

SPEECH BY SID MCDOWELL, CBE, VICE-PRESIDENT NI ASBAH

TO MARK THE 40TH ANNIVERSARY OF THE BELFAST BRANCH OF THE ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS HELD IN HILLSBOROUGH CASTLE, FRIDAY 9 NOVEMBER, 2007

Thank you very much Margaret (McKee) for that journey down memory lane. I think it right that from time to time, such as a 40th anniversary, we reflect on some of the people who have, in some way, played a part in our development.

The Belfast Branch of ASBAH was a major benefit for parents when it was formed in 1967. The incidence of children born with Spina Bifida and/or Hydrocephalus was high. indeed it was sometimes referred to as an Irish condition because with the exception, I think, of Japan the incidence was higher in Northern Ireland than elsewhere in the world and it was also high in parts of countries that had experienced high levels of Irish migration-West Coast of Britain, Australia, Canada and America.

Many parents at that time found that they were battling to cope with disability within their family, with issues such as incontinence and a range of other very complex problems. For example some were supplied with medical aids free, some were supplied and charged, some were denied any supply and the quality of aids supplied was frequently inconsistent- often it depended on where you lived. There was no apparent rhyme or reason to any of this.

When, for example, Attendance Allowance was introduced, some with broadly similar conditions received it, some did not. Some got it for a period but it was not renewed and they had to appeal even tho as a child got older it was self-evident that their problems would increase rather than reduce. We worked on the basis that the DHSS default position was to refuse and only deal with a claim seriously if an

appeal came in. In those days we did a lot of advocacy work for parents who had enough to cope with and needed someone to write and speak on their behalf.

And in those days the meetings which took place were like the Friday market at St. George's except that we were all busy trading information about our problems, our experiences and solutions-I can say that Iris and I and many other parents found those meetings a real life-saver.

In those days too facilities for housing families with a disability were abysmal-there was no such thing as purpose-built wheelchair accommodation. Many families struggled to cope in housing which was quite dreadful and often with a total absence of any supplementary heating beyond their coal fire, steps up to the house, doorways too narrow, no downstairs loo and so on.

Also at the time of our formation medical advances in the treatment of SB & H were only really in their infancy and the life expectancy of children born with those conditions was very poor. Indeed it wasn't until the 1960's that figures were published revealing that infants with SB whose backs were closed surgically within a short time after birth actually gained some improvement in the power of their legs.

It was, in fact, the interest of paediatric surgeons Duncan Forrest and Prof Robert Zachary that led them to form ASBAH in England in 1966. Not surprising then that we in Northern Ireland joined in just a year later because of the high incidence of SB here.

From the start ASBAH has always been interested in funding research and, nationally, Dr Laurence first received a grant in 1968 to research the role of folic acid deficiency in producing spina bifida. In NI our Belfast Branch helped fund research in this area which was being carried out by Prof Norman Nevin at Queen's University. We have enjoyed a close and productive relationship with Prof Nevin over many years and there are many people walking around today who

owe their existence to the wise and sensitive counselling their parents received from Norman Nevin. It is good to see Professor Nevin and his wife with us this evening. It is also good to see Mr Piggott and his wife here. For so long Mr Piggott was 'our' orthopaedic surgeon establishing a wonderful rapport with the children and their families, bringing his wonderful professional skills to the care of our children and like Professor Nevin regularly attending our children's Christmas party. To both of you we owe a great deal of gratitude; thank you.

Time allows only a brief opportunity for reflection but we have to salute the fact that medical advances in the treatment of SB & H mean that the prognosis today for those with the condition has been transformed. The incidence of SB has fallen dramatically during our 40 years because of new, sophisticated screening technologies, improved vitamin intake and other factors. In 1975 there were a staggering 120 births; 1981-70; 1987-43; 2004-11; 2005-14.

More children today survive with hydrocephalus because of medical and surgical interventions, for example the wonderful Holst shunt. And our challenge has changed so that the needs of adults with SB form a large proportion of the demand for our support. Specially built and adapted mobility housing is provided by the Housing Executive and Housing Associations. Our members, thanks to mobility allowance and Motability, can travel about in adapted, reliable cars. Many are living independent and fulfilling lives and finding satisfaction in realising their potential in the worlds of education and employment.

A great deal has therefore been achieved along this 40 year journey. The nature of the challenge facing us has changed. Success has brought with it fewer members as the incidence of children born with Spina Bifida falls. It is therefore more difficult to get volunteers to help with things such as fundraising. But in the Belfast and District

Branch we have 300 members and they have needs which require to be met and research still needs to be funded.

So we intend to remain in business and to face up to the challenge. Tonight though we can reflect on a journey of 40 years well and successfully travelled. We can reflect on a job well done and acknowledge with gratitude:

the work of our volunteers and our Branch Officers and Committee;

the splendid help of our professional Advisers in ASBAH's NI Regional Office:

our colleagues in the medical and social care professions;

we can acknowledge all of them and accordingly look forward with confidence.

I want to thank you for coming along this evening to mark the occasion with us. Your attendance is appreciated especially our friends from other ASBAH Branches who have travelled some distance. So could I conclude by asking you to give yourselves a really warm round of applause?

Now, I have the pleasure of introducing Lisnagarvey Operatic Society. The Society have travelled a good part of the journey with the Belfast Branch because for very many years they have, each Christmas, raised funds for us by carol singing at Sprucefield and many will remember the quite splendid concert they put on for us at our Gala Evening in Belfast City Hall. I reckon that they must have raised something of the order of £20,000 for us by their efforts. Tonight their programme will be introduced by Heather Campbell. Would you welcome please Lisnagarvey Operatic Society (LODS)?

Concert by LODS

Wasn't that really splendid? Thank you so much for your help tonight and for all your fund raising efforts over the years. Now ladies and gentlemen we are much indebted to the Secretary of State for making available to us these lovely facilities at Hillsborough Castle. And while we have been sitting here enjoying ourselves Shaun Woodward and Mrs Woodward will have been toiling away in the kitchen rolling out the filo pastry, filling the vol-au-vents, putting the toad in the hole or whatever it is we're getting. That is the end of the formal part of the proceedings so please enjoy the buffet, mingle and enjoy the rest of the evening-and, in due course, safe home.