

# LINK-UP

WINTER 2003

GOING ....

GOING....

HAPPY  
NEW  
YEAR



## MAGGIE GETS THE CHOP FOR CHARITY

Maggie Griffiths said goodbye to her flowing flame red hair in October, with the help of Radio 1 DJ Mark Radcliffe.

It was her way of thanking a string of organisations for the support she has received in caring for her 4-year-old daughter Ellie, who has severe neurological problems after being born six weeks premature.

Her sponsored headshave was watched by supporters at the James Pringle Centre in Llanfairpwll and filmed by the BBC for their 'Children in Need' Appeal. It will raise at least £1,800 which will be shared between five Charities, including ASBAH.

Mark Radcliffe admitted to being a bit nervous as he helped out, supervised by a team of professional hairdressers. "I think it is wonderful what Maggie has done and in a way it was sad to see her hair disappear - it was so beautiful."

Maggie, a member of our Executive Committee from Gwalchmai, Anglesey, took the whole thing in her stride. "I just had to do something to help the kind organisations who have helped me. For many people they are unsung heroes.



...GONE!



# NWASBAH NEWS

## SERVICE OF THANKSGIVING

North Wales ASBAH celebrated its 35<sup>th</sup> Anniversary with a Service of Thanksgiving at St. John's Methodist Church, Llandudno, on 19<sup>th</sup> October. The Service was attended by members and friends, a clutch of civic

dignitaries and a member of the Welsh Assembly. Alistair Wood, a Trustee and founder member, gave the Address, reprinted here for the benefit of members who were unable to attend.

Last week, going through some old files, I found a copy of a letter written 35 years ago, which was published in the North Wales Chronicle. It invited parents who had babies born with spina bifida and hydrocephalus to come together for a house meeting in Llanfairfechan. The idea behind the invitation was simple: it was felt that we needed to support each other both emotionally and in practical ways, to share each other's experiences, to improve our knowledge and understanding of others, to campaign to secure the best possible resources for our children - not for charitable reasons but as a right.

From this small initiative, our Association was born and, 35 years, on here we are. It would be foolish not to acknowledge that the passing years have brought their moments of personal difficulty, frustration and indeed sadness, but we have come here today to celebrate and give thanks for the continued work of the Association and for the courage, hard work and achievement of so many people which have enabled us to keep faith with our founding aims.

Things have changed so much. In the early 1960's, the courage and skill of a group of pioneering surgeons changed our world. At that time only three centres in the country undertook life saving surgery on spina bifida babies: Alder Hey, under the leadership of Peter Rickham, Sheffield and Great Ormond Street, London. At the same time the Spitz Holter valve, invented by an American engineer to help his own child, became available and transformed the prospects of those born with Hydrocephalus. For these and for all the subsequent developments in medicine and surgery we give thanks.

In the 1960's the culture of deference was alive and well in the worlds of medicine and education and it was sometimes a struggle for parents to be recognised as partners when key decisions needed to be taken on our children's behalf. It was not always a case of pushing an open door to secure what was needed, sometimes it needed a good kick to persuade the hinges to move and so many of us have cause to be grateful to the Association at such times for the support and expertise of our officers and fellow members. For this we give thanks.

So far I have spoken from the parents' point of view - please forgive me, but parents often tend to do this. Let me get the balance right. From the outset there was a belief, a hope that the Association was being held in trust for the babies who would grow to become children and then adults. A hope that as far as possible the Association would come to be run, not just on behalf of, but with the major involvement of the new generation. The Association must always be the conduit for your views and hopes and must always be acting to support your needs and priorities. For those who have become involved in so many different ways we give thanks. It is your Association and ultimately it is you who will need to control and determine its future.

The world seems to become more and more complicated for us all. Just look at the big issues: health and medical provision, education, the world of benefits, allowances and pensions, employment, housing, mobility, access and so on - each one undergoing constant change. These changes are being orchestrated by central government, the Assembly, the County Boroughs, the Community Councils, the new Local Health Boards - again the list goes on.

How can we best deal with this? In the very early years it seemed much simpler. It was a matter of giving each other support in ways that were individual and local and, where appropriate, help was given - as it still is - towards the cost of equipment or meeting travelling and other expenses. We recognised early on that because many members lived in rural areas personal contact could be difficult, so we started a regular newsletter and we realised that home visits from our specialist field workers (Area Advisers) would make such a difference. The more we did the more it became essential to raise money. Raising money requires time, energy and considerable know how and the continued work of the Association was made possible by the superhuman efforts of members, most of whom didn't have a lot of spare time and energy. For everyone who over the years has worked to raise funds - organising coffee mornings, standing outside Tesco's, running the 100 Club, organising special events from pram pushing to golfing competitions - we give thanks.

.../contd p3

In the beginning our task was to tell as many people as possible about spina bifida and hydrocephalus because no one knew, but as the Association developed it became increasingly obvious that we needed to develop our network of contacts to develop a range of partnerships with people and organisations that could help us: national ASBAH, ASBAH Wales, Disability Wales plus the many local statutory and voluntary organisations. For everyone who has helped us in this - and in this I must particularly mention Elin - we give thanks.

Over the years the work of the Association has been sustained by so many people - there just isn't time to list every one - so may I acknowledge our indebtedness to Arthur our chairman and all the present committee, to Carol our administrator and to Gill and Peter our Area Advisers and thank them both as individuals and also as symbols of the tradition of devoted service which has sustained the Association over 35 years. To all our thanks.

To me it seems so fitting that we should come to St. John's to celebrate our anniversary. We all have days when we don't feel like celebrating, but this is one day when we can all say that we have something to celebrate. The Association has symbolised the energy, courage, willpower, hopes, dreams and faith of so many people over so many years. This is surely a moment of pride. May God bless the Association in its future work and may God sustain and bless us all.

After the Service, guests enjoyed refreshments in the church hall and we would like to thank Val Conway for baking and decorating a beautiful cake and for everyone who provided food and helped in the kitchen. We would most particularly like to thank the minister, Peter Shilling, for welcoming us to St John's and conducting the service and to all the church stewards who were so helpful.

## FINANCE

**INCOME** from September to November totalled £1,902.68 and included:

**Donations:**

In Memory of Eric Hardy	185.00
Mayor of Penmaenmawr	20.00
Marie Edwards	5.00
Cath Morrilly	5.00
Touch of Class	500.00

**Fundraising:**

Maggie Griffiths Head Shave	100.00
Raffle	208.52
Sharron Morris Memorial Bowl	108.50

**Grants:**

Colwyn Bay Town Council	200.00
-------------------------	--------

**EXPENDITURE** during the period was £3,586.45, including £964.50 in direct services to members.

## RAFFLE

Our 35th Anniversary Raffle was drawn on 25th October at the Royal British Legion Club in Llandudno. The First Prize winner, who wishes to remain anonymous, donated his prize of £100 to the Association. Other lucky winners were Sue Jones (2nd) and Linda Thorpe (3rd). We are indebted to the Royal British Legion for hosting the Draw and for donating £250 to North Wales ASBAH.

The net profit was £208.52, so very many thanks to everyone who sold tickets - and better luck next time to all those who didn't win!

## A Letter from Adam

Dear Gill and Everybody at North Wales ASBAH, I am writing to say thank you for your generous grant towards my trip to Barcelona. Our football team won the 5-a-side tournament, the A-team came 3rd overall (11-a-side). We played teams from all over Britain and we were all based in the Hotel Samba in Lloret-de-Mar. We also went to have tours around Barcelona's and Lloret-de-Mar's ground and watched Real Sociedad. Next year, we are hoping to go to Italy.

Our team now plays in two leagues - the Yorkshire and Premiership - which we were promoted to this season. Thank you once again for all your help

*Adam Evans*

Colwyn Bay (PS The beach at Lloret - I'm on the left...)

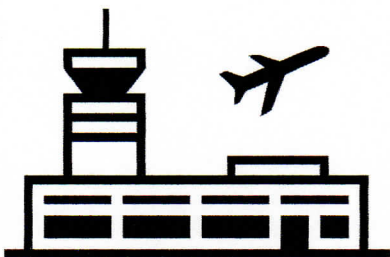


## FEAR OF FLYING

For some disabled people, the greatest deterrent to air travel is not about flying in an aluminium tube at 30K ft, but the possibility of being manhandled in all weathers on steep flights of aluminium stairs just to get on board.

After more than six years of unsuccessful lobbying at Stanstead airport, the Uttlesford Access Group recently sought support help from the Health & Safety Executive (HSE). The HSE immediately threatened to impose Prohibition Orders unless all future disabled passenger boarding and disembarkation activities are undertaken only via either air-bridges or proper ambulift vehicles. The manhandling of passengers is now permitted only in extreme emergencies.

Clearly, a valuable precedent has been established within the UK. Sadly, however, neither the codes of the International Civil Aviation Organisation nor the European Civil Aviation Conference appear yet to address this issue.



\*\*\*\*\*

## DIRECT PAYMENTS CONFUSION

Question: What's the difference between Direct Payments and Direct Payment? Answer: Read on.

**Direct Payments** *The Community Care (Direct Payments) Act 1996* gives local authorities the power to make cash payments for community care directly to individuals who need services, offering choice in the way in which services are arranged and control over how the services are provided. Welsh Assembly Health Minister Jane Hutt recently announced that the offer of direct payments is to be mandatory for all local authorities in Wales, affecting all adult groups by the end of 2005. You can find more information by contacting your local Social Services Community Care Office.

**Direct Payment** is the term being used by the Department for Work and Pensions for the new way to pick up your benefits, state pensions and war pensions and the way all of them will be paid in the future. The DWP is phasing out order books and giro cheques and will be paying straight into bank, building society or post office accounts instead. At some time over the next two years, you will be asked to make the change to Direct Payment. You'll receive a personal letter that will explain what you need to do. Further information is available on Freephone 0800 107 2000

## THANKS...

TO EVERYONE who helped with the summer collections at Safeway's and Tesco (Bangor) and to the organiser, David Hallows. The two collections raised £280.59

£ £ £ £ £ £ £ £ £

## 100 CLUB WINNERS

Oct & Nov  
D.L. Bayley, Mr E. Davies,  
M. Mason, Mr & Mrs Millington,  
Mrs A. Williams, P. Wood



## NWASBAH EXECUTIVE COMMITTEE

**CHAIRMAN** Arthur Todd 01492 870054  
**VICE CHAIRMAN** Michael Mason 01745 825738  
**SECRETARY** Val Conway 01492 878225  
**TREASURER** Jennifer Hayes 01978 661054

### ASBAH AREA ADVISERS

**North West Wales** Jill Bartlett 01248 671838  
**North East Wales** Peter Bennett 01978 852254

### ADMINISTRATOR & EDITOR OF LINK-UP

Carol Buxton, NWASBAH Office,  
Canolfan yr Orsedd, Ffordd yr Orsedd,  
Llandudno, LL30 1LA

01492 860140 [nwasbah@zoom.co.uk](mailto:nwasbah@zoom.co.uk)  
Registered charity no. 257828