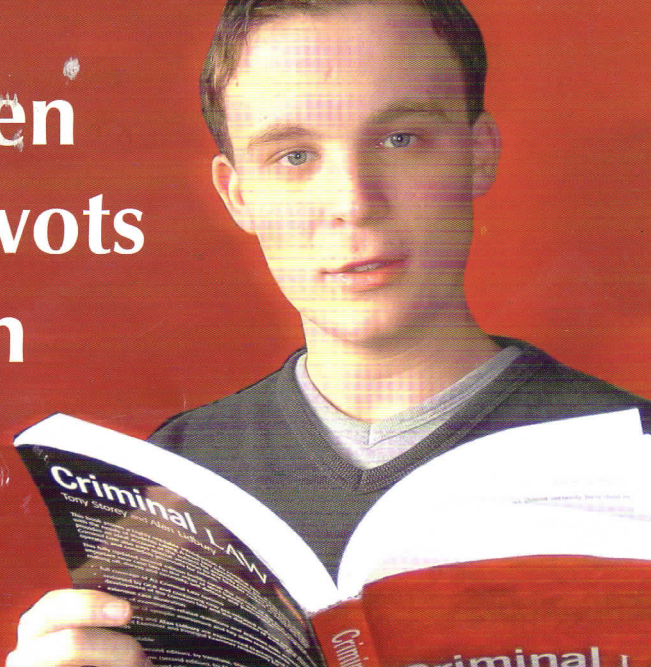


Ben  
swots  
on



Abigail -  
full of life



Go, go, go,  
Naoishe

# ASBAH Active

Summer 2003



Matthew  
- class act

Just the job  
for Tunde



Trudi  
makes the  
running



ASBAH

Association for Spina Bifida and Hydrocephalus  
*Getting the most out of life*



# Direct from Donna

Welcome to the first edition of *ASBAH Active*, a newsletter about how donors, like you, are helping people with spina bifida and hydrocephalus to get the most out of life.

ASBAH is a registered charity which relies entirely on voluntary donations to carry out its vital work. It is through ASBAH's supporters like Trudi Green (see cover pic) and her husband Laurence who raised over a £1,000 by running the London Marathon, that ASBAH is able to provide the support and information needed.

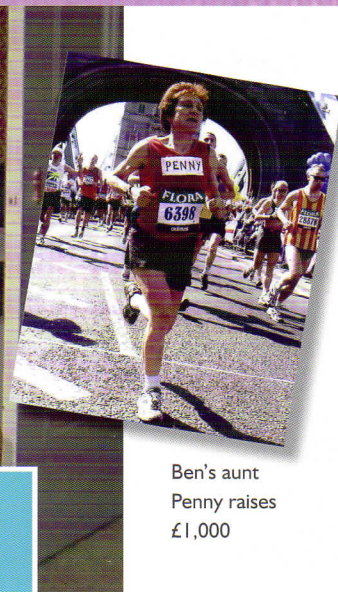
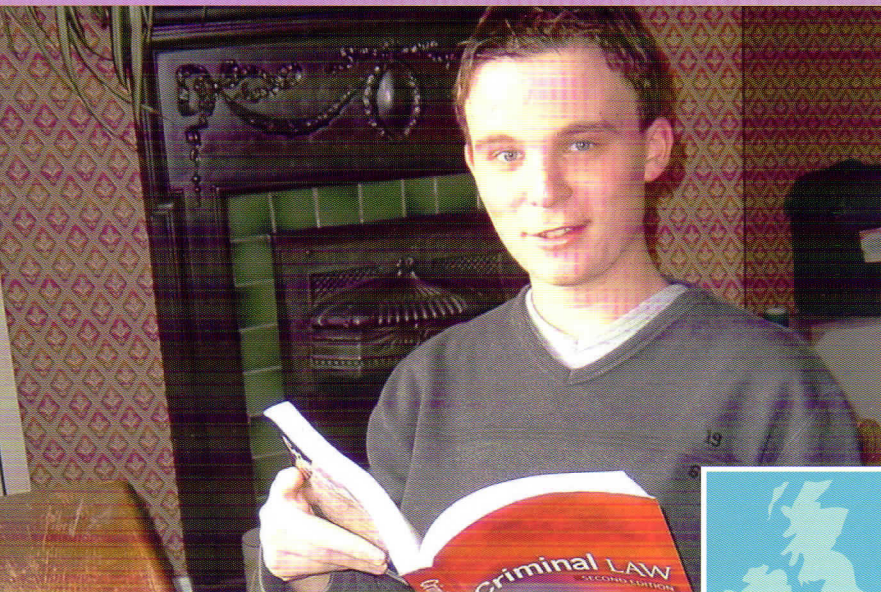
Over 15,000 families seek support and information on spina bifida and hydrocephalus. From providing information and advice, to promoting awareness and carrying out research, the money you give is

already helping ASBAH make a huge difference to lives of many individuals and their families.

*ASBAH Active* is an opportunity for us to show you how your money is making a real difference. I hope you enjoy reading these stories of people from around England, Wales and Northern Ireland who know they can rely on ASBAH for support. Without your help this work would not have been possible.

A big thank you to all of you who have taken the time and effort to raise much needed funds for ASBAH. Knowing we can rely on regular gifts helps us to plan for the future with confidence.

**Donna Treanor** - Fundraising Manager



Ben's aunt Penny raises £1,000



## Swotting up

Having spent the last few months hitting the books ahead of his A-level exams, 18-year old Ben Edwards from Birmingham knows the importance of learning. But when it comes to finding out the latest information about hydrocephalus, it's ASBAH he turns to.

Sometimes Ben wonders if he is the only one who is experiencing problems but articles in *Link* (ASBAH's magazine) have reassured him that he's not alone. *Link* is also a great way for him to find out about the latest hydrocephalus developments: "When I had a programmable shunt fitted I knew a little, but not enough. I read an article in *Link* and discovered that I shouldn't go through airport security systems. I didn't know that."

He also says: "The information leaflets ASBAH produce are very useful. I find their website very good and have downloaded articles on the side affects of hydrocephalus as well as information about shunts."

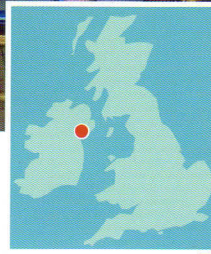
Ben's aunt, Penny, raised over £1,000 by taking part in this year's London marathon. But Ben wants to see ASBAH receive even more money so they can continue to carry out valuable research, particularly on why shunts block. "There isn't anyone else apart from ASBAH providing the most up to date information or carrying out the research. They are the only ones."

### ASBAH active:

- *Link*
- website
- research
- information literature







## Out and about

Naoishe Quinn, aged five from Newry, County Down, has spina bifida and hydrocephalus. She attends a mainstream school where she is well loved by both the teachers and pupils. But when it comes to meeting other children in wheelchairs her parents, Aileen and Frank, rely on ASBAH's Wheelie Kids Club in Belfast.

Held approximately every eight weeks, the Wheelie Kids Club also provides an opportunity for Aileen and Frank to meet other parents of children with spina bifida and hydrocephalus to share experiences and knowledge. Aileen adds: "The kids play games and the mums and dads also get into wheelchairs, which helps us understand what it's like for our children."

The Quinn family has found the seminars held by ASBAH on hydrocephalus, learning issues and continence invaluable. Aileen comments: "We went to a continence seminar, but although Naoishe was too young for this to be an issue it was good to find out what the future holds. It told us what to expect so we were prepared. It was also another opportunity to meet other parents."

A big thank you goes to the Quinns who have also raised thousands of pounds in recent year's through their fundraising activities for ASBAH. It's really appreciated.

### ASBAH active:

- Wheelie Kids Club
- area adviser support
- seminars
- information literature



## Like a duck to water



Starting school is always a difficult time for children and their families, but when the child has hydrocephalus parents have additional worries to deal with. This was certainly true for Sarah Coates from York, whose son Matthew, was born with hydrocephalus in July 1997.

Thanks to the hands-on support of ASBAH's education advisers, when the time came for Matthew to go to school he took to it like a duck to water. Sarah explains: "I got in touch with ASBAH when Matthew was about to start reception and they arranged for their education adviser, Joanne Grenfell, to come with me when I visited the school. She looked at the classrooms, spoke to the teachers and assessed what needed changing if Matthew was to settle in quickly."

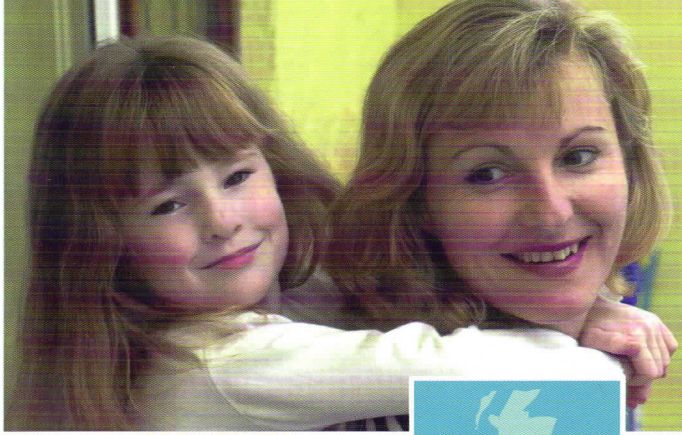
ASBAH will be joining Sarah again for her next appointment at the school for Matthew's interim review. It's this practical, hands-on support which Sarah feels is most important. She adds: "I've really benefited from having ASBAH there when I need them. Although I know ASBAH's education advisers are stretched, it would be great if as many other families as possible could benefit from ASBAH advisers working with them in their homes and schools. Matthew's growing up to be a confident boy, a real character!"

### ASBAH active:

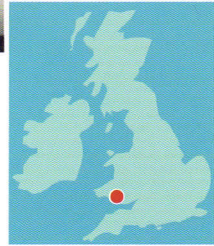
- area adviser support
- specialist education advice
- information literature
- seminars and open days







## Food for thought



"What is or isn't normal? Should she be behaving like this or not?" These were the questions Angela Maguire from Swansea asked herself after her daughter Abigail developed hydrocephalus following an intercranial haemorrhage when she was only six days old.

Abigail is now seven years old and during those early years her mother relied on the support of ASBAH's medical advisers to answer her questions and put her mind at rest. Angela explains: "It's not appropriate to contact a neurological doctor with non-medical, development problems. But you still need someone to turn to who won't think your question is daft."

Abigail's attitude towards food has been a continual area of concern. Angela says: "By the age of four Abigail still hadn't started eating solid foods. She had an attitude towards eating - she didn't even like to see me eat." A call to one of ASBAH's medical advisers alleviated her fears as they explained that this was one of the less known possible side affects of hydrocephalus.

Angela adds: "It's about having a life, not just keeping your child alive." The hospitals may help with the latter but it is ASBAH who are there to help families achieve the best quality of life possible. ASBAH are lifesavers, they let you know that you're going to be OK and that you will come out the other side."

### ASBAH active:

- specialist medical advice
- advice on travelling
- shunt alert card
- family weekends



## It's hard work



Many people will experience office politics at some stage during their working life, but usually it's a harmless irritation, forgotten once you get home. However, for 32 year-old Tunde Kassim from Chelsea, working life has been a continual battle to make his employers understand how hydrocephalus affects his approach to work.

He says: "Like most people who have hydrocephalus I can have difficulty remembering all the stages in a sequence of tasks and sometimes have to ask people to repeat directions they have recently given me. This doesn't mean I'm stupid or lazy - the hydrocephalus can make me forgetful but I am as capable as anybody else."

Tunde called on ASBAH to reinforce what he was telling his employers: "Because you can't tell I've hydrocephalus by looking at me, people often accuse me of being a hypochondriac. In the past I've called on ASBAH to back up what I say to add weight to my words. ASBAH also know all about the legal side of things, so I can call on them to find out what my rights are."

ASBAH have also put Tunde in touch with other people his age who have hydrocephalus. He explains: "It's reassuring to talk with other people and discover that they experience the same problems with employers."

Tunde is keen to see ASBAH continue their role in raising awareness about hydrocephalus amongst employers: "It should be a priority to tackle their ignorance," he says.

### ASBAH active:

- information leaflets
- rights advice
- liaison with employers
- contact with other ASBAH service users

# A BIG thank you from all of us for your help.

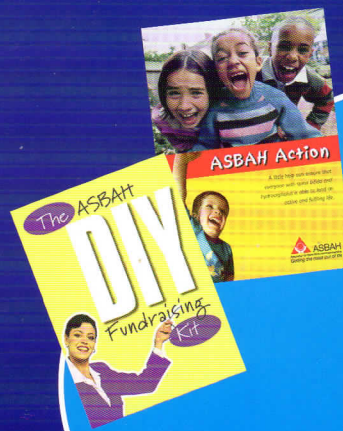


## ASBAH

Association for Spina Bifida and Hydrocephalus  
*Getting the most out of life*

ASBAH, 42 Park Road, Peterborough PE1 2UQ  
Tel 01733 555988 Fax 01733 555985  
email [info@asbah.org](mailto:info@asbah.org) [www.asbah.org](http://www.asbah.org)

Registered charity number 249338



**NEW**  
**Fundraising packs**  
**NOW available.**  
**Just call Ian Morley**  
**on 01733 555988 to**  
**order your pack!**  
email [ianm@asbah.org](mailto:ianm@asbah.org)