



ASBAH

Issue 4

Active

NEWSLETTER FOR THE VITAL
SUPPORTERS OF ASBAH

IN THIS ISSUE:

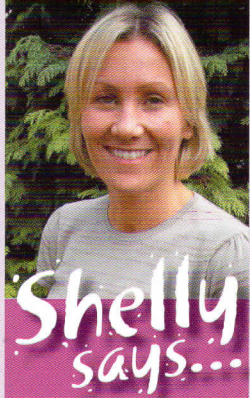
- Invaluable support for Qasim
- Advice for Emma
- Katie put in the picture



ASBAH

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





Shelly says...

Looking back at all the wonderful fundraising by our supporters during this year really makes you realise how fortunate we are to be able to help children like Emma, Qasim and Katie and our many other service users.

The Danny Mills Golf Classic was one of the highlights of 2004, raising an impressive £33,000 for a helpline and information service. The Great North Run was another money-spinning event, with 28 people running for ASBAH. More good news is that for the first time we had runners in the Great South Run in Portsmouth.

As you know, ASBAH relies completely on voluntary donations, so without your continued support, we couldn't help the 15,000 families who need the support and information we provide.

Families vary in their needs and require many different means of support. Sometimes basic information is all that is required, while other families benefit from practical and emotional support. It is a constant comfort for them to know that there is always a friendly person to turn to in their hour of need.

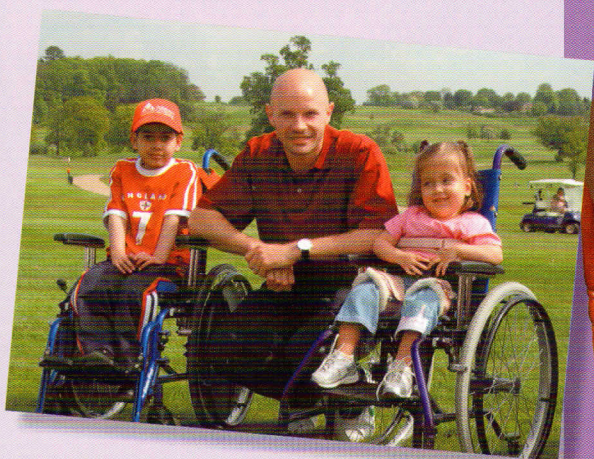
Through ASBAH Active you can meet some of the families we have been able to help because of your hard-earned money. Thanks to your efforts we have been able to make a real and valuable difference to their lives.

A special thank you goes to the people who, year after year, continue to respond to our appeal letters. These donations, no matter how small, really do make a huge difference.

Without our fund-raisers and supporters we wouldn't be able to provide this vital service. So a huge thank you from everyone at ASBAH and the families your money helps.

Shelly Bullard

Donor Development Officer



Man. City and England footballer Danny Mills meets Qasim Pervase (left) and Sarah Boussetta (right) at his recent golf day

Peace of mind

Katie, who's now three-and-a-half, was born ten weeks early. She was very ill to begin with and, after being diagnosed with hydrocephalus, had a shunt fitted when she was four weeks old.

I got in touch with ASBAH straight away. They were brilliant, very reassuring and could always answer my many questions. I've been in contact many times since then and there has always been someone available to talk to me.



Invaluable support



We discovered that Qasim, who is now six, had spina bifida when my wife had her 12-week scan. We didn't really know anything about the condition at all, so we got in touch with ASBAH straight away.

From that day on their help, advice and support to our family has been invaluable.

Our local adviser has been wonderful, finding out who we need to contact when we experience problems, and she helped us complete Qasim's statement for the educational psychologist. I don't know how we would have managed without her.

for Paula

Thankfully Katie's hydrocephalus hasn't caused her any real problems, but we had a lot of concerns, especially during her first year. It's a worrying time for any new mother, without the added burden of hydrocephalus.

An ASBAH medical adviser is coming out to Katie's nursery to talk about the implications surrounding shunts, to give the staff a clearer idea of what problems could arise. That helps to give me peace of mind.

Katie is still very young, but ASBAH's Benny Bear books have helped her to understand and accept what a shunt is. Now she's eagerly awaiting the next book.

Paula Wright

ASBAH active:

- area adviser support
- specialist medical advice
- specialised literature
- telephone support



Qasim, who also has hydrocephalus, attended ASBAH's family weekend on the Isle of Wight earlier in the year. It was wonderful for him to be able to meet other children with spina bifida and hydrocephalus. It makes them realise that they aren't alone.

Qasim was also invited to the Danny Mills charity golf tournament in May, and had a fantastic time.

Khalid Pervase

ASBAH active:

- family weekend
- area adviser support
- specialist medical advice
- specialised literature



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I would like to give ASBAH a gift of:

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Registered Charity No 249338
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Thank you
for your
continued
support.

Breaking the silence

It was a terrible shock when Emma was diagnosed with hydrocephalus at the age of four months.

The hospital gave us very little information about the condition but the staff at ASBAH were brilliant and explained clearly and calmly what to expect. Once I learnt more about hydrocephalus I felt I could deal with it.

Through ASBAH I have met two other families with children who have hydrocephalus and Linda Knight, our nearest area adviser, has been over to talk to us.

Emma, now 14 months, goes to a nursery two days a week, and Linda has promised to visit and talk to staff about the condition.

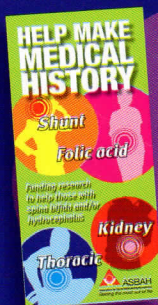
We went on holiday to France this summer and ASBAH gave us information about the nearest neuro-surgical unit where Emma could have emergency treatment. Having that knowledge meant we could relax and enjoy the break.

Sue Fairhurst

ASBAH active:

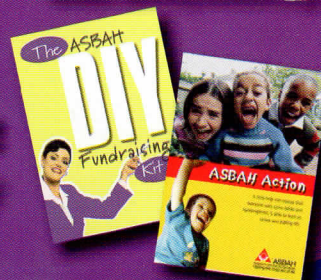
- area adviser support
- specialist medical advice
- specialised literature

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



Shape the future of research
Just call Shelly Bullard on
01733 555988 to order your guide!
or email shellyb@asbah.org

Fundraising packs available
email ianm@asbah.org



ASBAH

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

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