

SBHI WORLD CONGRESS – “WHAT’S THE NEXT STEP?”

DUBLIN, IRELAND 11TH & 12TH JUNE 2010. In Conjunction with THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS...

A RESOUNDING SUCCESS

On behalf of Spina Bifida Hydrocephalus Ireland and our voluntary Board of Directors, and together with the International Federation for Spina Bifida Hydrocephalus, we would like to extend a sincere thank you to the more than 400 delegates from Ireland and around the world who made this congress a resounding success.

In the words of President McAleese

“A familial spirit of solidarity and friendship characterises our local organisation and the International Federation. You came to Dublin to enhance the work, to search out and build on best practice, to interrogate all the pockets of knowledge and experience which need to be probed to ensure that babies, children, teenagers and adults with Spina Bifida and Hydrocephalus have access to the best treatments, advice, support networks, opportunities and lives that are lived to their fullest potential.”

This was achieved by each and every delegate who “shared their individual wisdom deeply and generously and listened attentively to those from other perspectives who shared with you. A new level of insight and enthusiasm was developed – enough to guide our next steps to a better world for those with Spina Bifida and Hydrocephalus.”

To view presentations please see below. Congress photos are available [here](#) and [here](#).

CHAired BY DAVID PROUD, JOHN FULHAM, CHRISTY O'NEILL, ELI SKATTEBU, HELEN HEALY, FRANCES HALLIGAN

YOUTH AND ADULT FORUM

As young adults with spina bifida, we all too frequently encounter individuals who simply don't know what spina bifida is. Of those individuals who have heard of spina bifida, they often have extremely negative perceptions of our disability. Awareness about the role of folate in preventing spina bifida is extremely important, but awareness about what spina bifida is and creating a positive public perception of spina bifida is equally important. The world needs to be aware of the importance of folate, but the world also needs to be aware that people with spina bifida can lead full, meaningful, and productive lives. JENNIFER FITZ-ROY. For more feedback from the youth and adult forum, [please click here](#)

BENJAMIN C. WARF MD

Hydrocephalus – ETV the way forward?

The burden of Hydrocephalus in East Africa is enormous. We have estimated that in the country of Uganda, between 1500 and 2000 infants per year develop Hydrocephalus. Taking

into account the reported birth rates and populations of other countries in the region, this can be extrapolated to 6500 infants per year in East Africa and more than 45000 infants per year in sub-Saharan Africa. *Unfortunately this presentation is not available online. Please contact Dr Warf directly on benjamin.warf@childrens.harvard.edu to request a copy.*

TIMOTHY BREI MD

Spina Bifida - Adolescent Beliefs, Expectations and Perceptions

Adolescents with Spina Bifida, though hopeful and positive in their attitudes toward Spina Bifida and generally able to perform activities of daily living independently are not fully engaged in the range of adolescent activities and decision-making or achieving full success in the areas of self-management and work experiences necessary to make a successful transition to adulthood. This talk will discuss these findings in greater detail and ideas on how professionals might facilitate or support persons with Spina Bifida to support autonomy in persons with Spina Bifida. To view this presentation [click here](#).

KATHLEEN J. SAWIN, DNS, CPNP-PC, FAAN

Enhancing Independence in Adolescents with Spina Bifida

Developing the skills to manage Spina Bifida and assume adult roles begins early in childhood. However, for the adolescent and emerging adult achieving these skills becomes critical. This presentation discussed research findings describing adolescent's, young adult's and their parent's expectations about when these skills should be mastered as well as areas of similarity and differences between parent and adolescent. Discussion will focus on the risk and protective factors associated with adolescents doing well and ways for professionals and families to assist the adolescent in the achieving these important skills. To view this presentation [click here](#).

MR. M.T.SATTAR. MBBS., F.R.C.S.I., M.Phil., F.R.C.S.

Hydrocephalus – From diagnosis to surgery – What's the Next Step?

The diagnosis, treatment and management of Hydrocephalus remains a complex issue, particularly for diagnosis and prognosis of Hydrocephalus, improving current shunt treatment, predicting its success and evaluating its functionality.

Mr. Sattar discussed in detail this complex issue from diagnosis, through classification and onto management. He approached this issue from a medical prospective which was balanced through his empathetic understanding of the condition formed through his vast experience working with those with Hydrocephalus and with SBHI. To view this presentation [click here](#).

ALICE RAJARATNAM Dip. COT. (MAOTI) Sr. Occupational Therapist, Manager SBHI Resource Centre, Dublin Branch

Drawing Smiles – Learning interventions for individuals with Spina Bifida

Alice presented her "Drawing Smiles" project which focuses on developing new learning strategies, improving ability and promoting ease of learning, though a journey of self-discovery where individuals discover their strengths, gain in self-confidence and

consequently improve their quality of life. The project is about drawing as many smiles as possible!

The project was borne from Alice's concern for children in mainstream education who struggled daily in their academic learning and performance. Educators appear to resolve their classroom problems and their lack of understanding of "Hydrocephalus" by "labelling" these children as being "dyslexic", "autistic" and "hyperactive", rather than seek the root cause of the problem. To view this presentation [click here](#).

DR CAROLINE TEULIER, PH.D

Understanding motor development during the first year of life

Caroline discussed her teaching and research interests which focus on the evolution of motor coordination when humans learn a new motor skill across the life span. Caroline's research emphasis focusing on babies with myelomeningocele and babies with typical development on the development of their walking pattern. To view this presentation [click here](#).

DR TRUDI EDGINTON

Cognitive and behavioural implications associated with Hydrocephalus and Spina Bifida.

This focused on the implications of these cognitive and behavioural difficulties associated with Hydrocephalus and Spina Bifida and will review the specific role of self-awareness and insight. This research has investigated the role of self-perception and carer perceptions of cognitive abilities and has revealed specific areas of disparity and concordance between subjective self-perception, carer perception and actual cognitive performance (Edginton et al, 2010). These findings have important implications for the role of effective metacognition and cognitive appraisal in understanding and developing strategies to cope with the cognitive, emotional and behavioural difficulties associated with Hydrocephalus and Spina Bifida. To view this presentation [click here](#).

TIMOTHY BREI, MD & KATHLEEN J. SAWIN, DNS, CPNP-PC, FAAN

The Experience of Parenting an individual with Spina Bifida

Parenting a child with a disability can be stressful and, in the case of Spina Bifida, is complicated by both the presence of physical challenges and the possibility of learning disabilities. In this session we will present research related to parenting in Spina Bifida, and we will have open discussion and dialogue about parenting individuals with Spina Bifida and ways for parents to facilitate promoting positive outcomes for their children with Spina Bifida. To view this presentation [click here](#).

Spina Bifida – Self Concept, Family and Peer Relationships

Although the overall self-concept for many youth with Spina Bifida is positive, youth face many challenges living with Spina Bifida such as developing peer relationships, school-based issues, and bullying and teasing. Findings from studies of adolescents will be presented including the protective impact of close relationships with parents. Discussion will address strategies to enhance self-concept and peer relationships. To view this presentation [click here](#).

FRANCES HALLIGAN & BERNADETTE KERRY

Skin Care, Bowel & Bladder Interventions – What's the Next Step?

Frances presented and discussed Spina Bifida as a multifaceted condition with a particular focus on bowel & bladder interventions. She offered support and guidance on the condition, what the future holds for the person with Spina Bifida and what treatments and management interventions are available. She also discussed how to meet the needs of the person with Spina Bifida in relation to their continence choices and the social stigma that can be associated with incontinence. To view this presentation [click here](#).

Bernadette discussed the relationship between Spina Bifida, Continence and Skincare and how this relationship can be managed. She offered delegates an in-depth understanding of this relationship by looking at how the person with Spina Bifida can best manage their skincare, what strategies to use and how best to accommodate their personal needs, while balancing the importance of a regular skincare routine.