



# ability

Magazine of Spina Bifida Hydrocephalus Ireland

Winter 2009



**HAPPY  
CHRISTMAS  
TO ALL OUR  
READERS**

*Edel Browne Curran,  
Family Support Worker at our  
conference in Ballinasloe*



## What's Another Year



Our 41st year was our first as the National Association for Spina Bifida and Hydrocephalus Ireland Limited trading as Spina Bifida Hydrocephalus Ireland. This transition has not been as smooth as the board would have liked but the perceived difficulties will, through working together, be seen not to exist.

Spina Bifida Hydrocephalus Ireland has made great progress with many successful events. This success has led to requests for branch structures in areas not covered at present. Our hope is that this expansion happens quickly as our branch system is highly praised and offers our members an invaluable service. To our present branches and our officers who year in year out provide this service, a sincere thank you for your continued hard work. To all our volunteers who have helped us throughout the year, particularly during our Summer Project, we could not do this without you.

Our youth forum has had a very productive year and I know that with Ann Reid at its head that productivity will continue into the future. To our CEO George and his staff, the ever-expanding need for your services is being ably handled by you and I thank you for your trojan work.

You will have read many inspiring stories from our members in the **Ability** and it is with a sense of pride that we read these articles. Life has challenges for us all and whether they are big or small we would love you to share them with us. Who knows, perhaps you will help others by telling your story. We have a number of more senior members in our organisation who have so much to give and we are looking forward to working with them and listening to their needs.

We have a "first" for our organisation next year as we are hosting a World Congress in June 2010. I would ask that all the branches get behind this event and ensure that anyone who wants to attend does so. This will be a chance to hear speakers from Europe and worldwide. It will also be an opportunity to meet other members from several different countries. There is much interest in this event within the International Federation and we want to show them that our Association is capable of producing a Congress to remember.

Another important body of people are the Board who I have worked so closely with this year. They are a pleasure to work with and I look forward to another year with them. As Christmas is almost upon us it only remains for me, on my own behalf and behalf of the Board, to say Happy Christmas to you and I ask you to spare a thought for those who have passed to their eternal reward and their families, the huge void in their lives must be unbearable.

My last wish is that Santa is kind to us all.

Happy Christmas and a Happy New Year.

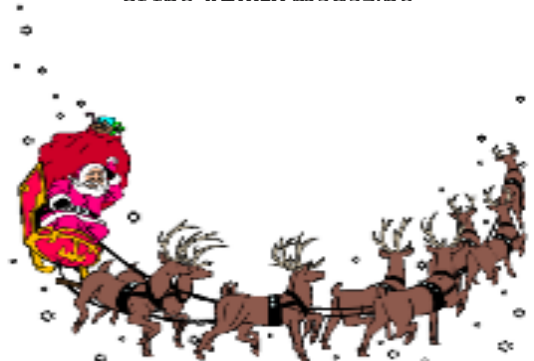
– **Fiach McDonagh,**  
**Chairman**

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## Season's Greetings

I would like to thank you all for the articles and photos for this edition of the *Ability* magazine.



## Spina Bifida Hydrocephalus Ireland (SBHI)

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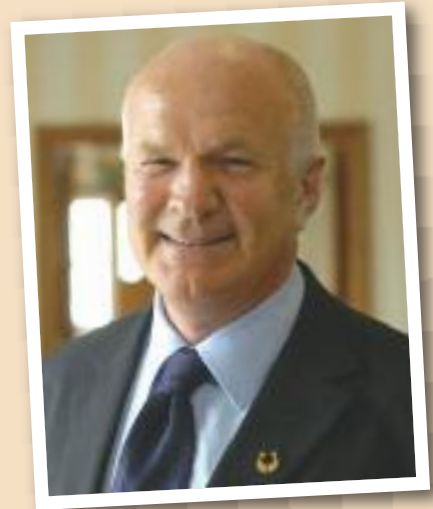
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# A Word from Our CEO, Mr. George Kennedy



Once again we have come to the end of the year and the Festive Season will soon be upon us. It was a very busy and eventful year with a much increased demand for our services.

The whole team in the National Resource Centre has noticed a near 50% increase in the workload and have been extremely busy in attempting to cope with this extra work. In particular there has been a significant increase in new members. These new members are people who were not previously involved with Spina Bifida Hydrocephalus Ireland and also newly-pregnant mothers whose babies have been diagnosed with Spina Bifida and/or Hydrocephalus or mothers who have recently delivered babies with either or both conditions. Even with this extra workload we guarantee that everyone who needs our service will be catered for. In particular there has been a major increase in attendance at various activities such as coffee mornings for parents and toddlers, a range of sporting and social activities, young adult support activities, continence advice, outreach services and several other areas of interest to people with Spina Bifida and/or Hydrocephalus.

Many youth and respite activities were run in 2009 in conjunction with the Youth Officers of all our branches. The Youth Forum, which involves the youth of our association from all over the country, was activated and ran during the year. This grouping had several meetings with the high point being their presentation to our Conference in Ballinasloe in May. This was a particularly excellent presentation and revealed the excellent talent that permeates our organisation. In order that all of these activities were run effectively and efficiently it took a major effort on the part of all members of the staff and, due to that effort, all the activities were run very professionally.

As usual, our Summer Project, SHINE was an outstanding success. More than 70 members attended the various weeks which were held in Clondalkin, Clarinbridge, Co. Galway and in the Lake District in the UK. I want to thank all volunteers, helpers, staff and the people who attended. Their combined efforts ensured the success of the project for all concerned.

The Hydrocephalus Day which was held in Beaumont Hospital on October 9th attracted an attendance of 125 people. This was made up of parents, carers and medical professionals who service our sector. Again this was an outstanding success and we plan to organise and run similar events regionally in 2010 (*see separate details inside*).

These are just some of the events we ran throughout the year but we covered many other topics of relevance to members on a regional basis such as Continence Training, Manual Handling Techniques, First Aid Training, Hydrocephalus Information etc. These programmes were generally well attended and we plan to continue to run them throughout 2010.

I would like to thank all our contributors, instructors and volunteers who helped make these programmes the undoubted success they were. In particular I want to say a special thanks to Frances Halligan who ran our Continence Evenings in several parts of the country and who also gave clinics in Clondalkin on a monthly basis throughout the year. Frances, who gives of her time on a voluntary basis, is an invaluable asset to our association in general but in particular to our members, parents and carers.

We plan to continue all programmes in 2010 and, if possible, to expand them to more regions, finance permitting. The funding cutbacks may have a serious impact on our future plans, however we will advise you further of our programmes as the year progresses.

Finally to our volunteers, branches, workers, everybody who helps in any way and in particular to you, our parents and members, I want to wish you a Peaceful and Happy Christmas and every good wish for 2010.

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

# Preparing for Budget 2010

**S**pina Bifida Hydrocephalus Ireland has been working with DFI (Disability Federation of Ireland) over the last few weeks to influence the Review of the Programme for Government. Together we have argued that Government needs to urgently agree with the disability sector on a five-year plan detailing how the National Disability Strategy will be protected and advanced during the difficult period ahead. We have proposed that the disability sector can actively work with the State to ensure maximum value and outcomes. Protection of services for people with disabilities and those with special health needs is an essential element in the State's battle to emerge from the recession and to ensure that a viable social provision infrastructure is in place to support people with disabilities and all special health needs.

SBHI welcomes the disability commitments within the review of the Programme for Government. However, there is still much to be done before the Budget. It is critically important now that all members in our organisation keep the pressure up locally with T.D.s and Senators, and ensure that disability remains a high priority on the agenda nationally and locally. In addition to these efforts however we must all prepare for a challenging Budget for 2010. If the full effect of the €50 million cuts proposed through the McCarthy Report is applied universally, this will equate to an approximate 5% cut to an organisation's funding. We appreciate that further cuts on top of those already assimilated by organisations in 2006 will cause great difficulty within our organisation and may affect the sustainability of the services our organisation provides.

## Cost of Disability and the 'McCarthy Report' Implications

SBHI is of the strong view that, if implemented, the McCarthy Report<sup>1</sup> recommendations would seriously undermine the National Disability Strategy and the wellbeing of people with disabilities in society. This is because the Report approaches expenditure by individual departments, and ignores the reality

## 1. Income Support for People with Disabilities

The McCarthy Report recommends a flat rate cut to social welfare of 5%. This poses a considerable threat to the welfare of vulnerable, disabled people who, through no fault of their own, experience a higher cost of disability. Already the disabled are at greater risk of poverty because the money they receive on long-term disability payments such as



*A challenging Budget for 2010.*

whereby public services are designed around the individuals and their requirements as they move through the life stages.

Many of the recommendations made in the McCarthy Report would hit people with disabilities harder than non-disabled citizens if implemented. There is a clear lack of understanding and consideration of the 'cost of disability' and how additional cuts in this context would affect people with disabilities.

The following is a snapshot of the potential effect of further cuts recommended by the McCarthy Report on disabled people.

Disability Allowance (currently €204.30), does not stretch as far as mainstream welfare payments (such as Job Seekers Allowance). For instance, a person with mobility difficulties may require extra heating in order to keep warm. They may also require special clothes and in some instances have special dietary requirements. In other words a 5% cut in their social welfare will have a greater negative impact on the life of person with a disability and must therefore be avoided.

## 2. Employment for People with Disabilities

SBHI recognises the value of secondary benefits as important social inclusion

1. The Report of the Special Group on Public Service Numbers and Expenditure Programmes 2009.

2. For instance the 'half-rate carers allowance', the higher payment for people with disabilities on CE, FIS.

and activation measures for people with disabilities and their carers, and which must be protected in Budget 2010<sup>2</sup>. For instance, the higher rate of payment to people with disabilities in Community Employment Schemes must be continued in recognition of the extra 'cost of disability' and high rate of unemployment among people with disabilities.

### 3. Support to Carers

The McCarthy Report recommends that the half-rate Carers Allowance be discontinued. SBHI believes that removing this payment would be a mistake. We are already disappointed at the failure to publish the Carers Strategy, which was committed to by the Government. Carers play a very valuable role in our society, saving the State millions of euro by providing home care to elderly and disabled people. The average cost of residential support in a community setting is in the region of €80,000 per annum and can be up to €300,000, and in some cases more for people with complex and high support needs. The McCarthy Report recommendations must be considered within this context and in the context of the need to support carers in their important work.

### 4. Medical Card and Health Expenses

The McCarthy Report recommendations will impact to a greater degree on families with disabled members who are not entitled to any allowances because the family income is above the means test limit. Recommendations such as the proposed reduction of Child Benefit and the discontinuation of treatment benefit will have a huge impact on the finances of this group, as mainstream measures such as these go towards offsetting the cost of disability to some extent. Any reductions would erode their income more so than a family which does not include a disabled member who experiences extra costs of disability.

In addition, such families will be further affected if recommendations linked to

other departments are introduced. This includes the proposal to increase the threshold for the Drugs Payment Scheme to €125 and to introduce a co-payment of €5 for each prescription under the General Medical Scheme (GMS). These examples serve to point to the need to disability-proof proposed budgetary measures.

### 5. Transport for People with Disabilities

The McCarthy Report recommendation to abolish the Rural Transport Initiative (RTI) would come as a significant blow to people with disabilities living in rural communities. Under this scheme communities have been able to

develop accessible community-led transport to serve remote areas of the country. Without the RTI many of these people would simply not have access to other services nor have access to their local communities.

Any decision to discontinue the RTI has an impact on social welfare customers in receipt of long-term illness and disability payments. They will be forced to order private taxis which are more expensive and this would significantly erode their welfare payment of €204.30. It would be another cost of disability. In the worst cases, where no accessible taxis are available, people would be left isolated and alone. ■

## Implementation of the Home Care Package Scheme

(NESF Report No. 38 September 2009).

The National Economic and Social Forum (NESF) launched its comprehensive report on the implementation of the home care packages scheme on 28th October. The report found that despite the existence of a national strategy and guidelines, this scheme is being implemented in different ways in different HSE local health offices. The result is that applicants encounter different eligibility criteria, means tests and funding depending on where they live. Further details are available on [www.nesf.ie](http://www.nesf.ie).

## Training and Funding

### Lifelong Learning Programme, European Commission and Léargas

The European Commission has integrated its various educational and training initiatives under a single umbrella, the 'Lifelong Learning Programme'. This programme enables individuals at all stages of their lives to pursue stimulating learning opportunities across Europe.

There are four sub-programmes, each focusing on different stages of education and training, and continuing previous programmes:

- **Comenius** for schools
- **Erasmus** for higher education
- **Leonardo da Vinci** for vocational education and training
- **Grundtvig** for adult education

The deadlines for the submission of applications have been announced for 2010. There are calls for submissions for a range of programmes, projects, assistantships and workshops.

For further information please contact the National Agency in Ireland, Léargas - The Exchange Bureau (Comenius, Leonardo da Vinci, Grundtvig, Study visits). Tel : (353) 1 8731411.

Website: [www.llp.ie](http://www.llp.ie) or [www.leargas.ie](http://www.leargas.ie) ■



# Kildare People of the Year Awards for Shirley

Shirley Keogh was named as one of the Co. Kildare People of the Year for 2009 and she was presented with her award at a black-tie banquet on the 6th November in the Keadeen Hotel, Newbridge. There was a big group of supporters from the Kildare Branch's sports group in attendance on the night and everyone had a great night and were delighted to see one of their own group receiving such a prestigious award.

Shirley was described on the night as a powerhouse on wheels. The following is a brief synopsis of the work that Shirley has taken part in down through the years.

She is an excellent advocate for people with disabilities and she is adamant about equal opportunities in life, sporting and social activities. Shirley has Spina Bifida and she joined the Kildare Branch in 1996 and served as secretary, youth officer and sports co-ordinator. Along with others, she helped start Club 2000, where members enjoy basketball, javelin, shot-putt, discus and wheelchair activities. They meet Thursday nights in St Lawrence's GFC, with annual sports-days and weekend trips organised. Despite having dialysis treatment three times a week and horrendous restrictions thereby imposed on her diet and lifestyle, Shirley along with her husband, Brendan, try to make club meetings.

In 1986, Shirley married Brendan and the couple have one son, Brendan Jnr. When her son was aged eight, Shirley became a full-time wheelchair-user but felt angry about the different way people treated her when she was on wheels. She found people addressed other family members when she was present e.g. asking her son in a shop what she required. In Shirley's own words: "My legs gave way, not my mind!". She is passionate in her support of

Spina Bifida Hydrocephalus Ireland as she understands both the frustration of youth coping with disability and the concerns of anxious parents. Shirley continuously lobbies Athy Town Council about the lack of parking and accessible amenities in the area.

2008 was a bad year health-wise for Shirley but it doesn't stop her keeping house, gardening, pet minding or active involvement in the events of the association. She is a woman who has refused to allow the wheelchair to dictate her lifestyle and, instead, the wheels go where Shirley takes them!

Spina Bifida Hydrocephalus Ireland would like to congratulate Shirley on receiving this prestigious award and for continuing to support the members in their sports endeavours. We thank you for all your work, past and present, and we wish you all the best in the future. ■



*Shirley Keogh, Kilmeade, Co. Kildare.*



*Kildare members enjoying the People of the Year Awards.*



# Hydrocephalus Study Day

October 9th, 2009, was the date for our Hydrocephalus Study Day which was held in Beaumont Hospital. Once again, due to the hard work of the staff this was a very successful event with a large turnout. There was a host of interesting speakers and topics. We were delighted to have Mr. M. Taufig-A-Sattar, Consultant Neurosurgeon who generously gave of his time to present his paper and facilitate a questions and answers session. We also welcomed back Dr. Trudi Edginton whose presentation you can read in this edition of the magazine. Marie McGonnell and Katherine McCurry joined us from Northern Ireland ASBAH. We were all delighted to meet both Katherine and Marie and look forward to working with them in future. One of the most popular speakers on the day was our own Andrea Fox who gave a very detailed and personal account of everyday life with Hydrocephalus. You can also read Andrea's presentation later in this edition. There was very positive feedback from the event and great participation from those who attended. Our Family Support Workers, Edel Browne Curran and Sally Hibbs, gave a presentation on the services available to our members through their Family Support Workers. It was very informative and stressed the range of services available through our FSWs.




Mr. M Taufig-A-Sattar, Consultant Neurosurgeon and Marie McGonnell from Northern Ireland ASBAH.

One of the most important messages that came out of the day was if you are a parent of a young child with hydrocephalus or have the condition and if YOU think there is a problem with the shunt (and who would know better than the person themselves) please DO NOT WAIT TO SEEK MEDICAL ATTENTION. Act immediately and always carry your Shunt Alert Card with you or wear medical alert jewellery.

We would love feedback from our members on what topics they would like to see covered at a forum such as this. If you have any ideas you would like to put forward please contact the office on 01 457 2329. Again I would like to extend our thanks to all our speakers for making this a very successful day. ■

**To be used in an emergency**



SPINA BIFIDA  
HYDROCEPHALUS  
IRELAND

**SHUNT ALERT CARD**  
I have Hydrocephalus  
which is controlled by a  
**VP Shunt / VA Shunt**  
*(delete whichever does not apply)*

Name: .....

D.O.B.: .....

Address: .....

**Signs of a Shunt Malfunction:**  
Vomiting or nausea, sensitivity to light, dizziness, seizures, headache & other visual disturbances, drowsiness, fatigue, behaviour changes, general malaise, decline in academic or work performance, visuo-perceptual problems, being just "not right".

**To be used in an emergency**

Front of Shunt Alert Card



Katherine McCurry from Northern Ireland ASBAH.

**To be used in an emergency**

If the cardholder is showing signs similar to those which occur when there is a shunt malfunction – urgent assessment of shunt function should be carried out in a specialist neurosurgical unit in order to eliminate shunt failure as a cause.  
**If you suspect a shunt malfunction please contact the following as a matter of urgency:**

Neurosurgical Hospital:  
.....

Neurosurgical Consultant:  
.....

Neurosurgical Telephone:  
.....

GP Name:  
.....

GP Telephone:  
.....

**To be used in an emergency**

Back of Shunt Alert Card

# The 2nd Annual Packie

The 2nd Annual Packie Bonner SBHI (Spina Bifida Hydrocephalus Ireland) Golf Classic raised over €10,000 for the organisation and its services. The event took place at the exquisite Palmerstown House, PGA National Golf Course at Johnstown, Co. Kildare.

The Golf Classic resulted in an impressive turnout from 23 teams at the fantastic course with 110 people enjoying a barbeque afterwards. The winning team came from Limerick and the prize winners were presented with their awards by Packie. Later that evening during the award ceremony, he commented that: "The SBHI event is by far the best Golf Classic that I know of. A thoroughly enjoyable day was had by all for a very worthy charity."

Palmerstown House is the official PGA National Golf Course that stretches over 7,419 yards and is both challenging and fair to all levels of golfer. Breathtaking scenery covers this magnificent course which any golf enthusiast would relish playing on. It is no wonder PGA have set up their official Irish headquarters there.

It was a great day and the weather was fantastic. It was good to see such a good turnout of teams from all four provinces. The course was fantastic and the scores reflected the quality of the facilities on offer.

The day would not have been possible without the generosity of the main sponsor, Bernie Mac of **Bernie Mac's Pub** in Clonmel, Co. Tipperary, as well as that of the companies who donated the spot prizes.

We look forward to next year's event so all you golfers out there watch this space for further updates on our 3rd Annual Packie Bonner SBHI Golf classic. ■



# Bonner SBHI Golf Classic



*Plenty of Style –  
On and Off the  
Golf Course!*



# DARE [www.accesscollege.ie](http://www.accesscollege.ie)

## What is the Disability Access Route to Education?

The Disability Access Route to Education (DARE) is a supplementary admissions scheme for school leavers with disabilities which operates on a reduced points basis. DARE has been established by a number of higher education institutions as clear evidence shows that disability can have a negative impact on educational attainment at school and progression to higher education.

## Who is it for?

School leavers who have the ability to benefit from and succeed in higher education but who may not be able to meet the points for their preferred course due to the impact of a disability.

## What places are available?

Each participating HEI has allocated a quota of places on a reduced points basis for students entering through DARE.

The quota of places available through DARE differs from one institution to another. Details of quotas can be found on the website of each of the participating institutions.

All DARE applicants must provide evidence confirming that their disability has had a significant impact on their educational performance. DARE applicants must meet the minimum entry (matriculation) and subject requirements of the institutions to which they apply. Applicants will then compete for a quota of places based on their Leaving Certificate results.

Details on the selection and admission policies of the individual institutions can be found on the websites of the participating institutions.

## Participating Higher Education Institutions:

- Athlone Institute of Technology
- Dublin City University
- Dublin Institute of Technology
- Mater Dei Institute of Education
- National College of Ireland
- NUI Galway
- NUI Maynooth
- Trinity College Dublin

- University College Cork
- University College Dublin
- University of Limerick

## Applicant Requirements

All DARE applicants must provide evidence confirming that their disability has had a significant impact on their educational performance. DARE applicants must meet the minimum entry (matriculation) and subject requirements of the institutions to which they apply.

Applicants will then compete for a quota of places based on their Leaving Certificate results.

## How do I apply to DARE?

School leavers who wish to be considered for DARE must:

- Apply online at [www.cao.ie](http://www.cao.ie) as part of the CAO application process by 1 February 2010.
- Disclose a disability or specific learning difficulty on the appropriate section of the application form. Applicants will then be directed to the separate online Supplementary Information Form which will ask them to provide additional information about their disability or specific learning difficulty (Sections A-C).
- Applicants must indicate their wish to be considered for DARE (final Section on Supplementary Admissions Routes).

- Applicants must submit supporting documentation by 1st April 2010.

## Supplementary Information Form

There are four separate sections to the Supplementary Information Form which must be completed by the applicant, the applicant's school and the Medical Consultant/Specialist verifying the disability.

- Section A – applicants must complete a Personal Statement which outlines, from their perspective, the academic impact of the disability or specific learning difficulty.
- Section B – applicants must return a Second Level Academic Reference completed by their school. This form provides background information on the applicant's educational experience and helps to determine appropriate supports at third level.
- Section C – applicants must return the Evidence of Disability Form completed by the accepted Medical Consultant/Specialist. This form provides verification of the applicant's disability and helps to determine appropriate supports at third level. All applicants must complete this form with the exception of the following:
  - Applicants who have an existing report completed within the appropriate timeframe by the accepted Medical Consultant/

## Better Options College Fair for Students with Disabilities & Specific Learning Difficulties

This one-day event for students with a disability and specific learning difficulties who are considering their college options in Ireland in 2010 is key in learning about DARE and completing the CAO Supplementary Information Form as part of the online DARE process, as well as checking out the services and supports available in universities and institutes of technology.

The event will be hosted by UCD in association with AHEAD (Association for Higher Education Access & Disability) and DAWN (Disability Advisors Working Network). The fair will take place on Thursday 10th December, 2009, from 11 a.m. to 3 p.m., in the Student Centre, Astra Hall, UCD. All are welcome, including students, guidance counsellors, resource teachers, learning support tutors, SENOs, NEPs & Parents.

Further information, please contact Lorraine Gallagher, Information Officer, AHEAD. Tel: 01 7164396, Email: [lorraine.gallagher@ahead.ie](mailto:lorraine.gallagher@ahead.ie), Web: [www.ahead.ie](http://www.ahead.ie).

Specialist. The report must contain the same detail as the Evidence of Disability Form.

- Applicants with specific learning difficulties who must provide a full psycho-educational assessment completed by an appropriately qualified psychologist. The report must be less than 3 years old i.e. must be dated after 1st February, 2007.

- Supplementary Admissions Routes – applicants must indicate their wish to be considered for DARE.

### Closing Dates for DARE

DARE is a supplementary admissions route that requires a significant degree of processing on the part of the CAO and the participating higher education institutions. In order to allow adequate time for the completion of this work the following closing dates apply:

#### By 1 February 2010:

Complete all elements of the online DARE application (Section A and the final Section on Supplementary Admissions Routes) as part of CAO application process. Applicants who are unable to complete the online form must submit the paper application form by the same date.

#### By 1 April 2010:

Submit both Second Level Academic Reference (Section B) and Evidence of a Disability (Section C) to the CAO.

### Next Steps in the Application Process

Once all applications have been processed for DARE eligibility, applicants will be informed in writing of their DARE status.

Applicants who are not eligible for DARE will be informed of the reasons for their ineligibility. An applicant can request that his/her application be reviewed should he/she have reason to believe that an error occurred during the screening process.

If you are not eligible for DARE, you can still get into college through the CAO if you meet the entry requirements.

### Evidence Of Disability

Applicants must return the Evidence of Disability Form (Section C) completed by the accepted Medical Consultant/Specialist. This form provides verification of the applicant's disability and helps to determine appropriate supports at third

The table below lists the accepted Medical Consultants/Specialists and the age limit of reports.

Type of Disability	Accepted Medical Consultant/Specialist	Age of Report
Asperger's Syndrome/ Autism	Appropriately qualified psychiatrist/psychologist who is a member of their respective professional or regulatory body	No age limit
Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder	Appropriately qualified psychiatrist/psychologist who is a member of their respective professional or regulatory body	No age limit
Blind/Vision Impaired	Ophthalmologist/ Ophthalmic Surgeon	No age limit
Deaf/Hearing Impaired	Professionally qualified Audiologist and/or ENT Consultant.	No age limit
Dyspraxia	Appropriately qualified psychologist and Occupational Therapist/ Physiotherapist who is a member of their respective professional or regulatory body	No age limit
Mental Health Condition	Psychiatrist	Must be less than 3 years old i.e. must be dated after 1st February 2007
Neurological Conditions (incl. Brain Injury, Speech & Language Disabilities)	Neurologist or other relevant Consultant	No age limit
Significant Ongoing Illness	• Epilepsy: Neurologist • Diabetes Type 1: Endocrinologist • Cystic Fibrosis (CF): Consultant respiratory physician or paediatrician • Gastroenterology Conditions: Gastroenterologist • Others: Relevant consultant in area of condition or Consultant Registrar/Registrar	Must be less than 3 years old i.e. must be dated after 1st February 2007
Physical Disability	Orthopaedic Consultant or other relevant Consultant such as Rheumatologist or Paediatrician	No age limit
Specific Learning Difficulty (incl. Dyslexia)	Enclose a full psycho-educational assessment completed by an appropriately qualified psychologist.	Must be less than 3 years old i.e. must be dated after 1st February 2007
Other Disabilities	Relevant medical consultant/specialist	No age limit

level. All applicants must complete this form with the exception of the following:

- Applicants who have an existing report completed within the appropriate timeframe by the accepted Medical Consultant/Specialist. The report must contain the same detail as the Evidence of Disability Form.
- Applicants with specific learning difficulties who must provide a full psycho-educational assessment completed by an appropriately qualified psychologist. The report must be less than 3 years old i.e. must be dated after 1st February 2007.

### How are applications processed?

Applications to DARE are assessed by professionals in participating Higher Education Institutions (HEIs) who have expertise and an in-depth knowledge of

the impact of disability on educational attainment.

To assess an applicant's eligibility for DARE, specific criteria have been developed to determine the significance of each disability and the impact on educational attainment.

The criteria used for assessing the impact of disability were developed by HEI Assessment Boards, which included HEI professionals and representatives from expert external organisations.

### How do I contact DARE?

To speak to a DARE expert in the Disability/Access Office of each of the participating institutions please use the following contact details:

**Athlone Institute of Technology**  
 Patricia Kearney, [pkearney@ait.ie](mailto:pkearney@ait.ie)  
[www.ait.ie](http://www.ait.ie) 090 646 8141

**Dublin City University**

Anne O'Connor, [anne.oconnor@dcu.ie](mailto:anne.oconnor@dcu.ie)  
[www.dcu.ie](http://www.dcu.ie) 01 7005208

**Dublin Institute of Technology**

Olive O'Connor, [olive.oconnor@dit.ie](mailto:olive.oconnor@dit.ie)  
[www.dit.ie](http://www.dit.ie) 01 4027656

**Mater Dei Institute of Education**

Annabella Stover  
[admissions@materdei.dcu.ie](mailto:admissions@materdei.dcu.ie)  
[www.materdei.ie](http://www.materdei.ie) 01 8086502

**National College of Ireland**

Stephen Kennedy, [skennedy@ncirl.ie](mailto:skennedy@ncirl.ie)  
[www.ncirl.ie](http://www.ncirl.ie) 01 4498556

**NUI Galway**

Elizabeth Walsh  
[elizabeth.walsh@nuigalway.ie](mailto:elizabeth.walsh@nuigalway.ie)  
[www.nuigalway.ie](http://www.nuigalway.ie) 091 493541

**NUI Maynooth**

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**CAO Application Process**

The CAO Application Process opens on November 3rd, 2009. All applications for DARE need to be made before February 1st, 2010. Supporting documentation must be submitted by April 1st, 2010.

CAO Helpline - To assist the applicant in making a full application to DARE, CAO will operate a helpline from November 1st, 2009, through to March, 2010.

More information can be found on [www.cao.ie](http://www.cao.ie).

**DARE 2010 Application Guide & Brochure**

The Guide and Brochure can be downloaded from the website [www.accesscollege.ie](http://www.accesscollege.ie) and from the following websites [www.cao.ie](http://www.cao.ie) and [www.qualifax.ie](http://www.qualifax.ie) ■

# Flour Fortification Initiative (FFI)

We are making progress in flour fortification efforts around the world, with Kazakhstan being the newest country to require flour fortification as part of its public health programme. The country's new Health Code includes mandatory enrichment of high and first-grade wheat flour with iron, folic acid, zinc, niacin, riboflavin, and thiamin. Flour fortification in Kazakhstan is expected to reach 70 percent of the Kazakhstan population of more than 11 million. In addition, 15 million individuals in countries that import Kazakh flour will benefit from the extra nutrients.

In West Africa, Togo began its flour and oil fortification programme in August, and several neighbouring countries are following the example. In East Asia, Sri Lanka is also pursuing mandatory flour fortification, and in India, the state of Gujarat began using fortified flour in its mid-day meal programme serving 4.4 million schoolchildren.

See the Periodic Update for more details on these events, plus information on FFI activities in the fourth quarter of 2009. As always, these efforts are the result of hard work by a multitude of partners. We honour these collaborative efforts and look forward to continuing to work together for smarter, stronger, healthier people worldwide.

*Sincerely,*

**The FFI Team.**

Kathleen "Kat" Peters,  
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Flour Fortification Initiative (FFI),  
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[www.sph.emory.edu/wheatflour](http://www.sph.emory.edu/wheatflour)

Update yourself on what's going on at an international level by visiting [www.ifglobal.org](http://www.ifglobal.org) ■

## Comfort Keepers

Comfort Keepers is a family-owned homecare provider dedicated to helping people remain as independent as possible in their own homes. Their ethos is to care for their clients as they would a member of their own family.

Bob Power founded Comfort Keepers after his father needed some assistance at home. With the help of homecare, Gerry Power remained at home for five years when otherwise he would have required nursing-home care.

Comfort Keepers prides itself on the professional care it provides that families can trust in. This focus on quality and professionalism is illustrated by Comfort Keepers being the first and only homecare provider to be accredited with the Q Mark for Quality. Comfort Keepers offices service 12 counties around Ireland.

The majority of Comfort Keepers' clients are older people, those recovering from illness or injury, or those with disabilities. Comfort Keepers' carers are carefully screened through a series of six background checks, and are fully insured. All caregivers are employees of Comfort Keepers and Comfort Keepers takes care of paying all employee taxes, including PRSI, so that families do not have to register as employers which they would have to do otherwise.

Comfort Keepers offers a wide range of home-based, non-medical services ranging from a daily visit, help with personal care to running errands and grocery shopping.

For more information, contact:  
Lorna Carney, Alchemy Communications Ltd.  
Mobile: 087 2872741. Tel: 01675 5147. Email: [lorna.carney@alchemycommunications.ie](mailto:lorna.carney@alchemycommunications.ie) ■

# Walk Away and Forget Him

## Gerry Maguire



**By way of introduction, my name is Gerry Maguire. Now that is not a name that will be forgotten easily thanks to Tom Cruise immortalising it in the movie! My story differs ever so slightly from the movie though!**

I am 46 years old. For all of those years, for all of those getting on for 17,000 days, I have had Spina Bifida. And for all of those years and days I have hated having Spina Bifida as it has stopped me doing so many things in my life – basically it has stopped me living the life of an able-bodied person. Over the last few years I have had a fairly crappy time of it. It seemed like one misfortune followed another.

Following one of these misfortunes when I smashed my arm in a fall at home, I was in hospital in the National Orthopaedic Hospital in Clontarf. A friend of mine was visiting me one day and said: “You should write a book. God knows after all you’ve been through you’ll have enough to write about.” And there began “Walk Away and Forget Him”.

When I smashed my arm in June 2005, the damage was so extensive that the doctors were afraid to operate to repair it as they feared that in doing so they may cause nerve damage which would render my arm permanently useless. Were that to happen I would then have a virtually useless left leg, a three-quarter (at best!) functioning right leg, a totally useless left arm and a fully functioning right arm. Try putting that jig-saw together! From June to November of that year, I sat in a wheelchair, either in hospital or at home, with my arm in plaster of paris praying that the shattered bone would mend naturally as the consequences or potential consequences of surgery were too horrific to contemplate. During that time I took my friends advice and one day I took out an A4 copybook and started writing. Initially my intention for writing was to clarify

in my head just how firm a grip my disability had on both my mind and my body and how that grip seemed to be getting tighter and vice-like with every passing day. But quickly the book became a homage to my mother who was told to put me in a home when I was born and to go and enjoy her three other able-bodied children. The doctors exact words to her were: “Walk away and forget him.” That wonderful woman, who sacrificed so much of her life for me, refused to take their advice and so began our intertwined lives. A few months before my fall, my mam died. So as you can imagine, 2004 and 2005 were not my best years.

After painstakingly writing all my thoughts down in long-hand and then typing them out with my “good-hand” on my laptop, I decided to lash it off to a few publishers to see would they be interested in publishing it. After a few rejections which, in fairness, were always accompanied by words of encouragement that the book was good and to persist, I got a call from Merlin Publishers who expressed an interest in publishing. When I met them for the first time, I could not believe that somebody, other than those who knew and loved me, was speaking so positively about something which I had done and done alone. That meeting was in May 2008. There followed a whirlwind of activity which culminated in the book being published in April. The buzz, the adrenaline rush, the general “feel-goodness” of that year has been just incredible. I never believed that I would have such utterly positive feelings in my life and now I want more!

And yet all along maybe I had such positivity at my fingertips and never fully acknowledged it. Before the book ever took its first breath, I had my own home, a beautiful car, a career spanning over 28 years in the Civil Service during which time I had competed success-

fully against my able-bodied colleagues for promotion. I had a family who loved me and friends who valued me. And I was a Chelsea supporter at a time when we achieved unheard of success due in no small part to our Russian benefactor!

Writing the book has liberated me. It has shown me that there is nothing wrong with voicing your dislike or indeed, as I have done, your hatred of your disability. But what I discovered was that I spent too much of my life pining for the things that I couldn’t do instead of focusing on the things I could do. In essence, if you are given the parts and tools to build a car, there’s little point in spending your time trying to build an aeroplane with them. It’s not about limiting your dreams. It’s about using the talents you’ve got while striving for your dreams. When Gerry Ryan tells the nation after interviewing you live on radio that the book you have written is “unputdownable” then you really realise that you have an ability and for too much of my life I have been hung up on putting the pre-fix of “dis” before that word.

So I already had much to be proud of – the book was an added bonus. Okay I walk slowly and differently to many others. Okay sometimes I use a wheelchair when walking is not an option. Okay I was never able to play at Stamford Bridge for my beloved Chelsea! But at long last I found belief – belief in myself. I found pride – pride in myself. I found confidence – confidence in myself. And by God am I determined that I will do all I can to ensure that now that I have achieved all of these things that I will never, ever let them go again. ■

*“Walk Away and Forget Him”,  
written by Gerry Maguire,  
is available in all leading bookstores.*

## Away Week 2009



# SBHI 2009:





# A Year in the Life...



## SBHI – Shine '09



**Presentation by Dr. Trudi Edginton on October 9th, 2009, at Hydrocephalus Study Day, Beaumont Hospital, Dublin.**

### Hydrocephalus: Cognitive and Behavioural Interventions

**Dr Trudi Edginton**

Department of Psychology, University of Warwick, Coventry, CV4 7EF, UK  
 School of Neurology, Beaumont Hospital, Galway, Co. Galway, Ireland  
 Department of Psychology, University of Warwick, UK

### Overview

- Aetiology and classification
- Clinical Implications
- Cognitive and behavioural difficulties
- Cognitive assessment
- Cognitive profiles
- Triangulating data: ASBAH funded project
- Implications
- Interventions with emphasis on insight
- Need for further research

### Aetiology and classification

**Definition of an (communicating) hydrocephalus aetiology**

**Obstructive**

- Spina Bifida
- An adult Cerebral Haemorrhage or stroke
- Rupture of the septum of a foetus

**Acquired**

- Intrauterine infection
- Infection (meningitis, encephalitis)
- Acquired neurodegeneration
- Trauma or surgery
- Tumour (benign or malignant)

**Spina Bifida (communicating) hydrocephalus aetiology**

Brain tissue defects (due to abnormal cell division) and/or brain ventricle overproduction, which is not normally absorbed, causes excess and causes abnormal pressure and brain function

### Neuroanatomical consequences

**Accumulation of CSF and ventricularly:**

- Disrupts transmission of information between cerebral cortex
- Affects neuroplasticity and other
- Disrupts and disrupts cerebral motor system
- **Disrupts CSF production and drainage**

**Consequences of increased ventricular and cerebrospinal fluid in adult**

Disrupts upon location of hydrocephalus CSF accumulation in a large ventricular lobe in the posterior location

(Moser et al. 2007; Levin et al. 2008)

### Neuroanatomical links to cognitive and behavioural function (Biopsychosocial approach)

### Neuronal transmission

Damaged neuronal transmission associated with:

- reduced processing speed
- impaired input and output from the hippocampus (linked to memory)
- impairments in information transmission between hemispheres

### Posterior to frontal pattern

- Posterior cortex more vulnerable, particularly on the right side affecting attentional system
- Reorganisation of frontal areas can result in frontal 'locking' and can affect executive functioning and result in organisational difficulties, impulsivity and mood swings

### CSF disruption

**Consequences of disrupted ventricular and cerebrospinal fluid in adult**

Disrupts upon location of hydrocephalus CSF accumulation in a large ventricular lobe in the posterior location

(Moser et al. 2007; Gatt et al. 2008)

**Consequences of disrupted ventricular and cerebrospinal fluid in adult**

Disrupts upon location of hydrocephalus CSF accumulation in a large ventricular lobe in the posterior location

(Moser et al. 2007)

**Neuroanatomical consequences of disruption in posterior brain**

includes an attentional, memory, impulse inhibition (Bower et al. 2002)

### Incidence

- Estimated prevalence of constant HC is 1 in 1000 births (Bosman, 2007) Rates can vary between 0.41-0.81%

**Up until 1990s common point**

- with less than 50% of individuals surviving
- Less than a third reaching adult life
- Two thirds with impairments in intellectual functioning

### Associated with

- Early diagnosis and early intervention
- Advances in treatments
- Antibiotic - impregnated shunt materials
- Heightened awareness

**Results in:**

- Improvements in intellectual functioning

**However - subtle cognitive difficulties can remain**

### Cognitive assessment

**Assess:**

- processing speed
- Different components of attention (eg. sustained attention, selective attention)
- Learning ability
- Different components of memory (eg. long term and short term memory)
- executive functioning
- language production and comprehension

**Note - wide variability - impact for education**

### Cognitive tasks

- Processing speed and attentional flexibility and assessed using Trail making task
- Language understanding assessed using WAIS vocabulary and DKEFS Proverbs
- Executive functioning assessed with verbal fluency tasks
- Learning and memory functioning assessed using Hopkins list learning and WMS story recall

### Intriguing modal cognitive profile

<b>Strengths</b>	<b>Weaknesses</b>
<ul style="list-style-type: none"> <li>• Elaborate use of language</li> <li>• Verbal IQ</li> <li>• Working memory performance</li> <li>• Long term memory performance</li> <li>• Postsingle measure</li> </ul>	<ul style="list-style-type: none"> <li>• Poor comprehension</li> <li>• Poor calculation</li> <li>• Poor learning</li> <li>• Poor short term memory</li> <li>• Poor planning</li> <li>• Poor strategy use</li> <li>• Attentional deficits</li> </ul>

### Implications

- Self-perception
- Perception of career and professionally
- Potential for education programme
- Essential for goals and outcomes

**Cognitive assessment provides baseline and can be used to monitor change associated with shunt, biologic**

### Behavioural assessment

**Assess**

- Anxiety and/or depression
- Anger, frustration, irritability
- Emotional regulation
- Coping skills
- Insight
- Situational difficulties and needs
- Coping strategies
- Self-esteem and self-perception
- Plans, hopes and dreams

### Behavioural assessment

- Hospital Anxiety and Depression Scale
- Behavioural assessment questionnaire
- Observation
- Self-report
- Caret report

**Reveals need for more detailed assessment tools**

### Psychosocial consequences

- Mood disorder including depression, anxiety, mood swings, poor emotional regulation
- Low level self-esteem
- Perceived difficulties
- Actual behavioural difficulties
- Distraction
- Attention/Inattention
- Apathy
- Tripartite on family, friends, peers, advocates and more (esp. through out child development and adolescence)

### Rationale for our study

- Understand what HC of an adult requires a programme which range from subtle to disabling
- Identify insight into the recognition of HC in family, friends and employees
- Focus on:
  - Cognitive and behavioural difficulties and how it can impact on day to day life
  - Interventions targeted to these cognitive and behavioural
- Long term research funded by ASBAH, Action Learning, Learning, Memory & Insight
- Vision to formulate a set of guidelines for day to day life of clients, their family, their employees and their situation

### Stage 1

**Development of a new questionnaire to assess:**

- the impact of cognitive and behavioural difficulties on everyday life in adults with hydrocephalus
- the insight/perception of individuals with HC and how this links to others' perception

**Plan to make questionnaire freely available to use as a standardised clinical tool for adults with HC**

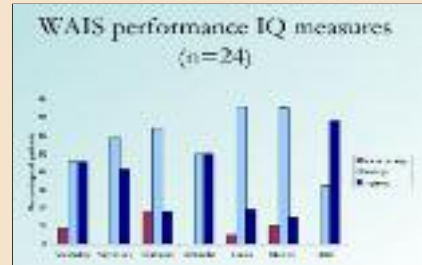
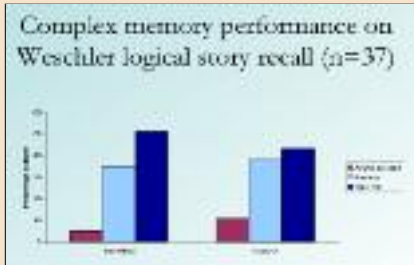
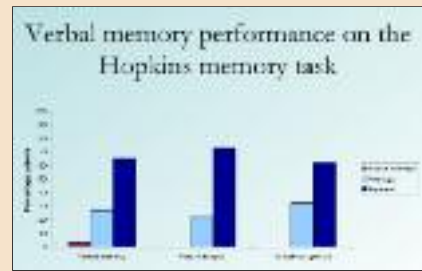
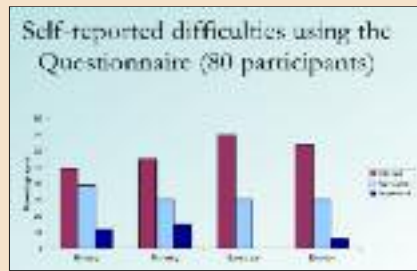
### Stage 2

**Triangulate data**

- Aim to correlate self-reported difficulties with observed difficulties and actual neuropsychological performance on a detailed battery of tasks that assesses memory, attention, planning, language, performance IQ

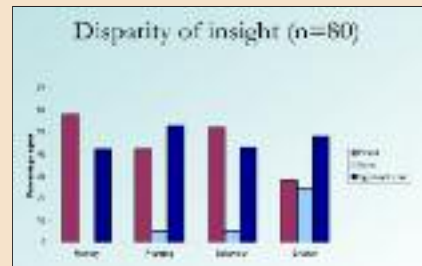
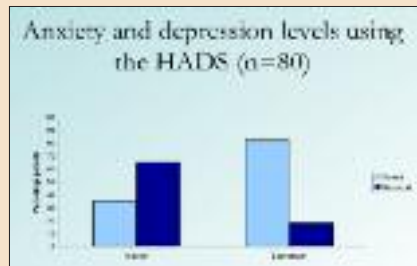
### Study design

- Questionnaire data for 80 individuals with HC (with and without SH) and significant other participants in the multidisciplinary clinic at Chelsea and Westminster
- Neuropsychological data for 30 (15/15 male to female) with HC, mean age 36 of those chosen to formally assess memory, planning and attention
- More detailed neuropsychological assessments for 30 (14 males, 16 females, mean age 36) of those chosen



### Initial findings

- Manual memory and structural dementia self-reported by individuals with HC
- Consistent with actual difficulties in verbal memory learning, recall and recognition and structural learning
- Further contrasts with decreased perceived performance IQ measures and working memory performance in the sub group although good use of vocabulary can mask underlying comprehension difficulties



### Summary

- Confirmation of mixed profile - strengths and weaknesses in cognitive areas (e.g. average working memory in contrast to dementia that impaired short term memory recall)
- Range of difficulties appear to be under-estimated by individuals with HC
- Lack of strategy use indicated
- 60% individuals with HC experience increased anxiety
- Mixed profile of capacity between individuals with HC and their significant others that requires further exploration

### Implications

- Cognitive difficulties have wide ranging impact on everyday functioning
- Need to increase understanding of cognitive profile and specific cognitive strengths and weaknesses for individuals with HC, relatives, teachers and employers
- Reduced insight has implications for strategy use and negative interventions
- Disparity of insight needs to be further explored
- Questionnaire a useful tool to integrate perspectives with objective neuropsychological data

### Interventions

- Primary aim to improve insight
- Individual assessment necessary to identify pattern of strengths and weaknesses
- Avoid disparity
- Assess willingness for strategy interventions
- Structured approach to interventions required
- Note lack of systematic evidence-based studies - neuropsychological rehabilitation literature

### Cognitive interventions

### Insight

- Be aware of strengths and weaknesses, maximise strengths to augment weaknesses
- Discourage self evaluation
- Inform others of cognitive strengths and weaknesses
- Discuss expectations

### Information processing strategies

- Provide additional time to allow for slowed processing speed
- Minimise distractions
- Work at own pace and ensure regular breaks are taken
- Ask for material in advance
- Create manageable chunks
- Check understanding
- Awareness of personal strengths and weaknesses

### Learning and memory strategies

- Encourage use of external aids (e.g. diary, mobile, camera) for retrospective & prospective memory
- Use what works best for each individual
- Understand and organise aids effectively
- Use cues, prompts, alarms
- General memory strategies - rehearsal, chunking, imagery, mnemonics

### Executive function strategies

- Introduce time management and project management strategies
- Set out structure, set achievable and measurable goals, plan action, evaluate
- Encourage self monitoring and self evaluation
- Ensure provision of support and encouragement

### Behavioural interventions

- Insight
- Encourage self-monitoring
- CBT - management of negative perceptions
- Preventive interventions to strengthen coping resources
- Anger management strategies
- Family intervention

### Behaviour management

- Ignore negative behaviour if possible
- Reward desired behaviour
- Distraction techniques can be useful
- Maintain consistent approach wherever possible
- Establish appropriate boundaries
- Try to remain calm
- Discussion, negotiation and communication
- Learning process for everyone!

### Final thoughts

- Insight for individual, carer and professionals
- Variation requires individualised approach
- Acknowledgement of strengths and weaknesses
- Willingness to incorporate and evaluate strategy
- Dynamic process
- Maximise strengths
- Need for further research and dissemination
- Any other useful strategies!

### Acknowledgements

ASHAH for funding the project

Ann Wing for co-ordinating the client reviews and helping with the smooth running of the project in the clinic

All of the willing clients and significant others at the Chelsea and Westminster multidisciplinary clinic who agreed to take part

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# Living With Hydrocephalus

By Andrea Fox

**M**y name is Andrea Fox and I am a member of the Dublin Branch. I would like to share with you my experiences of living with Hydrocephalus. These experiences are just mine and it may be different for others. I am going to divide them up into three areas.

**(1): Childhood/Primary School**

**(2): Secondary and College**

**(3): My current life**

**(1): Childhood Experiences**

When I was born I was never diagnosed with Hydrocephalus or any other form of disability. It wasn't until my 7-week check-up in Our Ladies Hospital that the doctor measured my head and informed my parents of my condition. It was all very new to my parents. I was put on a drug to help reduce the swelling but after one month this was not a success and my very first V.P. shunt was put in. Because my parents were not very knowledgeable of my disability they asked no questions and reared me just like they did my brothers.

I started into a mainstream school at the age of four years. I was unaware of having Hydrocephalus so took part in everything that I wasn't supposed to do. Mum said I loved school and was always a happy child. Although school had its challenges it wasn't until 3rd class that I found each day hard. So at the age of eight mum decided to explain to me about the shunt and that's why my school was so hard for me. She used the words *I was a special child* and that I will have many a hard day. My weakest subjects were: Maths, English and Irish. If I had been given the chance to drop Irish I would have. My homework each night would take me from the time I got home from school until late that night. One thing that will always stick in my mind was having to write about the news. That was one part of my homework I really struggled with as I had to try and remember what was said. Mum came up with a great idea of taping the news so that I could play it back at my own pace and write each sentence slowly.

At the age of ten I had a bleed to my head. When I came out of recovery I couldn't remember who I was or the



basic day-to-day things like walking, or remembering different things I had done. The biggest shock of all was when I returned to school I remembered nothing – from my handwriting to reading and even my co-ordination had gotten worse. I knew that the learning process had to begin all over again. One teacher in primary used to buy the resources I needed to help me recall what I had previously learned. To overcome my fear of reading in class she used to give me the passage to read at home so that I would be well prepared for the next day. While I was doing my homework I had to ensure that I was in a quiet place so that I could concentrate on what had to be done. After a full year I had come a long way. I continued to work extra hard. I spent many times crying but mum and dad supported me a lot. We had to sit a final exam for our entrance into secondary school but, with exams being one of my weaknesses, I failed my entrance exam into the secondary I wanted to go to.

**(2): Secondary & College**

The word Secondary I feared from day one. This was because the secondary school I had to go to was more academic than what I could cope with. However I had made my mind up that I would take each day as it came. The first two weeks I will always remember the change of subjects and the amount of books I had

for each day. But the biggest thing of all was trying to use my memory to recall where each classroom was. There were so many corridors and each room looked the same. I came up with a great system to help me overcome these problems, the first was with my timetable and what books I needed for each subject. I decided to colour-code my timetable e.g. I would colour the subject English in yellow and for each book and copy related to English I put matching colour stickers. This was one less thing I had to worry about. And to overcome my sense of direction to each classroom I used to take landmarks (just make sure the landmarks you use are not moving objects). Each day brought a new challenge but I overcame this by preparing my day in advance.

The year of my Junior Cert I seemed to be struggling, it was having to remember everything and to write down the answer in a certain amount of time. I had a lovely resource teacher who took it upon herself to help me to prep for my exams. She knew that the novels in English reading was one of my weaknesses, and so she showed me how to make bullet points onto a sticky pad at the end of each second page. This meant that at the end of the chapter I only had to put the notes all together. Although it was challenging and frustrating at times, I loved school work and never dreaded attending any day. I sat my Junior Certificate with everyone else in my class without any extra time, and I am happy to say I passed with flying colours.

During the next three years leading up to my Leaving Cert, I did extra tuition after school. It was suggested to me that I drop Irish and Maths to foundation level. It wasn't as easy as it sounds but the formulas that you were required to remember were given to me.

During Secondary we were always asked what we wanted to be when we grew older, this was something I never really thought about. But the big day finally arrived, I was older and now I had to take control of my decisions in life. I got my Leaving Certificate results while away in Spain. I was dreading it as I had found

the exams so hard. However I am happy to say I passed with honours and passes. Grades didn't really bother me as long as I passed.

I went on to do a PLC Course in Crumlin College in Computers and Business Studies. I enjoyed the course but I found the theory end of it very draining and hard to remember. It wasn't like primary or secondary, it didn't consist of the method I loved so much and that was *Show Me Don't Just Tell Me*. During the year I had to get work experience. I took up my placement in a local Computer Training Centre, where the boss let me assist him with teaching the children the computers. I loved it and went on to do some work outside of college for him. I realised that the dream I always had in the back of my mind was to help teach others.

I left college after the first year. I knew college was not for me, so in order to fulfil my dream I went on to do part-time and home study courses in Computers and Special Needs. While doing my courses I worked at many jobs from cleaning in a local pub, to office work and much more, and cleaning in a local garda station. If it wasn't for the help of my parents I would not have got through it all.

### (3): My Current Life

After three years of studying at my own pace I went on to follow my dream. In 2006, I set up my own little computer training business catering for adults, senior citizens and children aged 6 years up, many of whom had some sort of learning difficulty. I knew it would be tough but after being told in a job I would never be a trainer, I was more determined to prove them wrong. The very first year was the most challenging, although I knew my computer work I still had a lot to learn. Both my brothers work with computers, but whenever I was stuck I used to be told to RTFM (Read the F... Manual). I used to get upset and wondered why they just couldn't help me. Looking back on it now it was the best thing they could have done for me, as it made me stronger and research more into how things worked. I started off teaching adults, I loved the senior citizens. I had one businessman aged 72 when he started (he knew a little but not very much). He was my biggest challenge and a very rewarding challenge to have taught. About one year ago he ended up bed-ridden and could not come out of the house to do

his business work but now that he had become a computer "nerd" he did it all from home. Many a night I got a SOS phone call but I was always able to talk him through it. He helped me grow stronger with the business side. Later that year I took on the children who find learning very difficult – I know as I was one of those children and I knew how hard it can be for them. I started to research for different types of application software that would help them with their school work.

When the business started to take off, I found it difficult to keep track of day-to-day students and topics I had to cover. So dad bought me a mini PDA which I used to record what I had done and what was to be covered next week. Also I used the calendar on both the PDA and my mobile phone to record class times. School nowadays has changed a huge amount since I was in school, I know this as I worked as a Special Needs Assistant for a year and throughout that time I even learned more about special needs and daily challenges. This is why I will always continue to teach and research different resources for them, and I will continue to follow my dream. Now that I am 29, and I

am getting old (just like my brothers keep reminding me), each day is still a challenge, so in order to stay on top of everything I plan my day in advance and take notes for everything I am required to remember.

The social end of living with Hydrocephalus I did not mention yet. Socially I found it hard to tell people about my disability and so I used to hide myself away in my room. I was in a comfort zone of my own and nobody could hurt me. It wasn't until I joined Spina Bifida Hydrocephalus Ireland that I moved out of my comfort zone and started to live my life and have some fun without the worry of what others thought of me. I have to say if it wasn't for the help of Claire, my family support and the Youth and Respite services, I would not have become less dependant on mum and more dependent on myself about things I do. Life can be very hard and confusing from time to time and my days can contain very difficult tasks, but I always try to stay positive.

**My final words are that everyone is different but no matter how hard you find things, follow your dream and it will come true. It won't be easy but for every pitfall you come across there is a light at the end of the tunnel. ■**

## Andrea's Helpful Hints & Tips for School & College

- When reading novels or English stories, highlight important parts of the page you are reading so that if you are asked to pick an important piece in the book you will find it much easier to find.
- The "Show Me Don't Just Tell Me" method is a good way to get through everyday work; this can include home things like cooking, ironing, washing, or in school work. Seeing things done first then memorising and visualising makes it much easier to recall again at a later stage.
- Take landmarks around the school or when out on your own. Look for a particular picture to help direct you to what way you should be going (just make sure the landmarks can't move).
- Colour-code your school timetable and both the books and copies the same colour relevant to the subject (e.g. all English books and copies I will put a red sticker on them and colour English red on my timetable).
- Practise reading the night before class so that if you are asked on the spot to read you will be familiar with the words.
- Visualise things such as pictures in a history book this will help you remember what you have read about in the chapter and help you write about it in exams. Visualising is a great way of being able to remember and understand things.
- PDA and mobile phones are a great way to keep track of appointments. Set reminders on the phone so that it will beep at you the day before.
- Spellchecker programs on a computer are a great way of helping to spell a word.
- Learn through fun and games (snap cards for memory games etc).
- **Practice, Practice, Practice.** This is the best way to remember how to do things, as you are using all senses in your body, such as touch, sight, smell etc. The more you do it the more you can visualise and remember.

# The Irish Pilgrimage Trust (IHCPT)

In 1858 Our Lady appeared to Saint Bernadette and invited her to ask people to come and pray in Lourdes. Bernadette discovered a spring near the place of the apparition and for over a century people from all over the world have come to pray and to drink and bathe in the spring water.

The Irish Pilgrimage Trust is a voluntary organisation which invites young people with learning and physical disability and behavioural issues to apply to go to Lourdes each Easter. Each group has a designated nurse, chaplain and doctor.

Since 1971 groups have travelled from all over Ireland on Easter Sunday and participated in a unique week in Lourdes. Each pilgrim with the Trust is assigned to a group and is identified in Lourdes by his or her group number and colours.

One thousand pilgrims (some 450 young people and around 550 adult carers) from all over Ireland join almost five thousand pilgrims in Lourdes from the UK, Slovakia, Croatia, Romania, the West Indies and U.S.A. We are the largest English-speaking pilgrimage that comes

to Lourdes during their pilgrimage season.

We leave Ireland from Dublin, Belfast, Shannon, Cork and Knock airports to Tarbes airport, just 10km from Lourdes. When we arrive we are ferried by a fleet of coaches to our hotels in Lourdes. The groups share a wonderful fun-filled week together that includes large Masses full of music and colour, going to the baths, day outings, the Candlelight Procession on Tuesday night and daily visits to the Grotto. Petitions in envelopes can be left at the sanctuary at the Grotto as intentions for loved ones who have died or who have asked us to pray for them. There is also an opportunity for carers to go to the grotto late in the evening. It's a different place at night: quiet, tranquil and prayerful.

It's not all praying however. Great fun is had by all in Lourdes during the week. On Wednesday we travel by bus to the village of Gavarnie. We celebrate our group Mass in one of the many open fields surrounded by the Pyrenees mountains. Afterwards we have our packed picnic lunch and play games, e.g. ball games, football, etc.

Thursday night is party night in Lourdes. Many groups come together to celebrate. Fancy dress is the order of the day. All are encouraged to do their party piece, karaoke and magic, Irish dancing, poems and jokes.

Friday is a relaxed day with a chance to do a little shopping and visit the town of Lourdes itself. Lourdes is full of souvenir shops with water bottles (to carry Lourdes holy water back to Ireland), statues, candles, medals, videos and crafts. After dinner our group makes a final visit to the grotto. The group candle has been prepared by group members: decorated with symbols of the group, marked with prayers and intentions that the group wish to leave behind at the sanctuary.

The young people are given IHCPT diaries to record their experiences each day. IHCPT postcards are also written and posted to family and friends. During the week pilgrims sing the words of what has become the Trust anthem, Rise and Shine: "The Lord said to Noah there's going to be a flood, floody..."

The wonderful joy of the Trust pilgrimage is shared with all. Easter week in Lourdes is a very different week.



*IHCPT group on pilgrimage in Lourdes*



*John & Caroline Henry*

Comments from 'great', 'marvellous' to 'why can't Mass be like this every day' are usually the reaction of those who are in Lourdes for the first time with the Trust.

Whereas the Trust cannot bring all young people on pilgrimage, preference is given to those who are disadvantaged, ill, disabled or marginalised in society.

There is no fare / charge for the young person who travels. Carers pay their own fare and help to fundraise during the year in order to bring young people to Lourdes, e.g. organising fundraising events, church-gate collections, etc.

The Trust also provides respite care in its purpose-built home from home in Kilcuan, Clarenbridge, Co. Galway. Since its opening in 1998, Kilcuan has been the venue of many friendship weeks and has welcomed many organisations (including SBHI) with a similar ethos as The Irish Pilgrimage Trust. Situated in the beautiful woodland setting of the grounds of the Brothers of Charity, the building was designed with the special needs of our guests in mind. All rooms are en-suite and are wheelchair accessible. A carefully designed oratory welcomes all into a wonderfully peaceful sacred space.

I have been deeply enriched by my involvement with IHCPT, firstly having travelled to Lourdes as a young person

with spina bifida in 1988, then later as a carer whilst attending university in Galway, and presently as group leader of the Mayo group. The Mayo group (Group 95, our group colours being red and green obviously) normally comprises nine young people (between the ages of 12-18 years of age) and thirteen carers (including the group leader, group chaplain and group nurse).

Lourdes is the place where I gained confidence and was blessed to have met my wonderful wife, Caroline. I have got so much more from being part of the Trust than I could ever give back.

*– John Henry*

If you are interested in finding out more about the Irish Pilgrimage Trust please see details below:

IHCPT Headquarters  
The Irish Pilgrimage Trust  
Kilcuan, Clarenbridge, Co. Galway  
Tel: 091 796622 Fax: 091 796916  
Email: [info@irishpilgrimagetrust.com](mailto:info@irishpilgrimagetrust.com) ■

## IWA Youth Cafés

### **IWA Youth Service New Youth Café?**

A youth café is a relaxed, safe space for young people with or without disabilities to come and hang out, have fun, make new friends, and have new experiences and learn new skills.

Young people themselves will choose what activities take place in their youth café. They are encouraged to take an active part in the running of the project alongside adult volunteers. Youth cafés offer young people a chance to develop socially and personally, to reach their full potential, to work together, and to be involved in their community as a whole.

IWA youth cafés are open to young people with and without physical disabilities and a key goal of each café is to create an inclusive atmosphere where everyone is welcome and valued equally.

### **Is there any training for volunteers?**

Yes, the youth service will be running a full training programme for volunteers, including topics such as Working with Young People, Child Protection, basic Manual Handling and Health & Safety. IWA Youth Service staff will make sure they're fully prepared for volunteering

with us. Volunteers who complete the training will receive IWA certificates. All Volunteers are also required to agree to Garda vetting.

### **Where is all this happening?**

There are a number of youth café projects being developed in Dublin, Kildare & Wicklow area:

**North Dublin:** Clontarf No Name Club

**West Dublin:** Knockmitten Youth Café (Clondalkin)

**Kildare:** Athy Youth Café

**Wicklow:** Bray Youth Café

### **How do I get involved?**

If you'd like to know more please contact the IWA Youth Officer in charge of the relevant youth café.

#### **North Dublin & Wicklow:**

Stephen Moynihan  
01 818 6430 or 086 332 0449  
[Stephen.Moynihan@iwa.ie](mailto:Stephen.Moynihan@iwa.ie)  
(Clontarf & Bray)

#### **West Dublin & Kildare:**

Marion Dowling  
01 630 2414 or 087 050 6946  
[Marion.Dowling@iwa.ie](mailto:Marion.Dowling@iwa.ie)  
(Clondalkin & Athy) ■

## SBHI Torc



We would like to thank Scroll Work Signs & Crafts who made up these Torcs especially for our organisation. They are handmade using the finest craftsmanship. If you would like further details on their products: Scroll Work Signs & Crafts  
Silverstream Close  
Stamullen, Co. Meath  
Tel: 01 841 3033  
[brennersm@eircom.net](mailto:brennersm@eircom.net)



# Reeling in the Years

In mid-September, a small group of older adult members held an informal get-together with our CEO, Mr. George Kennedy. The purpose of this meeting was to discuss the Association's relevance to the different age groups it serves.

The consensus was that this Association has a blind spot when it comes to its older members and this is true across all aspects of the Association and its activities. As the life expectancy of the population in general continues to rise, so too does the age profile of members. Most of the group that met would be older than the majority of parent members.

It is recognised that the support levels needed to assist families with babies and young members can be high. Our needs are somewhat different but given that we are a growing group we do feel that our existence does need to be acknowledged. So we ask the following question: Is this an Association for children with SB and their parents or an Association for all those with SB regardless of their age?

There is a definite feeling among the adult members of SBHI that they have been the unseen and largely forgotten part of this Association. Perhaps now is the time to address these concerns. Adult members are continually striving to achieve and maintain independence but this should not be seen as not needing support from time to time. On the other hand, older members are more than willing to share their ongoing life experience for the benefit of younger members and their parents.

It is perhaps understandable that older members have been "invisible" because of their numbers. However,

as with society in general, this Association must acknowledge the growing number of older members and face the fact that the proportion of older members will continue to increase.

The **Ability** magazine is one forum of communication where older members could make contact with

the wider SB community. This group intend to submit regular articles covering a diverse range of topics relative to older members but these should also be of interest to fellow members and parents.

We would welcome any comments.

- David Crinion ■

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

If you are interested in volunteering please contact Sarah Jacobsen  
Family Support Communications Officer  
01 457 2329 or [sjacobsen@sbhi.ie](mailto:sjacobsen@sbhi.ie)



# A Wheelchair Paradise in the Sun

Have you ever dreamed of being able to push your wheelchair over the sand and swim in the sea? Well, in a resort in Italy you can do just that. San Felice de Cicero, in the Latino district, is situated an hour and a half from Rome. It boasts a totally accessible private beach. The beach is owned by Salvatore and Ellen d'Avagliano who run a holiday centre about two miles away. There are paving stones on the beach leading right down to the sea. The sunbeds are on the same level as the seat of your wheelchair for ease of transfer. There is a lifeguard who will bring you into the Mediterranean in a special wheelchair. You have the choice of staying in the chair or, if you are brave enough, you can have a swim. There is a snack bar on the beach or if you want to go for a stroll along the seafront. There are accessible transfers by bus from the centre to the beach each day. Transfers to and from the airport are also included.

The centre has all bedrooms en-suite, with wheel-in showers. Some are in the form of villas with areas to sit out in and sun yourself in the grounds. The rooms are basic but comfortable. This is a family-run complex and has a very homely atmosphere and is set in the countryside. The accommodation is full board and the food is typically Italian. If you like pizza, pasta etc. this is for you. Dining is al fresco. For the less adventurous there is always an alternative option. In the evenings, Topsy's bar is open for you to gather with friends and enjoy a drink or two! There is a grand fiesta every week with a fine buffet of typical Italian fare, with music and dancing afterwards.

Occasionally day trips are arranged to places like Rome, also Rome by night which is very enjoyable as the heat is not as intense as it is during the day. Of



course there is also the local market to browse in on a Tuesday. The old town is a pleasure to explore and the local lighthouse is the only remaining manual lighthouse in Italy.

If you are looking for the bright lights of the strip with discos, pubs etc and the comforts of a modern hotel this is not the place for you. However, if you want a holiday in the sun, fine food and wine, and a relaxed atmosphere, you need look no further. One thing to note though is that assistance is not provided so you need to bring your own carer or personal assistant if necessary. This year was my fourth trip

there. I would recommend September as it is generally not too hot, although this year was an exception. The Germans usually go in September with the Italians going in July and August. Some of the staff have good English but it is a good idea to go with friends as the language can be a bit of a barrier with the other guests at times. ■

Web: [www.centroferiesalvatore.com](http://www.centroferiesalvatore.com)  
Email: [germany@centroferiesalvatore.com](mailto:germany@centroferiesalvatore.com)  
Tel: 0049/0201/70 68 95

Bookings at:  
Reisebuero, Salvatore Avagliano,  
Janssenstr. 20, 45147 Essen.

– **Ann Richards**





# Date for your diary !!!!!

A fun evening of ice skating and socialising for all ages.

**When?** 6.30–7.30pm on Wednesday 9th December 2009

**Cost:** €8 per ice skater

**Location:** Charlestown on Ice, Charlestown Shopping Centre, Dublin.

Please contact Youth & Respite team in the National Resource Centre, Clondalkin on 01-4572329 for further details.



## Irish Gerontological Society Strategy

The Irish Gerontological Society aims to develop a broad portfolio of ageing research in Ireland, and the Executive Committee membership includes representatives of social, psychological and healthcare aspects of ageing. The Society recently launched its strategy for the period 2009-2012. For a copy of the strategy please email: [marianhughes@ireland.com](mailto:marianhughes@ireland.com) or phone 087 7463310. ■

## Family Support Workers Contact Details:

**Edel Browne Curran:** [ebrowne@sbhi.ie](mailto:ebrowne@sbhi.ie) 086-8520616  
Kildare/North Dublin

**Doreen Costello:** [dcostello@sbhi.ie](mailto:dcostello@sbhi.ie) 087-6527175  
Wexford/Waterford/Carlow/Kilkenny

**Hazel McGeough:** [hmcgeough@sbhi.ie](mailto:hmcgeough@sbhi.ie) 086-8194790  
Louth/Meath & Cavan/Monaghan

**Sarah Jacobsen:** [sjacobsen@sbhi.ie](mailto:sjacobsen@sbhi.ie) 085-7119062  
Family Support Communications Officer

**Sally Hibbs:** [shibbs@sbhi.ie](mailto:shibbs@sbhi.ie) 087-9395371  
Mayo/Leitrim/Roscommon/Galway

**Clare Riordan:** [criordan@sbhi.ie](mailto:criordan@sbhi.ie) 086-8194791  
Wicklow/South Dublin

**Or contact the office on 01 457 2329.**

As from 20th November, Judy Long is covering Doreen Costello's maternity post. She can be contacted on 087 6527175/ 056 7751599. Unit 5B, Prior's Orchard, John's Quay, Kilkenny. [dcostello@sbhi.ie](mailto:dcostello@sbhi.ie). On behalf of all our members, parents and staff I would like to take this opportunity to wish Doreen all the best.

## Lámh-a-Song Nursery Rhyme DVD Using Lámh Signs

Lámh, the manual sign system used by children and adults with intellectual disability and communication needs, has joined with Down Syndrome Ireland in producing and launching a new nursery rhyme DVD. The Lámh-a-Song DVD gives young users the chance to see Lámh signs on the TV screen for the first time, with each of the 15 popular songs on the DVD presented through vivid animation and a rich soundtrack that appeals to younger viewers. Lámh, which was developed in the early 1980s and has a vocabulary of 500 signs, is used in Ireland by children and adults with Down syndrome, as well as those with intellectual disability, physical disability and autism.



The DVD costs €15 plus €1.50 post and packing. See [www.lamh.org](http://www.lamh.org) for more details.

For more information, please contact Mary Cullen, Lámh Development and Liaison Officer, 059-9139657, Email: [info@lamh.org](mailto:info@lamh.org) Web: [www.lamh.org](http://www.lamh.org) ■



# The Irish National Organisation of the Unemployed

## Introduction to the INOU

The INOU was formed in 1987 against a backdrop of high unemployment, low participation rates, long-term unemployment and mass emigration. At the time, the scale of the unemployment crisis was such that collective action was needed both to bring forward potential solutions and to ensure that unemployed people had access to programmes and services and reasonable social welfare payments whilst unemployed.

From its fledgling roots, the organisation has developed over the last 21 years and now has 183 member groups including community-based resource centres, Citizens Information Services, Money Advice and Budgetary Services, national NGOs, trade unions and branches of unemployed people.

The INOU works at local and national levels on issues affecting unemployed people. They support local groups through services such as training, information and analysis of Government policies. The INOU also participates in Social Partnership through membership of the Community and Voluntary Pillar. The INOU has also a Northern Ireland division, the Organisation of the Unemployed Northern Ireland (OUNI).

## INOU Aims:

The aims of the INOU are set out in the organisation's Constitution. These are to:

- Seek to represent the interests and views of all unemployed people and their dependants at a national level;
- Campaign for an acceptable standard of living for all unemployed people and their dependants;
- Campaign towards the achievement of full employment at an acceptable rate of pay;
- Assist the establishment and development of local unemployed groups;



*John Stewart (INOU Co-ordinator), Minister Mary Hanafin and Ann Fergus (INOU Chairperson) at Launch of 15th Edition of Working For Work*

- Develop close liaison with the Trade Union movement while ensuring the autonomy of the INOU;
- Build on the common interest between the unemployed and employed;
- Build links with other national and international bodies that share the same interests.

**The Irish National Organisation of the Unemployed,**  
**Araby House,**  
**8 North Richmond Street,**  
**Dublin 1.**

**Email: [info@inou.ie](mailto:info@inou.ie)**

**Tel: +353 1 8560088**

**Fax: +353 1 8560090**

**Web: [www.inou.ie](http://www.inou.ie) ■**



*INOU marching on O'Connell Street, Dublin*



## Wicklow Branch

### Huge thanks from the Wicklow Branch to Martin Savage and staff of the Bank Of Ireland.

The **Give Together** Initiative was created by Bank Of Ireland to support their employees who wish to volunteer their time and support causes that are important to them. It involves commitment by Bank Of Ireland to give each of their employees one day's leave per year to volunteer their time to a cause of their choice. Bank Of Ireland has also put in place a fund to support these endeavours and which allows Bank Of Ireland to contribute to employee fund-raising achievements.

To this end, staff in Bank Of Ireland Computer Centre recently organised a charity day in aid of Spina Bifida and Hydrocephalus. The day involved payment for casual clothes, and various quizzes. One member of the team, Gerry Grehan, who undertakes sports psychology outside of work, held a chat on applying sports psychology to your everyday work. The big fund-raiser on the day was a cake sale. Staff were on site from 7:00am to set up and many others scoured their local supermarkets for donations. This culminated in a baking competition between two of the teams in the department.

A total of €2,151.00 was raised by the staff. The Bank Of Ireland Give Together Fund added a further €2,000.00 to this fund giving an overall total of €4,151.00.

### Calling All Young Adults From The Wicklow Branch

Next Social Night will be on Thursday the 26th November in The Martello Hotel, Bray. Hope to see you all there. ■



Wicklow Branch SBHI Bank of Ireland fundraiser



## Kildare Branch

Coffee Morning takes place the 1st Wednesday of each month in Little Joey's Play Centre, Naas, from 10.30am. It is going strong and it is a very useful way of parents exchanging their own expertise and experiences. For further information please contact Edel on 086 852 0616.

### 5-Day Life Skills Programme

The Kildare Branch in conjunction with Edel Browne Curran (Family Support Worker) are running a 5-Day Life Skills Programme, which will take place from Monday 7th – Friday 11th December 2009 in the Newbridge Respite Centre. It is a unique respite centre for people with physical disabilities.

The premises, located beside Cill Mhuire, houses five holiday, independent apartments and is operated by Cheshire Ireland for the benefit of people in Kildare and surrounding counties.

The life skills programme will assist members to learn the basic skills of daily living. Services may include training in the ability to travel about their community; to live independently in a private residence; to maintain health through self-care and use of medical services; to live within their personal income; to maintain grooming and appearance; and to learn cooking skills that can be used at home, with a focus on budgeting and maintaining a healthy diet.

All the places for this upcoming programme have been filled, but depending on the success of the programme in December, there is a possibility of running this on other occasions. If you have any queries regarding this, please contact Edel Browne Curran on 086 852 0616 or [ebrowne@sbhi.ie](mailto:ebrowne@sbhi.ie) ■

## Mayo Leitrim Roscommon Branch

The Branch Christmas Party is taking place on Sunday 6th December in the McWilliam Park Hotel, Claremorris, Co. Mayo.

Hoping to organise a night out for adult members in Castlebar on Friday 11th December. Please contact Sally Hibbs or any member of the Committee for further details.

## Kerry

There was a very successful meeting held recently in Kerry. Our CEO George and Chairman Fiach travelled down to make a presentation to the assembly. Frances Halligan hosted a very informative session on Continence issues. There was very good feedback from the meeting and they are very enthusiastic and keen to become involved with our Organisation. ■

## 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.

## Louth / Meath

The Brains of Louth/ Meath, got together recently to hold a very successful fundraising night. It was an extremely enjoyable occasion and a lot of fun.

## Youth Forum Day Out



The Youth Forum organised a day out at the Navan Nitro Nuts Club which took place recently. This was the first outing of its kind and all who attended enjoyed it very much. It is definitely an experience to be repeated.

For further information on this venue check out their website [www.nnn.ie](http://www.nnn.ie) ■



*Louth / Meath  
Table Quiz  
night out.*

**Keep in touch  
with your  
Youth Officer  
for further  
events.**

## Wexford Branch

Wexford Branch continue to hold their regular swimming lessons. Their Youth Officer, Bernadette Flood, is very active on the Youth Forum and would like to hear any ideas for events from the Wexford members.

## Dublin Branch

The new committee of the Dublin Branch are well and truly up and running. They will be in touch with all members in the Dublin area over the next couple of months and they would love to hear from you as to what you would like to see in your branch. Please do not hesitate to contact any of the committee members:

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

**Don't forget that all the branches out there are always here for you, our members.** ■



# SPINA BIFIDA HYDROCEPHALUS IRELAND

## WORLD CONGRESS

11<sup>th</sup> & 12<sup>th</sup> June 2010  
City West Hotel Dublin

Visit:  
[www.ifsbhireland2010.com](http://www.ifsbhireland2010.com)



In conjunction with  
INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA AND HYDROCEPHALUS

**We have a “first” for our organisation next year as we are hosting a World Congress in June 2010. We would ask that all the branches get behind this event and ensure that anyone who wants to attend does so. This will be a chance to hear speakers from Europe and the Continent. It will also be an opportunity to meet other members from several different countries. There is much interest in this event within the International Federation and we want to show them that our Association is up to it and we will give them a Congress to remember. So shoulders to the wheel and let's make 2010 even better for our members.**

### Welcome...

Spina Bifida Hydrocephalus Ireland and our voluntary Board of Directors, together with the International Federation for Spina Bifida Hydrocephalus, would like to invite all those interested to the Annual World Congress which takes place in Dublin on the 11th & 12th June 2010.

The venue for the congress is the 4 star Citywest Conference & Resort Hotel situated just 15km west of Dublin city. This makes it the perfect location for delegates and their families to explore both Dublin and the stunning landscape of the surrounding areas.

The World Congress will build on the success of previous conferences with the objective of further enhancing our understanding of Spina Bifida and Hydrocephalus. We will address topical aspects and learn about the latest advances in treatment, from both

professional and personal points of view.

This is an excellent and exciting opportunity to meet with people from the Spina Bifida Hydrocephalus community from all over the world, to share views, experiences and information and to network and collaborate with likeminded people.

The Congress will maintain the quality of previous conferences by focusing on new advances in intervention techniques and treatment while incorporating new and exciting features, such as Youth and Adult Forums and Insights Breakout sessions. All of this will take place in an environment which offers opportunities to liaise with other people, families and carers affected by the conditions and with other experts and professionals.

The programme is packed full of the foremost experts in the area of Spina

Bifida and Hydrocephalus from all over the world. This includes a distinguished line-up of keynote speakers such as: Dr Benjamin Warf (USA), Dr Timothy Brei (USA), Dr Trudi Edginton (UK) and Mr Pierre Mertens (BEL). Also included in the programme will be personal accounts from Eli Skattebu (NOR) and John Fulham (IRE).

Rarely, if ever, will such an opportunity present itself again for health professionals and families alike.

We are excited by the prospect of a truly successful congress in all of the traditions of the previous ones. And, whatever the weather may have in store for us, we can promise that this will be a thoroughly memorable and educational event.

We look forward to welcoming old and new friends to this exciting World Congress. ■