



# The 29<sup>th</sup> International Conference on Spina Bifida and Hydrocephalus

*Diverse Needs, Same Rights*

Programme Book  
5<sup>th</sup> - 9<sup>th</sup> September 2022



# The 29<sup>th</sup> International Conference on Spina Bifida and Hydrocephalus

## *Diverse Needs, Same Rights*



Co-funded by the European Union

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# WELCOME FROM THE IF PRESIDENT

Dear Colleagues,

I am honoured as President of the International Federation for Spina Bifida and Hydrocephalus (IF) to welcome you on behalf of the IF Board to the 29th International Conference on Spina Bifida and Hydrocephalus.

It is an ambitious programme with speakers from all around the world. We are extremely grateful to our international keynote speakers and presenters worldwide.

We are proud to organise this 29th edition of the International Conference on Spina Bifida and Hydrocephalus and we hope you enjoy it.

**Cato Lie**

*IF President*

A promotional banner for the 29th International Conference on Spina Bifida and Hydrocephalus. The banner has a dark blue background with white and yellow text. On the left, it reads "THE 29<sup>th</sup> INTERNATIONAL CONFERENCE ON SPINA BIFIDA AND HYDROCEPHALUS" in large white letters, followed by the tagline "DIVERSE NEEDS, SAME RIGHTS" in yellow. Below this, two orange boxes contain the dates "From 5th to 9th of September 2022" and "Online, Zoom". On the right side, there is a QR code with a "SCAN ME" label below it. At the bottom right, there is a link "https://bit.ly/C2SBH29" next to the text "Agenda & Registration" with a right-pointing arrow. Logos for the European Union and the IF SBH are in the top right corner.

# WELCOME FROM THE CONFERENCE ORGANISERS

Dear Colleagues,

On behalf of the organising committee, it is my pleasure as Secretary General of the International Federation for Spina Bifida and Hydrocephalus (IF) and chair of the scientific committee to say a few words about this 29th International Conference on Spina Bifida and Hydrocephalus Diverse Needs, Same Rights, from September 6 to 9 2022, including a pre-conference day on September 5.

We have many participants from all over the world. In addition to the participating individuals with Spina Bifida and or Hydrocephalus and their families, the professionals and researchers, even young scholars, are well represented. Together with our Member Associations we form a real Spina Bifida and Hydrocephalus family.

This is the 29th International Conference on Spina Bifida and Hydrocephalus! The theme of the 29th international conference was voted for by IF Members. During this conference, we together with YOU can strive for an inclusive society, where people with SBH and their families can enjoy all rights on an equal basis and access to all opportunities including education, employment, skills training, healthcare and other public services, and a full participation in society which includes being a stakeholder in policy and decision-making.

The conference programme reflects key topics relevant to the Spina Bifida and Hydrocephalus community. On September 5th, the pre-conference workshop is focussed on independent living for youth with Spina Bifida and or Hydrocephalus. On the first day, IF Members will share their country updates in 5-min presentations. The second day is aimed at prevention. The third day focusses on perspectives from individuals with SBH, parents, and healthcare professionals. Last but not least, on the fourth day reflections will be shared on surgical care in the Global South as well as surgical management from other country perspectives.

Decisions about prioritising integrated healthcare and effective prevention approaches to pursue in the near future are important. For individuals with spina bifida and hydrocephalus and their families, multidisciplinary care calls for an improved approach, recognizing the reality of the complexity between science, practice, and policy. During this conference IF can facilitate further discussion regarding challenges such as prevention and integrated care that now address the Spina Bifida and Hydrocephalus community.

This conference covers a variety of aspects of care for individuals with Spina Bifida and or Hydrocephalus, from very fundamental issues to practical applications, and should therefore not be missed by anyone interested in improving the prevention and optimization of management and care.

**Dr Sylvia Rozen**

*IF Secretary General*



# SCIENTIFIC COMMITTEE



**Prof dr Amara  
Naicker**



**Victoria Sandoval**



**Prof dr Jacques  
Scheres**



**Prof dr Leopold Curfs**



**Dr Quentin Johnson**

# Prof dr Amara Naicker



Professor dr Amara Naicker-Naysaduray is a consultant Rehabilitation Medicine Physician with the Faculty of Medicine, National University of Malaysia (UKM). She has been working in UKM Medical Centre since 2003 and has been actively involved in clinical work in several areas of rehabilitation such as Spinal cord injury, Brain injury, Paediatric and Musculoskeletal rehabilitation to name a few. She also has a special interest in Nutritional Medicine.

As an academic she is a passionate teacher and researcher and takes every opportunity to share and learn both locally and internationally. She has interests in both clinical and basic sciences researches and has made much contributions in the form of academic writings and publications.

She graduated from Karnatak Medical University, India in 1991 with a medical degree and later graduated in Master in Rehabilitation Medicine from University of Malaya in 2001.

Upon graduation she continued to work as a specialist in University of Malaya and later at the National University of Malaysia since 2003 where she continued to upgrade her knowledge and skills in various aspects of rehabilitation with a focus on Paediatric Rehabilitation. She has been actively involved in the Multidisciplinary Pediatric clinics for Cerebral Palsy and Spina Bifida and her passion for disability care in the community led to her co- found the Spina Bifida Association of Malaysia (SIBIAM) in 2007 for which she is the current President.

Since 2017, she has since been actively involved with the International Federation for Spina Bifida and Hydrocephalus (IFSBH) as well as more recently the South Asian Network for Spina Bifida.

More recently she has steered the association to get involved in Malaysia's Folic acid fortification efforts in collaboration with the Nutrition division of Ministry of health.

# Victoria Sandoval

Victoria Sandoval is board member of the International Federation for Spina Bifida and Hydrocephalus and by profession she practices law as lawyer in Guatemala.

As a woman with Spina Bifida and Myelomeningocele her interest and work areas are aimed at Human Rights, Family, Commercial and Civil law.

In 1995, alongside her mother, Victoria Caceres, she started the Asociación Guatemalteca de Espina Bífida (AGEB). Moreover, Victoria worked on the COMUDEB (Spina Bifida multidisciplinary clinic) where she achieved programs that support children and their families to obtain access to multidisciplinary healthcare and support.

Through her work and active involvement in the international Spina Bifida and Hydrocephalus community, Victoria inspires others. In her words “our disabilities do not define us, it is what we think of ourselves what defines us”.



# Prof dr Jacques Scheres



Prof dr Jacques Scheres is a Medical Doctor and Biologist. Both studies and his PhD were completed at Radboud University Nijmegen, the Netherlands. Longstanding work in pre- and postnatal clinical-genetic diagnosis (University Hospitals Nijmegen, Maastricht, Utrecht). Discovered two genetic diseases with immune deficiency, repeated infections, hypersensitivity to irradiation, and fatal cancer at young age.

For over 10 years he was the Medical Director of the Health Council in the Province of Limburg, the Netherlands. Subsequently, he became the Euregional Coordinator to the Board of Directors of the University Hospital Maastricht and leader of EU-funded projects and working groups in the field of international and cross-border healthcare co-

operation in European border areas Euroregions, including projects on nosocomial infections and antibiotic resistance.

Guest professor for Public Health Genomics, National Institute of Hygiene, Warsaw, Poland; former guest professor public health Department International Health, University Maastricht; advisor to the Department Medical Microbiology, University of Groningen. From 2004-2016 representative of the European Parliament in the Management Board of the European Centre for Disease Prevention and Control ECDC in Stockholm (Vice-Chair and Acting Chair ECDC 2008-2012).

Advisor to the Polish Public Health Society. Member of P.H.A.G.E. (Phages for Human Applications Group Europe) and Advisor to the international/intercontinental COVID-19 project ORCHESTRA.

Former President of the Subcommittee European Affairs of the European Association of Hospital Managers (EAHM); Honorary Member of EAHM since 2014. Medical Geneticist and Cell Biologist of Velvack/Panacea Research and Development center, Colombia/Texas.

# Prof dr Leopold Curfs

Professor dr Leopold M.G. Curfs is strategic professor and director of the Governor Kremers Centre at the Academic Hospital Maastricht - Maastricht University, the Netherlands. He was awarded with the 'Governor Kremers' professorship at the Faculty of Health, Medicine and Life Sciences of Maastricht University.

The Governor Kremers Centre (GKC) is a Centre for research into the care for people with intellectual disabilities in which Maastricht University Medical Centre and its research schools CARIM, MHeNS, NUTRIM, CAPHRI and GROW (recognized by the Royal Dutch Academy of Sciences) work together with service providers and parent associations for people with disabilities. The GKC has close links with the chair of intellectual disabilities and palliative care of Kingston & St George's University of London.

He has published and presented extensively on medical, behavioral and psychiatric aspects of genetically determined neurodevelopmental disorders.



## Dr Quentin Johnson

Dr. Quentin William Johnson is a professional with 48 years of New Product Development, Quality Assurance, Food Safety and Regulatory Affairs experience in the milling and baking sectors of the food industry.

For the past 26 years, he has provided technical assistance in 97 countries worldwide in the design, development and implementation of staple food fortification programmes with particular reference to wheat flour and maize meal fortification with Folic Acid, B group vitamins, Iron and Zinc.

In 2011, Dr Quentin Johnson received an Honorary Degree of Doctor of Laws, honoris causa by the University of Guelph, Canada for his contribution to the advancement of staple food fortification around the world. As international consultant, Dr Johnson showed his leadership in supporting partnerships of millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions to implement fortification efforts at local level.



# ABOUT IF

**The International Federation for Spina Bifida and Hydrocephalus (IF)** is the international organisation representing people with SBH and their families worldwide. IF has country members in Africa, Americas, Asia-Pacific, and Europe with unique and expert knowledge on SBH.

The **mission** of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of neural tube defects and Hydrocephalus by primary prevention through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

The **vision** of IF is a society that guarantees human rights of children and adults with SBH, and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy to all.

## CONTACT DETAILS

The International Federation for Spina Bifida and Hydrocephalus

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🌐 [www.ifglobal.org](http://www.ifglobal.org)



# KEYNOTE SPEAKERS

## Dr Quentin Johnson

Dr. Quentin William Johnson is a professional with 48 years of New Product Development, Quality Assurance, Food Safety and Regulatory Affairs experience in the milling and baking sectors of the food industry.

For the past 26 years, he has provided technical assistance in 97 countries worldwide in the design, development and implementation of staple food fortification programmes with particular reference to wheat flour and maize meal fortification with Folic Acid, B group vitamins, Iron and Zinc.

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## Prof dr Wladimir Wertelecki



Wladimir Wertelecki is a Ukrainian-American physician and Emeritus Professor and Chairman from the University of South Alabama where in 1974, he established one of the first free-standing Department of Medical Genetics. Among his goals was the successful creation of a regional network of clinics across southern Alabama and West Florida.

Following an initial sponsorship by USAID, he established OMNI-Net programs in Ukraine, a not-for-profit network to provide training and to engage Ukrainian professionals to conduct monitoring of the frequency of birth defects.

By upholding international standards, OMNI-Net qualified to full membership in EUROCAT, a consortium of birth defects monitoring systems in Europe. OMNI-Net teams promptly detected an epidemic of Spina Bifida and associated malformations collectively known as neural tube defects (NTD). In 2021, OMNI-Net restarted a Spina Bifida – Hydrocephalus prevention initiative by petitions to the President and Prime Minister to introduce folic acid mandatory fortification of flour in Ukraine.

He published extensively on different topics and received a Doctor Honoris Causa from the National University of Kyiv-Mohyla Academy, Ukraine (2003), and a Doctor Honoris Causa from Lviv Medical University, Ukraine (2010).

# KEYNOTE SPEAKERS

## Diana Akhmedzhanova



Diana Akhmedzhanova is the head of Information and Analytics Department, Khmelnytskyi City Childrens Hospital (Khmelnytskyi, Ukraine).

Diana is the Legal Entity Appointed Representative (LEAR) from OMNI-Net Ukraine in EUROlinkCAT - the European Union's Horizon 2020 Project and the data manager in Ukrainian part of collaboration study of OMNI-Net Ukraine and International consortium on Fetal Alcohol Spectrum Disorders funded by U.S. National Institutes of Health - National Institute of Alcohol Abuse and Alcoholism - a cohort study of alcohol consumption and nutrient status of pregnant women and their pregnancy outcomes.

For the OMNI-Net Ukraine: Khmelnytskyi OMNI-Center (Khmelnytsky, Ukraine), Diana Akhmedzhanova is responsible for different roles including Information Specialist; Birth Defects Registry coordinator, Data Manager. She is in charge of Birth Defects Registry management and coordination; data and quality management; analysis and interpretation of data; coordination of work with EUROCAT (European network of population-based registries for the epidemiological surveillance of congenital anomalies) and ICBDSR (International Clearinghouse for Birth Defects Surveillance and Research); birth defects awareness and prevention campaigns, seminars and round tables; public awareness; telemedicine; website and social network page management; coordination of activities and communication with Ukrainian and International partners.

# CONFERENCE AGENDA

## PRE-CONFERENCE WORKSHOP SEPTEMBER • 5 • 2022

HOURS IN PM (CEST)

*Chair: Dr Sylvia Roozen*

**WORKSHOP:** Independent Living for Youth with Spina Bifida  
and/or Hydrocephalus

**2.00 - 4.00**

## DAY 1 SEPTEMBER • 6 • 2022

HOURS IN PM (CEST)

### WORD OF WELCOME

**2.00 - 2.20**

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### SESSION I: COUNTRY UPDATES

**2.20 - 3.25**

*Moderator: Prof Dr Amara Naicker*  
*5-min-Country-Update Presentations*

**TALK 1:** Li-Shun Chua - A Look at the Past Year and Beyond! -  
Spina Bifida Association of Malaysia

**TALK 2:** Slaveya Kostadinova - Introduction of Multi-IN Project by  
Bulgaria and Slovakia

**TALK 3:** Mian Awais - Prevalence and Trends of Spina Bifida and  
Pakistan Shared Responsibility

**TALK 4:** Patrick Essuman - Ghana's Update on Spina Bifida and  
Hydrocephalus Management

**TALK 5:** Papatya Alkan-Genca - How to Ensure Effective  
Participation of Disabled Children in Decision-making Processes:  
a Case Study by Turkish Spina Bifida Association

**TALK 6:** Mariana Koshmaniuk - The Program of Multidisciplinary Online Support of Children with Spina Bifida in Ukraine

**TALK 7:** Laura Zirel & Ksenia Sokolova - Progress in Estonia

**TALK 8:** Anna Kostyleva - New Programs 2021-2022 by the Russian Spina Bifida Charity Fund

**TALK 9:** Luh Wahyuni - Physical Medicine and Rehabilitation Management in Spina Bifida and Hydrocephalus: a Multidisciplinary Approach in Indonesia

## Q & A

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**BREAK**

**3.25 - 3.40**



**SESSION II: COUNTRY UPDATES**

**3.40 - 4.45**

*Moderator: Victoria Sandoval*

*5-min-Country-Update Presentations*

**TALK 10:** Giulia Bizzotto - Italian Best Practices and Update on 2022 Activities

**TALK 11:** David Bolong - A Two-decade Effort to Make a Dent in the Philippines

**TALK 12:** Yessenia Vargas - Country Updates from Guatemala

**TALK 13:** Sneha Sawant - Updates from Spina Bifida Foundation India

**TALK 14:** Mario Sel - Side to Side, a Wheelchair Trip in 10 days from the East to the West of Flanders, Belgium

**TALK 15:** Adriana Tontsch - Emerging Responses by the Association for Spina Bifida and Hydrocephalus in Romania

**TALK 16:** Kennard Pondani - Lived Experiences of a Man with Hydrocephalus in Malawi

**TALK 17:** Amanda Garzon - Current State of Hydrocephalus in the United States of America

**TALK 18:** Ruth Nalugya - A Sustainable World for Inclusive Services for Persons with Spina Bifida and Hydrocephalus in Uganda

**Q & A**

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**CLOSING**

**4.45 - 5.00**

DAY 2

SEPTEMBER · 7 · 2022

HOURS IN PM (CEST)

**WORD OF WELCOME**

**2.00 - 2.10**

*Dr Sylvia Roozen & Dr Luz DeRegil (WHO)*

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**KEYNOTE 1:** Quentin Johnson - Food Fortification: Scalable Approaches to Reduce Risks of Neural Tube Defects

**2.10 - 2.30**

**SESSION III PREVENTION**

**2.30 - 3.30**

*Moderator: Prof dr Jacques Scheres*

*15-min-Regular-Oral Presentations*

**TALK 19:** Ayoub Al-Jawaldeh - The WHO Eastern Mediterranean Journey on Fortification and Prevention

**TALK 20:** Maria Nieves Garcia Casal - Development of WHO guidelines on staple foods fortification from the interim consensus statement in 2009 to the current guidelines

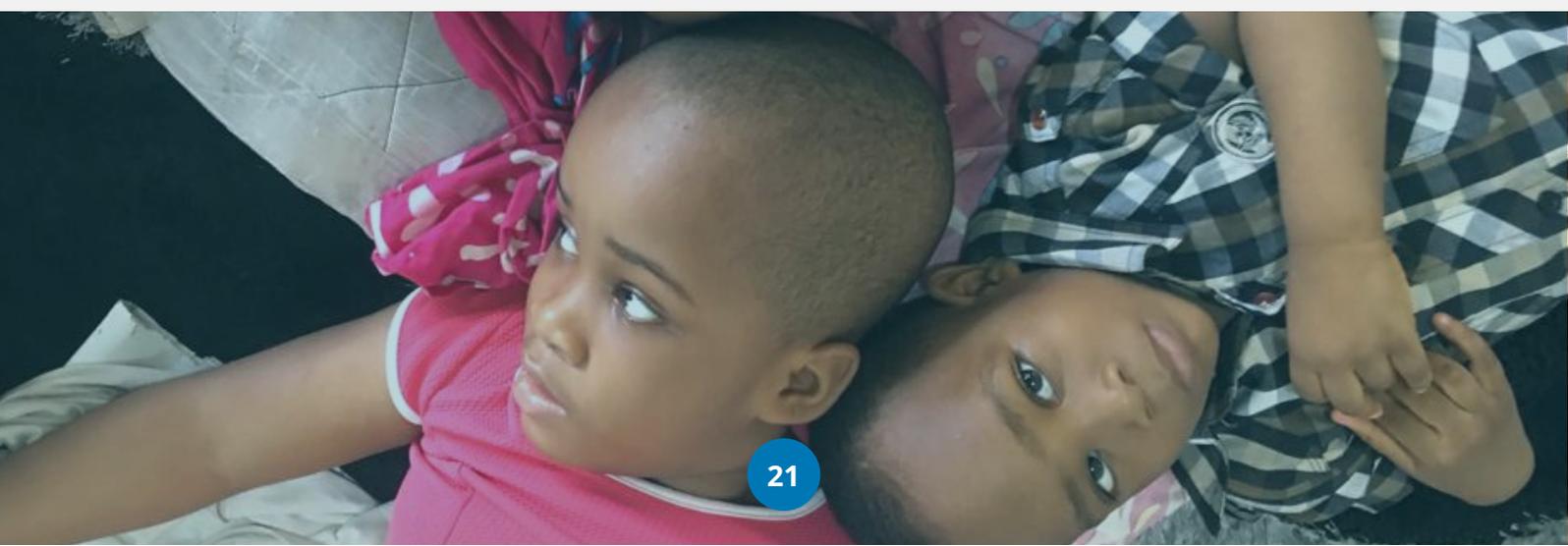
**TALK 21:** Saskia Osendarp - Effective Interventions for Micronutrient Deficiencies

**TALK 22:** Hildur Önnudóttir - From Local to Global - How to Influence International Actions through National Advocacy

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**BREAK**

**3.30 - 3.45**



**SESSION IV PREVENTION**

**3.45 - 4.45**

*Moderator: Prof dr Jacques Scheres*

*Give-me-5-min Presentations*

**TALK 23:** Vijaya Kancherla - A 2020 Global Update on Folic Acid-preventable Spina Bifida and Anencephaly through Mandatory Fortification of Cereal Grains

**TALK 24:** Camilla Aukrust - Comprehensive Policy Recommendations for the Management of Spina Bifida and Hydrocephalus in Low Resource Contexts

**TALK 25:** Boris Groisman - Prevention of Neural Tube Defects in Argentina

*15-min-Regular-Oral Presentations*

**TALK 26:** Helena Pachón - Folic Acid Fortification: The Safe and Effective Action towards Spina Bifida Prevention

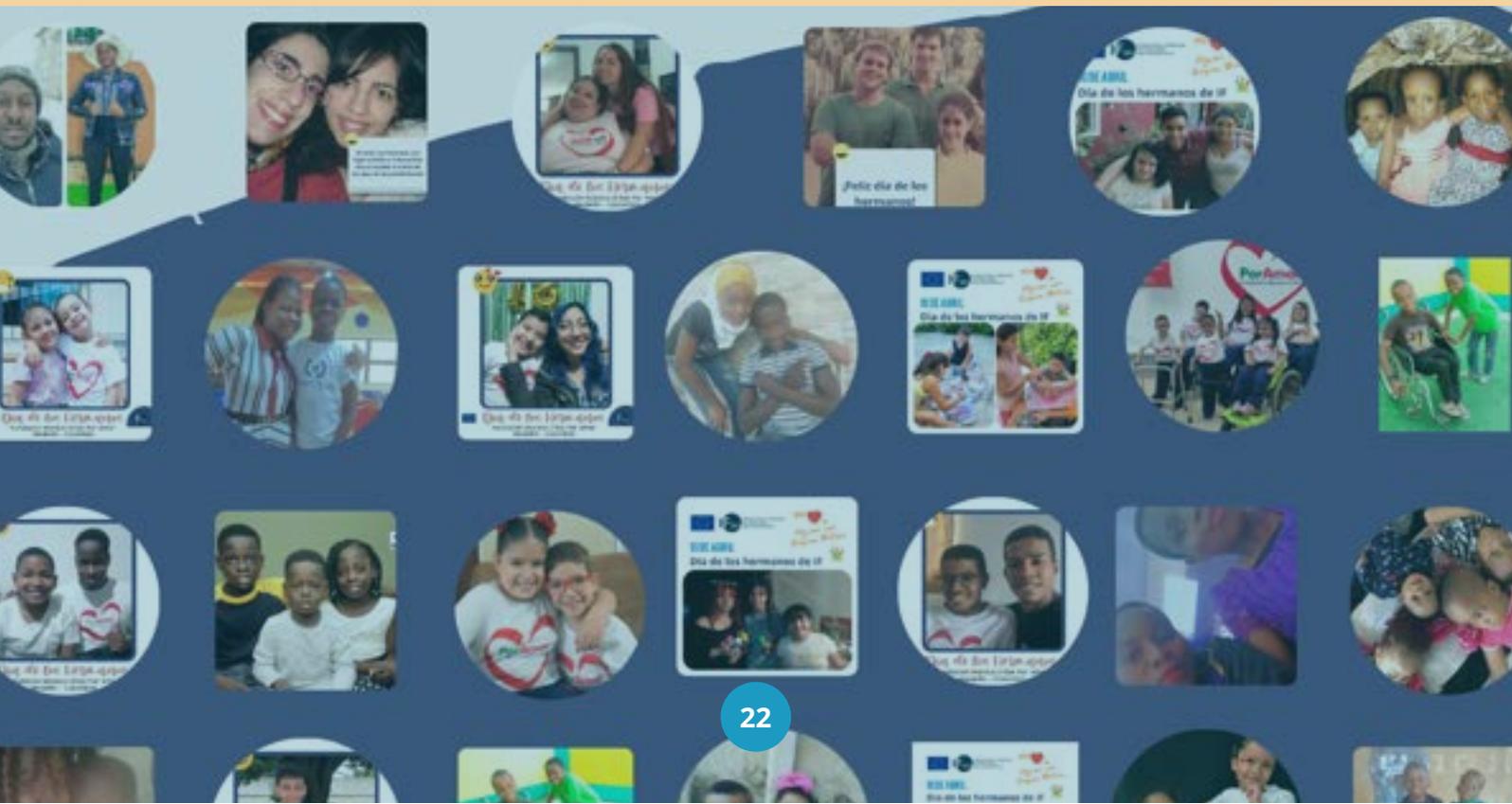
**TALK 27:** Scott Montgomery - Smarter Futures: A Public-private-civic Partnership

**Q&A**

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**CLOSING**

**4.45 - 5.00**



DAY 3

SEPTEMBER · 8 · 2022

HOURS IN PM (CEST)

**WORD OF WELCOME**

**2.00 - 2.10**

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**KEYNOTE 2:** Wladimir Wertelecki & Diana Akhmedzhanova -  
Spina Bifida in Ukraine: A Reality in Science and Practice in  
Times of War

**2.10 - 2.30**

**SESSION V PARENTS PERSPECTIVES**

**2.30 - 2.55**

*Moderator: Elena Záppoli*

*Give-me-5-min Presentations*

**TALK 28:** Maman Broalet - Knowledges and Attitudes of  
Mothers of Children with Spina Bifida in Abidjan Côte d'Ivoire

**TALK 29:** Franziska Wadehul - 'Wheeling into Nothingness'. A  
Photovoice Project Exploring Parents' Perspectives of Transition  
to Adult Care

**TALK 30:** Alexandra Wattinger - Transition – A World Turned  
Upside Down – Experiences of Parents

**Q&A**

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**SESSION VI ADVISORY PANELS**

**2.55 - 3.30**

*Moderator: Papatya Alkan-Genca*

*15-min-Regular-Oral Presentations*

**TALK 31:** Cillian Dunne - Independent Living through the Eyes of  
Youth with Spina Bifida and Hydrocephalus

**TALK 32:** Kevin O'donnell - Best Practices on Ageing with Spina  
Bifida and Hydrocephalus

**Q&A**

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**BREAK**

**3.30 - 3.45**

**SESSION VII PATIENT JOURNEYS**

**3.45 - 4.10**

*Moderator: Emma Suardiaz*  
*Give-me-5-min Presentations*

**TALK 33:** Ammi Andersson - The Making of a Patient Journey and Why

**TALK 34:** Tamires Carvalho - Management of a Shunt Dysfunction Case using Non-invasive ICP Waveform Monitoring

**TALK 35:** Giacomo Grotti - Impact of SARS-CoV-2 Pandemic on Quality of Life in Children with Spina Bifida and Hydrocephalus

**Q&A**

**SESSION VIII UROLOGY**

**4.10 - 4.45**

*Moderator: Prof dr Giovanni Mosiello*  
*15-min-Regular-Oral Presentations*

**TALK 36:** Nagla Mohamed - Effectiveness of Educational Program on Vesico-ureteric Reflux among Non-compliant Mothers of Children of Spina Bifida at Khartoum State

**TALK 37:** Francesco Mariani - Impact of Constant Antibiotic Prophylaxis in Children Affected by Spinal Dysraphism Performing Clean Intermittent Catheterization

**Q&A**

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**CLOSING**

**4.45 - 5.00**

DAY 4

SEPTEMBER · 9 · 2022

HOURS IN PM (CEST)

**WORD OF WELCOME**

**2.00 - 2.15**

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**SESSION IX NEUROSURGERY, DOING LESS BUT BETTER: A GLOBAL SOUTH PERSPECTIVE**

**2.15 - 3.00**

*Moderator: Prof dr Jacques Scheres*

**TALK 38:** Panel Discussion

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**BREAK**

**3.00 - 3.15**

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**SESSION X SURGICAL MANAGEMENT**

**3.15 - 4.45**

*Moderator: Dr Santosh Karmarkar*

*15-min-Regular-Oral Presentations*

**TALK 39:** Frank Kaphesi - Motor Development Outcomes in Children with Hydrocephalus Undergoing Endoscopic Third Ventriculostomy and Ventriculoperitoneal Shunt Insertion

**TALK 40:** Raphael Bertani - Analysis of the Intracranial Pressure Waveform in Hydrocephalus Patients Using a Non-invasive Device

**TALK 41:** Vladimir Gonchar - Surgical Treatment of Perineal Disorders in Children with Neural Tube Pathology

**TALK 42:** Zhengqiang Zhu - Factors Impacting Volume Decreasing and Symptoms Improvement of Pediatric Arachnoid Cysts: A Retrospective Analysis

**TALK 43:** Jiancheng Zang - Deformity Correction and Function Reconstruction on Foot and Ankle of Spina Bifida

**Q&A**

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**CLOSING**

**4.45 - 5.00**

# ABSTRACTS

*In order of presentations*

## Pre-conference Workshop

**Trainer:** Kamil Goungor, European Network on Independent Living

**Background:** Historically, the independent choice and control of persons with a disability have been rejected, with the belief that they are unable to live independently by themselves. They are commonly the last in society to have their needs met; to be supported to live independently with a satisfactory and equal quality of life compared with peers (of the same socioeconomic status) living without a disability. The lack of support available is limited to meeting basic needs of hygiene and nutrition, but miss providing possibilities to fully participate in the community and addressing personal preferences and needs. This has a negative impact on the emotional stamina and mental health of persons with a disability. Especially for youth with Spina Bifida and/or Hydrocephalus (SBH), this can be more challenging as they require specific support and guidance. Youth are facing the transition from adolescence to adulthood, and this milestone can be extremely difficult for some individuals. It is imperative that youth with SBH can plan for such transitions to enable them to take full control over their own life, leading to successful independent living.

**Objectives:** The target audience of the pre-conference is youth with disabilities.

The objective of the pre-conference is to provide the youth community with more in depth knowledge of independent living, and create a platform for youth to discuss different aspects of independent living. By the end of the workshop, youth have more awareness on:

- What does independent living for persons with disabilities mean?
- Why is it important?
- How to advocate for the rights to independent living?

Moreover, in this pre-conference workshop youth will be inspired by examples of persons with disabilities who successfully live independently and advocate for their rights.

*Li-Shun Chua, Yean Koon Chan, Rashidah Ismail Ohnmar Htwe, Kribanandan G Naidu, Amaramalar Selvi Naicker*  
*Spina Bifida Association of Malaysia, Malaysia*

**Background:** The Spina Bifida Association of Malaysia (SIBIAM) had an eventful year as we continued advocacy, education and peer support efforts while facing challenges of the COVID-19 pandemic. SIBIAM began 2021 with mixed feelings of uncertainty but also enthusiasm to restart our activities, as pandemic restrictions loosened.

**Methods:** SIBIAM was eager to kick off main project: The Training Healthcare Professionals and Special Needs Teachers on the Management of Spina Bifida project, a collaboration with District Action Group on Spina Bifida and Hydrocephalus (DASH), is a 3-phase project supported by the Rotary International Global Grant. Although Phase 1 had begun, the launch finally took place online on 31 July 2021. It was graced by key leaders from Rotary District 3300 and the International Federation for Spina Bifida and Hydrocephalus. World Spina Bifida and Hydrocephalus Day was celebrated with a local event highlighting SIBIAM's many talented members, on 30 October 2021. Early 2022 was dedicated to Phase 2 of the Global Grant project.

**Results:** The Training The Trainers workshop, held on 25-26 March 2022, saw 20 experts in various disciplines share their knowledge and experience in Spina Bifida management with 34 healthcare professionals from across Malaysia. The participants will bring what they've learned to their respective localities in Phase 3, which opened with the first regional workshop in Negeri Sembilan in July.

**Conclusion:** The trans-organisational partnerships SIBIAM formed have proven valuable in realising long time plans for a nationwide Spina Bifida awareness campaign. The association is excited for what is to come!

**Slaveya Kostadinova<sup>1</sup>, Terézia Drdulova<sup>2</sup>**

<sup>1</sup> *Spina Bifida and Hydrocephalus-Bulgaria*

<sup>2</sup> *Center for Early Intervention Trnava, Slovakia*

**Background:** The Spina Bifida and Hydrocephalus-Bulgaria (SBHB) together with Center for Early Intervention Trnava (CVI Trnava) collaborate on a two-year Erasmus Plus project named Multi-IN, co-financed by the European Commission. The project aims at improving the knowledge and skills of involved groups in schools and early childhood education for students with Spina Bifida and Hydrocephalus (SBH).

**Methods:** The project Multi-IN encourages all involved stakeholders to apply a multidisciplinary approach in the education of children with SBH and support them in developing specific skills and knowledge. Among the main stakeholders in the educational process, Multi-IN identifies the following target groups: teachers, school leaders/school administration, special teachers, school psychologists, school nurses, personal assistants, parents and family members, students with SBH.

**Results:** In the project Multi-IN, several resources are developed including a resource kit of general guidelines with a set of manuals and a set of educational video courses for each of the eight target groups identified. They all are based on previous international experience, research, and good practices in the field of education and care for children with SBH. The case studies are conducted with parents and children from Bulgaria and Slovakia. The printing materials will be ready by the end of 2022, followed by the education videos by the end of 2023. In order to support the inclusive education of students with special needs in different countries, all resources will be free to download, share and adapt on the Multi-IN website and available in three languages – Bulgarian, Slovak, and English.

**Conclusion:** Through the Multi-IN project, both organizations support the inclusion of students with Spina Bifida and Hydrocephalus in school and kindergarten. At the same time, it encourages children on their way to independent, self-aware and empowered adults.

**Mian Awais**<sup>1,2</sup>, **Akhtar Muner**<sup>1</sup>, **Rimla Ayesha**<sup>3</sup>

<sup>1</sup> PediatricNeurosurgery Department, Lahore Medical City, Lahore, Pakistan

<sup>2</sup> The Pakistan Federation for Spina Bifida and Hydrocephalus

<sup>3</sup> Mujahid Hospital, Faisalabad, Pakistan

**Background:** In Pakistan, prevalence of open neural tube defects (NTDs) has been estimated to be seven to eight per 1000 live births and among them Spina Bifida accounted for 28.85%. Neural tube defect was the most common form of congenital anomaly and Spina Bifida accounted for 19.5% of all the congenital anomalies.

**Methods:** Experts from the Pakistan Federation For Spina Bifida and Hydrocephalus agree on the role of Folic Acid in primary prevention of NTDs, yet, despite best efforts, the use of Folic Acid has reduced NTDs by only 50%.

**Results:** In this presentation, the Pakistan Federation For Spina Bifida and Hydrocephalus will share prevention efforts in Pakistan. Moreover, decision making processes with respect to medical judgment, ethics, social, cultural and Muslim religion value systems in Pakistan will be shared.

**Conclusion:** For primary and secondary prevention efforts in Pakistan, collaboration between different stakeholders is important. In Pakistan's experience, the coordination between different healthcare professionals is emphasised to support informed decision-making.

**Patrick Essuman***Rickmes Foundation, Ghana*

**Background:** In Ghana, not much is known about Spina Bifida and Hydrocephalus (SBH) and its management. According to Ofori et al, out of 6, 550 CT head examinations that were carried out between 2007- 2012, 251 (representing about 3.8% ) were cases of Hydrocephalus. In the Northern region of Ghana, the prevalence of neural tube defects (NTDs) is 1.6 per 1000 births. Korle Bu Teaching Hospital estimates that every week, five new cases of SBH are recorded, with a total of 260 cases in a year. It has been an unpleasant observation that persons with SBH and their caregivers have been experiencing family conflicts, feeling of loneliness, rejection of their self- worth by friends and family members, ridicule and mockery, alienation, and financial constraints.

**Methods:** Rickmes Foundation has embarked on public education tours, seminars/training, observation of SBH international days, and provided financial support to raise awareness about the conditions. The organization envisions to conduct a research on SBH in Ghana, conduct mass surgeries project to reduce the backlog of SBH cases in the health facilities, and to initiate annual SBH conference in the coming years.

**Results:** The knowledge of Ghanaians about SBH has been improved through different educational and awareness raising programs, and networking events. Many support has also been provided for persons living with these conditions and their carers such as free diagnostic and medical care.

**Conclusions:** Spina Bifida and Hydrocephalus are socio- medical conditions which need both social and medical interventions in managing them. Poverty has remained the major barrier in accessing healthcare among persons with SBH and their caregivers in Ghana.

**Papatya Alkan-Genca, Cevval Ulman, Aslihan Aykara, Selma Calik, Nurdan Anli, Selen Kaynak**  
*Turkish Spina Bifida Association, Turkey*

**Background:** Turkey signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 and ratified it in 2009. However, there has not been a child-friendly version in Turkish, nor has there been substantial research on how children with and without disabilities perceive and understand UNCRPD and disability rights.

**Methods:** Advocating for the rights of people with Spina Bifida and the importance of children's participation in decision-making processes have always been top priorities for Turkish Spina Bifida Association (TSBA). TSBA is also keen on promoting UNCRPD through collaborative work with other NGOs and ensuring children with and without disabilities know these rights. To this end, TSBA launched an EU-funded project titled "CHIP IN: Effective Participation of Disabled Children in Decision-Making Processes" in collaboration with Hacettepe University Research and Application Centre for Children's Rights and Association of Dyslexia and ADHD.

**Results:** The project is three-fold: (1) provide training for NGOs working with various disability groups on how to engage and ensure participation of disabled children in decision-making processes; (2) produce the child-friendly version of CRPD in Turkish through several workshops with children and experts; and (3) develop a board game and its digital version through which children can learn about the rights identified in CRPD. In this presentation, the project will be introduced as well as its preliminary results on the designed game in its digital and real-life form, and call for its adaptation/implementation in other languages and countries.

**Conclusion:** The project titled "CHIP IN: Effective Participation of Disabled Children in Decision-Making Processes" shows how using games as a means of teaching UNCRPD to children as well as to NGOs working or hoping to work with children can improve advocacy efforts. Collaboration between different NGOs also enriches and strengthens this advocacy work. Further projects should be developed so that the designed game can be translated and adapted into different cultural contexts

**Mariana Koshmaniuk**

*Association of Parents of Children with Spina Bifida and Hydrocephalus "Lights of spirit", Ternopil city, Ukraine*

**Background:** The work by the Association of Parents of Children with Spina Bifida and Hydrocephalus "Lights of spirit" has become most urgent since the beginning of the full-scale war led by Russia in Ukraine. After all, the constant danger of rocket attacks, psychological stress, everyday inconveniences, limited access to medical, social and educational services cause the deterioration of the health of children and adults with Spina Bifida. As a result of the war, some families were forced to move abroad, but most families remain in Ukraine.

**Methods:** The program of multidisciplinary online support for children with Spina Bifida and Hydrocephalus in Ukraine was implemented by the Association of Parents of Children with Spina Bifida and Hydrocephalus "Lights of spirit" with the assistance of the international organisation.

**Results:** Special attention will be paid to coordinated complex medical care, informational, psychological, social and right support of children and adults with Spina Bifida, cooperation of NGO "Lights of Spirit" with parents, scientists, leading doctors, and specialists of Ukraine.

The project provides online meetings for parents and children with the participation of doctors, specialists, individual consultations, direction to examination and treatment of children in medical institutions of the country, partial provision of care products and medicines considering individual needs. Informational support for families staying abroad.

**Conclusion:** The effectiveness of treatment, rehabilitation and socialization of children and adults with Spina Bifida depends entirely on multidisciplinary, coordinated support, modern standards of medical and social services and their availability for this category. Especially, these measures are necessary during emergency conditions of war. It is important to establish a system of cooperation between doctors, specialists, the public, and authorities for the exchange of experience, solving current problems, and diverse assistance to families with special lifestyles.

**Ksenia Sokolova, Laura Zirel**

*Estonian Spina Bifida and Hydrocephalus Society*

**Background:** Until 1985 in Estonia Spina Bifida and Hydrocephalus pathology was considered to be untreatable and there were no actions to handle it.

**Methods:** In 1988 the first initiative was started to register all the Spina Bifida and Hydrocephalus and provide treatment at the Tallinn Children Hospital. Since 2012 Estonian Association has started to implement programmes for raising awareness on the importance of folic acid for preventing Spina Bifida and Hydrocephalus pathology. Today there are 127 Spina Bifida and 233 Hydrocephalus patients being followed in Estonia.

**Results:** We have observed a sharp decrease in birth rate of children with Spina Bifida and Hydrocephalus pathologies and have initiated a project to analyse genetic data collected in collaboration with Estonian Gene Bank to explore this. The project is run under EU ERASMUS+ programme.

Estonian Association actions have led to creating a stable system for childhood age Spina Bifida and Hydrocephalus patients for both treatment and social care. Current struggle is to make a system to last for adulthood patients for ensuring their better health and employability. This would improve patients' independent living.

**Conclusion:** We would be happy to collaborate with bigger Spina Bifida and Hydrocephalus associations on sharing their experiences in developing treatment and social care support systems for adult patients.

**Anna Kostyleva**

*Charitable Foundation Spina Bifida, Russia*

**Background:** The Russian Spina Bifida Charity Fund renders comprehensive assistance to children and adults who have Spina Bifida (SB). There are more than 1000 families with children with SB and about 100 adults who benefit from the fund.

**Methods:** The fund helps families, orphanage houses and boarding schools, in which children with SB grow, and also medical institutions, in which such children are being treated. The main goal of the fund is to improve the life quality of the children and adults with SB.

**Results:** The main programs of the fund are systemic. In 2021-2022 several new programs were started:

- Support program for pregnant women expecting a child with SB: informing about possible routing and experts in carrying out medical treatment, childbirth and rehabilitation, legal and medical support, accommodation compensation, assistance in the organization of expert management of a child until one year;
- Free transportation for individuals with Spina Bifida and their families in 25 cities;
- SB Institute is the first step in developing a system of professional medical and rehabilitation assistance for children with SB all over Russia;
- A sports project aimed at popularizing adaptive sports as one of the rehabilitation components and a tool for socialization;
- SB Club 14+, brings together people with SB. The club provides information and brings people in contact with qualified SB specialists from different fields to receive timely advice and support where need;
- School of foster parents has been launched. This unique project consists of a series of webinars on the most pressing issues of new and still inexperienced foster parents, as well as candidates for foster parents of children with SB;
- A project of systemic assistance for children with SB has been launched (more than 250 children in the project): home visits, neurological examinations, targeted assistance and systematic online training.

**Conclusion:** The new program 2021-2022 by the Spina Bifida Charity Fund helps to improve the life of persons with Spina Bifida in Russia.

**Luh Karunia Wahyuni, Rizky Kusuma Wardhani, Budiati Laksmitasari.**

*Physical Medicine and Rehabilitation Department, Faculty of Medicine, Universitas Indonesia, Ciptomangunkusumo Hospital, Indonesia*

**Background:** Indonesia does not yet have a database specifically for the prevalence of neural tube defects (NTDs). However, the Ministry of Health in Indonesia has carried out surveillance on congenital abnormalities and reported that NTDs including Spina Bifida are 22% of the 15 most common congenital disorders.

Spina Bifida can cause various functional problems that can hinder children's activities and participation.

**Methods:** Physical medicine and rehabilitation (PMR), also known as physiatry or rehabilitation medicine, aims to enhance and restore functional ability and quality of life to those with physical impairments or disabilities, including children with Spina Bifida.

Indonesian Health Insurance policy is that all disabled patients must be managed by a PMR specialist. As the biggest national referral hospital, Ciptomangunkusumo Hospital provided PMR services for children with Spina Bifida in a medical rehabilitation team consisting of PMR doctor, physiotherapist, occupational therapist, speech therapist, orthotist prosthetist, psychologist, rehabilitation nurse, and social worker.

**Results:** PMR services include comprehensive functional assessment, in-depth functional assessments (such as assessment of cognitive, gait, urination, defecation, and activity of daily living). Treatments that can be given include ADL training, gait training, modalities, orthosis, assistive devices, and psychosocial management. PMR specialists work multidisciplinary with other specialists such as pediatricians, urologists, neurosurgeons, and orthopedics. The application of the multidisciplinary approach that has been carried out include a collaborative patient management, case discussion, comprehensive guidelines, and joint webinar.

**Conclusion:** In the future, it is recommended that Indonesia has the database on Spina Bifida, better collaborative activities, and better quality of PMR services.

**Giulia Bizzotto**

*Associazione Spina Bifida Italia, ASBI Italy*

**Background:** Associazione Spina Bifida Italia (ASBI) was born in 1989 and founded by some parents of children with Spina Bifida (SB) with the aim to improve the life of people living with the condition. It became a national association in 2007 and from then it has always tried to build a strong network with regional/local associations for Spina Bifida but also with companies, institutions and supporters in general.

**Methods:** Today ASBI is active in the Italian territory with several activities during the year and it covers numerous Spina Bifida related topics, especially on prevention, counselling and facilitating the social integration and employment of people living with SB, through winter/summer camps as well as projects directed to young people, minors and women.

**Results:** In 2022 ASBI has organized numerous activities and events, some of them listed below:

- Sport activities. The Winter Camp in January in collaboration with FreeRider Sports Events & the Adventure Camp in June, addressed to minors from 12 to 16 y/o which was the first inclusive camp involving both people with and without disability. Participants developed skills in contact with nature, shared experiences with their peers and tried new adventures such as canoeing and pitching a tent;
- ASBI has entered into an agreement with Handytech, a company specializes in the design and construction of equipment for driving and transporting people with mobility difficulties. The collaboration aimed at disseminating information regarding the preparation of vehicles for driving or transporting people with motor disabilities, tax breaks and obtaining special licenses as well as the participation at specific events. ASBI reserves to all its members, a 10% discount on the national list prices to be used within the network of Handytech Authorized Centers;
- Update on the Italian Registry. 700 patients' data are being loaded on the platform "RegistRare" of which almost half of them thoroughly. Follow up meetings (National Congress of the Italian Spinal Cord Injuries Society in November) will be organized to evaluate the progresses of the project and increase awareness amongst other Spina Bifida Centers.

**Conclusion:** ASBI organizes lot of events and activities during the year and focuses especially in strengthening the collaboration with its partners both locally, nationally and more widely in Europe. There are of course lot of other projects ASBI is willing to plan, involving different stakeholders, such as the Italian SB Centers as well as school personnel.

**David T. Bolong**

*Spina Bifida Support Group Foundation, the Philippines*

**Background:** The Spina Bifida Support Group Foundation, Inc was founded in 1998 as Aruga ng Nanay sa Anak na may Kapasanan (A.N.A.K.) which meant in the Filipino language as a deep care of a mother to her child with disability. It is non-profit organization committed to promote the welfare and improve the quality of life of children with Spina Bifida, Bladder Exstrophy and severe disorders of sexual differentiation.

**Method:** We stood alone for about 20 years caring mostly post-surgical repair of Spina Bifida patients.

**Results:** The Spina Bifida Support Group Foundation gets referrals of 2-4 newborns with Spina Bifida per week coming from around the country. Some observations and lessons learned throughout the years:

- In the Philippines, there is a need to network with like-minded groups and share resources.
- The foundation's website is the best advertisement. Mothers of children with Spina Bifida have their own account where they find that there are such foundations that can help.
- Obvious spine lesions are the primary concern of parents, but still in our country long term concerns of renal, bowel and rehabilitation care is still low. Many of the patients that we see are already in the fourth or fifth year of life. Most will have had recurrent urinary tract infections, hydronephrosis and with severe constipation/encopresis.
- Urodynamics is expensive so the foundation has learned to do a poor-man's urodynamics using simple cystometry and voiding cystography to initially gauge bladder-sphincter profile. Treatment program of clean intermittent catheterization plus/ minus anticholinergics/ B3 agonists are started. Bowel care with cleansing enema are started early on concomitantly.

**Conclusion:** For the Spina Bifida Support Group Foundation in the Philippines, there is still a long way to go to realise access to multidisciplinary care. In this presentation, results from a two-decade effort will be shared.

**Sneha Sawant**

*Spina Bifida Foundation India*

**Background:** The Spina Bifida Foundation is registered as a non-profit organization in India. The foundation works for prevention and awareness of Spina Bifida and rehabilitation for adults and children with Spina Bifida as well as their families.

**Method:** The Spina Bifida Foundation India organised the following activities:

- Out-reach program in Jawahar, Maharashtra;
- Meeting Maharashtra State Health Minister for taking lead in starting awareness campaign, Birth Defect Registry, and Fortifying food with Folic Acid and Vitamin B12 to prevent NTDs;
- Meeting with Food Safety and Standards Authority of India (FSSAI) Scientific Committee for increasing standards of Folic acid and Vitamin B12;
- Webinar on “The disabled can have it all: Pregnancy and motherhood”;
- Free counselling for Spina Bifida individuals;
- Treatment of Mast. Rohit Belkar from Jawahar camp;
- Treatment of Baby. Ariz Ansari.

**Results:** In the presentation, updates of those above mentioned activities will be shared.

**Conclusion:** The Spina Bifida Foundation India has already planned upcoming activities including:

- Seminar on “Neural Tube Defects and it’s prevention” in Senior College;
- Out-reach program and CME in Kathmandu, Nepal;
- Out-reach program and CME in Cochin, Kerala;
- Out-reach Program and CME in Ballari, Karnataka;
- Out-reach program and CME in Andaman.

**Mario Sel**

*Vereniging voor Spina Bifida en Hydrocephalus Vzw, Flanders, Belgium*

**Background:** Last year, Mario Sel, an education officer at the Spina Bifida and Hydrocephalus Association in Belgium made a wheelchair trip "Side to Side" from the east to the west of Flanders, Belgium. The aim of this project was to raise awareness, to bring people together and to raise funds.

**Method:** From the launch of this project till the start of the trip, the association published some stories to give a complete view on living with Spina Bifida and Hydrocephalus (SBH). Newspapers and radio and television stations also published some stories about this project.

**Results:** In 10 days, Mario drove 300 km. More than 300 people took part in this project by giving him a place to sleep, encouraging him along the way, and together taking part in the events during this journey.

The association raised a total of 26.000 euros, which is beyond expectation;

In 2022 Side to Side will continue in 3 different ways;

- The association will publish inspiring stories from people with SBH;
- The association will publish a book about this trip and Mario's life with SBH;
- The youngsters of the association will organize a Side to Side trip as well.

**Conclusion:** This project allowed the association to raise awareness about Spina Bifida, both by citing themes that are taken from life and by focus on prevention. For this the media was used to reinforce awareness. The book covering this journey also supports this. Also other positive developments showed that Side to Side was a success including an increase in the number of members, and inspired young people.

**Adriana Tontsch**

*Association for Spina Bifida and Hydrocephalus in Romania*

**Background:** A large number of people with Spina Bifida and Hydrocephalus (SBH) and parents complained about two important issues - the health care system and sociocultural factors. It is known that the health care system in Romania is considered as one of the worst in Europe. In addition, scarce resources, inadequate infrastructure, poverty, lack of necessary equipment, inadequate medical facilities, and insufficient supplies have resulted in failing medical care. The Association for Spina Bifida and Hydrocephalus in Romania should mention that Romania has one of the highest levels of poverty, social exclusion, and limited access to education in the EU.

**Methods:** The Association for Spina Bifida and Hydrocephalus in Romania developed new strategies and with specific priorities for the association to respond to Covid situations. In order to support its members and to reduce the burden of the pandemic, the association developed a plan which includes information about Coronavirus and the Vaccine, medical information and advice provided by medical staff, we organized different campaigns and Zoom conferences.

Moreover, the association created an action plan with specific priorities to meet the needs of the refugees from Ukraine in Romania and Moldova.

The impact of the crisis in Ukraine shows how it is affecting people with SBH in Romania. Higher food and energy prices and budget cuts in the healthcare system will impact the quality of life of persons with SBH and their families.

**Results:** The association has been working together with persons with SBH, parents and families to identify where the association can play a useful role and what are the matters they want/need to talk about or how the association can better communicate with them.

This experience gave the association the opportunity to understand their changing needs during the pandemic. Members have said how important they find the possibility to come together and to share their fears, worries, anger and most important their needs. This fact played a crucial role to achieve greater team spirit and confidence in members. The association has good cooperation with the Association for SBH in Germany (ASBH) and received support, information and advice during the pandemic and the crisis in Ukraine from ASBH.

**Conclusion:** Reflecting on the past helps the association see the mistakes in the past and to learn to avoid repeating them in the future. Ignoring fears, anger and needs of the citizens is not a solution. When WHO declared the pandemic in March 2020 the association was not well prepared to understand the meaning of the Coronavirus and its consequences. A long time was taken to respond to the challenges and to deal with the crisis. The Covid-19 pandemic coupled with the war in Ukraine caused not only an economic crisis but also a humanitarian crisis with devastating consequences on persons with SB/H. According to many research and observers, the short and long term effects of Covid-19 pandemic and the war in Ukraine might have big impact on mental and physical health such as depression, anxiety, withdrawal from social life etc. This is an opportunity to rethink the future.

**Kennard Pondani**

*Parents Association of Spina Bifida and Hydrocephalus Limited, Malawi*

**Background:** Malawi has been one of the countries affected by Spina Bifida and Hydrocephalus (SBH) and with the recent interventions has shown that children with SBH still have a chance to pursue their education dream. Being one of the living examples of Hydrocephalus, Kennard Pondani, at the age of 12 was identified with Hydrocephalus and since then has lived with shunt up to date.

**Methods:** Over the years he has completed primary, secondary and tertiary education which now enabled him to be employed by PASHL despite the fact that the brain of SBH children is affected. In advocating SBH he has managed to attend IF African workshops which made him to participate with his fellow youths from Kenya and Tanzania in advocating SBH through a song "NEVER GIVE UP" and also as part of advocating SBH he took part in a movie "TINGATHE" where by youth with SBH showed different artisan talents that they are capable to do proving to the society that disability is not inability.

**Results:** If a child with SBH receives adequate medical and parental support, the child can be like any normal child in accessing health, education and employment and can contribute to the development of the country because disability is not inability.

**Conclusion:** It is of great importance that every child has equal access to all aspects of lives including education. In Malawi, education is the key to improving the lives of children with disabilities.

**Amanda Garzon***Hydrocephalus Association, USA*

**Background:** There are over 1 million Americans living with Hydrocephalus in the United States, from infants to seniors. Anyone at any age can develop the condition. Often thought of as a pediatric condition, today in the U.S. there are more adults living with Hydrocephalus than children. There is a crisis in care, however, as many adult-focused neurosurgeons and neurologists lack the needed knowledge and/or motivation to manage adult patients.

**Methods:** The Hydrocephalus Association works on two fronts to change the future of Hydrocephalus – through an aggressive research program and through direct patient education, advocacy, and support. Our Research program funds innovative, high impact research to improve diagnosis and management of the condition, with the ultimate goal of preventing its development. On the patient-side, we continue to serve as the trusted source of information on Hydrocephalus.

**Results:** HA supports two clinical research networks with institutions in the U.S., Canada, and Great Britain, as well as a basic and translational research network with scientists from over 129 countries. HA has funded 11 compounds that could prevent or improve the treatment of Hydrocephalus. Our clinical research networks have reduced shunt infections by 36%. Recently, our adult-focused network was awarded a \$14 million grant from the National Institutes of Health to study the efficacy of shunting in seniors diagnosed with NPH.

**Conclusion:** Truly impacting the future of Hydrocephalus requires an aggressive strategy rooted in a partnership with medical professionals, industry partners, emerging scientists, commercial innovators, government, and, of course, patients and their loved ones.

**Ruth Nalugya**

*Spina Bifida and Hydrocephalus Association of Uganda (SHAU)*

**Background: Spina Bifida** and Hydrocephalus association (SHA-U) is an umbrella body of organizations of persons with Spina Bifida and Hydrocephalus (SBH) in Uganda. These organizations represent a total number of 12,000 persons with Spina Bifida and Hydrocephalus in Uganda. SHAU was launched as an initiative to enable people with disabilities especially those living with Spina Bifida / Hydrocephalus to access and be included in all service delivery processes at various levels of governance within the public, private as well as the civil society sectors in Uganda. The founders demand for more concrete initiatives and strategies to minimize discrimination and disparities in the delivery of socio-economic services across the country.

**Methods:** SHAU is committed to improve the quality of life of people with Spina Bifida and Hydrocephalus and their families, and to reduce the incidence of neural tube defects and Hydrocephalus through primary prevention; public awareness, and through policy advocacy, research, community empowerment and human rights education.

**Results:** The activities by the Spina Bifida and Hydrocephalus Association of Uganda are aligned with the UN CRPD articles 4.3 and 33.3, "Nothing About Us Without Us".

**Conclusion:** The association has made remarkable contributions in the field of inclusive education, health and rehabilitation and human rights advocacy since 2016 when it was initiated by a few groups of persons living with Hydrocephalus and Spina Bifida and their caregivers. In the presentation, an update will be shared.

### **Quentin Johnson**

*Food Fortification Consultant, Canada*

**Introduction:** This keynote is dedicated to the memory of the late Dr Anna Verster who was a strong advocate of food fortification as a preventive measure addressing Neural Tube Defects.

**Background:** The World Health Organization has recommended that national nutrition programmes should follow an integrated approach of interventions to address malnutrition in countries. These interventions include staple food fortification, supplementation, nutrition education, dietary diversification, crop productivity, and crop biofortification.

**Method:** This presentation will focus on the role of food fortification with Vitamin B9 to reduce the risk of Neural Tube Defects. Food fortification has been carried out in some countries for as long as 70 years. Folic Acid has been added to wheat flour in North America since 1998. Today, 91 countries have mandatory flour fortification with at least folic acid and iron (source: Food Fortification Initiative).

**Results:** This presentation will cover the role of the milling and baking industry on fortification, and the impact of flour fortification with folic acid and iron in the diet. The impact includes both the health benefits and economic benefits of flour fortification as a proven intervention. In particular to address both folic acid and iron deficiencies as cost effective public health measures.

**Conclusion:** Food fortification addresses both a health and economic issue. Primary prevention of Neural Tube Defects through food fortification with folic acid is a successful, cost-effective and safe public health initiative and should be implemented as such. Since food fortification is not a single solution to a multi-sectorial problem, involvement of various stakeholders in public health interventions are important.

*Al-Jawaldeh Ayoub, Mansour Nashwa, Ibrahim Eman, Leppaniemi Hanna, Abbass Marwa*

WHO - EMRO

**Background:** Fortification is an important public health intervention to improve micronutrient status. Fortification of industrially processed wheat flour when appropriately implemented is a simple, inexpensive and effective strategy for supplying vitamins and minerals. The World Health Organization (WHO) Regional Office for the Eastern Mediterranean together with international partners launched an initiative in 1999 which led to that nearly all the countries of the Region by 2022 are fortifying wheat flour with at least iron and folic acid. Currently, wheat flour fortification is widely used in countries of the Eastern Mediterranean Region through voluntary and mandatory regulations (nineteen countries). There is only three countries in the Region who are not implementing wheat flour fortification (Libya, Somalia and Tunisia).

**Methods:** Effective approaches to improve nutrition are based on the transformation of food systems which ensures access to and availability of good quality diets. Strategies should take a socio-ecological perspective in addressing dietary diversity, nutrition education and food fortification.

**Results:** In this presentation, a summary will be provided on the current state of wheat flour fortification in the Eastern Mediterranean Region, common challenges and lessons learned from country experiences will be identified, and the latest guidance on best practices will be outlined. Finally, recommendations to advance appropriate wheat flour fortification in the Region will be shared.

**Conclusion:** Further actions are needed to expand coverage of wheat flour fortification and to ensure that it is effective. Lessons learned from country experiences as well as guidance on best practices will be shared.

**Maria Nieves Garcia-Casal, Lisa M. Rogers**

*Department of Nutrition and Food Safety, World Health Organization*

**Background:** The main objective of the World Health Organization's (WHO) fortification guidelines is to provide locally adaptable, clear, evidence-informed global recommendations on the fortification of staple foods with vitamins and minerals as a public health strategy to improve the micronutrient status of populations. These guidelines are grounded by gender, equity and human rights approaches with the aim of leaving no one behind. Since the 2009 interim consensus statement on the fortification of wheat and maize flours, the WHO Department of Nutrition and Food Safety has developed guidelines on maize flour, rice and wheat flour fortification.

**Methods:** WHO developed evidence-informed recommendations using the procedures outlined in the WHO handbook for guideline development. The steps in this process included: (i) identification of the priority questions and outcomes; (ii) retrieval of the evidence; (iii) assessment and synthesis of the evidence; (iv) formulation of recommendations, including research priorities; and planning for (v) dissemination; (vi), equity, human rights, implementation, regulatory and ethical considerations; as well as (vii) impact evaluation and updating of the guideline. The Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology was followed to prepare evidence profiles related to preselected topics, based on up-to-date systematic reviews and other narrative syntheses of the evidence.

**Results:** In this presentation, the development of WHO guidelines on fortification of rice kernels and maize and wheat flours will be presented, starting from the 2009 interim consensus statement to the current guidelines on fortification.

**Conclusion:** The fortification recommendations are particularly relevant to the design and implementation of programmes fortifying staple foods as part of a comprehensive food-based strategy for combating micronutrient inadequacies and deficiencies. The recommendations are intended for a wide audience involved in the design, implementation and scaling-up of nutrition actions for public health. However, evidence gaps remain in some areas and further actions are needed to support countries and partners to make informed decisions on the mandatory fortification of staple foods with vitamins and minerals as a public health strategy.

**Saskia J.M. Osendarp, PhD***Executive Director, Micronutrient Forum, USA*

Micronutrients, vitamins and minerals, are substances our body needs in only tiny amounts but with vital functions for growth and development. Vitamin B9 for instance—also known as folate or folic acid—plays a vital role in fetal brain and spinal cord development and the heart and circulatory system. Early in pregnancy, folic acid supplementation can reduce the risk of neural-tube defects like spina bifida by up to 70%. However, deficiencies of folic acid seldom occur in isolation.

Recent estimates suggests that more than half of all preschool children and two-third of women of reproductive age worldwide suffer from micronutrient deficiencies, including deficiencies of iron, vitamin A, iodine, zinc and folic acid. A shortage of these micronutrients will have devastating life-long consequences, including lower resistance against infectious and non-communicable diseases, sub-optimal growth, compromised cognitive development, and lower adult productivity levels. Poor quality diets, low in nutritious foods, are a key cause of micronutrient deficiencies. An estimated 3 billion people worldwide cannot afford a healthy diet and COVID, climate disasters and food and fuel price increases will further increase this number, putting millions more at risk of micronutrient deficiencies and subsequent longer term health impacts. To improve access to healthy diets and prevent micronutrient deficiencies, an integrated approach is required across food- and health systems including social protection measures, diversification of local food systems, and cost-effective nutrition-specific solutions to prevent micronutrient deficiencies: the promotion of breastfeeding and healthy diets, micronutrient supplementation, food fortification and biofortification.

**Hildur Önnudóttir**

*International Federation for Spina Bifida and Hydrocephalus, Brussels, Belgium*

**Background:** Contrary to promotion of voluntary dietary changes which are demonstrably ineffective, mandatory fortification of food staples with folic acid (Vitamin B9) have repeatedly been shown to be highly effective in reducing NTDs in various societies and continents. Fortified foods are very effective in enabling women to consume sufficient levels of folic acid (Vitamin B9) before conception. Countries which have introduced mandatory fortification of folic acid (Vitamin B9) in staple foods have seen a drastic reduction in the rates of Spina Bifida and other NTDs. Yet despite the clear evidence that fortification of folic acid (Vitamin B9) is the most effective policy for the primary prevention of Spina Bifida and other NTDs there are still many countries that have not implemented mandatory fortification of folic acid (Vitamin B9). There is a big opportunity and need to expand the policy of mandatory food fortification worldwide of a nutrient which is relied upon by virtually the whole population.

**Methods:** Actions on the international level taken by international organisations such as the United Nations (UN), the World Health Organization (WHO) and the European Union (EU) have significant influence on the direction of policies, such as disability rights, public health, nutrition and social policies, which are of high importance to the SBH community. However, the push for change on the European and international level must come from the grassroots at the local and national level. Without the support of the global SBH community, the rights and needs of the SBH community cannot be advanced. It is imperative to have the push for change come from the national level and the voices of the SBH community be loud and visible in these actions, thereby advancing the rights and needs of persons with SBH.

**Results:** For the primary prevention of NTDs different stakeholders need to be involved. Food fortification involves the input of various stakeholders from the public, private and civic sectors. Awareness raising among all these stakeholders on NTDs and the positive role which fortification plays in reducing their prevalence is essential for the implementation of fortification policies.

**Conclusion:** Reducing the prevalence of preventable Spina Bifida and NTDs is essential in order to reach the ambitions of the international community as laid out in the 2010 WHA resolution on birth defects, the SDGs and their targets and more. International partners including flour millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions can support efforts in making food fortification a reality in countries around the world. The role of civil society in shaping the activities of international organisations and how campaigns for actions will be highlighted. Moreover, recommendations to other stakeholders will be shared.

**Vijaya Kancherla**<sup>1</sup>, **Kaustubh Wagh**<sup>2</sup>, **Pretty Priyadarshini**<sup>2</sup>, **Helena Pachón**<sup>2</sup>, **Godfrey P. Oakley**<sup>1</sup>

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**Background:** In 1991, the Medical Research Council Vitamin Study in the United Kingdom, using double-blind, randomized clinical trial data, provided unequivocal evidence that folic acid prevented a large proportion of Spina Bifida and anencephaly. Our objective was to estimate the global proportion of folic acid-preventable Spina Bifida and anencephaly (FAP SBA) prevented through mandatory folic acid fortification of cereal grains (including wheat and/or maize flour and rice) during the year 2020, marking 30 years of knowledge on folic acid's FAP SBA prevention potential.

**Methods:** The Food Fortification Initiative database was used to identify countries with mandatory fortification policies with folic acid added to cereal grains. We built FAP SBA prevention models assuming mandatory folic acid fortification at 200 mcg/day of folic acid fully protects against FAP SBA and reduces their prevalence to a minimum achievable 0.5 / 1,000 live births.

**Results:** Our analysis found 63,340 FAP SBA cases were prevented in the year 2020 through mandatory folic acid fortification of cereal grain in 58 countries, translating to only 23% prevention of all total possible prevention of FAP SBA globally. Many countries in Africa, Asia, and Europe are yet to implement fortification, and yearly, over 218,000 preventable FAP SBA cases are occurring in countries without fortification.

**Conclusion:** Global prevention efforts for FAP SBA are inadequate 30 years after gaining knowledge on FAP SBA prevention. There is an urgent need for champions to influence universal fortification policy in all countries to prevent FAP SBA and associated elective terminations, stillbirths, and child mortality.

**Camilla G. Aukrust,<sup>1</sup> Colette J. White,<sup>2</sup> Ahmed Negida,<sup>3</sup> Vigneshwar R Veerappan,<sup>4</sup> Roisin McNicholas,<sup>5</sup> Jogi Pattisapu,<sup>6</sup> Kee B. Park**

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<sup>3</sup> Global Neurosurgery Initiative, Program in Global Surgery and Social Change, Harvard Medical School, MA, USA

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<sup>6</sup> College of Medicine, University of Central Florida, Orlando Fl., USA

<sup>7</sup> Program in Global Surgery and Social Change, Harvard Medical School, MA, USA

**Background:** Low-and-middle income countries (LMICs) bear a double burden of Spina Bifida and Hydrocephalus as they shoulder the highest incidences while grappling with multifactorial challenges related to exhausted health systems. The comprehensive policy recommendations for Spina Bifida and Hydrocephalus were crafted to aid LMIC Ministries of Health and policymakers in the administration of these two complex conditions.

**Methods:** A comprehensive literature search was conducted to identify relevant studies; data were used to formulate recommendations spanning six chapters 1) surveillance/screening, 2) prevention, 3) prehospital care, 4) surgical systems, 5) rehabilitation, and 6) transitional/follow-up. These were structured into the WHO's health systems framework; a) workforce, b) service delivery, c) financing, d) information management, e) governance, and f) infrastructure. The recommendations underwent substantial revisions after feedback from a multidisciplinary team of global experts.

**Results:** Recommendations include folic acid supplementation for women of childbearing age, adoption of routine head circumference measurements of children, the establishment of training centers across healthcare delivery services, and upscaling of public health campaigns to decrease stigma and delayed presentation to treatment facilities. To reduce the financial burden of healthcare, it is advised that management be incorporated as part of national health plans. Furthermore, it is suggested common data elements and national registries will aid resource allocation and systematic data collection.

**Conclusion:** These comprehensive policy recommendations are offered as tangible means for a multi- and inter-disciplinary life course approach in LMICs. They may aid Ministries of Health and policymakers reduce the burden of Spina Bifida and Hydrocephalus.

**Boris Groisman**

*Red Nacional de Anomalías Congénitas (RENAC), Argentina*

**Background:** The National Network of Congenital Anomalies of Argentina (RENAC) is a hospital-based congenital anomalies public health surveillance system. RENAC collects, analyses and disseminates data about major structural congenital anomalies, and also contributes with local interventions and prevention. We present the activities developed by RENAC related to prevention of neural tube defects in Argentina.

**Helena Pachón***Food Fortification Initiative, USA*

**Background:** Folic acid is a bioavailable form of vitamin B9. When consumed by women in the peri-conceptual period, folic acid reduces the birth prevalence of neural tube defects. Food fortification, also known as enrichment, is the addition of nutrients to foods during their processing. Eighty countries include folic acid in their fortification standards for wheat flour, 18 do so for maize flour, and 11 for rice. The purpose of this presentation is to present safety and effectiveness evidence from countries with folic acid fortification.

**Methods:** Reviewed country data with respect to several outcomes: (1) masking of vitamin B12 deficiency, (2) adenoma risk, (3) cancer incidence and deaths, (4) neural tube defects, and (5) cost-effectiveness.

**Results:** There are five main results from the reviewed country data:

(1) If fortification with folic acid masks vitamin B12 deficiency, the percentage of people with vitamin B12 deficiency but no anemia should increase after fortification starts. Two studies from the US show the contrary—the prevalence of individuals with vitamin B12 deficiency and no anemia, did not change between the pre- and post-fortification periods, suggesting that fortification with folic acid does not mask vitamin B12 deficiency. (2) A study examined if there was a relationship between free folic acid in blood and the risk of getting colorectal adenomas, which are benign tumors that can develop into cancer. Study participants were followed for two three-year periods. Based on relative risks, free folic acid levels in blood do not increase the risk of adenomas. (3) Data from the US report colorectal cancer incidence per 100,000 population from 1975 to 2015. During this period, voluntary fortification of breakfast cereals with folic acid began in 1973 and mandatory fortification of grains with folic acid became effective in 1998. For women and men, incidence consistently decreased during this time period. Researchers reviewed US data on annual mortality from colorectal cancer from 1950 to 2010. For both women and men, there was a decrease in annual deaths from colorectal cancer over this 60-year period. (4) A meta-analysis with almost 20 million births found a 41% reduction in the odds of neural tube defects after fortification with folic acid. (5) Three countries have compared the costs of adding folic acid to flour with the costs of treating people with Spina Bifida, a type of neural tube defect. Each study showed significant net savings in healthcare expenses when Spina Bifida is prevented.

**Conclusion:** Fortifying food with folic acid is safe because it does not mask vitamin B12 deficiency, it does not increase the risk of developing adenomas, and it does not cause cancer or increase deaths from cancer. Additionally, fortifying food with folic acid is effective because it reduces the risk of neural tube defects. And it is cost-effective because it costs less than treatment of individuals with neural tube defects.

**Scott Montgomery**<sup>1</sup>, **Sylvia Roozen**<sup>2</sup>

<sup>1</sup> Food Fortification Initiative, USA

<sup>2</sup> International Federation for Spina Bifida and Hydrocephalus, Brussels, Belgium

**Background:** From 2007-2021, the Smarter Futures program helped make fortification of wheat flour, maize flour, and rice a reality in dozens of countries across Africa. Food fortification, which is the process of adding vitamins and minerals like folic acid to food as it is processed, is a cost-effective, food systems approach used globally to reduce micronutrient deficiencies. Without requiring consumer behavior change, food fortification delivers essential nutrients through inexpensive, shelf-stable foods that most people consume every day. When consumed by women of childbearing age, foods fortified with folic acid can reduce the birth prevalence of neural tube defects.

**Methods:** A unique public-private-civic partnership, Smarter Futures convened key stakeholders and provided technical support to grain millers, governments, vitamin and mineral suppliers, international organizations, and academic institutions. Smarter Futures brought relevant fortification stakeholders together to collectively identify gaps, craft solutions to close gaps, and ensure greater alignment of efforts for the Africa region.

Smarter Futures partners include the Global Alliance for Improved Nutrition and the International Federation for Spina Bifida and Hydrocephalus as project holders, the Food Fortification Initiative as the main implementing partner, and steering team members: Buhler, Helen Keller International, Mühlenchemie, Nouryon, Nutrition International, and the World Food Programme. Funded by the Ministry of Foreign Affairs of the Netherlands, Smarter Futures did not itself invest large program resources but instead supported and strengthened the efforts of its network partners.

**Results:** In 2007, only seven countries in Africa had legislation for mandatory or voluntary fortification of a grain. As of July 2022, 30 countries had legislation to mandate the fortification of wheat flour alone or in combination with maize flour, five countries allowed the voluntary fortification of either flour, and—though no country in Africa mandates the fortification of rice yet—Smarter Futures has mapped opportunities for rice fortification on the continent.

**Conclusion:** Tremendous progress has been made across Africa since Smarter Futures began in 2007. The unique public-private-civic partnership helped create robust fortification programs that will continue to prevent debilitating health consequences of vitamin and mineral deficiencies, such as neural tube birth defects and impaired learning capacity, for years to come. And yet there is still a need for fortification programs to be strengthened and new fortification programs to be built. Food fortification is one of the most powerful tools we have to tackle micronutrient malnutrition due to its distinct combination of qualities including scalability, sustainability, and cost-effectiveness.

**Wladimir Wertelecki, Diana Akhmedzhanova**

*OMNI-Net Ukraine Programs, Rivne, Ukraine*

**Background:** Population-based surveillance of Neural Tube Defects (NTD) in two regions of the Rivne province in Ukraine, one impacted by Chernobyl radiation (Polissia), is ongoing since 2000. The NTD rates (per 10,000 livebirths) during the period 2000-2009 were in Polissia (24.36) and not-Polissia (14.37). During 2010-2019 period the rates in Polissia were 18.77 and not-Polissia 15.22. Concurrently, measurements of incorporated Cs-137 obtained from 15,324 pregnant women, show elevated levels of ionizing radiation (IR) (Bq/kg) only among those residing in Polissia. Also, the elevated Bq/kg IR levels show a decrement similar to that of NTD rates. The concurrence of both decrements limited to Polissia suggests a cause-effect association. However, further investigations are indicated via specific protocols to address teratogenic impacts of IR in terms of NTD or other outcomes such as microcephaly. In this respect, concurrent investigations of Microcephaly as a manifestation of alcohol teratogenesis are directly relevant. Since 2008 we have investigated Fetal Alcohol Spectrum Disorders, a subject beyond the scope of this presentation. The ongoing assault by Russian troops, referred by Russian leaders not as 'war' but as a 'special operation' is waged with an emphasis on the destruction of civil society as well as healthcare facilities in Ukraine. Under such circumstances, our teams opted to fully dedicate their attention to the care and prevention of recurrence of NTDs.

**Methods:** Our NTD-related data stem from an active, population-based surveillance process, strictly upholding international standards which qualifies OMNI-Net Programs in Ukraine to be Full Members of the EU-EUROCAT consortium of congenital malformation surveillance systems. Cs-137 in terms of Bq/kg whole body counts was obtained from women who volunteered to undergo the process.

**Findings:** An overview of data will be presented with an emphasis of an urgent need for international collaborations. The impact of the Russian assault and destruction of health facilities across Ukraine on the quality of life, health and physical safety of patients, families, and, in particular, persons with disabilities will be presented.

**Conclusion:** The positive and critical role for international, national, private, and parental group agencies is essential. Documentation of the consequences of the Russian 'special operation' s' impact on Ukraine including on those confronted with NTDs is critical for defining amelioration strategies.

**Maman You Espérance Broalet**<sup>1</sup>, Kiyali Tidiane Ghislain Silué<sup>2</sup>, Jean Baptiste Kéké<sup>3</sup>, Landry Tédi<sup>3</sup>, Mohamed Kaba<sup>3</sup>

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<sup>3</sup> Department of Neurosurgery University Hospital Bouaké Côte d'Ivoire

**Background:** Spina Bifida strongly compromises the functional prognosis. The mothers are at the forefront and on a daily basis in the care, which is heavy and long. The objective was to assess the level of knowledge and to describe the attitudes and difficulties of mothers who have already had children with Spina Bifida.

**Methods:** Descriptive retro-prospective study conducted at the neurosurgery department of the Yopougon University Hospital from January 2013 to December 2019, focusing on mothers of children who were hospitalized for Spina Bifida.

**Results:** A total of 24 mothers responded to the survey. Their average age was 23.9 years. The socio-economic level was low in 70.83%. They were unschooled in 66.67%. Poor knowledge of the disease was noted in 62.5%, and of the role of folic acid deficiency in 62.5%. The announcement was felt as a shock in 91.67%. In 41.67% a denial of the disease was noted. The means of care were the mothers' own resources in 91.67%, helped by the family in 62.5%. No psychological support was noted. In 87.50% the child was totally dependent on mothers, who noted economic difficulties in 95.83% of cases. 79.17% of mothers noted a lack of communication with health personnel.

**Conclusion:** Could the explanation be the low level of education or rather the lack of communication from the nursing staff? Interest in raising the awareness of mothers, but above all of health professionals, through a National Control Program.

**Franziska Wadephul**<sup>1</sup>, **Talent Nyamakope**<sup>1,2</sup>, **Deirdre Desmond**<sup>1</sup>, **Amanda Coughlan Santry**<sup>2</sup>, **Rebecca Maguire**<sup>1</sup>, **Laura Coffey**<sup>1</sup>, **Rosemary Gowran**<sup>3</sup>, **Katherine Dunphy**<sup>2</sup>, **Irwin Gill**<sup>4</sup>, **Gillian Fortune**

<sup>1</sup> *Maynooth University; Ireland*

<sup>2</sup> *Spina Bifida Hydrocephalus Ireland (SBHI)*

<sup>3</sup> *Limerick University; Ireland*

<sup>4</sup> *Temple Street Children's Hospital; Ireland*

<sup>5</sup> *Children's Health Ireland, Crumlin; Ireland*

**Background:** For many teenagers with Spina Bifida and/or Hydrocephalus (SB/H) the transition from paediatric to adult healthcare systems can be problematic. Here we aim to capture experiences of transition through a photovoice research project.

**Methods:** Photovoice is a participatory research approach in which participants take photographs to express their experiences, views, and emotions. Five mothers of teenagers and pre-teens with SB/H, all living in Ireland, took part. After an initial online meeting to discuss the project, participants took between three and ten photographs each, which were discussed in four subsequent online focus groups. Themes were developed based on the photographs and group discussions.

**Results:** Five preliminary themes were developed, each illustrated with several photographs. (1) Impact of SB/H, (2) '... not a hospital number', (3) Transition as a 'black hole', (4) The (hidden) work parents do, (5) What needs to change?

**Conclusion:** Participants described a lack of timely, adequate services before, during, and after transition, and inadequate coordination between paediatric and adult services. Children's current needs were often not met, and parents were concerned about an uncertain future in terms of healthcare. They emphasized the importance of looking at each child as an individual, not 'just a statistic', and expressed a strong commitment to improving services for their own children and other children and adults with SB/H.

Improved services must not just address the current lack of a well-planned transition, but also the lack of integrated care for all children up to transition and inadequate services for adults with SB/H.

**Alexandra Wattinger, Brigitte Seliner**

*University Children's Hospital Zurich, Zurich Center for Spina Bifida, Switzerland*

**Background:** The transition from pediatric to adult health care services is becoming increasingly important as adolescents with Spina Bifida grow up. This requires parents to adapt their previous parental role with regard to changing responsibility for their adult children. Health professionals play a central role in this process of change. The aim was to give those parents a voice who are undergoing this process to understand their experience of the transition and the needs they may have.

**Methods:** The qualitative study used semi-structured interviews to examine the experience of parents with a child with Spina Bifida before and during the transition process, as well as after transfer. The ten interviews were analyzed using theoretical coding based on grounded theory.

**Results:** Confronting transition catapults parents into a continuum of reorientation that turns their previous world upside down. Transition must be considered in the context of school, family and health. Parents experience ambivalent feelings that are manifested in the contradiction between handing over responsibility to their child and at the same time protecting their child and his or her health.

**Conclusion:** The parents' experience of ambivalence is observable throughout the transition process and remains after the transfer. This ambivalence in the contradiction between letting go and protecting complicates the parental adjustment process. Professionals play a central role in the transition process. Close support, acknowledging parents' difficulties and providing comprehensive information are helpful for a good transition and the success of the transfer.

*Cillian Dunne, Mirela Bukovac, Parth Hendre, Rereloluwa Adeolu, Samuel Opeyemi, Patricia Albertova, Laura Rosillo Beneyto, Malik Armughan Ali, Rebecca Austin, Ajok Proscovia*  
*International Federation for Spina Bifida and Hydrocephalus Youth Group SBH*

**Background:** United Nations statistics showed that the youth with disabilities are among the poorest and most marginalised of the world's youth. They do not have the same opportunities to make choices and decisions over their own lives as their counterparts. Additionally, it is worth noting that many youth with disabilities are unaware of their rights to independent living. Considering this issue, the IF International Youth Group SBH chose independent living as one of the key themes for this year 2022.

**Methods:** Throughout the year, the IF International Youth Group SBH planned several activities including the training on the concept of independent living, the campaign on the International Youth Day 2022 in which all youth with SBH are able to share their views of independent living and their stories of independence, followed by a webinar for the youth community to share experiences on this topic.

**Results:** The results of activities on independent living will be shared in the presentation. Especially, a reflection will be made from the pre-conference workshop on independent living during the 29th International Conference for Spina Bifida and Hydrocephalus - Diverse Needs, Same Rights.

**Conclusion:** For youth with SBH, it is imperative that youth with SBH can be empowered to take full control over their own life, contributing to achieving successful independent living. The IF International Youth Group SBH will continue to promote the topic of independent living for their youth community.

**Kevin O'Donnell**<sup>1</sup>, **Mario Sel**<sup>2</sup>, **Teije Dijk**<sup>3</sup>, **Filipe Pereira**<sup>4</sup>, **Eva Toft**<sup>5</sup>, **Judy Thibadeau**<sup>6</sup>

<sup>1</sup> *Spina Bifida Hydrocephalus Scotland*

<sup>2</sup> *Vlaamse Vereniging voor Spina Bifida en Hydrocephalus, Belgium*

<sup>3</sup> *SBH Nederland, the Netherlands*

<sup>4</sup> *Associação Spina Bifida e Hidrocefalia de Portugal*

<sup>5</sup> *Spin-off, Sweden*

<sup>6</sup> *Spina Bifida Association, USA*

**Background:** Spina Bifida and Hydrocephalus (SBH) are among the most severe congenital disabilities compatible with life, and affect over a quarter of a million annual births worldwide. Advances in technology and improvement in healthcare have resulted in a significant increase in the life expectancy of babies born with SBH, meaning that for the first time in history there is a substantial SBH community in their late 50s and early 60s. Therefore, the topic of ageing is important for the SBH community. Previously, the IF working group on ageing has mapped lived experiences of those ageing with SBH. In follow up, the working group explored best practices examples of programmes and interventions to meet the needs of the ageing SBH community.

**Methods:** The IF Working Group on Ageing with SBH mapped best practices from existing programmes by IF members associations aimed at adults with SBH around the world. This was done through a survey and online interview.

**Results:** So far, seven best practices were shared. Results showed there are a range of types of projects for adults with SBH in different countries. For example, workshops were developed to increase awareness and knowledge about SBH, and exchange lived experiences with SBH at older ages. Moreover, an educational program was developed to provide job training and job opportunities for adults with SBH. The results from the interview also showed that despite the success of different projects, there remain challenges for SBH associations to develop and maintain programs aimed at the ageing community with SBH due to a lack of funding, human resources, and competences.

**Conclusion:** For the ageing community with SBH, there exists specific projects to enhance knowledge, skills and experiences. The difference between projects is country specific; however, there are commonalities in terms of what the SBH ageing community needs and how these needs can be addressed. The practices as part of this study shows opportunities for different countries and IF member associations to learn from each other and to improve programmes aimed at persons ageing with SBH.

**Ammi Andersson**<sup>1</sup>, **Renée Jopp**<sup>2</sup>, **Matt Bolz-Johnson**<sup>3</sup>

<sup>1</sup> *European Reference Network for Rare Malformation Syndromes, Intellectual and Other Neurodevelopmental Disorders*

<sup>2</sup> *International Federation for Spina Bifida and Hydrocephalus, Belgium*

<sup>3</sup> *European Organisation for Rare Diseases*

**Background:** The Patient Council at European Reference Network for Rare Malformation Syndromes, Intellectual and Other Neurodevelopmental Disorders (ERN ITHACA) gathered common needs of people with different rare congenital diseases to inform a patient journey.

**Methods:** Patients' needs and the required support for a patient with Spina Bifida and Hydrocephalus (SBH) were identified through sharing personal experiences, obtaining oral testimonies from parents and patients with SBH, and using publications such as IF statement on multidisciplinary care. The information from these obtained resources were transferred to a map reflecting the patient journey of SBH.

**Results:** In the presentation, different stages of a journey for persons with SBH in the healthcare sector will be described.

**Conclusions:** The experienced healthcare pathway by persons with SBH differs per region and country. The patient journey map can serve as the information to healthcare professionals and other relevant stakeholders. The current patient journey is a first step to map the needs and necessary support. The ERN-ITHACA patient council will explore further steps to make this patient journey applicable to different countries.

**Tamires Guimarães Cavalcante Carlos de Carvalho,<sup>1</sup> Caio Perret,<sup>2</sup> Stefan Koester,<sup>3</sup> Savio Batista,<sup>4</sup> Paulo Santa Maria,<sup>2</sup> Tamires Guimarães Cavalcante Carlos de Carvalho,<sup>5</sup> Nicollas Rabello,<sup>6</sup> Raphael Bertani<sup>6</sup>**

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<sup>5</sup> Universidade Nove de Julho, Brazil

<sup>6</sup> University of São Paulo, Brazil, Department of Neurosurgery, Brazil

**Background:** A 61-year-old patient was admitted to the Emergency Department with gait disturbance, behavioral changes, and urinary incontinence for 48 hours which led to a mild TBI due to a fall from his own height. The family reported a 3-year history of diagnosis of intermittent pressure Hydrocephalus, which was treated with a ventriculoperitoneal shunt using a programmable valve, also 3 years ago. A CT scan of the head was performed, which showed ventricles of normal dimensions, and a CT scan of the abdomen, which was inconclusive as to the integrity of the catheter. Abdominal ultrasound showed a small amount of free fluid.

**Methods:** We report a case of a patient with a programmable valve to treat intermittent pressure Hydrocephalus whose diagnosis of valve dysfunction was aided by an intracranial pressure waveform analysis device, allowing calculation of the P2/P1 ratio, without numeric values for ICP.

**Results:** The ICP waveform analysis through the device showed a P2/P1 ratio of 1.6. Distal obstruction of the system was suspected. The patient underwent shunt revision. At 48 h postoperatively, the patient was asymptomatic, with a P2/P1 ratio of 1.0, The patient returned to clinic for follow-up, asymptomatic and an outpatient analysis showed a P2/P1 ratio of 0.6.

**Conclusion:** Seemingly simple cases of Hydrocephalus may prove to be diagnostic challenges in the event of valve dysfunction, either by the differential diagnosis with infections or by nonspecific symptoms. Intracranial pressure waveform analysis can be effective as a diagnostic aid method, as well as a follow-up parameter.

**Grotti Giacomo**<sup>1</sup>, **Villani Leonardo**<sup>2</sup>, **Massimi Luca**<sup>3</sup>, **Ausili Emanuele**<sup>1</sup>, **Mariani Francesco**<sup>4</sup>, **Rendeli Claudia**<sup>1</sup>

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**Background:** Evaluate the impact of the COVID-19 lockdown on the well-being of a cohort of children and adolescents with Spina Bifida and their caregivers at Fondazione Policlinico Universitario A. Gemelli during the first wave of the pandemic in Italy.

**Methods:** We administered a questionnaire to the caregivers of children or to the patients themselves aged  $\geq 18$  years old between May and September 2020 investigating their health status and well-being during the Italian lockdown. We collected data regarding age, diagnosis, and autonomy grade and we performed descriptive analyses for all variables and Fisher's exact test to assess the association between the variables.

**Results:** We collected 91 questionnaires. For 48 caregivers (52.75%) referred to an increase of anxiety about the health status of children due to the pandemic and 25 (27.47%) expressed the need for psychological support. In total, 26.37% of caregivers referred to an increased family friction. Almost 60% of our sample experienced problems of communication with the reference care centers in the hospitals, and 81.32% believed it would be useful to set up a telemedicine service.

Fifty-seven patients (66.66%) were unable to continue their therapeutic activities (physiotherapy, psychomotricity, speech therapy), and 30 (32.97%) changed their nutrition habits (with an increase of the intake of food for 80% of them). No significant difficulties in maintaining friendship relations were referred to.

**Conclusion:** The COVID-19 pandemic is certainly having a negative impact on SB patients and their families. Psychological support programs for parents, adequate education on healthy nutrition, an increase in accessibility to therapeutic activities and an effective telemedicine program could represent excellent offers.

**Nagla Mohamed,<sup>1</sup> Salah Ahamed,<sup>2</sup> Aziza Moustafa Enaeema<sup>3</sup>**

<sup>1</sup> Faculty of Nursing Sciences University of Khartoum, Sudan

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**Background:** Clean Intermittent Catheterization was effective and safe methods in managing Spina Bifida patients with neurogenic bladder, its effectiveness needs compliance which is not previously documented in Sudan. The aim of this study is to assess the effectiveness of educational program on vesico-ureteric reflux among non-compliant mothers of children with Spina Bifida at Cheshire Home, Sudan.

**Methods:** A quasi-experimental study design was conducted, which involves one group pre and post intervention. A total of 36 mothers of children out of 42 of Spina Bifida who weren't compliant with clean intermittent catheterization were randomly selected. Of these, 24 mothers were enrolled in educational program (the response rate is 66.7%). The educational program consisted of: Phase 1 - Pre intervention (Micturating cysto-urethrogram); phase 2 - An educational program for mothers which included (a) Theoretical education about clean intermittent catheterization (b) Hands on practice of clean intermittent catheterization (c) Follow up every month for the first three months with voiding diary; phase 3 - Post intervention (Micturating cysto-urethrogram) for those who had reflux.

**Results:** In total 54.2% of children aged from 7 to 12 years while 37.5% are older than 12 years. The vesico-ureteric reflux appeared in 29% of children pre intervention, 71.4% showed improvement in vesico-ureteric reflux, 28.6% showed an increase in vesico-ureteric reflux post program.

**Conclusion:** The education program showed effectiveness of adherence, and improvement in renal function. It is recommended to increase the number of trained nurses on clean intermittent catheterization.

**Mariani Francesco**<sup>1</sup>, **Ausili Emanuele**<sup>2</sup>, **Zona Margherita**<sup>1</sup>, **Grotti Giacomo**<sup>2</sup>, **Curatola Antonietta**<sup>1</sup>, **Gatto Antonio**<sup>1</sup>, **Rendeli Claudia**<sup>2</sup>

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<sup>2</sup> Department of Woman and Child Health and Public Health – Unità Operativa Spina Bifida e Uropatie Malformative, Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy

**Background:** The most frequently used approach to manage neurological bladder in patients with spinal dysraphism is based on clean intermittent catheterization (CIC) and anticholinergic drugs. The purpose of this study is to investigate the role and the real effectiveness of antibiotic prophylaxis in the reduction of incidence of urinary tract infection (UTIs) in patients with Spina Bifida performing CIC.

**Methods:** The data of all patients performing CIC with SB was collected followed in a center, Rome, Italy. Data collected included demographics and clinical information, including the number of UTIs in the two years prior to the last follow-up.

**Results:** A total of 121 patients with SD performing CIC were included in the study; 66 (54%) presented  $\geq 1$  episode of UTIs in the last two years and 55 (46%) none. During the study period, 85 (70%) patients received antibiotic prophylaxis (ABP group) and 36 (30%) did not (NABP group): no statistically significant difference in terms of UTI development was observed between the two groups ( $p=.17$ ). We also evaluated compliance to the therapy; 71 patients (59%) took antibiotic prophylaxis constantly (CABP group) and 50 (41%) did not do antibiotic prophylaxis constantly or did not do antibiotic prophylaxis at all (NCABP group): we observed a statistically significant difference in terms of UTIs with a 2.2 times higher risk of development at least one episode of UTIs in NCABP group.

**Conclusion:** Antibiotic prophylaxis performed constantly, without interruption, is associated with a lower risk of developing urinary tract infections and consequently to develop renal failure in adulthood.

**PANEL DISCUSSION****Panelists:**

Pierre Mertens, President, Child-Help International, Belgium

Dr Hamisi Shabani, Professor Neurosurgery at MOU Dar es Salaam, Tanzania

Dr Gerald Daudi, Neurosurgeon, Bugando Medical Center, Mwanza, Tanzania

Dr Kachinga Agrippa Sichizya, University Teaching Hospital, Lusaka, Zambia

**Background:** Persons with disabilities living in developing countries are on average more likely to have less access to multidisciplinary care. Medical standards and protocols are important and necessary to monitor quality in care and improve outcomes, but what to do when a child has progressive Hydrocephalus with the risk of becoming blind and medical imaging like CT scans or MRI are not available or a barrier due to the price? Can the child and mother be sent home with the request to get a scan first?

**Objective:** Making neurosurgery accessible in the Global South.

In this panel discussion, global experts will share their experiences in making healthcare available and accessible from the perspective of Global South countries. The experts will discuss how limited available resources can be used to reach as many children in need as possible. The example of neurosurgery will be taken to highlight fundamental challenges confronting healthcare systems. Lessons learned will be shared including new approaches for moving upstream.

**Frank Kaphesi**

*Kamuzu University of Health Sciences, Malawi*

**Background:** *Hydrocephalus* is one of the commonest neurological conditions in children worldwide. In developing nations, the major surgical approach for treating Hydrocephalus has been ventriculoperitoneal shunt insertion (VPSI). Despite VPSI's success, emerging complications have led neurosurgeons to seek an alternative approach for treating Hydrocephalus. As an alternate treatment, endoscopic third ventriculostomy (ETV) has been introduced. The aim of this study was to determine the motor development outcomes in children with Hydrocephalus up to two years of age, undergoing ETV and VPSI at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi.

**Methods:** A cross sectional study design was used in this quantitative analysis. The study included two groups of children with Hydrocephalus: those with at least six-month time lapse after undergoing ETV and VPSI and those hospitalized for surgery for the first time. Gross motor, fine motor, language, and social development were measured using a well-validated Malawi Development Assessment Tool (MDAT).

**Results:** A total of 37 participants were recruited, of which 13 had undergone ETV, 12 had undergone VPSI, and 12 had presented to QECH for the first time for surgical intervention. Moreover, 12 (48%) females and 13 (52%) males were among post-surgical participants. There were 10 (83.33%) females and 2 (16.67%) males among pre-surgical participants. The post-surgical and pre-surgical groups had mean ages of 16.44 months (SD 6.14) and 9.08 months (SD 3.68) respectively. In reference to the baseline, ETV group had a higher percentage of children who were developing normally in both gross and fine motor domains, but VPSI group had a lower percentage. However, for all domain scores, there was no significant difference between participant groups.

**Conclusion:** Findings of this study have demonstrated that there are no statistical differences in motor development when comparing children with Hydrocephalus treated with ETV and VPSI. The results further show that children undergoing ETV have at least better outcomes than those undergoing VPSI.

**Raphael Bertani**<sup>1</sup>, Caio Perret,<sup>2</sup> Stefan Koester,<sup>3</sup> Savio Batista,<sup>4</sup> Paulo Santa Maria,<sup>2</sup> Tamires Guimarães Cavalcante Carlos de Carvalho,<sup>5</sup> Nicollas Rabello,<sup>1</sup> Ruy Monteiro<sup>2</sup>

<sup>1</sup> University of São Paulo, Department of Neurosurgery, Brazil

<sup>2</sup> Hospital Municipal Miguel Couto, Department of Neurosurgery, Brazil

<sup>3</sup> University of Vanderbilt School of Medicine, USA

<sup>4</sup> Federal University of Rio de Janeiro, Brazil

<sup>5</sup> Universidade Nove de Julho, Brazil

**Background:** Non-invasive devices that reliably monitor brain compliance can reduce patients' exposure to potentially harmful or costly imaging modalities. The aim of this study is to assess this situation with a new non-invasive headband device.

**Methods:** Patients were submitted to either surgical or valve adjustment procedures and monitored before and after the procedure by a headband device. Sixteen symptomatic patients with a previous radiological diagnosis of Hydrocephalus, in need of intervention, between the ages of 26 and 73 were analyzed.

**Results:** Out of these patients, five were submitted to external ventricular drainages (EVD), nine to ventriculoperitoneal shunting (VPS), and two to valve adjustment. All patients had an abnormal cerebral complacency wave, with  $P2 > P1$  before the procedure, and after, 75% of the patients changed to a normal pattern with  $P1 > P2$ . All patients self-reported feeling comfortable with the device.

**Conclusion:** By providing practitioners the Intracranial Pressure (ICP) waveform and values of the  $P2/P1$  ratio, without quantification of ICP values, this non-invasive device can decrease costs, the time needed to diagnose whether changes or revision of the shunt, and complications of invasive methods for ICP monitoring. Moreover, it can be used in scenarios where invasive ICP monitoring is not indicated, yet would still be insightful.

**Vladimir Gonchar**

*Department of Pediatric Surgery, Shupyk National Healthcare University of Ukraine*

**Background:** Anorectal and perineal disorders in children with Spina Bifida, which are based on two main causes. The first cases include cases of occurrence or pathology of the spinal cord. The second includes damage to the peripheral parts of the spinal nerves.

Patients of the first group - children with severe open malformations.

The number of children in the second group is underestimated. There is evidence that the frequency of occurrence of latent forms of Spina Bifida reaches 70% in the population.

A feature of the innervation of the perineum is its bilateral nature. Due to the asymmetry of bone deformities in the sacral spine, asymmetric damage to the spinal nerves and the pudendal nerve also occurs. Due to non-symmetric damage to the spinal nerves, a violation of the functions of the nerve occurs, which leads to a lack of synergy in the work of the receptor apparatus and the muscular complex.

We have proposed a method of surgical treatment of violations of the symmetry of the innervation of the perineum.

**Methods:** In 2014-2022, 57 children were operated on at the Department of Pediatric Surgery of the P.L. Shupik National Public Health Institute of Ukraine. Treatment outcomes were analyzed one year after surgery.

**Results:** Results are currently available for 49 children. None of the children's condition worsened. One patient showed no laboratory or clinically proven improvement. The remaining 48 children showed significant progress in their condition. Thus, 29 children made a full recovery. In 12 children, the condition improved significantly and complaints are reduced to periodic phenomena of partial urinary incontinence or calomasia. The frequency of such manifestations ranged from one time per week to one time per month. In the remaining seven children, the condition also has a significant positive component. All children had symptoms of urinary tract infections, independent emptying of the intestines and bladder appeared.

**Conclusion:** Surgical treatment of perineal dysfunctions of the pelvic organs is effective.

**Zhengqiang Zhu, Qiang Wang**

*The National Key Clinical Specialty, The Engineering Technology Research Center of Education Ministry of China, Guangdong Provincial Key laboratory on Brain Function Repair and Regeneration, Department of Neurosurgery, Zhujiang Hospital, Southern Medical University, Guangzhou, China*

**Background:** Surgery for children with arachnoid cysts is controversial. Medical records were retrospectively analysed to investigate the possible factors that may influence the reduction of cysts and the improvement of symptoms in children with arachnoid cysts.

**Methods:** Through the medical record data collection system of Zhujiang Hospital of Southern Medical University, we retrospectively collected 96 children with a primary diagnosis of arachnoid cysts from January 1, 2015 to October 31, 2021. According to the children's cyst reduction and symptom prognosis, SPSS 25 software was used to analyze the influence of children's gender, age, onset symptoms, operation, cyst shape, diameter, and location using chi-square test method.

**Results:** Surgery can significantly reduce the cyst size in children ( $p < 0.001$ ), but gender, age, onset symptoms, cyst shape, diameter, and location had no significant effect on the cyst size in children ( $p = .825$ ,  $p = .319$ ,  $p = .825$ ,  $p = .319$ ,  $p = .175$ ,  $p = .185$ ,  $p = .153$ ,  $p = .063$ ). Surgery, cyst diameter and onset symptoms of children had significant effects on the prognosis of children's symptoms ( $p < 0.001$ ,  $p = .008$ ,  $p = .001$ ). Children's own gender, age, cyst shape and location had no significant effect on the prognosis of children's symptoms ( $p = .3$ ,  $p = .724$ ,  $p = .2$ ,  $p = .511$ ). Among the seven children with Hydrocephalus who underwent surgery, four had significantly reduced cysts and three had significant improvement of symptoms.

**Conclusion:** Surgery can significantly promote the reduction of cysts and the improvement of symptoms in children. Surgical treatment has positive significance. Preoperative evaluation of the diameter and symptoms of the cysts in children can effectively evaluate the prognosis of children.

**Jiancheng Zang**<sup>1,3</sup>, **Sihe Qin**<sup>2,3</sup>

<sup>1</sup> Chinese Academy of Medical Sciences/Peking Union Medical College

<sup>2</sup> Rehabilitation Hospital of National Research Center for Rehabilitation Technical Aids

<sup>3</sup> Chinese Spinal Bifida Society

**Background:** To analyze the characteristics of foot and ankle deformity with ulceration in patients with Spina Bifida, to conclude experiences on management with improved Ilizarov method in one stage.

**Methods:** From January 2008 to June 2019, 77 cases suffering foot and ankle deformity with ulceration of Spina Bifida were included, in which 30 male and 47 female, aged six to 46 years with an average age of 22.86 years. There were 10 cases on left, 14 on right and 53 on both. The improved Ilizarov method combined soft tissue surgery, bone osteotomy and Ilizarov technique in one stage, by which the ulcer was dressed aseptically and avoid weight bearing preoperatively, no special treatment, no debridement, no flap coverage and no bacterial culture. Antibiotics were given for three days routinely, and the dressing was removed five days later. If there was exudation, gauze could be used to wrap continually, if there was no swelling and exudation, no need further more caring. General appearance and radiological image of ulcer and deformity were observed during the period of evaluation and treatment, surgical method and complications, foot and ankle function and overall function were evaluated using AOFAS scoring system and special table designed by authors.

**Results:** The total of 77 cases were followed up for six to 132 months with an average of 50.5 months. Achilles tendon subcutaneous lengthening was performed in two cases, posterior tibial tendon and Achilles tendon simultaneous released for 31 cases, subtalar joint arthrodesis 25 cases, calcaneus osteotomy five cases, triple osteotomy 28 cases, ankle arthrodesis 19 cases, internal rotation osteotomy of tibia was performed in one case and one case in external rotation osteotomy. There were 67 cases using Ilizarov fixators and ten cases using Hybrid fixators for immobilization and correction. Stable feet were obtained and ulcers healed simultaneously when all deformities of foot and ankle had been corrected. The healing time of ulcer was average 26.5 days ranging seven to 36 days, and there was no infection or delayed healing occurred in any case. Ankle ankylosis in 25 cases, three cases of pin tract infection, two wires were broken. The AOFAS score significantly increased from 70.5 preoperative to 81.6 postoperative; based special table evaluating, Excellent 28 cases, Good 42 cases, Fair seven cases.

**Conclusion:** The patients with foot and ankle deformity and ulceration suffered from spinal bifida can be treated by improved Ilizarov method in one stage, and the results are satisfactory with short treatment period and decreased complications.

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