

HRH The Duchess of Gloucester GCVO, meets Victoria Nice and her mother Katrina at the recent 40th anniversary celebrations

**40** ASBAH  
1966-2006 Challenging the future  
Association for Spina Bifida and Hydrocephalus

# Connect

Welcome to *Connect* – a quarterly news and information bulletin for ASBAH Local Associations

## Local associations help celebrate 40th anniversary

Representatives from many local associations joined in ASBAH's 40th anniversary celebrations at Peterborough Cathedral.

More than 160 guests were invited to attend the Service of Thanksgiving – among them ASBAH's royal Patron, HRH The Duchess of Gloucester GCVO.

The Service, held on Saturday 10 June, reflected on four decades of invaluable work and looked forward to a successful future.

The multi-faith service, which was 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; Dr Jeffrey Tate CBE, President of ASBAH and ASBAH's Chairman, Richard Astle.

Dr Tate, praised the "dedication and commitment of men and women throughout the Association."

He said: "Their service has enriched the lives of countless numbers of people."

Three other 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 adviser 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 wonderful 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."



**ASBAH Helpline**  
**0845 450 7755**  
**NOW OPEN**





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 Moneypenny, 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



## Monday Lottery boosts Family Weekend fund

**Around 20 families will be invited to ASBAH's Family Weekend - the first to be held for several years.**

Funding for the event was completed by ASBAH's proceeds from the first draw in the new Monday online lottery.

The weekend will give parents 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.

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.

Launched in April, it allows the online lottery players to choose which of the featured registered charities should benefit from their lottery ticket purchases.

To register and play visit  
[www.playmonday.com](http://www.playmonday.com)

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

## Switching to a new telephone system

**From August anyone contacting ASBAH's Peterborough office will be dealt with by an automated switchboard.**

Callers will be asked to select from several options to direct them to the new Helpline and other departments.

The main number remains the same 01733 555988 - or if you know the direct dial number call 01733 42 + the extrn.

## Southampton signs up



**ASBAH has welcomed Southampton & District's decision to sign up to the Compact.**

Stanley Fitzgerald, Chairman of the Southampton & District association, told Connect: "Our local association has always been affiliated to ASBAH and the committee 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.

Stanley added: "We are always there to provide help and support for families and individuals, and we organise several events each year.

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



# ASBAH BOARD OF TRUSTEES MEETING: 6 July 2006

## Report:

- ASBAH's Statutory Annual Accounts for 2005/06 were approved.
- Forthcoming retirements/re-elections of trustees from the Board were discussed. Mrs Brenda Sharp announced that she will not be re-standing, but will maintain her attendance and interest in ASBAH Cymru.
- The review of Auditors and the appointment of Saffery Champness in place of PKF, was confirmed. It is hoped that the new auditors will improve ASBAH's VAT reclaim.
- A strategic discussion, looking at long-term opportunities and trends of Fundraising and Telesales performance, prospects and problems took place, including reports from Donna Treanor and Tom Logan. This discussion will continue at future meetings. The Board expressed approval of the skill and commitment of all of its fundraising staff.
- ASBAH's 40th Anniversary events (Peterborough in June and London in October) were discussed. The Cathedral event was praised.
- An update was given by Mary Malcolm on the Helpline and Information Service operation, and the appointment of a manager and staff. Paul Dobson reported on arrangements to replace the switchboard by an auto-attendant switchboard.
- Peter Farrall gave a presentation on ASBAH's brand. Proposals for change will be brought to the Board of Trustees meeting on 1 December 2006.
- Andrew Russell reported on principal campaigning matters: the Trustee Skills Audit, Medical Advisory Committee and research, and the International Federation for Hydrocephalus and Spina Bifida meeting 29 June – 2 July 2006.
- A report by Your Voice was given, covering forthcoming planned events, the website and the Your Voice elections.
- Four items of Any Other Business were raised:
  - One member felt that Local Associations should be informed about the new switchboard, and it was agreed to do this;
  - One member reported that a Local Association had objected to ASBAH's participating in the Chariot Monday Lottery without informing/consulting them;
  - The EU Peace programme had agreed to fund a project promoting independence/employment in the border counties of Northern Ireland, to be run by ASBAH in partnership with Irish ASBAH;
  - Questions were raised about the government's review of Incapacity Benefit.

*Andrew Russell, Chief Executive  
14/7/2006*

## New look for ASBAH

**ASBAH is set to get new branding as part of a drive to modernise and improve the organisation's image and identity.**

Detailed questionnaires will be sent out to Local Associations in the near future. Any member of a local association who wishes to air their views should complete the questionnaire and return it to Peter Farrall at ASBAH House.

It is hoped that the new logo will be implemented during 2007.

## Welfare Grants - criteria for local associations

For local charities, giving small grants directly to individuals or families is often seen as a valuable way of supporting people in stressful and difficult situations.

**The amount given varies widely, according to what is affordable, and the priority given to welfare grants as opposed to other aspects of the charity's aims and role.**

For local ASBAH associations, the power to make grants is conferred by the model Constitution, which most affiliated associations have adopted.

**"To provide financial assistance, to make grants and donations and to provide aids for such persons\* and generally to provide such other assistance calculated to be of benefit to such persons collectively or individually."**

Where the beneficiary is a child, this obviously extends to

include the child's parent or carer, who can receive the funds where appropriate on the child's behalf for the intended purpose.

The decision to award a grant is entirely up to the Trustees of the local association.

In practice, the process of considering applications is quite properly delegated to a small sub-committee, helping to preserve a measure of confidentiality for the applicant whilst exercising accountability for the use of charitable funds.

It is suggested that three committee members are formally delegated, as the welfare grants sub-committee, to undertake

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\*by "such persons" the Constitution means:- "persons who have spina bifida and/or allied or related disorders who are resident or were formerly resident in the beneficial area"



this role, to include the Hon Treasurer.

Reports to the main committee should be made in a general way, with accurate financial details, but omitting names.

Decisions of the Welfare Grants Sub-Committee should be minuted, but the minutes should remain confidential in normal circumstances. These should be made available to the auditor (or, for small charities below £10,000 turnover, an independent, competent person doing an annual financial review/check on the accounts).

Confidentiality is important both for the applicant and the reputation of the local association.

In accordance with your constitution, all service users with spina bifida and their families within the local association's designated area qualify for financial assistance from Welfare Funds.

Charity law determines that the benefits of the charity must in principle be available for the public, not just for members of the charity.

However, grants should not be considered towards items that Statutory Authorities have a duty to provide. Where local authorities have the power to make a grant it is sometimes appropriate for a charitable association to assist, or provide partial funding for an appropriate purpose.

It is normal policy for no more than one welfare grant to be considered in any financial year. However, in exceptional circumstances, this might cover regular expenditure like hospital visiting or where a particular difficult situation arises, which could not have been foreseen, when grants may be awarded.

All cheques should be made payable to the supplier of the item being purchased and not to individuals except for grants towards hospital visiting and other similar requests.

It is recommended that grants are made according to the following guidelines:

### **1. Household Items/White Goods**

Applications should be considered sympathetically.

### **2. Mobility**

**Wheelchairs** – grants for wheelchairs are usually requested to meet shortfalls from the voucher scheme and should be considered sympathetically. However, there are many funding bodies that will assist with grants towards wheelchairs.

**Repairs** – all requests for repairs to wheelchairs should be considered but only if carried out by reputable dealer/repairer.

**Driving Assessments of Learner Driving Courses** – grants should only be given after careful investigation of financial status and assurance that adequate guidance and assessment of the individual's capabilities has been provided.

**Car Adaptations** – each case should be considered individually.

**Car Deposits** – grants should only be considered in exceptional circumstances. Motability offer a grants scheme for car deposits.

### **3. Housing Adaptations/Improvements**

Financial assistance should only be given in exceptional circumstances. The most effective way of assisting is to finance a piece of equipment after the adaptations have taken place. Local authority help and information should be sought, and an application for Disabled Facilities Grant (DFG) considered.

### **4. House purchase**

Grants should not be considered under any circumstances.

### **5. Loans**

Loans should not be considered under any circumstances. The provision of loans may increase financial hardship for a family or individual and could result in the charity having to bear the cost of debt recovery.

### **6. Funeral Expenses**

Requests for funeral grants should be considered. However it should be noted that any grant awarded to a service user or family will affect their right to a DSS funeral grant if they are on welfare benefits.

### **7. Holidays**

Grants for holidays could be considered. It is important to note that there are many organisations that give holiday grants for families with a disabled child e.g. Family Fund Trust and should applicants should be encouraged to access these sources of funding.

### **8. Household Debts**

Grants requests for household debt should be treated with great caution. Applicants should be encouraged to contact CAB and other organisations who are set up to provide assistance with household and other debt problems as they receive specialist training in dealing with this problem.

### **9. Hospital Visiting/Living Costs**

Grants should be considered for this purpose as the cost of long hospital stays can be very costly to a family and they often incur loss of earnings.

### **10. Specialist Items**

Applications for special pieces of equipment for medical or purely practical use should receive sympathetic consideration. However, care should be taken that grants are not awarded for items of equipment that the statutory agencies, such as the NHS, have an obligation to provide.

*Further copies of this Guide for Trustees – Welfare Grants will be available from ASBAH House or the ASBAH website.*

## **What would you like to see?**

Please get in touch with your stories and pictures for *Connect* and send them to Peter Farrall, ASBAH, 42 Park Road, Peterborough PE1 2UQ or email [peterf@asbah.org](mailto:peterf@asbah.org)