

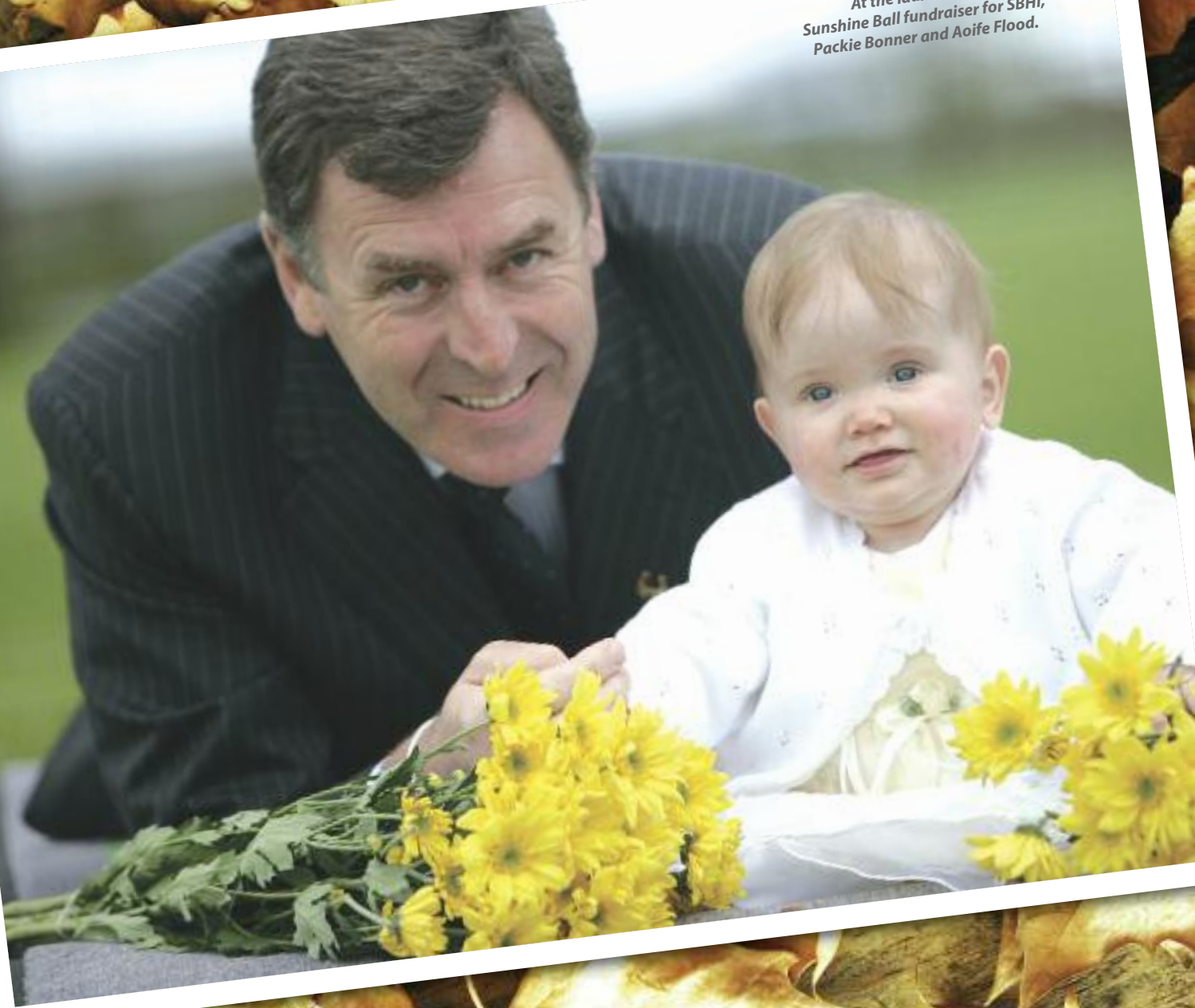


ability

Magazine of Spina Bifida Hydrocephalus Ireland

Autumn 2009

*At the launch of the
Sunshine Ball fundraiser for SBHI,
Packie Bonner and Aoife Flood.*





Message from the Chairman

Welcome to this edition of our **Ability** magazine. It has been a long and exciting time for us within our organisation. We have now made the

transition to our company, Spina Bifida Hydrocephalus Ireland. We have held our first Annual General Meeting and I would like to congratulate those who were elected to the Board. Our Vice-Chairman Peter Landy and Hon. Secretary Thelma Cloake were both re-elected to their positions. We as a board are looking forward to the next 12 months with enthusiasm and hope. We are an organisation growing all the time and we now find ourselves in the position that we have a number of members 21+ within the organisation and the needs of these people have to be met. We would love to hear from this group of members in particular and to work with you to achieve a balanced and progressive organisation. We are in the process of updating our website and this will be launched soon, further details of this will be in the next edition.

I would like to thank the staff and branches for their continued co-operation with the Board. To all those who support us by contributing to our church-gate collections, those who participated in the marathon, the organisers of the Sunshine Ball, the golf classic and to all who have supported our fundraising efforts in any way. I am sure you are all aware that during this economic climate we need all the help we can get and I would urge you to think of anything that might help us boost our income and if you can help in any way we would be delighted to help and support you.

I hope you enjoy reading this edition of **Ability** and I look forward to meeting you all again soon.

– **Fiach McDonagh, Chairman**

Featured in this issue:

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A Word of Thanks

I would like to thank you all for the articles and photos for this edition of the **Ability** magazine. I hope you enjoy it and I look forward to receiving articles for the next edition, the deadline is November 13th. You can forward your articles or thoughts to me directly on thelma.cloake@gmail.com.

– **Cheers, Thelma**

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Happy Birthday to
Chairman, Fiach,
who recently
celebrated a
significant birthday

A Word from Our CEO, Mr. George Kennedy



Welcome to the autumn edition of our **Ability** magazine. We have had a very active few months. Following on from the ongoing work between our staff and members, we have been working diligently on some of the issues continuously arising. One of the topics which has arisen time and time again is the issue of employment and education. We have given presentations, on a number of occasions, to various groups with regard to the work of SBHI. Groups consisted of Partnerships, FÁS, IWA, Enable Ireland, Supported Employment, HSE, County Councils, PWDI.

These presentations were given in Monaghan, Cavan, Kilkenny and Galway. Requests have come from Louth/Meath, Dublin and Kildare and we will do our utmost to facilitate any organisations who may require this information.

We have ongoing contact with the Health Service Executive in different areas of the country and are working in partnership to continue providing high level of services to our members.

The educational forum "A Vision for the Future" was planned, organised and run in May. Key points on this are as follows: Workshop prior to forum attended by 25 European organisations. (More on this in this issue). Prior to the conference, SBHI organised and ran a disability awareness training programme for the hotel staff. We found this to be an invaluable exercise from our point of view and that of the hotel staff in that it benefited all concerned in the running of the conference and the participation in it.

The summer project "SHINE '09" ran during the months of June, July and August, with a large number of youth and adults participating. The Away Week to Calvert Trust catered for a number of adults. A great time was had by all during the entire six weeks. The level of management/supervision was top class and the quality of volunteers was probably the best we have encountered. Well done and a great "thank you" to all the volunteers who generously gave of their time and expertise. We look forward to seeing you all next year. Appreciation to all branches for all the assistance and advice. Without this help this invaluable project would not be possible.

Congratulation to the Kilkenny Branch which was recently set up. This branch will include the Carlow area as well. Best wishes to all the new officers elected to their branches following their AGMs.

The "Sunshine Ball" was organised by the Flood family from Inistioge, Kilkenny. Enjoy viewing the pictures inside.

There are a number of events coming up in the near future – see inside for further details.

We are looking forward to hosting the 2010 World Congress in Dublin. This will be held in conjunction with the International Federation (IF) and will be a very momentous occasion for us as an organisation. We have a website www.ifsbhireland2010.com which you can visit for further information.

Finally, on behalf of myself, the staff and the Officer Board, I would like to extend my sympathies to the families of Donal Allison (who was a huge addition to the staff here in Clondalkin) and Chloe Kearney. Donal and Chloe will be greatly missed by us all.

Fois siorraidh dha Chloe agus Donal.

– **George Kennedy, CEO,**
Spina Bifida Hydrocephalus Ireland

The Sunshine Charity Ball

The Sunshine Charity Ball was launched by our patron Packie Bonner and Aoife Flood on 1st May 2009 (see photo on front cover).



Team Sunshine: Michelle Flood, Christine Keohane, Trish Lee, Naomi Hunt

Christine Keohane, Trish Lee, Naomi Hunt – Team Sunshine. The success of the ball exceeded all expectations in terms of the monies raised and the sheer enjoyment of the occasion. This was due to the tireless effort of Michelle Flood and Team Sunshine.

The ball raised a whopping €19,000 and there is more money still coming in. ■

The Ball itself took place on Saturday 6th June and was a huge success. The event, which included entertainment from the Camembert Quartet, was held at the Kilashee House Hotel. Everyone who attended had a fantastic night.

The evening was organised by a group of friends, Michelle Flood,



Message from the Forum...

My Name is Andrea Fox, and I am a member of the Youth Forum. Since I joined the association and got involved in the Youth Forum, I have had a lot of fun. It is a great way for me to get out and meet others who have a similar or the same disability as me - Hydrocephalus.

At first I was very nervous meeting up for the first Forum meeting but

everyone made me feel very welcome. Since then it has helped me so much to move out of my comfort zone of staying in all the time.

Events take place throughout the year such as bowling, cinema, and meals etc. I have made a lot of friends from attending these meetings. It also gives members a

chance to make their suggestions as to things that they would like to take place in relation to social events.

I would certainly encourage members to join. It is a forum where everyone is equal and there is nobody to judge you on anything you do or say. For details of future events you can contact me on andreadf28@gmail.com ■



My Life Story

Bernadette Flood

I am going to write about my life from the beginning to where I am now, I hope you all enjoy reading it.

My name is Bernadette Flood and I live in Co. Wexford. I am now 22 years old. I was born on the 27th November 1986. I was born with a condition called Spina Bifida and Hydrocephalus. The first few years of my life I spent a lot of time in hospital having to have loads of different operations due to my disability. I have had 22 operations. My mother stayed in hospital with me every time I was in.

At the age of four years I started in playschool in Gorey. At the age of five years I started primary school in Boolavogue. I wore callipers to help me walk and used my hand-propelled trike to get around the school playground quicker to keep up with my friends. I had many falls off it, but it didn't stop me for long – I just got back up and went off again flying!

For my Communion I walked up the isle with my class mates and I had a great day. A couple of years later my scoliosis got worse so I was unable to continue to wear the callipers and ended up in a wheelchair full time.

When I finished in national school I started secondary school in Enniscorthy Vocational College, where I spent five years. I got a good result in my Junior Cert and Leaving Cert.

During my school years in secondary school I started getting very bad headaches that I couldn't get rid of. I had to take loads of tablets. The shunts were not blocked, thank God for that, but the doctors didn't know what the headaches were from. I was fed up with getting them. Someone said to my mother about acupuncture. I said I would try anything to get rid of the pain. I got the acupuncture done. The lady came to my house each time and after a couple of sessions I had got rid of my headaches.

When I had finished secondary school, Colette Darcy was the Family Support Worker at the time. She told me about a course that she was going to be starting up in the Enniscorthy Enterprise Centre with Robbie and John for people that had different kinds of disabilities. The name of the course was Data Processing Project and it was connected with W.I.T. College in Waterford. I really enjoyed the course. I graduated in June in Ferrycarrig Hotel and received a Fetac Cert, and in November I graduated in W.I.T. with a Hetac Cert.

A few weeks after the course finished I got an interview with a company in Enniscorthy called Chevron Training, and I got the job. I started the following week. I am nearly two years working there now and I am really enjoying it. Everyone is really kind and helpful to me and I am really thankful to them for this.

During the year on the course I started getting driving lessons with a driving instructor called John Murphy. I had one lesson a week. I had the lessons for about a year. In March of last year I had my driving test in Gorey and I passed it. I was delighted with myself – a big thank you to John for helping me to drive and passing my test. In June of last year I bought myself a car, a Ford Focus 3 door, and I am delighted with it. I have my own freedom. I get in to my car and go off for a drive any time I want to. I had to get a new wheelchair due to the last chair being too heavy to lift into the car. Now with the new wheelchair I am able to lift it in over me and leave it on the passengers seat beside me.



Me and my driving instructor John Murphy in my new ford focus.

I am hoping everyone who reads this story enjoys it and, for those with this condition of Spina Bifida & Hydrocephalus, it is still possible to enjoy your life. ■

CHLOE

A SPECIAL POEM FROM BERNADETTE

*Each and every day you were the first person on my mind
You were the light of my eyes
A precious little angel in disguise
Your kisses and smiles I always will remember
Your beautiful strength will live on forever.*

*I will never forget your face in the pool in Courtown
A smile like yours from a swimmer never seen before
You were there to see me nearly drown
But now I know you will be there to keep me safe forever.*

*There were three helpers in the pool with us
And when you and your Mam stepped in to the water
It was plain to see, how much you were loved and adored
Each of us hanging on for dear life
As you were doted upon and rightly soaked it all up.*

*With Santa and Mrs Clause coming to our Christmas party each year
Your smile became brighter and wider to see
When you took to the floor with St Nick
We couldn't count the amount of kisses you blew at him so quick.*

*Last year in Cork at our AGM
You sat up smiling till the early hours watching us drink
But I do reckon now Chloe you had the last laugh
When we all woke up with sore heads like a bag of cats.*

*A special treat we did have
In the RDS a family day out
And throughout the day you did smile
As we watched all the glorious horses go by.*

*Now you are up in heaven smiling down
An angel as beautiful as anyone has ever seen
And I can see you now looking down on us
And saying Bernadette you are beautiful in Pink.*

*All week in the hospital you knew how much you were loved
With your Mam and your Dad and brothers and sisters all there by your side
And when you alone decided it was time to go
A cuddle from your Dad and a flash of the lights
And you my little angel were gone to God above.*

*I will never forget the kiss you blew at me Tuesday night
One that will live in my memory forever to come
Now Chloe my friend have fun dancing on the clouds above
And I will be here to catch all your kisses as they fall from the skies above.*

REST IN PEACE CHLOE



Normal puberty

The way puberty works is quite complicated. The time the process begins in any child depends upon many factors. Some of these are hormonal, some are genetic and others are environmental. The whole process works a little like a chain reaction. Two bodies within the brain, the hypothalamus and pituitary gland, coordinate it.

As we know puberty brings a number of different changes to the body. In boys, the change begins with sexual development and is followed by the development of pubic hair, acne, increased growth, increased strength, deepening voice and skeletal maturation.

In girls the changes begin with breast development and finish with menstruation. Along the way there is increased growth, skeletal maturation, body shape changes and uterine development.

Puberty usually extends for about two years for both boys and girls.

Precocious puberty

Currently the onset of puberty is not considered premature unless it occurs before the age of 8 in girls and 9 in boys. However, it does depend on a number of factors like a person's race, for instance. Afro-Caribbean children tend to reach puberty earlier than Caucasian children.

Diet and nutrition also affect the timing of puberty. Girls today reach puberty 2-3 years earlier than they did 100 years ago. This is thought to be largely due to better nutrition today.

Precocious puberty is when the right things happen in the right sequence but at the wrong time. Sometimes things can happen in the wrong order or sometimes puberty may begin and then stop. These are not considered to be precocious puberty.

What causes it

Why people with Spina Bifida are more likely to go through precocious puberty is not certain. It is thought that the alteration to the brain anatomy associated with Hydrocephalus somehow affects the pituitary gland. Other children with central nervous

Puberty & Spina Bifida

system disorders, brain tumours, meningitis and trauma are also more likely to have an early onset of puberty.

What problems are there?

There are a number of problems likely to follow from or be associated with precocious puberty.

1. Before puberty a child usually grows at a steady rate, adding about 5-8cm per year to his or her height. Upon reaching puberty, the child undergoes a growth spurt. During this time, he or she grows about 10-15cm per year. While the sex hormones accelerate growth, they also speed up the process that ends growth. Children who start puberty prematurely are tall for their age, but since their skeleton matures and growth stops at an earlier age than normal, they never reach their full height potential as adults. There are other factors involved with Spina Bifida which contribute to short stature, but adults with Spina Bifida, on average, are about 30 cm shorter than the average person without Spina Bifida.
2. Behaviour may change to that typical of an adolescent. Some girls who start puberty prematurely go through periods of moodiness and irritability, much like teenage girls. Some boys become more aggressive than their peers and develop a sex drive. On top of the self-consciousness and lower self-image involved with being a person with a disability, being physically more mature than other children the same age is another issue to be self-conscious about.
3. Teasing from other children about sexual development can also be a problem. Such teasing is especially common for girls who develop

breasts. Parents can help by acknowledging that the teasing is upsetting and by helping children find a way to deal with it.

4. Children with Spina Bifida often feel isolated and rejected socially. This is particularly true when, because of their learning disabilities, they have not been able to learn social skills appropriate to their age. Having another set of problems which leads to age-inappropriate behaviour adds to the problem.

Diagnosis

A number of medical investigations can be undertaken to assess what is happening in the child's body.

- Blood tests can be done to look for elevated levels of sex hormones and pituitary hormones.
- An X-ray of the hand can be performed to see how advanced the bone age is.
- In girls an ultrasound can detect enlargement of the uterus.
- The child's rate of growth can be measured.

Treatment options

1. The first option is to treat with a drug such as Medroxy-progesterone. This drug has been used to suppress activation of the pubertal process. However, it is not fully effective in inhibiting bone maturation or in improving adult height. It can also have side-effects such as weight gain, moodiness and depression.
2. The second option is to treat with LHRH, another name for GnRH. Higher levels of this hormone in the body switch off the pituitary gland. No side-effects for this treatment have been noted, but it is very expensive.



3. The third option is to do nothing. The side-effects of this may be the problems noted above, however these may not affect everyone to the same degree. The decision to treat or not to treat has to be arrived at with all of the information and must be made by the doctor and parents based on the diagnosis, prognosis and any other associated factors.

To be effective, treatment (if it is to given) must begin early in puberty. For instance, it would be too late to treat a girl who has begun menstruation. Because menstruation occurs at the end of puberty, the changes that would be deferred by earlier treatment would already have taken place.

Summary

Children with Spina Bifida and Hydrocephalus are likely to have an increased incidence of precociousness or early puberty. Investigations carried out by a paediatric endocrinologist are aimed at confirming the diagnosis and giving an estimate on prognosis in terms of the pace of future development and final height.

One extra problem with precocious puberty for children with Spina Bifida is that the early rapid growth can increase the likelihood of tethering of the spinal cord.

What triggers puberty?

The hypothalamus releases a hormone (gonadotropin-releasing hormone GnRH) which in turn prompts the pituitary gland to secrete a set of hormones itself. These are called gonadotropins. The two main ones are luteinising hormone (LH) and follicle stimulating hormone (FSH).

In turn the gonadotropins induce the development of the ovaries and testes, which then release the gonadal steroids. These are the ones that most people have probably heard about.

Testosterone is secreted from the testes in males and oestrogen and progesterone are secreted from the ovaries in females.

The whole process is regulated a bit like a thermostat in the refrigerator. When the fridge gets too hot, it turns the motor on and when it gets too cold, it turns it off.

The brain senses the level of steroids in the blood and, when they get too high, it decreases the production of GnRH which decreases the LH and FSH which then signals the gonads to slow the production of steroids.

When the level drops, the opposite happens. GnRH production is increased; LH and FSH increase and the gonads produce more steroids.

As children, the hypothalamus is very sensitive to the level of gonadal steroids in the blood, and not much is produced. But when we reach puberty, the hypothalamus becomes less sensitive and so the levels rise. It is as if the

thermostat in the fridge has been turned up.

The exact cause of this change is not completely understood, but it is known that genetic and environmental factors are involved.

In girls another important change occurs. The hypothalamus matures so that there is a positive feedback system instead of a negative feedback one. That is, an increased level of oestrogen in the blood leads to an increase in LH and FSH which leads to a greater level of oestrogen and so on. It is this surge in LH and FSH which triggers the female's first ovulation. From then on, gonadotropins are released in monthly surges, which regulate the cyclical timing of ovulation and the menstrual cycle. ■

We would like to thank Spina Bifida Hydrocephalus, Australia, for this article.

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Sally Hibbs:	shibbs@sbhi.ie Mayo/Leitrim/Roscommon/Galway
Clare Riordan:	criordan@sbhi.ie Kildare/North Dublin

Or contact the office on 01 457 2329

Useful Information

Check out the following websites for information on specially adapted clothing:

www.silverts.com www.able2wear.co.uk
www.adaptawear.co.uk

More about this in future issues.

The Trip of a Lifetime Down Under

Sharon Foley



My holiday to Australia started on Friday the first of August 2008. I set out with my mom and sister from Castlebridge, Co. Wexford, at 4.30am. We arrived in Melbourne on Saturday the 2nd. It was a long trip bearing in mind Australia is nine hours ahead of us here in Ireland. Forgetting the exhaustion and jet-lag and overcome with excitement I was ready for Australia.

We spent four nights in Melbourne and I have to say it was the highlight of my trip. A good friend of mine "Elissa" met us. I met Elissa in 2002 when she spent some time in Ireland and we have remained friends ever since. We have always managed to keep in touch throughout the years. My family and I received a very warm Australian welcome from Elissa and her family. She showed us around Melbourne. We went to Ramsay St, where they film 'Neighbours'. Elissa took us on a tram around Melbourne. It was wheelchair accessible. We also spent some time shopping and ate a fabulous meal in Southbank.

From Melbourne we flew to Brisbane. Here we visited a 'Seaworld' and got to sample what types of fish live in the shores of Australia. We also went to an Australian outback centre. Steve Irwin's family has a zoo in his honour in Brisbane. It was the first time I ever got to hold a crocodile and yes I still managed to keep a smile on my face.

From Brisbane we flew up to Cairns. The heat hit my face as soon as we got off the plane. It was lovely. I remember the beautiful esplanade that was very wheelchair accessible. While in Cairns we took a few day trips. The hotel was very accommodating. We were able to book a wheelchair accessible bus to bring us from our hotel to where the tour began. We took a trip to Green Island. This package included our lunch and there was a coffee shop/restaurant on site. We were able to get a glimpse of the magical world of the Great Barrier Reef.



While in Cairns we took a day trip to Kuranda – a beautiful village up in the rainforest.

We got to see some magnificent waterfalls. From Kuranda we took a sky rail trip over the rainforest. It was out of this world and very entertaining to see Pam Foley (my mom) scared out of her skin. We survived the sky rail trip and finished our day with a visit to the Tjapukai Aboriginal Cultural Park. I really enjoyed trying out the boomerang. Later we got a sample here of the aboriginal way of life. This included a buffet BBQ.

From Cairns we flew back down to Sydney. We found it much cooler in Sydney.

What a city! I would highly recommend it. The beautiful Opera House and the Harbour Bridge. We enjoyed a cruise around Sydney harbour. We had wished to take a cruise where you could enjoy a meal on board however the only accessible boat they had didn't offer this.

Sydney Tower was like a magical experience. Here we got to have lunch at the top floor of the tower. The restaurant revolves very slowly. You would hardly even notice only that the scenes change. It's a fantastic opportunity to see the city by night with all the lights.

We enjoyed some shopping in Sydney and managed to catch up with a neighbour from home. A great spot to meet plenty of Irish. We finished our amazing trip with a spectacular show "Phantom of the Opera". It was a night to remember.

As holidays go I had the holiday of a lifetime. I would highly recommend Australia. In August, when we travelled, there was a state in Australia that had weather to suit all. We found the Australians to be beautiful, friendly and very laid back. Because they speak English there is no language barrier



making things easier. They have a great variety of food to suit all needs. My favourite was their ice cream. I have to admit I didn't care for the chocolate over there.

We flew from Dublin - London - Hong Kong - Melbourne. Returning via Sydney - Singapore - London - Dublin.

I would recommend Australia as a holiday destination and I'd go back there in the morning.



Tips for anyone travelling to Australia:

Ring the airport two to three days beforehand to let them know you are a wheelchair user.

I found Melbourne airport to be excellent as regards wheelchair support, however Sydney airport was poor. Again I would ring the airport in advance.

Sharon is pictured here with her mum and sister. ■

Irish Dogs for the Disabled



tance puppies in training visit people in long-term residential care, special needs facilities and hospitals.

Irish Dogs for the Disabled is a pioneering charity that trains specially selected dogs to carry out a range of practical tasks to assist disabled children and adults in order to achieve greater independence. We are a young charity – 2008 saw the first of our dogs entering into their partnerships and with over thirty dogs in training our future looks bright.



Our mission at Irish Dogs for the Disabled is to assist people with disabilities to enjoy a greater independence and a better quality of life and, where possible, to help them into education and employment, through the provision of specially trained Assistance Dogs.

We aim to improve the quality of life for individuals with special needs whilst at the same time promoting independence and providing social interaction for people in long-term residential care.

Our aim is to train dogs to the required standard set by the Assistance Dogs International. All Assistance Dogs are specifically trained to assist people with physical disabilities with their particular needs.

As part of our community visitation and home companion programme our assis-

An Assistance Dog acts as a great ice-breaker enabling our clients to break out of the isolation often experienced



IRISH DOGS FOR THE DISABLED

through disability. Every dog is trained to help with simple everyday tasks such as opening doors, picking up the morning post, emptying the washing machine, even retrieving dropped items such as a TV remote, keys or a wallet.

Many of our partnerships now feel confident enough to take on new activities and become active members of their community. For one disabled adult it may simply mean being able to do a weekly shop, for another the ability to return to work or to allow a disabled mother to look after her children. A disabled child can ask his dog to carry a bag home from school.

Every Assistance Dog trained by the charity offers practical help to the people we support. Our work with physically disabled adults opens doors to independence, giving a new sense of confidence and freedom, often long forgotten. Children too are benefiting from Assistance Dogs giving a new sense of purpose and hope for the future.

For further information please check out our website: www.dogsfordisabled.ie ■

SBHI Annua



Left to right: Thelma Cloake, Hon. Sec. SBHI, Cllr. Pat O'Sullivan, Mayor of Ballinasloe, George Kennedy, CEO SBHI, Maureen Cahalan, Sponsor, John Moloney, Minister for Disability, Equality & Mental Health, Fiach McDonagh, Chairman SBHI.



Conference 2009



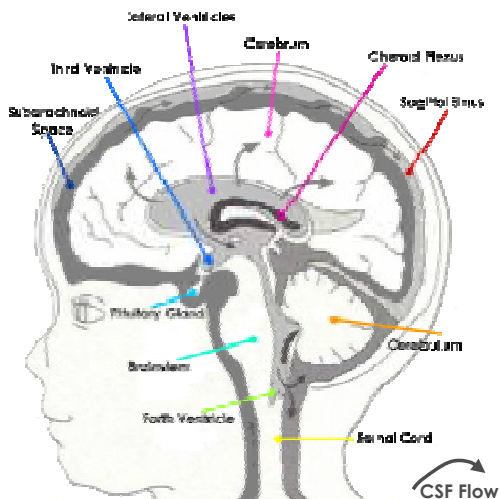
International delegates



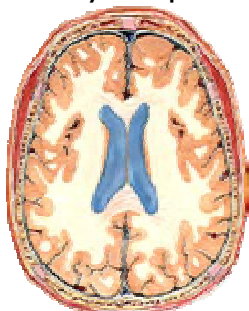
Thomas Webb, M.D., Medical Director of the Paediatric and Adult Spina Bifida Clinics, Cincinnati Children's Hospital Medical Center, who spoke at our conference in Ballinasloe.



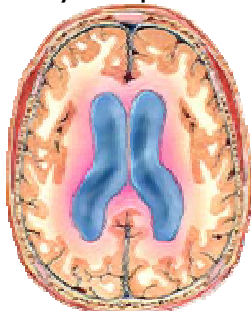
Hydrocephalus Terms



Non-Hydrocephalus



Hydrocephalus



Communicating & Non-Communicating What's the difference?

Within both areas of congenital and acquired, Hydrocephalus can be described as communicating or non-communicating.

Communicating Hydrocephalus occurs when the flow of CSF is blocked after it exits the ventricles. This form is called communicating because the CSF can still flow between the ventricles, which remain open. Hydrocephalus as a result of NTD's, Arnold-Chiari Malformation, Intraventricular Haemorrhage, Meningitis, Head Injury and Prematurity can all be described as communicating forms of Hydrocephalus.

Non-communicating Hydrocephalus - also called "obstructive" Hydrocephalus occurs when the flow of CSF is blocked along one or more of the narrow passages connecting the ventricles. Hydrocephalus as a result of Aqueductal Stenosis, Arachnoid Cysts, Dandy-Walker Syndrome and Brain Tumours can all be described as non-communicating forms of Hydrocephalus.

CSF: Cerebrospinal Fluid is a clear, watery substance produced to cushion the spinal cord and the brain.

Cerebrum: The main part of the brain, in two halves one on each side (left and right hemispheres).

Cerebellum: The smaller part of the brain at the back of the head, involved in muscular coordination.

Ventricles: Connected spaces inside the brain, where CSF is produced. There are two lateral ventricles (one each side), a third ventricle and a fourth ventricle. CSF flows from here over the outside of the brain before being absorbed back into the bloodstream.

Choroid plexus: The organ that makes CSF.

Sagittal Sinus: The major vein that runs over the centre of the top of the brain and collects CSF, draining it back into the central bloodstream.

Pituitary Gland: A gland situated in the brain cavity but just behind the face. It is very important in secreting a large number of hormones that regulate body function and development. An example is growth hormone, and others are involved in sexual development.

Brainstem: A very important area connecting the spinal cord to the brain. It controls breathing and other vital functions.

Spinal Cord: A complex trunk of nerves transmitting impulses to all parts of the body, allowing muscle movement, sensation and reflexes.

Subarachnoid Space: The subarachnoid space is the compartment within the spinal column and the brain which contains the cerebrospinal fluid (CSF).

Hydrocephalus Strategies



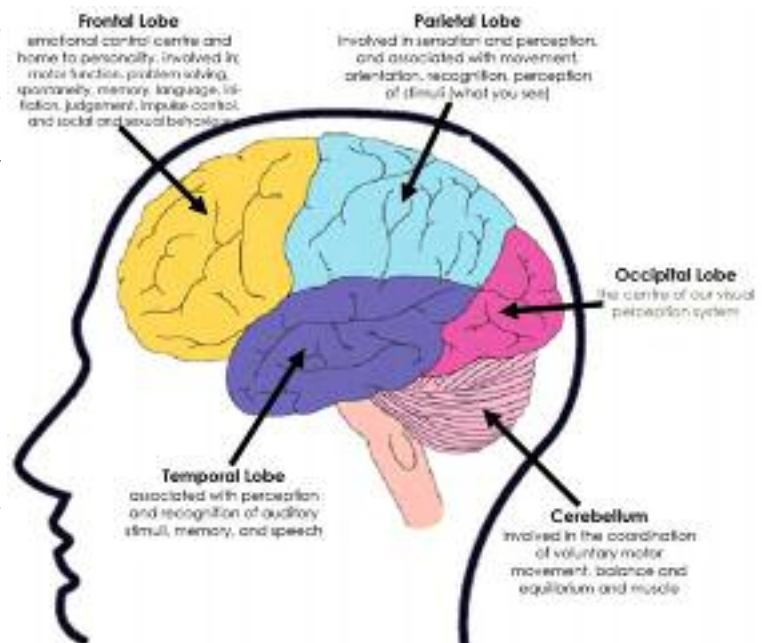
Strategies for Concentration and Memory

Strategies to Improve Information Processing

- Pacing – Ask people to slow down when giving instructions or during conversation or ask them to write it down
- Timing - Develop awareness of the best times to complete more complex activities
- Write lists or notes
- Check and re-check your work
- Use paper to break up information on a page so as to avoid overloading
- Use index cards to summarise information
- Underline key words or phrases in instructions
- Work in periods of 20-30 minutes with short breaks in between

Strategies to Improve Attention

- Minimise distraction
- Time management – plan a programme of activities ahead of time.
- Where possible put allow preparation time before making a transition to a different activity or place
- Pacing – distribute the activity over a period of time, including frequent breaks
- Rehearsal – Repeat what someone has said in your own words ie 'let me repeat this to you to see if I have it'
- Use cues and prompts – cue the person that what you are saying is important, colour code timetables
- Write down anything you feel might confuse you or you might forget
- Chunking – break complicated tasks into smaller, carefully arranged steps
- Finish one activity before starting another
- Sequencing – sequence tasks from simplest to most complex



Strategies for Improving Insight

- Ask for feedback from friends and family
- Attend activities/groups where you can meet others with similar difficulties – learn from them
- Read books, leaflets and other information about Hydrocephalus
- Watch yourself on video
- Make mistakes and fail, but learn from those mistakes and failures
- Ask to be sent medical letters and reports
- A neuropsychological assessment can be helpful in highlighting strengths and difficulties and in tailoring appropriate rehabilitation interventions

SBHI – Proud Hosts of International Federation (IF) Workshop

Spina Bifida Hydrocephalus Ireland was delighted to be the host of the International Federation Workshop which was held in conjunction with our Annual Conference in the Shearwater Hotel, Ballinasloe, recently.

The Workshop was attended by representatives of the following countries:

Spain • UK • Norway • Turkey
Romania • Slovakia • Belgium
The Netherlands • Sweden
Czech Republic • Estonia
Serbia • Portugal • Ireland

The aims of the workshop were:

- To discuss how to move forward with the national organisation and how to find new ways to run the organisation
- Building an international/ EU voice – looking for international co-operation
- To share activities and experiences
- How to include people with Spina Bifida & Hydrocephalus in the organisation
- To receive feedback on their own organisation
- To meet colleagues
- Learn to know each other
- Creating a common discourse

The Workshop was facilitated by Pierre Mertens (President) and Lieven Bauwens (Brussels Office). During the discussions a number of areas were covered including working with volunteers, adult participation within the organisation, financial stability, how to attract new and young parents, creating a European discourse and volunteers working with paid staff.


Each representative participated fully in the discussion and the facilitators allowed a full and frank discussion on each relevant subject.

The workshop was a very successful and worthwhile exercise and as a result the Workshop for 2010 is going to be held in Ireland again prior to our World Congress in June.

If you require a full report of the findings of the workshop please contact our IF

representative, Thelma Cloake on 087 288 3279 or email: thelma.cloake@gmail.com

This Workshop was able to take place thanks to the financial support of the European Commission's programme "Progress". ■






**Spina Bifida
Hydrocephalus
Ireland**

**Positive Life Choices
presents a**

Hydrocephalus Study Day

A unique opportunity for individuals, families, carers and professionals to learn about and share information on this complex condition.

**October 9th 2009 – Beaumont Hospital
Carmichael Lecture Hall – 9.30am to 5.30pm**

Speakers include:

Mr M Taufiq-A-Sattar -
Consultant Neurosurgeon

Dr. Trudi Edginton -
Neuropsychologist

Marie McGonnell -
Nurse Advisor ASBAH

Katherine McCurry -
Education Advisor ASBAH

Andrea Fox -
Spina Bifida Hydrocephalus Ireland

To order a booking form and to book your place, please contact
Sarah Jacobsen
Event & Fundraising Manager
01 457 2329 or sjacobsen@sbhi.ie

*The seminar is brought to you by the
National Resource Centre, Old Navan Road, Donnellree, Dublin 22
T01 457 2329 Email: info@sbhi.ie Web: www.sbhi.ie*

My Story

Anna Shinnors



My name is Anna Shinnors and I have recently completed a B.A. in Applied Social Studies (Social Care) in the Institute of Technology Blanchardstown (ITB). I thoroughly enjoyed this experience and would recommend the course and ITB to anyone thinking about going to college.

I sat my Leaving Certificate in June 2005. During this year I visited many colleges with my parents to see which ones would be both suitable and accessible for me. There were some PLC and Diploma courses on offer in the area of social care. I applied for these as I did not think I would get enough points in the Leaving Cert to get straight into the college course I wanted. I intended using these as stepping stones for the degree. I also investigated NUI Maynooth and ITB as these colleges were close to home and offering courses in Social Studies/Care. Social Studies in Maynooth was my first choice on my CAO and ITB was my second choice.

When I visited ITB and went around the campus I instantly had a feeling I would love it there. A really nice lady introduced herself to us. She was very encouraging. Later I found out she was head of the Department of Humanities. She talked me through the course and the workload involved. I also met with one of the lecturers and she explained about the various modules in the course and the assessment structure. I discussed my concerns with her around what would happen if I became sick during one of my years at ITB. She assured me that we would deal with this if the need arose. She said that I could take the modules individually, if necessary, and take as many years to do the course as I needed. This put my mind at rest.

When I got the CAO offers I was delighted to have been offered a place in ITB. I was a bit disappointed at the time that I did not get my first choice in Maynooth, in retrospect ITB and the

Social Care course was perfect for me as the campus in Blanchardstown was modern and accessible while Maynooth was a more sprawling campus which would have been very difficult for me to get around.

I was very nervous on my first day but very quickly settled into college life. I was approached straight away by the student services officer and she asked me what help I might need to make my time at ITB easier. As my parents were driving me to and from college every day we felt a practical help would be the provision of a taxi to and from college, even for one or two days a week. However, the student services officer managed to organise funding for every trip to and from college for the remainder of the four years of the course. This was a huge help to myself and my parents. I had the same taxi driver bring me to and from college every day and he was very reliable and obliging. The college was completely accessible to me and I was given a key which worked on all the lifts in every building of the campus. The staff and students were also very helpful to me if I needed anything; they were willing but not intrusive.

As part of the course I had to do two placements, one in second year and one in third, each for a duration of three months. These placements were usually organised for the students by our year tutor but I was allowed to find my own. This meant I was able to pick one that matched my ability accurately. I thoroughly enjoyed both of these placements and felt this experience boosted my confidence about my abilities to work in this field.

Each module was assessed in two ways, by exam and by continuous assessment which was usually in the form of an essay and tutorial contribution. I was always very nervous about doing the exams but the lecturers were very good for having us well prepared for these. They provided revision weeks and extra

individual help on problem areas as requested. The student services officer also offered me any support I felt I might need, including the use of a scribe, a tape-recorder etc. I did not actually avail of these aids but it was great to know they were available every year if necessary. If I needed to use the bathroom during the exam I would be allowed an extra fifteen minutes for every hour of the exam.

All in all my college experience has been one of the best experiences of my life and I thoroughly enjoyed my time in ITB. I could not say enough about how good everyone was to me. I would highly recommend anyone with a disability to give college a go. Before I started I never imagined that I would get through it so easily but with the appropriate supports in place it can most definitely be achieved. I am now looking forward to my future where I will hopefully work in the social care field.

Most third-level institutions have Disability Liaison Officers. The Disability Liaison Officer may provide a number of services including assistance with applying for a reserved place, finding suitable accommodation and arranging any special access requirements and provisions for sitting exams. Some institutions reserve a number of student accommodation places for students with disabilities.

Students with disabilities are eligible for third-level grants on the same basis as other students. There are some grants specifically for people with disabilities. A special fund to help third-level students with disabilities is administered by the Department of Education and Science. You should apply directly to the third level institution at the beginning of the academic year. ■

Back to Education Allowance

INFORMATION

If you are unemployed, getting a One-Parent Family Payment or have a disability, you may be able to pursue approved second- or third-level education courses through the Back to Education Allowance scheme.

Participants in the scheme get a standard rate of payment that is not means-tested. Any local authority maintenance grant you may get will not affect your payment.

The allowance is payable for the duration of the course. If you were previously getting an unemployment or jobseeker's payment, you will not get the Back to Education Allowance (BTEA) during the summer period between academic years. If you are unable to secure employment during the summer months, you may be able to apply for Jobseeker's Benefits or Jobseeker's Allowance. However, you may continue to get BTEA if you are on work placement or experience that is an essential part of your course.

Changes to the Back to Education Allowance scheme

In the Supplementary Budget April 2009 it was announced that the Back to Education Allowance (BTEA) will be changed to allow earlier access to the scheme.

From 1 May 2009, to qualify for the second level option, the length of time you must be getting a qualifying social welfare payment will be reduced from 6 months to 3 months. You must also be a jobseeker and out of the formal education system for at least 2 years.

From 1 May 2009, to qualify for the third level option, the length of time you must be getting a qualifying social welfare payment will be reduced from 12 months to 9 months in line with National Employment Action Plan when recommended by a Facilitator from the Department of Social and Family Affairs (DSFA).

Cost of Education Allowance

In addition to your weekly payment, you will also be entitled to an annual Cost of

Education Allowance, which is payable at the start of each academic year. The amount of the allowance is €500. In September 2008, the Cost of Education Allowance was extended to people signing on for unemployment credits.

Retention of secondary benefits

If you qualify for the Back to Education Allowance, you will keep an entitlement to any secondary benefits you already have, for example, Christmas Bonus, Fuel Allowance, or Rent Supplement and Mortgage Interest Supplement under the Supplementary Allowance Scheme. However, any increase in income will be assessed and may affect your entitlement to Rent Supplement or Mortgage Interest Supplement or the amount of supplement you get. For example, if you changed from a reduced social welfare payment to the standard BTEA rate.

Spouse/partner can qualify for BTEA

You may qualify for BTEA if you are not getting a social welfare payment but your spouse/partner is getting an Increase for a Qualified Adult in their social welfare payment for you.

To qualify your spouse/partner **must** have an entitlement to BTEA and be getting an Increase for a Qualified Adult in his/her social welfare payment for you as an adult dependant. You must be a Qualified Adult (6 months for Second Level Option or 9/12 months for Third Level Option, see 'Rules' below), of a person who would qualify for the BTEA scheme.

If you qualify for BTEA because you are an adult dependant, you will get the same social welfare payment as your spouse/partner but at the maximum standard personal rate. Your spouse/partner will keep his/her entitlement to his/her personal rate of payment. You will also qualify for the annual Cost of Education Allowance.

If you get the Back to Education Allowance your spouse/partner can still keep his/her entitlement to the allowance.

RULES

To qualify for the Back to Education Allowance, you must be at least 21 years of age (24 years of age for a third-level postgraduate course).

If you wish to attend a second level course you must be getting one of the social welfare payments listed below for at least 6 months **immediately** before you start the course (3 months if you are a jobseeker and out of the formal education system for at least 2 years).

If you wish to attend a third level course you must be getting one of the social welfare payments listed below for 12 months **immediately** before you start the course (9 months if you are assessed and approved by FÁS under the National Employment Action Plan or a Facilitator from DSFA).

Qualifying social welfare payments are:

- Jobseeker's Allowance or Jobseeker's Benefit
- Farm Assist
- One-Parent Family Payment
- Deserted Wife's Benefit/Allowance
- Widow/Widower's (Contributory) Pension
- Widow/Widower's (Non-Contributory) Pension
- Prisoners Wife's Allowance
- Carer's Allowance (after your caring responsibilities have finished)

If you are getting **Illness Benefit** for 2 years or more you can also also qualify for the Allowance.

Time spent on BTEA, VTOS, FÁS training courses, Fáilte Ireland training course, Community Employment schemes, FIT, Rural Social Scheme, Back to Work Allowance, FÁS Job Initiative, Job Assist, Supplementary Welfare Allowance, in prison or in Direct Provision can count towards the qualifying period. You may go directly from one of the above schemes to Back to Education Allowance provided you were getting one of the qualifying social welfare payments listed above before you started the scheme. You must start your approved course of study within four

weeks of leaving the scheme. Otherwise you must be getting a qualifying social welfare payment immediately before starting an approved course of study.

If you are awarded statutory redundancy and entitled to one of the qualifying social welfare payments you may get the Back to Education Allowance.

If you qualify for credited contributions, these will continue to be awarded while you are taking part in the Back to Education Allowance scheme. If you are signing for unemployment credits only, you may qualify to participate in the scheme but you will not get a Back to Education Allowance. However, you will get the Cost of Education Allowance which is a once-off payment.

Exceptions to the age limit

To qualify for the Back to Education Allowance, you must be at least 21 years of age (24 years of age for a third-level postgraduate course).

However, if you are getting **Jobseeker's Allowance, Jobseeker's Benefit or One-Parent Family Payment** for the required period of time and aged between 18 and 20 and you have been out of the formal education system for at least 2 years you may qualify for Back to Education Allowance.

If you are **aged 18 or over** and getting **Blind Pension, Disability Allowance, Invalidity Pension or Incapacity Supplement** for the required period of time you may qualify for the Allowance. The allowance has also been extended to people with disabilities who have left Community Employment schemes and who, when beginning the scheme, were not receiving a qualifying social welfare payment. They must begin the course within 4 weeks of finishing the scheme.

Study options

There are two study options available under the scheme:

- Second-level option
- Third-level option.

Second-level option

You can attend a second-level course of education at any secondary, community, comprehensive or vocational school. The course must be full-time and to a certificate recognised by the

Department of Education and Science or approved by the Further Education and Training Awards Council, e.g., Junior Certificate, Leaving Certificate, Post Leaving Certificate or a City and Guilds Certificate.

Third-level option

You can attend a third-level course of education at any university, third-level college or institution, provided that the course is a full-time day course of study and is approved by the Department of Education and Science for Higher Education Grant purposes, VEC Scholarship Scheme or the Third Level Maintenance Grant Scheme for Trainees or has Higher Education and Training Awards Council recognition.

If you already have an undergraduate third-level qualification, (i.e., you already have a degree) your application for a Back to Education Allowance while pursuing post-graduate education will only be considered if you are doing certain courses. There have been much changes in this area in the past few months. You should get in touch directly with the Back to Education Allowance Section at the Department of Social and Family Affairs to check the current position. As with other education courses, your Back to Education Allowance is not payable during the summer months. You may however be eligible for Jobseeker's Allowance or Jobseeker's Benefit.

Monitoring arrangements

You must provide a certificate from the school/college in question confirming your registration, commencement and attendance at the course. You will be requested to supply this information before payment can begin. During the course of the academic year, you may be asked to provide confirmation that you are still taking part in the course.

If you are currently getting an unemployment payment and qualify for participation in the scheme, you will no longer be required to sign on at your local social welfare office.

RATES

Back to Education Allowance is paid at a standard rate, so if you are currently getting a reduced rate of payment, you

will be entitled to the maximum standard rate of payment. If you are already getting the maximum rate, you will continue to do so.

If you are getting an unemployment payment, you will be paid a Back to Education Allowance equivalent to the maximum standard rate of Jobseeker's Benefit or Jobseeker's Allowance. It will include any increases for a qualified adult and qualified children.

Back to Education Allowance is payable in the same way as your current social welfare payment.

HOW TO APPLY

Contact your local second- or third-level school or college to get details of the courses available. Schools or colleges will also advise you on how to obtain a place on the course of your choice.

When you are accepted on a course, you should notify the Department of Social and Family Affairs by downloading and completing the Back to Education Allowance application form (pdf), which is also available from your Social Welfare Local Office.

If you are getting an unemployment payment, you should return your application form to your Social Welfare Local Office.

If you are getting One-Parent Family Payment, Deserted Wife's Benefit/Allowance, Widow's/Widower's Pension, Prisoners Wife's Allowance or Blind Pension, return your completed form to the relevant section in the Pension Services Office, Department of Social and Family Affairs, College Road, Sligo.

If you are getting Disability Allowance, Invalidity Pension, Incapacity Supplement or Carer's Allowance you should return your completed form to the relevant section in the Social Welfare Services Office, Ballinalee Road, Longford.

If you are getting Illness Benefit (for 2 or more years), your completed form should be returned to the Back to Education Programme office.

For further information please log on to www.citizensinformation.ie ■



Wexford Branch

Adults get-together in Enniscorthy Co. Wexford.

Adult members meet the first Thursday of each month in the Riverside Park Hotel, Enniscorthy, 5pm-7pm. All are welcome for a casual bite to eat and chat. For further information or if you would like to attend please contact Family Support Worker for the South East, Doreen Costello, on 087 6527175 if you wish to attend. *Pictured are some of the Wexford Branch enjoying their recent get-together.*



Nicky Lacey, Teresa Ryan and Charlene Kelly, Wexford.



Happy 30th birthday to Teresa Ryan who celebrated her birthday with friends at the Wexford branch get-together recently. Congratulations Teresa!!!



Shane McDonagh who celebrated passing his driving test first time around, seen here with Colin Byrne, at Wexford branch get-together. Well done Shane!!!!



Judy Brown also enjoying the Wexford Branch get-together.

Around the Branches...

The branches around the country have been extremely active during the summer months. They had members participating in the Summer Project, Away Weeks and the Family Weekends and the Sports Day held recently in Navan.

A number of branches are running swimming lessons, bowling outings and various social events which are being very well supported by the members but we would love to see more new faces.

The **Mayo/Leitrim/Roscommon** branch held a very successful Mini Camp which ran over 2 weeks.

Congratulations to the **Wicklow** branch who have just purchased a new mobile home which is situated in Bettystown. It is hoped to have this up and running very soon.

Louth Meath had a very enjoyable trip to the Dogs in Dundalk along with putting in a new "safe play" area on their mobile site.

Wexford branch also had a successful summer in their mobile with a large number of families availing of it. They are also continuing their swimming lessons in the Ashtown Park Hotel.

Well done to all the member who did their exams.

The branches would like to thank all their volunteers for their continued support.

If you would like to know more about any of the activities in your area please contact your FSW or a branch member.

A huge welcome back to the **Kilkenny** branch who are in the early stages of finding their feet. They are a very enthusiastic bunch who are keen to get involved and are looking forward to the challenges and rewards ahead.

Congratulations to Shirley Keogh from the **Kildare** branch who has been nominated for the Kildare Person of the Year Awards. Well done to all from the Kildare Branch who returned home from the sports in Cork with a large number of medals. Find out more in the next edition.

Dublin Branch

Congratulations to the new Dublin Branch committee who were elected at the recent Dublin Branch AGM.

The following are the new officer board:

- Chairperson: Mr. Gerard Larkin (085 8326159),
- Vice Chairperson: Ann Marie Maher (086 0512747),
- Secretary: Louise Gilmore (087 0558377),
- Treasurer: Michael Russell (086 3883955).

Are you a parent with Spina Bifida &/or Hydrocephalus?

If so we would love to hear from you. We are interested in setting up a support group for members who are parents. This will be a platform to express views, exchange information and ideas and see what our organisation can do for you.

If you are interested please contact the office in Clondalkin @ 01 457 2329.

Wicklow Branch Member Meets His Hero

Killian, aged 15, was delighted to meet Richie Kavanagh during the summer. They had a wonderful time together singing all Killian's favourite songs and telling "Richie" stories. Killian's family would like to thank Richie, his wife Nancy, and their family for their generosity and kindness to Killian. It was a trip he will never forget and is still talking about it!!



Killian Cloake pictured here with his hero Richie Kavanagh.

Clonmel Coffee Morning

The group meets every three months usually during school holidays. Young children with Spina Bifida / Hydrocephalus and their siblings are welcome. Parents and carers meet for a chat and coffee while the children get an opportunity to play. New members are welcome. The next meeting will be in October during the school break.

For more information and if you wish to attend please contact Family Support Worker for the South East, Doreen Costello, on 087 6527175.



Emily McInerney, Clonmel, Melissa Power, Carrick on Suir, enjoying the Clonmel Coffee Morning.

Ladies Mini Marathon 2009

All the branches and the National Office would like to extend their thanks to all the ladies who participated in this year's Mini Marathon. One such group was from Aughrim and they raised €1,300. Many other groups throughout the country participated also and this is a great fundraiser every year. We are looking forward to meeting you all again next year.

Pic: Aughrim marathon group. Back row: Carmel Byrne, George Kennedy, Maureen O'Neill, Nicole Quigley, Amy O'Neill, Gerry Bell, Joanne Flynn. Front row: Julieanne Bell, Leighton O'Neill, Aishling Quigley. The five ladies raised €1,300 through their efforts. The cheque was presented in Paddy's Pub on 19th July. Thanks to all in Paddy's.



Kori Dennehy, Melissa Power and Emily McInerney, all enjoying themselves at the Tipperary coffee morning in The Planet Playground in Clonmel, Co. Tipperary.

Louth Meath Dogs Night



SBHI members enjoying a recent night out at the dogs in Dundalk.

Dates to Watch Out For...

UPCOMING EVENTS

October Mid-Term Break – Teenagers (age 13 to 17)

Share Activity Centre, Lisnaskea, Fermanagh. Tuesday 27th to Friday 30th October 2009.

The break will focus on team games and outdoor activities on land and water - such as canoeing, kayaking, orienteering, climbing etc. Please see <http://www.sharevillage.org/> for more information.

November Weekend Getaway – Adults

The Kilcuan Centre, Clarinbridge, Co. Galway. Friday 6th November to Monday 9th November 2009.

The weekend will focus on decision making, group work and life skills. The group will decide on activities and be involved in cooking and practical skills on the weekend.

Youth Forum Events - organised by the Youth Forum

Superstars Adult Bowling League, Dublin.

Long-term aim: for all local branches to start their own bowling club leading to a national league.

Chairperson: Ann Reid
ar.purplewheels@gmail.com

Secretary: Andrea Fox
andreafox28@gmail.com

Or contact via the National Office.

Thurs. 29th October Halloween Party

Roadstone Social Club,
Kingswood, Dublin 22.

8pm - 11pm. Open to all members and family and friends.



**Fundraising Drive
for National Resource Centre**

Our National Fundraising Campaign gets underway in November and we need volunteers to sell our SBHI Torc Pins and Ability Wristbands on the following dates:

100K	7 th & 8 th November
90K	HARBOUR PLACE SHOPPING CENTRE - MULLINGAR
75K	PAVILLIONS SHOPPING CENTRE - DUBLIN
60K	20 th & 21 st November
45K	ATHLONE SHOPPING CENTRE - ATHLONE
30K	26 th November
15K	BRIDGEHOUSE SHOPPING CENTRE - TULLAMORE
	8 th & 9 th January
	ARTANE CASTLE SHOPPING CENTRE - DUBLIN

If you are interested in volunteering please contact
Sarah Jacobsen
Event & Fundraising Manager
01 457 2329 or sjacobsen@sbhi.ie