic - if only we could hold more of them. It really does help to know that you are not alone with your problems, and that people do understand.

Youngsters air their views about planned website

Young service users from the north west met up to discuss ideas for a new ASBAH website made possible by a £3,000 Barclaycard grant.

The planned site will be aimed at 11-18 year olds from the Greater Liverpool area who have spina bifida and/or hydrocephalus.

It will be packed with information and an area where users can make new friends who have shared similar experiences.

The meeting, which took place at the city's Greenbank Sports Academy, involved discussions on the website's content, look and functions. The youngsters were keen to give their point of view on what makes a good website and were full of ideas on

what the new site should include.

Funding the website became possible when Sue Webb, whose daughter Laura has spina bifida and hydrocephalus, became aware of the opportunity to create a website for local service users.

Sue, who works for Barclaycard, told *Link*; "Over the last few years ASBAH has always been there for us so I was only too happy to approach Barclaycard with ASBAH's request for funding of a website to help young people with Spina Bifida and Hydrocephalus.

"Barclaycard are always interested in helping local communities through its Making a Difference funding scheme, so I was pleased to be able to link the two. Barclaycard were very impressed with the idea of a website and made a financial award towards the project."



Work has begun on the content and design of the new site, which should be up and running by the end of the summer, including a forum area where the children can talk to each other.



LINK

the lifestyle magazine for people with hydrocephalus and spina bifida



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Link is published quarterly (Winter, Spring, Summer and Autumn)

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incontinence

Kathryn Baldock, 23, developed an overactive bladder at the age of 13. For 10 years she suffered in silence until she was offered a surprising new treatment...

Botox cured my incontinence



Kathryn Baldock, 23, developed an overactive bladder at the age of 13. For ten years she suffered in silence, until she was offered a surprising new treatment....

"I was 13 when I started to leak urine without any warning. It was such a difficult age and I was too embarrassed to talk about it – I thought people would think it was disgusting. I didn't even tell my mum or friends, I just wore panty liners all the time.

Looking back, it's amazing how long I carried on without any help. I'd often end up going to the toilet two or three times an hour. But no one ever found out. Of course, it affected my life in many ways. It was hard when I started having relationships with boys. I was always thinking: "What if he finds out? What would he think of me?" I didn't feel normal.

At university, I plucked up the courage to see a doctor. He thought I might have an infection, but when the test came back negative he said there was nothing else he could do. I felt really let down.

Two years passed. Then one day while I was at work I found myself going to the loo for the third time in half-an-hour. Suddenly I thought: "That's enough – I

can't put up with this for the rest of my life."

Even before I sat down in the doctor's surgery, I was in tears. I was so desperate. Thankfully, this time the GP promised to help and sent me to a specialist at the Queen Elizabeth Hospital in Birmingham.

He told me to keep a bladder diary. He was really strict about it. I had to measure my urine every time I went to the toilet. I also has a urodynamics test, which looks at the urine flow, bladder and pressures on the bladder. It's not very dignified. You have to wear a catheter and have patches connected to a computer to test how your muscles work.

Then I had an MRI scan and was finally diagnosed with a very mild form of spina bifida, known as spina bifida occulta, which can affect bladder control. It's very common and many people don't realise they have it unless, like me, they experience bladder problems. I was given some medication, which calmed things down, but didn't stop the leakage.

Two weeks later, the specialist suggested Botox. I just laughed, but he explained that Botox paralyses overactive muscles. In my cases it would block the release of the chemical which causes bladder muscles to contract involuntarily,

I was apprehensive and asked for a general anaesthetic while they were giving me treatment – a series of injections around the bladder. The Botox takes about four weeks to work and the effects last for approximately 10 months. When it started to work, I was overjoyed.

I'm so much more confident now. I

can honestly say it's changed my life.

I've got a new boyfriend and when I told him about it, he was matter-of-fact and only concerned that I was OK. I couldn't believe it – after all those years of keeping this terrible secret and expecting everyone to find it repulsive."

This article was reproduced with kind permission of WOMAN magazine.

The expert's view...

Julian Shah, Consultant Urologist at the Middlesex Hospital says: "Kathryn has suffered with the condition of the "unstable" or overactive bladder for most of her life.

"It appears that the cause was neurological related to her later discovered spina bifida occulta. It is the loss of control of the inhibition of the bladder due to nerve damage from the spina bifida which has caused her to spend a life of distress with incontinence.

"Using Botox to "paralyse" some of the muscles of her bladder wall has caused a major improvement in her bladders "spasms" and has made a big difference to the quality of her life.

"This we have seen in many patients who have opted for this very simple treatment. The effects of Botox will wear off in due course and will need to be repeated in a year or so.

"More major surgery can provide a solution but this would need to be discussed with her surgeon. I am however very pleased that she has had such a good response to treatment"

New advisers help children to learn

Children In Need has provided ASBAH with three-year funding for two additional part-time education advisers to strengthen the team.

Carol Rubinstein and Pat Spencer work with behavioural and cognitive problems in children from 5-11 years who have hydrocephalus.

The advisers will work with, provide advice to and support parents of children with hydrocephalus and professionals working in education.

These specialist education advisers are crucial for ASBAH to be able to provide a quality educational service to ASBAH's service users in England and Wales.

Hydrocephalus is a complex condition, and no two children are alike. Many will have few or no behavioural problems while others will demonstrate far more difficulties, although not necessarily all at once.

Behavioural challenges can seriously hinder a child's progress at school. With the incidence of hydrocephalus rising in the UK due to the increased survival of premature babies, many mainstream schools will at some stage encounter a child with the condition.

But if these concerns are recognised and appropriate/positive support plans put in place, children with hydrocephalus can enjoy their school years and fulfill their potential.

Hydrocephalus is a relatively new disability - it has only been in the last few decades that the brain damage caused by fluid pressure on the brain can be specifically identified and certain techniques taught to help.

As a result, many teachers and parents aren't aware of the difficulties a child may be experiencing at school could be linked to their hydrocephalus.

ASBAH hopes Carol and Pat will be able to intervene at an early stage and provide the support the child needs as soon as possible to ensure they

achieve their full potential.

In extreme cases some children who experience difficulties in school need rapid, pro-active support from Education Advisers to enable them to be supported effectively in school. Some scenarios in the past have (in extreme cases) resulted in children with hydrocephalus being excluded from mainstream education. Obviously we need our advisers to intervene well before this situation could develop. Therefore the educational support should be seen as a vital aspect of our comprehensive services to children with hydrocephalus and their families.'

Mary Malcolm, (Assistant Director) Services said: "Our community advisers currently spend an average of 13 per cent of their time on education problems and this figure is expected to grow over the next four years as we know of some 300 young children with hydrocephalus who are due to start school.

"We want to develop this area of our work to meet this growing need. The advisers will work with parents and educators on issues relating to coping techniques for school work, statementing, educational tribunals and strategies for dealing with challenging behaviour."

With the necessary help and support, children can achieve their educational potential and improve their confidence and life skills either in mainstream school or specialist schools.

As parents become aware of their rights and have improved knowledge of special educational needs, they can push

for better services from the educational system for their disabled child.

If you are dealing with the effects of hydrocephalus - either as a parent, carer, or education professional - then visit www.asbah.org or ring the new ASBAH Helpline on 0845 450 7755



Case studies

Michael Davitt

Michael, who has spina bifida and hydrocephalus, travelled several miles each day to attend a special school.



When his younger brother started at the primary school across the road, seven-year-old, Michael, who uses a wheelchair, was desperate to join him there.

The boys' mother contacted ASBAH to see if anyone could help get Michael a change of provision.

The Primary School had never had a child with spina bifida and hydrocephalus, nor a wheelchair user, even though they were fully accessible.

After several few meetings with and ASBAH adviser teachers were happy to make reasonable adjustments and provide trained support.

Staff at the special school were happy to provide the expertise and specialist support the mainstream school needed so that Michael could attend the mainstream school, initially on a part-time basis. Michael's hours were gradually increased and his mother was eventually able to return to part-time employment.

Emma

Emma has epilepsy and some weakness in her legs and was diagnosed with hydrocephalus at the age of ten.

Emma had attended mainstream school but made very little progress and was eventually transferred to a special school.

At a meeting with her parents,

teachers described Emma as being lazy and lacking in motivation. Emma's parents were so angry that they had to be escorted off the premises by the senior management of the school.

To improve communication, an ASBAH adviser was asked to attend the next annual review. During the meeting it became clear that school staff were concentrating on Emma's epilepsy, and hadn't taken into account the behavioural problems hydrocephalus can cause.

Once the effects of hydrocephalus had been explained to the school staff, their attitude changed. Emma's parents immediately responded more appropriately and communication all round became more friendly and effective.

Two jobs for dedicated Naomi

South East region welcomed a new face in April when Naomi Marston joined the team as part-time education adviser.

Naomi, from Kent, enjoyed the work so much that she took on the additional part-time position of employment adviser in June.

The positions, which are both funded for three years by the Bridge House Trust, covers all 32 London boroughs.

Naomi has vast range of experience gained over 20 years in the voluntary and statutory education sector, working with children and adults with special needs in a wide variety of educational establishments.

Her work as education adviser for



Naomi Marston

ASBAH, deals with children aged from 14 to 19 years, and blends seamlessly into the area of employment.

Naomi said: "It does make sense for one person to do both jobs as there is always a crossover from education to employment at some stage.

"It certainly seems like a ground-breaking position and I haven't come across anyone doing a similar role in any other organisation. There has certainly been a huge gap in the market for a position like this."

She added:

"Everything has gone very smoothly so far, and I have received fantastic support from everyone in the south east region office."

Bridge House Trust



Education advisers

The national ASBAH team was boosted by the recent appointments of Carol Rubinstein and Pat Spencer, part-time education advisers.

Carol, who joined on 1 May, quickly settled into her new role and soon became immersed in the heavy caseload.

She said: "Pat and I handle anything centred round education. It can be giving advice to parents or teachers who encounter problems at school or dealing with Local Education Authorities and relevant support agencies. It really is a huge area.

"Many problems can be solved by a quick chat on the phone, or by sending out one of our education packs, which we're in the process of updating. But some cases do need a visit from either Pat or me. The problem can be so urgent that we have no option to go out and see how we can help resolve it."

The heavy caseload does mean that the education advisers have to prioritise, and a child on the verge of being excluded from school, usually goes to the top of the list.

Carol, who began her career as a teacher, has taught children ranging from 2 to 17 years, also worked at a local

authority support service as a special needs behavioural consultant.

She added: "I am really enjoying my role at ASBAH. It is incredibly satisfying when I help teachers and schools to understand exactly what problems can stem from hydrocephalus and how they can find ways round them, to help the child learn.

"Once they understand what they are up against, teachers often see it as a challenge and come up with some unusual but very effective ways to help the child."

Pat Spencer, took up her position on 1 June, and has tackled the work with relish.

She told *Link*: "After a career in different areas of the Education system in the UK, with a major focus on disability and Special Educational Needs, I am able to use these experiences to support children with Hydrocephalus and Spina Bifida and their families. I agree with Carol, that an important focus of our work is to explore the many different ways to understand the hurdles that children with these conditions may meet, and

how we can all work together to support children and young people effectively within our education system.

She added: Carol and I are currently

supporting a wide group of children, young people and their families across the UK, with support from other advisers linked to education and of course, our specialist medical advisers. We see the approach as a team effort, sharing expertise to provide comprehensive support for families and schools. We are currently devising some education programmes for groups of teachers and trainee teachers to support them proactively in understanding the conditions. We strongly believe in

this work, and to emphasise the positive aspects of having children with spina bifida and hydrocephalus in their schools and nurseries.



Carol Rubinstein



Pat Spencer

With these three additions to the education adviser team, ASBAH has four advisers including Joanne Grenfell in the northern region.

Geoffrey Kerr, Northern Ireland regional manager, reviews

Beyond the Steps and the Stares

by Raina Futrell

Beyond the Steps and Stares is the story of Cody Futrell, a 19 yr old with spina bifida and hydrocephalus, and his family, and their individual & joint experiences of life so far, in a family affected by this handicap.

Although Cody is a wheelchair user and has suffered the many traumas spina bifida brings: several surgical procedures, shunts, fractures, infections and so on, he is a first year student at college studying communications.

He graduated from High School, drives a 4x4 truck with hand controls, he is training for the 2008 Paralympics in China specialising in the power sports of discus & shot put.

He also plays the violin and has been part of the youth symphony orchestra, and, holds a choir scholarship at the University.

The book describes all the aspects of Cody's disability including the individual suffering and the challenge to come through and cope with things as a family. Equally, however, it highlights all the talents and skills he has and has worked hard at developing over the years.

But what the book does even more emphatically, or rather, what his mother as the author does, is focus on his personality which is so outgoing and giving in nature. Along with an attitude that is extremely positive and inspirational that it has created opportunities for him to be a mentor and role model to many other young people from all walks of life.

The coaches of the (American) football team were so impressed with his sporting achievements and his focus on successful performance that they asked him to deliver a pre-match talk to the school team. It was so inspirational that the team won every match for the rest of the season, and adopted Cody as their motivational coach.

The tone of the whole story is positive, inspirational, educational and motivational. Well worth a read.

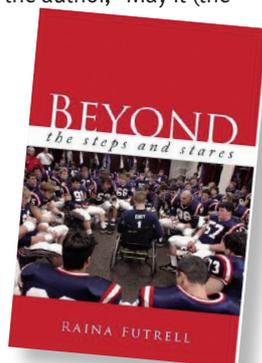
In the concluding words of the author, "May it (the book) be an inspiration to all who read it, and a guide to all who need it".

Beyond the Steps and Stares
by Raina Futrell

Published Tate Publishing
Available through Amazon

www.amazon.co.uk

price £9.25



Poppy's Poem

Poppy Batchelor was born on 7 July 2005, the day of the London bombings, at Tooting Hospital, in south London.

She was born with severe hydrocephalus but proud mother Debbie told *Link*: "Although she does have her problems, we think that she is absolutely beautiful.

Watching her much-loved daughter inspired Debbie to put pen to paper and this is the resulting verse.



POPPY

Please don't be sorry when you look into my cot.

Don't think of things I can't do.

Don't think of things I'm not.

I may not be quite perfect. What the future holds - who knows.

But I've still got all my fingers, and I've still got all my toes.

I can sit up with a little help, and hold my head with style.

I can roll on to my tummy, it might just take a while.

I have the gift of laughter and beautiful blue eyes, and when I smile at Mummy it's like she's won first prize!

I know that I am different, but I thank the Lord above that he's filled my world with happiness and surrounded me with love.

Letters

We welcome letters for publication, which should be sent to: Editor, *Link*, 42 Park Road, Peterborough, PE1 2UQ.

The editor reserves the right to edit letters, so please keep them short.

I have just received my copy of the *Link* magazine today and thought I would reply to your appeal for "Your Story"

I'm relatively new to hydrocephalus! I have seen articles in the magazine about people with age related hydrocephalus or being born with it, but as yet I haven't come across my condition which is adult acquired hydrocephalus.

So my story is a bit different from what you normally have, so it might therefore be of interest to someone else. I would just love to be in touch with someone with a similar condition to mine.

I am now 54 and a year and a half ago I had a brain haemorrhage. I would have died except for the fact that I was rushed to the Royal in Belfast where a lovely man saved my life by fitting me up with a shunt to drain the fluid from my brain as one of the ventricles was damaged through the haemorrhage.

A year and a half on and I'm back at work full time and still learning to live with the "hole in my head!"

Helene Doherty

Anyone wishing to contact Helene can contact her through *Link*.

Holiday let

When booking, check to make sure the accommodation suits your particular needs.

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Fully-furnished and equipped two-bedroomed bungalow. Beautiful area. Wheelchair-accessible. Site facilities, shop. Local indoor heated pool. Transport advisable. Excellent rates. Offers early/late season. **Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF**
Tel: 01983 863658, www.iwasbah.co.uk

PAIGNTON, DEVON

Six Berth all electric wheelchair accessible caravan situated within a mile of the beach. Site facilities include indoor and outdoor pools, sauna, steam room, children's play area, hire shop, amusements, licensed club and seasonal entertainment. All electricity & club passes are included at no extra cost. **Tel: Devon ASBAH on 01803 522256, (www.dasbah.com)**

PRESTATYN, NORTH WALES

Choice of two adapted caravans for disabled holiday makers. Each sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravans have ramp access and are overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £95-£275 per week; **for further information contact Leeds & Bradford ASBAH, c/o Jo Baxter, 8 Staveley Court, Shipley, BD18 4HF.**
Tel: 01274 591850, e-mail jo.baxter2@btinternet.com

TRENERRY LODGE, CORNWALL

Farm bungalow, mobility level 1 accessible. Sleeps 4, open all year. Short and long breaks. **Details: Angela Parsons tel: 01872 553755**
www.babatrenergy.co.uk

ROPERS WALK BARN, MOUNT HAWKE, CORNWALL

Opening August 2005, single storey accessible barn converted to a high standard by family of wheelchair user. Sleeps 4/5+cot. Short level walk to village, close north coast, 8 miles Truro. **Details: Liz/Pete Pollard, tel: 01209 891632**
www.roperswalkbarns.co.uk

BERWICK COTTAGE, EAST HARLING, NORFOLK

Purpose-built, self-catering accommodation for people with disabilities, their families or carers. Sleeps 6 (2 with disabilities). Facilities include Scan 700 beds, Clos-o-Mat toilet, bedroom-to-bathroom hoist, wheelchair shower and much more. Awarded highest National Accessible Scheme ratings. Weekly rates £295 - £645. Open all year. In pretty village with pub, shops and GP. **For bookings tel/fax: 01787 372343 (office hours) or email: info@thelinberwicktrust.org.uk website: www.thelinberwicktrust.org.uk**

For sale

SUNRISE MOBILITY AZTEC

4 WHEELED SCOOTER

Little used, fully serviced, excellent condition. Bereavement forces sale £700. **Further details contact P. Mason on 01529 460322.**

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Fits most estate cars, used twice. Bereavement forces sale. **Further details contact P. Mason on 01529 460322.**

Accommodation

ILKLEY, WEST YORKSHIRE

Flat 1 Wharfedale. Three bedrooms, living room, kitchen, bathroom and toilet. Fully wheelchair accessible and on the ground floor. The person to hold the tenancy must have a disability and need housing related support. Care and support packages can be arranged with Bradford Social Services. **Contact: Mark Best, Tel/Fax: 01943 603013, or write to Five Oaks Housing Scheme, Ben Rhydding Drive, Ilkley LS29 8BD.**

Diary dates

Contact your regional office for more details on the following dates:

Picnics in the Park

Bring a picnic and join us:
Tuesday August 15th: Queens Park, Crewe
Wednesday August 23rd: Castle Park, Frodsham, by the playground.
All picnics will be held between 12 noon and 2pm. Further information from Elizabeth Miers on 01490 450360

Evening Picnic 30th August 2006

ASBAH in Cheshire
6th Form Centre, Tarporley High School, Tarporley. 5pm - 8pm
For further details contact Elizabeth Miers on 01490 450360

ASBAH AGM

Saturday 23rd September
ASBAH House, 42 Park Road, Peterborough

Hydrocephalus Study Day

Thursday 12th October 2006
10.00am - 2.30pm
Talarly Hotel, St Asaph, Denbighshire
Contact ASBAH in Wales
Tel 01248 671345 or email wro@asbah.org

Eastern Region Local Association Forum Meeting

Saturday 14th October 2006
ASBAH House 10.30 am to 3.00pm
Contact ero@asbah.org or call 01733 555988 for more information

Your Voice Employment and Training Weekend

(held in memory of Janet Waugh)
29 September – 1 October
Leeds (more info to follow, see page 18 for more details)

Please e-mail the editor (link@asbah.org) dates of your events for the next issue of Link by Friday 6 October 2006, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Classified rates

£3.75 for 30 words max.
£5.50 for 30-45 words
£6.75 for 45-60 words

Cheques and postal orders should be made payable to 'ASBAH'. Classified adverts for the next issue of *Link* should be submitted by Friday 6th October 2006

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Speaking out to change the Church

John Naudé

PROFILE:

Name: John Naudé
Age: 44
Occupation: Vicar of the Church of the Good Shepherd, Crookhorn, Portsmouth.
Family: Married to Belinda. The couple have one son, Samuel, aged 2.

ASBAH’s former mobility adviser, the Reverend John Naudé, is a man with a mission.

John, who has spina bifida and uses a wheelchair, believes that part of his vocation is to ensure that disabled people are not excluded from any aspect of life and this includes the Church.

Shortly after his ordination in 1997, John, one of the speakers at ASBAH’s recently 40th anniversary celebrations at Peterborough Cathedral, became the founding chairman of a campaigning group within the Church to raise disability awareness.

He explained: “Sadly the Church is far behind the secular world in the way it views disabled people. It should be an ally of disabled people, not yet another system to struggle against.”



Since the launch of The Ecumenical Disability Advocates Network (EDAN), the group, which now has over 70 members from around the world, and has campaigned for disabled people to play a fuller role within the Church.

“Otherwise,” John explained, “disabled people will continue to be spoken for rather than heard for themselves.”

Thanks to a grant from the Archbishop of Canterbury, John was able to co-lead a group of EDAN members at the World Council of Churches Assembly in Brazil earlier this year.

John explained: “The mission statement for the World Council of Churches Assembly was, ‘God in your Grace - Transform the world.’ Sadly my feelings are that He firstly needs to start with the Church.

“Disabled people are still not being fully included in the complete life of the

Disabled people are still not being fully included in the complete life of the Church. Disabled people have a part to play within the Church as disabled people, not as people trying to be non-disabled.

Church. Disabled people have a part to play within the Church as disabled people, not as people trying to be non-disabled.

“The inclusion should not be seen as an option, but as a matter of course. The Good News of Jesus Christ is a message for all people.”

John, who recently moved to a new parish at Crookhorn on the outskirts of Portsmouth in July, told *Link* that the EDAN presentations at the Assembly went well, although the audience numbers were not

Contacting ASBAH



as big as was hoped, perhaps because disability is still regarded as a fringe issue.

He said: "Many of EDAN's participants continue to face discrimination in their own country, and the majority of them felt that their church, a place where they should be able to call a place of acceptance, was anything but.

"They told painful stories of healing services where they were told that their lack of faith or some unconfessed sin was the reason they were disabled and other stories of being discriminated by the church. Things are changing for the better, because disabled people are challenging such discrimination and speaking for themselves"

"I believe that whilst the journey towards inclusion seems slow and often painful, we will get there with God's help."

We wish John and Belinda every success in their new parish.

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Northern ASBAH Affiliated Local Associations:

BOLTON & BURY

Mr David Clyne
51 Cuckoo Lane,
Whitefield
Manchester M45 6WD
Tel: 0161-798 7804
(after 4pm)

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c/o ASBAH Northern Region
64 Bagley Lane
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North Scarle
Lincoln LN6 9EX
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(after 6pm)

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Alison Walter
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Local Association secretaries requiring changes to this list should contact:

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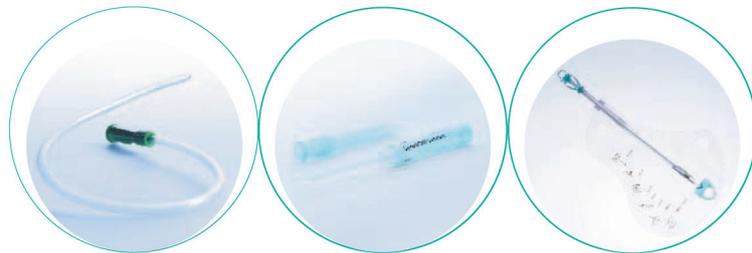
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