Martine Austin

Martine Austin is Programme Manager Global Prevention, for IF. Based in the UK, Martine joined IF in 2015 to build upon one of IF’s key objectives, primary prevention, developing the new Global Prevention Initiative.

An experienced voluntary sector worker, with a specialist knowledge of spina bifida, hydrocephalus, folic acid and neural tube development, Martine previously spent over 20 years with the UK charity SHINE, Europe’s largest organisation supporting those living with Spina Bifida and Hydrocephalus. Whilst at SHINE, she fulfilled a variety of roles, the last 4 years of which were focussed on developing a highly successful primary prevention campaign, working with government bodies, health professionals, and women of childbearing age to develop strategies to raise awareness of the importance of preconceptional folic to reduce the risk of pregnancies being affected by neural tube defects.

Martine is committed to improving the lives of those living with these lifelong conditions and has a passionate interest in research into maximising their primary prevention. Martine is currently studying towards a Masters Degree in Public Health.

Godfrey P. Oakley

Godfrey Oakley, Jr. MD, MSPM completed his MD at the age of 25 from the Bowman Gray School of Medicine, received a Masters in Preventive Medicine at 35 years from the University of Washington, School of Public Health. He was the first Director of the Division of Birth Defects and Developmental Disabilities of the Center for Disease Control and Prevention (CDC) and led the fight to successfully get mandatory folic acid fortification in the United States beginning in 1996. He joined Emory as a professor in 1998 and has worked to monitor the prevention of folic acid preventable spina bifida and anencephaly, having co-authored 4 papers on this topic. He is an elected member of the National Academy of Medicine.

Folic acid and the prevention of spina bifida FP and anencephaly FP, 25 years after proof that folic acid prevents

**Affiliation:** Center for Spina Bifida Prevention, Department of Epidemiology, Rollins School of Public Health of Emory University, Atlanta, GA

**Summary:**

In 1991, the MRC paper was published proving that folic acid would prevent spina bifida and anencephaly.

The GOOD NEWS 25 years on is the mandatory folic acid fortification programs prevent 35,000 children a year from having spina bifida FP or anencephaly FP (folic acid preventable spina bifida and folic acid preventable anencephaly). In the last decade 350,000 children have been protected. Mandatory folic acid fortification in the United States has prevented almost all if not all spina bifida FP, saving $150 for each dollar spent on fortification, saving a half a billion dollars a year. We know that the non folic acid preventable rate for spina bifida and anencephaly is 0.5 per 1000 or 1 in 2000. The BAD NEWS is that each year still 200,000 children develop these totally preventable birth defects. Thus, in the last 10 years, 2 million children around the world, including Europe, have unnecessarily had these serious conditions. We understand there are powerful un-recognized epidemics of spina bifida FP and anencephaly FP. In Boston in the 1930s, the epidemic was 10 fold. The epidemic in Belfast in the 1960s was 17 fold. The epidemic in northern China today is 20 times what it should be. In India at least 10, in Ukraine 4 times and most of Europe 2 times what it should be. To add perspective, the global epidemic of birth defects caused by the drug thalidomide damaged 10,000 children in total. Each year there are 20 times as many spina bifida FP and anencephaly FP as there were ever cases of thalidomide babies. Not preventing these birth defects by mandatory folic acid fortification is like having the polio vaccine and not using it. The failure of European countries to require mandatory folic acid fortification is, I am sorry to say again, PUBLIC HEALTH MALPRACTICE! European countries fail thousands of children and their families each year because they do not require mandatory folic acid fortification—a proven, highly effective, cost effective and safe public health intervention.

OPPORTUNITY: If prevention is to happen, the spina bifida community must be the force that makes it happen. Lyle Thurston, from New Zealand, is a parent champion whose persistence and partnership building is why Australia has near total prevention of spina bifida FP. I think total prevention will occur only when the spina bifida community in each country provides the leadership to see that mandatory folic acid fortification happens. It is wonderful that prevention is a part of the agenda of IF. I am proud to have partnered with IF to apply to the MacArthur Foundation for a grant to triple the global prevention over the next 6 years. If we do get resources to accelerate the pace, we will be working with as many in the spina bifida community as we can. Preventing spina bifida by folic acid fortification will save a lot of money that can be used to improve care for those with spina bifida and hydrocephalus - another goal of IF.
day 1 FRIDAY 28 OCTOBER

PREVENTION

Neural Tube Defects, Risk Factors, and Folic Acid

Aiguo Ren has been working in the field of birth defects research since 2000, focusing on environmental and genetic determinants of birth defects. Dr. Ren is currently professor of epidemiology at the School of Public Health, Director at the Institute of Reproductive and Child Health, and Director of Ministry of Health Key Laboratory of Reproductive Health, Peking University, China. He serves as the Chair of the Branch for Birth Defects Prevention and Control and Molecular Genetics in the Association of Maternal and Child Health Care of China. He is a member of Teratology Society and Editor-in-Chief of Chinese Journal of Reproductive Health.

Summary
The distribution of neural tube defects (NTDs) in China is characterized by higher prevalence in northern provinces than in southern provinces. A nationwide hospital-based survey conducted in 1986 to 1987 showed a perinatal (28 gestational weeks or greater) rate of 19.2 per 10,000 births for male and 35.7 per 10,000 births for female. In a northern province, the rate was 88.5 per 10,000 births for male and 144.0 per 10,000 births for female. The nationwide perinatal rate decreased to 1.8 per 10,000 births for male and 2.55 per 10,000 births for female in 2015.

However, the current rates were considered underestimations of the true population rates because of increasing use of ultrasound scan and elective pregnancy terminations following prenatal diagnosis of an NTD. Higher prevalence of NTDs in the rural populations than in the urban populations is another characteristic in NTD distribution.

The role of folate and environmental pollutants in NTD occurrence has been investigated extensively. For folate, the main findings include that 1) the blood folate level in women planning to become pregnant was very low, and dietary folate intake was extremely low in the high risk population; 2) a massive folic acid supplementation program began to implement in 2009 and folic acid supplements were available to all women with a rural household registration free of charge; 3) majority of women took folic acid supplements some time from before through early pregnancy, but a large proportion of women in rural areas began doing so when they knew that they were pregnant; 4) the nationwide NTD prevalence continues to decline but the rate remains high in some areas.

For environmental pollutants, polycyclic aromatic hydrocarbons (PAHs), a group of ubiquitous environmental pollutants, have been found to be associated with NTD risk: 1) a higher PAH concentration in maternal serum was associated with an elevated risk of NTD, and the association showed a dose-response pattern; 2) a higher PAH concentration in placental tissue was associated with an increased risk of NTDs in a dose-response manner; 3) higher levels of PAH-DNA adducts in cord tissue and cord blood in NTD cases than in healthy newborns were observed; 4) higher levels of oxidative stress markers were observed in serum of mothers of NTD cases than in mothers of healthy controls; 5) benzo(a)pyrene, a typical PAH, has been shown to be able to induce NTD in mice.

Low blood folate and higher PAH exposure may interact in inducing NTDs. Improvement in population folate nutrition and control of environmental pollution may help further decrease NTD prevalence.

Vitamin B12, Folic Acid metabolism, and NTDs

Anne Molloy is Associate Professor in the Discipline of Clinical Medicine, School of Medicine and Director of the Vitamin Research Laboratory, Trinity College Dublin in Ireland. She has 30 years’ experience in researching the molecular, nutritional and genetic factors that influence folate, vitamin B12 and related micronutrient function within the body. She has particular interest in understanding the role of folic acid in prevention of neural tube defects. In this research, her laboratory has received major funding over nearly twenty years and continues to collaborate with two institutes of the National Institutes of Health in the USA, both Eunice Shriver National Institute for Child Health and Human Development (NICHD) and the National Human Genome Research Institute (NHGRI). She has more than 150 peer-reviewed publications and over 20 reviews, editorials and book chapters. She is an associate editor of several nutritional journals and has served on expert advisory panels for the World Health Organization, the Food Standards Agency in the UK and the US Office of Dietary Supplements.

Summary
The role of folic acid in preventing neural tube defects (NTDs) is established and several studies suggest that this protection may extend to some other birth defects. Moreover, the evidence of NTD prevention has stimulated a re-evaluation of the role of low maternal folate status in other adverse pregnancy events, some of which were suspected for several decades to be linked to maternal folate status. These include spontaneous abortion, recurrent pregnancy loss, stillbirth, abruptio placenta and pre-term birth.

The metabolism of folate is closely linked to vitamin B12, and it is becoming recognized that there is a much higher global prevalence of low vitamin B12 status among women of childbearing age than hitherto suspected. Consequently, reports of the effects of nutritional vitamin B12 deficiency on maternal and neonatal health are appearing more often in the literature. The role of vitamin B12 in NTDs is of particular interest. There are no trials demonstrating that vitamin B12 can prevent NTDs. However, many studies that examined maternal and amniotic fluid vitamin B12 status both during and after an NTD affected pregnancy suggest that low maternal vitamin B12 status is an independent risk factor for having an NTD affected pregnancy. This presentation will review the current literature on folate and vitamin B12 in relation to NTDs.
Inositol for prevention of neural tube defects - results of the PONTI pilot study

Affiliation: UCL Institute of Child Health, 30 Guilford Street, London

Summary
Use of folic acid (FA) supplements in early pregnancy can prevent a proportion of neural tube defects (NTDs). However, there is increasing evidence that many NTDs are FA-non-responsive. Inositol (vitamin B8) may offer a novel approach to preventing FA-non-responsive NTDs. Inositol prevents NTDs in mice, and was well tolerated by women in a small study of NTD recurrence in Italy. We conducted the PONTI (Prevention Of Neural Tube defects by Inositol) pilot study designed to gain further experience of inositol usage in human pregnancy.

The study was a preliminary to a future large-scale controlled trial to evaluate the effectiveness of inositol in NTD prevention. Study subjects were UK women with a previous NTD pregnancy who planned to become pregnant again. Of 117 women who made contact, 99 proved eligible and 47 planned to become pregnant again. Of 117 women who had given birth to NTD-affected infants, but in only 10% of mothers of non-malformed infants. This provocative study suggests that maternal autoantibodies that bind to the folate receptor can block the intracellular uptake of folate by epithelial cells and increase the risk for spina bifida and other congenital anomalies. The lack of folic acid available to the developing embryo secondary to a protective or blocked folate receptor can result in cellular growth inhibition by blocking the uptake of folate (Ebel et al., 2007). These observations could explain the beneficial effect of periconceptional folate supplementation.

Our laboratory was able to validate the original Rothenberg study in mid-gestational serum samples from a cohort of California women carrying NTD-complicated pregnancies (Cabrera et al., 2008).

We have now extended this finding to a number of different populations from around the world. Mothers with high titers of blocking antibodies to the folate receptor have a higher risk of having babies with spina bifida. Additional population studies are being conducted in the Finnell Laboratory to determine if the risk associated with high antibody titers holds true for other complex-folate responsive birth defects such as craniofacial defects and outflow tract defects of the heart. Folate receptor autoimmunity has also been linked to both cerebral folate deficiency and autism spectrum disorders, as supplemental folate has been shown to be therapeutic in those individuals and others. This suggests that genetically altered folate levels suggest that genetically altered folate levels induce both neurobehavioral deficits and metabolic changes that mirror those seen in autism. This presents a novel target for intervention.

Pathogenic autoimmune responses arise when functional proteins become post-translationally modified such that they are damaged and no longer recognized as self. Autoantibodies targeting such proteins may cross-react with the unmodified proteins, causing a loss of function. Two such post-translationally modified, N- and S-homocysteinylated, are directly tied to folate metabolism and may initiate the processes that lead towards abnormal embryogenesis and birth defects such as spina bifida. The role of folate receptor antibodies in susceptibility to spina bifida will be the focus of this presentation.
Control of Neonatal Sepsis and Hydrocephalus in sub-Saharan Africa

**Affiliation:** Penn State Center for Neural Engineering

**Summary**

The majority of the world’s hydrocephalus of infancy is likely related to prior neonatal sepsis. Nevertheless, the microbial origins of neonatal sepsis remain largely uncharacterized in the developing world. Similarly, the routes of these infections remain uncharacterized. The number of infants affected is so large that this is in effect a neurosurgical epidemic for which there is no effective surgical option at the population level.

In this project, we are characterizing neonatal sepsis at regional hospitals throughout Uganda, and through exhaustive follow-up, identifying the sentinel cases that go on to develop hydrocephalus. Most bacteria cannot be grown in laboratories, and substantially fewer are recovered in the laboratories of the developing world than in the industrialized countries. We are employing next-generation DNA and RNA sequencing technologies to perform a broad screen for all microorganisms present in such infants – what we term the Neonatal Septisome. We seek the additional characterization of sequential and polymicrobial co-infections, especially the interaction of viruses and bacteria, that may underlie these conditions. We further seek a proteomic assessment of the characteristics of the host immune response to stratify the unifying factors of this syndrome when the causal agents are disparate. In recent work, we have recovered a bacterial agent through culture in less than 1/3 of cases of neonatal sepsis, but through genomics sequencing have uncovered a substantial number of leptospirosis cases where the bacterial agent cannot be recovered in diagnostic laboratories. Such infections are enzootic with the domestic animals that these infants are in close contact with. We are comparing genomic sequences from postinfectious hydrocephalic infants with age matched control populations presenting with congenital non-postinfectious origins of their hydrocephalus. We have uncovered a strong climate link to seasonal rainfall to neurological case numbers.

Our long-term goal is a model-based feedback control strategy seeking a rational, and optimal, framework to better treat and prevent neonatal sepsis and postinfectious hydrocephalus in developing countries, and in particular sub-Saharan Africa, where such infections and their sequelae remain out of control. This model-based framework will readily adapt to other regions of the developing world, with the potential for a substantial impact on global infant health.

Steven J. Schiff, Brush Chair Professor of Engineering and Director of the Penn State Center for Neural Engineering, is a faculty member in the Departments of Neurosurgery, Engineering Science and Mechanics, and Physics. A Pediatric Neurosurgeon with particular interests in Epilepsy, Hydrocephalus, Sustainable Health Engineering and Global Health, he holds an S.B. degree from MIT, and a Ph.D. in Physiology and M.D. from Duke University School of Medicine. His book, Neural Control Engineering, was published by the MIT Press in 2012. Dr. Schiff has been listed in the Consumer’s Research Council of America’s guides to top physicians and surgeons, serves on the editorial boards of multiple journals, and is a Fellow of the American Physical Society, the American College of Surgeons, and the American Association for the Advancement of Science. In 2015 he received the NIH Director’s Pioneer Award. He plays the viola in the Nittany Valley Symphony in an out of tune manner.

The World Health Organization response to the 2010 birth defects resolution

**Affiliation:** Evidence and Programme Guidance, Nutrition for Health and Development, World Health Organization, Geneva, Switzerland

**Summary**

In 2010 the Sixty-third World Health Assembly considered the report on birth defects and approved a resolution urging Member States “to set priorities, commit resources, and develop plans and activities for integrating effective interventions that include comprehensive guidance, information and awareness raising to prevent birth defects, and care for children with birth defects into existing maternal, reproductive and child health services and social welfare for all individuals and effective interventions to prevent tobacco and alcohol use during pregnancy” and “to support families who have children with birth defects and associated disabilities, and ensure that appropriate habilitation and support is provided to children with disabilities”.

WHO’s Director General was asked “to support Member States in developing national plans for implementation of effective interventions to prevent and manage birth defects within their national maternal, newborn and child health plan, strengthening health systems and primary care, and food fortification strategies, for the prevention of congenital anomalies and preterm births in headquarters and in the WHO regions. A birth defects surveillance toolkit has been published by the Birth Defects Surveillance Working Group, made up of clinicians, epidemiologists, health communication specialists, and health education specialists from WHO, ICBDSDR, and CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD). Also WHO has updated evidence-informed guidelines for the diagnosis of folate insufficiency in women with red blood cell concentrations.

Maternal folate insufficiency increases the risk of having a baby with a neural tube defect. WHO continue to promote preventive public health measures. Supplementation with folic acid and other B vitamins have demonstrated to reduce risk of occurrence and reoccurrence of neural tube defects. Recommendations on fortification of staple foods such as wheat and maize flour, and rice with folic acid and other B vitamins as well as supplementation programmes with folic acid reaching adolescent girls and women have been updated.
Preventable neural tube defects in Europe and the predicted effect of folic acid

**Affiliation:** University of Aarhus, Aarhus, Denmark

**Summary** Reducing child mortality and morbidity is an integral part of Europe strategy to achieve sustainable health. A significant part of neural tube defects can be prevented by supplementing folic acid (FA) to women before conception. Voluntary FA fortification in several European countries caused no reduction in NTDs in the last 10 years.

Objective: we examined the prevalence of two major FA-responsive NTDs - spina bifida and anencephaly in Europe; and estimated cost savings associated with preventing these defects in a specific country and year (Germany, 2009). Design: We examined live births, fetal deaths or stillbirths, and pregnancies terminated for fetal anomalies following prenatal diagnosis during years 2000 - 2010 in the European Surveillance of Congenital Anomalies (EUROCAT) (1). We assessed prevalence per 10,000 births (95% confidence intervals) using the EUROCAT data. Cost analysis were performed in Germany assuming theoretical prevention levels of 40% or 50% of NTD cases, should Germany implement FA fortification. Results: Each year, over 5000 births were affected with NTDs in Europe, about one fifth of which (~1000) were in Germany (11.0 per 10,000 births). Over 55% of cases with spina bifida were terminated prenatally. The estimated lifetime direct medical cost saving for the live births in 2009 in Germany was €32.9 million assuming 50% reduction, or €26.1 million assuming a 40% risk reduction. Conclusions: Europe has a two-fold epidemic of NTDs compared to countries that implement FA fortification. We here demonstrate the potential of live- and cost-saving by implementing FA fortification as a public health strategy. Primary prevention of NTDs by FA is expected to reduce child mortality and morbidity and reduce costs for health care.

Filip Van Bockstaele

Filip Van Bockstaele has completed his PhD on the microstructure and rheology of bread dough in 2011 at Ghent University. Since then he is working as assistant professor at the laboratory of cereal technology where he is responsible for teaching, research and collaborations with the food industry in the field of cereal technology. He specializes in the processing of cereals and the production and quality control of cereal based food products, especially bakery products. Since three years he is involved in the organisation of the QA/QC training on flour fortification with Smarter Futures.

**Affiliation:** Ghent University, Faculty of Bioscience Engineering, Laboratory of Cereal Technology, Ghent, Belgium

**Summary** Vitamin and mineral deficiencies, in particular deficiencies of iron, iodine, vitamin A and folic acid, cause significant economic losses through increased disabilities and mortality, reduced cognitive development and decreased work productivity of adults. Flour fortification involves adding essential vitamins and minerals to cereal flours (wheat, maize, sorghum) as it is produced, which in turn makes foods prepared with fortified flour more nutritious. Iron, zinc, folic acid, and other B-vitamins are commonly added to wheat and maize flours. This has proven to be a cost-effective means of reducing the prevalence of iron deficiency anaemia and neural tube birth defects and improving overall health. Flour fortification is applied both in developed and developing countries. Regions which implemented fortification programmes include North and South America, West Africa, Middle East and Australia. Specifically for Africa, the number of countries which implemented mandatory flour fortification increased from 2 in 2004 up to 27 in 2016. To obtain a successful national fortification programme, industry and government partners need to take their responsibility. They need to collaborate to produce high quality fortified foods. However, national fortification programmes are often hampered by poorly established or badly designed protocols and monitoring systems, lack of resources and insufficient qualified laboratory resources and expertise to test product samples. As these problems are undermining existing and possible future flour fortification programmes, training on quality assurance and quality control for flour fortification is an essential requirement for countries that are implementing or planning to embark on flour fortification. Since several years, the Smarter Futures project is organizing QA/QC trainings around Africa to support implementing fortification programmes. The strength of such a training is that it brings together the national stakeholders concerning food fortification which are the milling industry and the government agencies (health department, food control, etc.). This presentation will first focus on some technical aspects and challenges related to flour fortification. Further, the setup of the QA/QC training on flour fortification of May 2016, held in Kampala, Uganda will be presented. In this year’s edition, Ghent University, through support of VLIR-UOS (Belgian development cooperation), were able to include 14 participants from academia (MSc – PhD students and lecturers) as a third stakeholder in the training.
Denhard de Smit
Denhard de Smit, PhD, epidemiologist & healthcare researcher. Director of MediClara Projects, a company that supports health care workers in implementing changes and improvements effectively, and senior researcher at the department of Community Genetics and Public Health Genomics, VU Medical Centre Amsterdam (guest position). He has been involved in the education about and prevention of birth defects over the past twenty years. His focus is on the role of primary care workers like family physicians, midwives, community pharmacists, Well Baby Clinics staff and other public health bodies. He developed and evaluated the first guidelines on this topic for Dutch family physicians and midwives. After that his attention was directed to the primary prevention of neural tube defects by means of folic acid supplementation, in close collaboration with Academic Institutions, National organisations of care providers, the Ministry of Health as well as Pharmaceutical Companies his company developed targeted strategies to promote the periconceptional intake of folic acid supplements. His work is also related to the broader promotion of preconception health behavior that contributes to the optimization of the health of the pregnant mother and her future child.

Dutch public health campaign on folic acid
Affiliation: MediClara, Abcoude, Netherlands/Community Genetics & Public Health Genomics, Clinical Genetics & EMGO Institute for Health and Care Research, VU University, Amsterdam
Summary
From 1994 to 2015. Between 1994 and 2015 several attempts were undertaken to promote periconceptional folic acid (FA)-intake. The initiatives will be briefly described and the lessons learned with respect to feasibility and effectiveness will be presented and discussed. The initiatives comprise amongst others: mass media and intermediary campaigns; implementation of online sources: involvement of community pharmacies; involvement of Well Baby Clinics; implementation of primary care preconception consultation. We will explain why the target of 70% adequate FA-intake in 2010 as set by the MoH in 2005, was not achieved.

Where we are in 2016
In 2005 the adequate FA-intake reached a level of 50%, with marked differences between the lower- and higher educated. No increase was seen thereafter with subsequent effects on the prevalence of NTD’s. Apart from social inequalities also a marked difference is found in the adequate FA-intake between first and later pregnancies. Currently no major health authority body takes leadership or relevant action to promote FA-intake. Due to the introduction of market-mechanisms in Dutch health care in 2006 it has become more difficult to raise funds by NGO and private players in this field.

Future
Since the first FA-campaigns it has become clear that detailed designed and all comprising health promotion programmes are needed if we aim to achieve relevant and lasting effects. The knowledge, tools and experienced professionals to do that are now available. An initial outline of such a programme will be presented, based on the ‘Planning Health Promotion Programmes using an Intervention Mapping approach’ (Bartholomew et al). A prerequisite for such an approach however is that a dedicated and sufficiently funded body takes responsibility leadership. The feasibility of some possible solutions will be discussed. Finally a number of general questions that interfere with the understanding of the problems and the chances of FA-intake promotion will be discussed – Should we handle FA-supplementation as a single issue or integrate it in broader preconception care? How does FA-profilaxis do compared to abstinence of smoking and alcohol? What role do pregnancy planning play and what do we mean by ‘planned pregnancies’?

Aliki Weakland
Aliki Weakland has a MPH in Health Policy and Management from the Rollins School of Public Health of Emory University, a MSW in Social Service Administrative Practice from the Florida State University, and a BS in Political Science from the University of Connecticut. Aliki has over 25 years' experience developing and directing leadership and communication strategies for organizational improvement. She have worked extensively in social services and public health, in public and private sectors. Aliki is the founder and principal strategy consultant and leadership development coach at Core Engagement LLC and serves as the executive director of PUSHE.

Lieven Bauwens
Lieven Bauwens is the Secretary General of the International Federation for Spina Bifida and Hydrocephalus, and the chair of both Child-Help Belgium and Child-Help International, a charity dedicated to help children with SB/H in developing countries. In those capacities, he is a global advocate for the rights of persons with the disabilities while engaging actively in primary prevention of these impairments. He is a board member of the Food Fortification Initiative and the International Disability Alliance. He is also a founding partner of the global alliance for Spina Bifida and Hydrocephalus, PUSH, and Child-Help in Belgium, Germany, France and the Netherlands as well as the International umbrella. A background in Architecture and Business Administration, Lieven got involved in IF as brother of a young man with Spina Bifida and Hydrocephalus.

PUSH! Global Alliance: Better Together
Affiliation: International Federation for Spina Bifida and Hydrocephalus; Core Engagement LLC, Fort Collins Colorado USA
Summary
This presentation will provide an overview of the impetus for and formation of the PUSH Global Alliance. It will also describe the development and use of the first-ever global scorecards on spina bifida and hydrocephalus prevention and care. The scorecards are designed to aid policy makers and advocates in accelerating surveillance and prevention, and improving the care and quality of life for all affected by these conditions. They can also guide the PUSH Global Alliance in interventions within the country.
GROWING BRAINS: WHAT WE NOW KNOW ABOUT TREATING INFANT HYDROCEPHALUS WITHOUT SHUNTS

Affiliation: Professor of Neurosurgery, Harvard Medical School; Hydrocephalus and Spina Bifida Chair, Boston Children’s Hospital

Summary
Our understanding about what causes hydrocephalus and how it is best treated is changing. Since the 1950s, infant hydrocephalus has been treated by shunt placement, which creates life-long dependence upon a medical device with a high failure rate. Shunt-dependence is problematic and expensive in developed countries, and a life-threatening condition in the developing world.

ETV/CPC was introduced as a treatment alternative in 2001, with the first results reported in 2005. Infants with spina bifida in particular have benefited from this procedure, with fewer than 20% now requiring shunt placement in our current practice. This presentation will review what we have learned about ETV/CPC over the last decade in regard to its indications and outcomes.

New preliminary data from an ongoing randomized prospective trial will be presented that suggests ETV/CPC is as effective as shunt treatment for early childhood brain growth and development while avoiding the life-time risks of failure and infection. The case will be made for using shunt placement only as the last resort rather than the primary treatment for infant hydrocephalus.

LET’S TALK ABOUT SEX...AND MY SPINA BIFIDA. HOW DO YOUNG PEOPLE WITH SPINA BIFIDA TALK ABOUT SEXUALITY WITH THEIR PARTNERS?

Affiliation: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital; Dalla Lana School of Public Health and Rehabilitation Sciences Institute, University of Toronto

Summary
PURPOSE: Research focusing upon sexuality in those living with spina bifida has not specifically addressed adolescents and has been largely quantitative in design. Our study qualitatively explored how young people with spina bifida think about and discuss sexuality with their sexual and romantic partners in the context of their disability. This can help us understand how healthcare providers can best work with young people to prepare them for romantic and sexual relationships.

RESULTS: There were mixed views on the importance of disclosing their condition to partners. While some participants strongly believed that their disability was important to share with partners, others worried that potential partners would focus on the disability rather than them as a person. Participants reported challenges about the timing of disclosure, lack of confidence in their abilities to express their sexual needs and fears of rejection. After disclosure, however, participants often experienced increased confidence in themselves and their relationships. Participants identified a lack of spina bifida-specific sexual education and a desire to learn more from their healthcare providers.

CONCLUSION: The findings underscore the importance of empowering young people to become more confident talking about their disability, especially in the context of sexual and romantic relationships. Being able to discuss their abilities, needs and desires could potentially facilitate the development of healthy relationships during their transition to adulthood.
Parenthood and Spina Bifida

Affiliation: Vereniging voor Spina Bifida en Hydrocephalus, Belgium, University Hospital Gasthuisberg, Leuven, Belgium

Summary
Through medical advances and improved care, children born with Spina Bifida are now living into adolescence and into adulthood. In earlier days, misconceptions prevailed about the sexuality and fertility of people born with Spina Bifida. It was often assumed that men and women with Spina Bifida could not have children. As a result, very limited information exists in medical literature on the topic of parenthood and Spina Bifida. Mario Sel and An Meeussen are two adults born with Spina Bifida and both are proud parents. Mario is the father of 9-year-old twins, and An is the mother of two young children, 6 and 8 years of age. During this session, they will speak about their experiences, starting from the moment of having a wish for a child until their present-day situation. They will discuss the issues they encountered with regard to fertility, pregnancy and parenting, focusing on both physical and psychological aspects. Gynaecologist Kristel Van Calsteren will expand on the topic by discussing the medical aspects of parenthood and spina bifida.

Mario Sel
Mario Sel was born on June 20, 1980, in Duffel (Belgium) with Spina bifida and hydrocephalus. As a child, he took part in several activities of the Flemish Association for Spina Bifida and Hydrocephalus (VSH). When he reached 18 years of age, Mario started participating as a volunteer for VSH and in the summer of 2009 he received a part-time job as the education officer of the Flemish association. A job he still holds today. Being the father of 9-year-old twins, he still has some time left, next to his job at VSH and the busy family life, for hand biking and to volunteer for Child-Help, of which he is a board member for several years now.

Kristel Van Calsteren
Kristel Van Calsteren received her medical degree from the Katholieke Universiteit Leuven, Belgium in 2004. In 2009 she successfully defended her PhD thesis which handled different aspects of cancer and cancer treatment during pregnancy. She completed her specialist training in obstetrics and gynaecology in 2011 and her maternal-fetal medicine training in 2012 at the Katholieke Universiteit Leuven, Belgium. Currently she is a member of the staff of feto-maternal medicine at the university hospital Gasthuisberg in Leuven, Belgium. She has a special interest in high risk maternal medicine and the use of medication in pregnancy (pharmacokinetics, transplacental transfer, toxicity) in pregnancy. Together with Frédéric Amant, she initiated INCIPI: international network on cancer, infertility and pregnancy. She is a member of the ESGO task force on ‘Cancer in pregnancy’.

An Meeussen
An Meeussen was born on May 29, 1980, with Spina bifida. She is married to Kristof and they have two children of 8 and 6 years old. An works full time as a civil servant for GO! (Official education in the Flemish community of Belgium). She is a member of the Flemish Association for Spina Bifida and Hydrocephalus (VSH).

Martijn Klem
Martijn Klem is the father of three children, one of them having a congenital disability. Since 2011 he is director of BOSK, the association where parents and people with congenital disabilities meet and support each other. The BOSK gathers experiences and knowledge about living with a disability or with a kid with a disability. The BOSK disseminates these experiences and uses them to develop products for their members and to feed its advocacy efforts.

David Nolan Morrissey
David Nolan Morrissey is the Executive Director of United States International Council on Disabilities (USICD) since 2009. He represents and serves as a key spokesperson for USICD publicly, to national and international non-governmental organizations, media, and policymakers within the US Government. Prior to his position at USICD, he worked as project manager at the Association of University Centers on Disabilities (AUCD). David has been a member of the Expert Working Group on Spina Bifida Transition at the Centers for Disease Control and Prevention (CDC).

Ageing with a chronic physical disability

Affiliation: BOSK, Association of people with congenital disabilities, the Netherlands; USICD

Summary
Individuals with congenital physical disabilities like spina bifida are getting older. For most of them life expectancy does not differ from those of people without disabilities. However, healthcare providers, municipal consultants, researchers and policy makers lack attention for this growing group, even though they require specific care and support. Aging with early onset conditions often is accompanied by pain, fatigue and depressive symptoms, loneliness and the early manifestation of several health problems. The clustering of pain, fatigue and depressive symptoms is known from chronic illnesses. Experiences from people with congenital disabilities not only confirmed this clustering, but also showed how these clusters intertwine with participation problems. The gravity and reinforcement of participation and health problems in adults with physical disabilities aged 18-60 years have hardly been researched. To explore the situation in the Netherlands BOSK (the association of people with spina bifida) teamed up with Erasmus University Medical Center (Rotterdam). This resulted in the following findings.

Respondents reported fatigue (78%), loss of energy (71%), difficulty with walking (66%), and pain (59%) most often. Thirty-five percent had both fatigue and pain. 21% both fatigue, pain and depressive feelings. The strongest worsened health complaints were difficulty with walking (75%), fatigue (74%) and pain (84%). Respondents experienced difficulties in income (75%), deteriorated activities (71%) and deteriorated mobility (89%). 57% said the chronic condition hampered to maintain paid employment. Work-related problems were fatigue (41%), pain (31%), difficulty in concentration (29%), and psychological problems (22%). Twenty-six percent said the discouraging attitude of the employer was an obstacle at work.

After the investigation of the correlation between health/participation problems and unmet needs, various focus groups of people with congenital physical disabilities sat together to share their personal coping strategies to lessen or postpone these problems. Accepting the aging process and taking early preventive action on a regular basis was widely recommended. More specifically, five strategies were found: own initiative to participate, better energy management, ask for (formal) support, frequent medical examinations, learning from peers. Still, we found that many problems tend to go unrecognized or neglected by the adults themselves, and by primary care and support services; this is partly due to lack of knowledge and experience on how to tailor both healthcare and support services to individual needs.
Inclusive Education

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Field of Research: Disability Studies and Inclusive Education.

Summary: Due to the frequent use of certain concepts – like ‘inclusive education’ – we can observe a kind of “language pollution”: everybody uses a concept, it becomes a buzz word… We will try to avoid this buzz word trap by using a clear definition as suggested already in 1994 by Giangreco, Cloninger, Dennis en Edelman… Inclusive education has a least six basic characteristics: (1) ALL students are welcomed in general education classes in their local schools (2) students are educated together in groups in which the number of those with and without disabilities is proportional to the local population (3) students with varying characteristics and abilities participate in shared educational experiences while pursuing individually appropriate learning outcomes with necessary accommodations and supports (4) shared educational experiences take place in settings predominantly frequented by people without disabilities (5) educational experiences are designed to enhance individually determined valued life outcomes for students and therefore seek an individual balance between academic/functional and social/personal aspects of schooling (6) inclusive education exists when each of the previously listed perspectives in an ongoing debate about what is important. (Forlin et al, 2013).

Within this lecture we will develop five different perspectives:
2. A critical exploration of what inclusion looks like in schools and classrooms should include the voices of children and youngsters with disabilities (MacArthur & Kelly, 2004), since they are the recipients and participants of inclusive educational practices (Gordon, 2010)
3. From a human rights perspective children with disabilities form a priority target group: one that is subject to severe discrimination, segregation and exclusion from all aspects of life. A clear analysis of e.g. the Salamanca Statement, the UN Convention on Children’s Rights and the UN Convention on the Rights of Persons with Disabilities shows a growing understanding that all children have a right to education under international and national law; that all children are capable of being educated; and that it is a government’s responsibility to provide educational settings that respect these rights and capabilities. (Unicef, 2011)
4. From a syndrome specific/ medical model perspective we can learn how to understand e.g. specific cognitive, mathematical, numeric, problem solving strategies, of children and youngsters with Spina Bifida and Hydrocephalus (Dennis & Barnes, 2002; Dennis, Edelstein et al., 2004; English, Barnes et al., 2009). This syndrome linked insights can help teachers and school teams to think about ‘reasonable accomodations’, one of the key aspects of inclusive practices.
5. From more than 20 years of research (Bui, Quirk et al., 2010) more and more attention is going to (learning) outcomes for children with disabilities in general education classrooms. We will discuss some of the benefits for children with and without disabilities linked to practices of teachers and schools that really ‘work’.

Geert Van Hove

Dr. Geert Van Hove has a structural cooperation with e.g. Parents for Inclusion (Flemish Parents Movement) and Our New Future (Flemish self-advocacy movement).

He is the promotor of the PhD project of Femke Bannink concerning ‘belonging of children with spina bifida and hydrocephalus in Uganda’. At the moment, Dr. Van Hove holds a large research project in the Netherlands, together with Prof.dr. Petri Embrechts, to support more inclusive research projects within the National Dutch Research Program on Persons with Disabilities.

Pierre Mertens

Pierre Mertens served as IF President from 1995 - 2013. In 1993, when he was Vice-President of IF, he set up the International Solidarity group, which allows Spina Bifida associations in the developed Western World to help those in the developing world. To create a bigger impact on the quality of life of those living with Spina Bifida and Hydrocephalus in developing countries, Pierre founded the non-profit organisation Child-Help in 2006. When he stepped down as IF President, he received the IF Award 2013 in recognition for his outstanding contribution in the field of Spina Bifida and Hydrocephalus. Pierre’s work has always been inspired by his daughter Liesje, who was born with Spina Bifida and Hydrocephalus in 1978, but sadly passed away at the age of 11.

Erwin J.O. Kompanje

Dr Erwin J.O. Kompanje (1959) is assistant professor and clinical ethicist specialized in intensive care medicine and senior researcher ethical and societal consequences of intensive care. He is working full-time on the department of intensive care of the Erasmus MC University medical center Rotterdam. He obtained his PhD in 1999. He is member of several medical ethical committee’s and advisory boards. His fields of interest are medical experimentation of consent; brain death and organ donation; withdrawal of treatment and palliative care on the ICU; late consequences of ICU treatment; Empathy and compassion in patient care and the history of western medicine. He was actively involved in the ethical discussion in the Netherlands on deliberate termination of life in newborns with congenital malformations.

Luc De Catte

Luc de Catte is professor of obstetrics and gynecology at the Obstetrics - Gynecology Department of the University Hospitals Leuven in Belgium. He specialises in fetal (renal) pathology, imaging, invasive prenatal diagnosis, congenital malformation, echocardiography and fetal therapy.

Liesje

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Dominika Madaj-Solberg

Founder of a Polish organisation for Spina Bifida and Hydrocephalus named Fundacja Spina. Occupation therapist, working with people with mental disorders, studing social psychology at the University of Social Psychology in Katowice. Married to Jaroslaw, mother of Maksymilian, Matilda, Zuzanna (born with spina bifida) and Nikodem.

Dominika Madaj-Solberg is an occupation therapist, working with disabled children and adults since 1991 first in Poland and then in Norway and since 2008 with people with mental disorders in Norway. She is married to Jaroslaw and has four children- Maksymilian, Matilda, Zuzanna (born with spina bifida) and Nikodem. To get a diagnosis of spina bifida when she was expecting her third child was a real TURNING POINT in her life. Prenatal surgery to treat Zuzanna’s spina bifida was for Dominika a way to keep faith that there is a place for anyone in our world. Inspired by that, Dominika founded a organisation acting on behalf of people with spina bifida in Poland named Fundacja Spina.

Rein Fermon

Rein Fermon is a woman of 56 years, married to Rob, and the mother of 3 adult children. She was born with Spina Bifida. After working as a nurse for 21 years, looking after people with dementia, she had to retire due to back problems. Rein is a member of the Flemish Association for Spina Bifida and Hydrocephalus (VSH).

Nathalie Verbruggen

Nathalie Verbruggen was born on April 17, 1980, with Spina Bifida. Since she was 6 years old, she took part in the activities of the Flemish Association for Spina Bifida and Hydrocephalus (VSH), and from the age of 16, she became a volunteer within the organisation. Ten years ago, she joined the VSH Board of Directors. Since 2001, she works full-time for the Federal Public Service Finance in Belgium. Nathalie is in a relationship and is also the mother of 2 rascals of 5 and 8 years old. In addition, she plays the flute in local brass band.