



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

The International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care

Programme Book
14th - 17th September 2021

The International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care



Co-funded by the Rights, Equality and
Citizenship programme of 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 first online IF Conference on Multidisciplinary Care for 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 first online IF Conference on the topic of Multidisciplinary Care and we hope you enjoy it.

Cato Lie

IF President



The International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care

14th - 17th September 2021

Zoom Webinar



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 first digital IF Conference on Multidisciplinary Care for persons with Spina Bifida and/or Hydrocephalus from September 14 to 17, 2021.

We have many participants 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 a real Spina Bifida and Hydrocephalus family.

This is the first IF International Conference on Multidisciplinary Care for Spina Bifida and Hydrocephalus. One of the reasons to organise this conference was the recently published report presenting the work from an exploratory study on the best practices of multidisciplinary care in the European region.

Decisions about prioritising integrated healthcare approaches to pursue in the near future are important. For individuals with spina bifida and hydrocephalus and their families, multidisciplinary care requires an improved approach, emphasising on the reality of the complex factors between science, practice, and policy. With this conference IF facilitates further discussions on the important topics of integrated care that addresses the health and needs of persons with Spina Bifida and Hydrocephalus and their families.

Since this conference covers a variety of aspects of care for individuals with Spina Bifida and or Hydrocephalus, from very fundamental issues to practical applications, anyone interested in future progress in optimising management and care should not miss.

Dr Sylvia Roozen

IF Secretary General



SCIENTIFIC COMMITTEE



**Dr Aziza Mustafa
Elnaeema**



Dr František Horn



**Prof dr Jacques
Scheres**



Prof dr Leopold Curfs



**Prof dr Luc
Zimmermann**

Dr Aziza Moustafa Elnaeema



Dr Aziza Moustafa Elnaeema

Dr Aziza Moustafa Elnaeema is a pediatric surgeon and pediatric urologist in Sudan.

She is board member and advisor of the Spina Bifida Federal Association - Sudan and since 2016 board member of the International Federation for Spina Bifida and Hydrocephalus.

She obtained her MD clinical surgery at the University of Khartoum, Sudan, a Fellowship of the Royal College of Physicians and Surgeons of Glasgow, and a fellowship at the University of Toronto Canada. She was of the Sudan Medical Specialization Council, the president of the Pediatric Surgery Council (2018-2020) and the head of the examination committee of pediatric surgery (2013-2018).

Between 2016 and 2020 she was head of the unit of surgery of the School of Medicine, Ahfad University for Women (AUW), Sudan where she now holds her position as associate professor. She is consultant Paediatric Surgeon and paediatric urologist, Soba University Hospital, Sudan (2013-till now). Moreover, she is the head of the curriculum committee-paediatric surgery council-Sudan medical specialization board, and is president of the Sudanese association of pediatric surgery (SAPS).

Her research interest among other topics is aimed at epidemiology and risk factors for Spina Bifida and assessment of renal function and bladder and bowel management for individuals with Spina Bifida. She publishes and presents at international conferences about her Spina Bifida work. In Sudan, she is also actively involved in undergraduate and postgraduate research supervision.

Dr František Horn

František Horn, ass.prof., MD, PhD is a pediatric surgeon working with spina bifida patients more than 30 years. Beside surgeries he is also a coordinator of multidisciplinary care in National Institution of Children's Diseases in Bratislava, Slovakia.

He graduated (MD) in 1988 at LFUK in Bratislava and works there as a teacher. He graduated from pediatric surgery in 1996 and since then he has been dealing with the issue of congenital CNS defects. 2004 – PhD graduation and habilitation – 2021. He received also neurosurgical training at the University Hospital in Bratislava (2010-2013), Beth Israel Medical Center, Institute for Neurology and Neurosurgery, New York, USA (1998) and Queens Medical Center, Nottingham, UK (2014).

He was involved from the beginning in the creation of the first Pediatric Neurosurgical department in Slovakia (2019) and he works there. He specializes in the diagnosis and treatment of neural tube defects, hydrocephalus, craniosynostosis, surgical treatment of spasticity - baclofen pump implantation and selective dorsal rhizotomy.

He is a member of several professional societies: the European Society for Pediatric Neurosurgery, the European Club for Fetal Surgery and a board member of the International Federation for Spina Bifida and Hydrocephalus. Home: Slovak Society of Pediatric Surgery and Traumatology, Neurosurgical Society, Slovak Society for Spina bifida and hydrocephalus. He was the editor of the first independent textbook: Pediatric Surgery, SAP, Bratislava, 2015, awarded by the Literary Fund. He is the author of the monograph Spina Bifida, 2004, VMV, Prešov. It has a total of 269 domestic and foreign publications and 141 citations (updated June 21, 2021).

And as a doctor he knows that life is more than therapy.



Dr František Horn

Prof dr Jacques Scheres



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 was 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.



Prof dr Leopold Curfs

Prof dr Luc Zimmermann



Prof dr Luc Zimmermann

Professor dr Luc J.I. Zimmermann is senior medical director of the European Foundation for the Care of Newborn Infants (EFCNI). He graduated as MD in 1984 at the University of Leuven, Belgium and did his residency in Pediatrics at the same university, in the University Hospital Gasthuisberg Leuven, Belgium (1984-1989). He trained as a Fellow in Neonatology at the Hospital for Sick Children and the University of Toronto Perinatal Fellowship Program in Toronto, Canada from 1989 to 1992.

From 1992 to 2003 he was a staff Neonatologist at the Erasmus Medical Center – Sophia in Rotterdam where he was Chief of the Division of Neonatology a.i. from 2000 to 2003. His PhD thesis (in 1995) was titled 'Regulation of CTP: phosphocholine cytidyltransferase in fetal type II cells'.

In 2003 he became a staff neonatologist at the Academic Hospital Maastricht, in 2004 Professor in Paediatrics and in 2005 Chief of the Division of Neonatology. In 2006 he became Chairman of the Department of Paediatrics and Director of the Residency Program in Paediatrics.

Professor Zimmermann, past president of the European Society of Pediatric Research (ESPR), has been an active member of several EFCNI boards. His present work at EFCNI is located in Munich, Germany.

ABOUT IF

The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with Spina Bifida and Hydrocephalus (SBH) and their families worldwide. The organisation founded in 1979, represents Member Associations in countries all over the world 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 incidence of neural tube defects and hydrocephalus through primary prevention by improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

The **vision** of IF is a society that guarantees the 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 for all.

CONTACT DETAILS

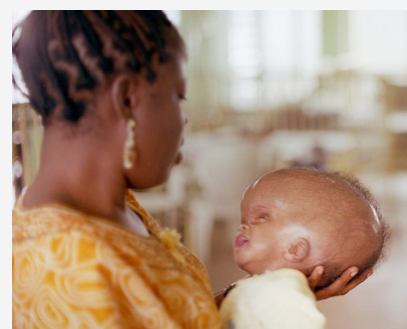
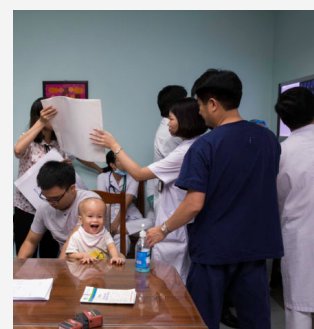
The International Federation for Spina Bifida and Hydrocephalus

📍 Cellebroersstraat 16,
1000 Brussels (Belgium)

☎ +32 (0) 471 84 41 54

✉ info@ifglobal.org

🌐 www.ifglobal.org



KEYNOTE SPEAKERS

In order of presentation

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.

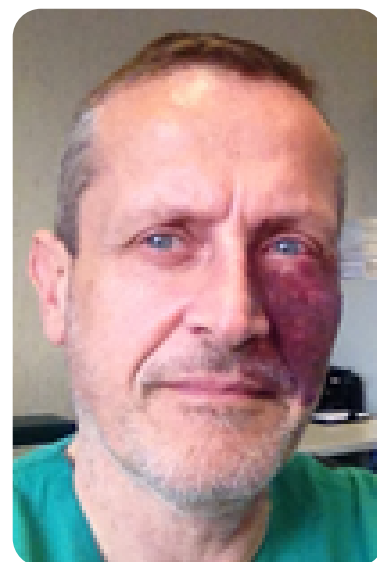
By upholding international standards, OMNI-Net qualified to full membership in EUROCAT, a consortium of birth defects monitoring systems in Europe. OMNI-Net teams promptly detected an epidemic of spina bifida and associated malformations collectively known as neural tube defects (NTD). In 2021, OMNI-Net 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).

Dr Giovanni Mosiello

Dr Giovanni Mosiello, MD, FEAPU, FECPS is a pediatric urologist. He is the head of the Clinical and Research Unit of Pediatric Neuro-Urology Unit, Department of Surgery at the Bambino Gesù Children's Hospital and Research Institute Rome, Italy.

His education includes a postgraduate education with specializations in pediatric surgery and urology. He has been a part of the speciality board status in the European Board of Paediatric Surgery since 1997 and a part of the European Board of Paediatric Urology since 2010. Dr Mosiello was trained in the following places: Madrid, Dallas,



Chicago, Cambridge, Utrecht, Goteborg, Aarhus, Halle and London (Pediatric Urology, Neuro-Urology, Urodynamics, Laparoscopy, kidney transplant).

He participated as faculty and tutor in surgical training and educational projects in Colombia, Bangladesh, Cambodia, EAU, Vietnam, Capo Verde, and Rwanda. He was the chair of the Children's Committee of the International Continence Society, board member of the Italian Society of Pediatric Urology, coordinator of the Children's Committee in the Italian Society of Urodynamics, member of the International Continence Society, the European Society of Pediatric Urology, and the International Society of Spina Cord lesion.

Dr Giovanni Mosiello is director of Training Center for Pediatric Urologist on behalf of European Board of Pediatric Urology, director of Training Center for Pediatric Urologist on behalf of the European Board of Urology /EAU, director of Training Center for Pediatric Neuro- Urologist on behalf of International Continence Society, coordinator of the Disease Area WS1.4 for European Reference Network for Rare and Complex uro-genital disease (EUROGEN), and co-chair of the Working Group on Spina Bifida for the European Reference Network EUROGEN and ITHACA.

KEYNOTE SPEAKERS

Dr Andrea Manunta



Dr Andrea Manunta born in Italy, is a consultant adult urologist in France.

In 1978, graduated in Medicine at Milan's University and did his postgraduate education in the United Kingdom.

In 1986, he received a Fellowship of the Royal College of Surgeons of England and in Mai 1996 a Fellowship of the European Board of Urology.

Since 2009, Dr Andrea Manunta is a member of the GENULF (research group in neurourology) and has been in charge of the coordination of the Centre de Référence Spina Bifida - Spinal Dysraphisms (Center of Excellence for the treatment of spinal dysraphism) in Rennes University Hospital, France. This University Hospital was set up in 2007 within the French Government Rare Disease Plan.

Dr Andrea Manunta main specialist expertise is on urological management of lower urinary tract dysfunction related to neurological deficit with a particular interest on spinal cord lesions both acquired and congenital such as spinal dysraphism.

KEYNOTE SPEAKERS

Dr Marinus Koning

Dr Koning received his medical training in the Netherlands and completed his surgical training in New York City.

Dr Koning specialized in General and Laparoscopic Surgery and Surgery of Trauma.

In 2004, he was awarded Center of Excellence status for his work in surgery for Morbid Obesity. He is a Fellow of the American College of Surgeons and the International College of Surgeons, and the Society for Bariatric and Metabolic Surgery.

Dr Koning retired from his surgical practice in 2008 to pursue humanitarian work internationally, teaching and doing surgery in Ethiopia, the second most populous country in Africa. In response to the need for enhanced medical services throughout Ethiopia and inspired by his unwavering belief that quality health care is a basic human right, he founded the ReachAnother Foundation, a Bend based non-profit healthcare organization in 2009. He was joined by his twin brother, Jan, who formed ReachAnother Nederland in 2013.

Ethiopia with 104 million people is the second most populous nation in Africa, but until 2009 had only 1 neurosurgeon at Addis Ababa University, the country's premier medical institution. Each year thousands of children are born there with Hydrocephalus, water on the brain, and Spina Bifida. If these children receive surgery soon after birth, they can grow up normally (as is routine in the US), if not, many will die. The ReachAnother foundation has taken up the challenge of providing these lifesaving operations and helping train additional neurosurgeons. After a successful pilot project to operate on 200 babies was concluded, the ReachAnother foundation in 2014 embarked on a 5-year plan to operate on 5000 babies and train 25 neurosurgeons by 2019. The Foundation is now working to help the new neurosurgeons become successful in their new practice locations and to develop Centers of Excellence in Pediatric Neurosurgery.



KEYNOTE SPEAKERS

Dr Santosh Karmarkar



Dr Santosh J. Karmarkar graduated in 1982 with a MBBS, in 1986 with a MS and 1989 with a M.Ch from GS Medical College & KEM Hospital, University of Mumbai.

He is a senior consultant pediatric surgeon, at the department of Pediatric Surgery, at Lilavati Hospital and Research Centre Bandra Reclamation, Bandra West in Mumbai, India.

Dr Santosh J. Karmarkar is the Founder Trustee of the Spina Bifida Foundation India and was a former board member of the International Federation for Spina Bifida and Hydrocephalus.

From 1990 to 1996, Dr Santosh J. Karmarkar was Lecturer in Pediatric Surgery, Sion Hospital & LTM Medical College. In 1996, he was recognised as a Postgraduate teacher in Pediatric Surgery and has been examiner for M.Ch - University of Mumbai. From 1996 to 2003 was Associate Professor & Unit Incharge at Wadia Children's Hospital and GS Medical College. Presently is a recognised teacher for Postgraduate training in Pediatric Surgery by National Board of Examinations (NBE).

During several years Dr Santosh J. Karmarkar was a visiting fellowship and professorship in several countries. In 1992, was a Visiting Fellow in Pediatric Urology at Children's Hospital of Philadelphia, USA. Visiting Fellow in Pediatric Surgery Liverpool Alder Hey Children's Hospital, UK in 1993. In 1996, he was a Visiting Fellow in Pediatric Hepatobiliary Surgery Kings college Hospital London. Visiting Professor Gaslini Children's Hospital Genoa Italy in 1998. In 2002, he was a visiting professor at British Council DFID, UK. In 2014, a visiting fellow in CHOP Philadelphia for Robotic Pediatric Urology and in 2019 he was a visiting fellow, in the Fetal Surgery unit at Katowice, Poland.

He was the organising Chairman/Secretary in many national and international prestigious conferences including IAPS National conferences; AAPS conference in Mumbai (1997), the first India national conference on Spina Bifida (2006), and the international conference on Pediatric Urology and Incontinence in Mumbai (2010). Recently, he organized together with the International Federation for Spina Bifida and Hydrocephalus (IF) and the Lilavati Hospital & Research Centre an online webinar on fetal surgery for Spina Bifida (2021).

He has trained several M.Ch & DNB students who are practicing all over the World, he received in 1994 the "Annual Best Research Paper" award at LTM Medical College & LTMG hospital. Besides the scientific publications he presented his work at national and international meetings. He has conducted live operative pediatric surgical workshops in various parts of India.

CONFERENCE PROGRAMME

DAY 1
SEPTEMBER • 14 • 2021

Chair: Prof dr Luc Zimmermann

Co-chair: Victoria Sandoval

HOURS IN PM (CEST)

WORD OF WELCOME **2.50 - 3.00**

SESSION 1

KEYNOTE 1 *Wladimir Wertelecki* - Spina Bifida Care - In Ideal, in Practice and in Reality **3.00 - 3.15**

COUNTRY UPDATES MULTIDISCIPLINARY CARE PART I **3.15 - 3.50**

TALK 1 *G. Bizotto* - Towards a Multidisciplinary Care Approach: The Italian Pros and Cons

TALK 2 *M. Pech* - A French Approach on the Availability of Multidisciplinary Care for children and Adults with Spina Bifida and/or Hydrocephalus

TALK 3 *D. Madaj-Solberg* - Towards a SBH Multidisciplinary Care Approach in Poland

DISCUSSION **3.50 - 4.00**

SESSION 2

HOURS IN PM (CEST)

TALK 4 *Y. Ashagre* - Experience of Establishing and Running a Multidisciplinary Spina Bifida and Hydrocephalus Center of Excellence at Bahir Dar University, Ethiopia **4.00 - 4.15**

COUNTRY UPDATES MULTIDISCIPLINARY CARE PART II **4.15 - 4.40**

TALK 5 *S. Levy* - Celebrating Multidisciplinary Care Approach for SBH and Informing the National Framework in Scotland

TALK 6 *A. Drdul* - A SBH Multidisciplinary Care Study in Slovakia

TALK 7 *R. Höglin* - Multidisciplinary Care for Adults with SBH in Sweden

TALK 8 *B. Seliner* - Advanced Practice Nurses - The Superglue in a Multidisciplinary Spina Bifida Clinic **4.40 - 4.50**

DISCUSSION **4.50 - 5.00**



DAY 2

SEPTEMBER • 15 • 2021

Chair: Dr Santosh Karmarkar

Co-chair: Dr Aziza Elnaeema

HOURS IN PM (CEST)

WORD OF WELCOME

2.50 - 3.00

SESSION 3

KEYNOTE 2 *Giovanni Mosiello* - Neurogenic Bladder and Bowel Dysfunction in Spina Bifida; Pediatric Guidelines

3.00 - 3.20

INCONTINENCE MANAGEMENT

3.20 - 4.00

TALK 9 *E. Gavrilova* - SB Patients in Russia: The First Experience of Multidisciplinary Evaluation

TALK 10 *J. Albaugh* - To Tell or Not to Tell: Navigating Incontinence Disclosure

TALK 11 *S. Karmarkar* - SBH Continence management - Indian Experiences

TALK 12 *G. Masnata* - Telephone-Clinic in Patients with Neurogenic Bladder During the COVID-19 Pandemic: To Make a Virtue out of Necessity

DISCUSSION

4.00 - 4.10

SESSION 4

HOURS IN PM (CEST)

KEYNOTE 3 *Andrea Manunta* - Should We Have European Guidelines on Adult Urological Management of Spinal Dysraphism (Spina Bifida)?

4.10 - 4.30

OPTIMISING CARE

4.30 - 5.10

TALK 13 *V. Gonchar* - Specifics of X-Ray Diagnostics of Anorectal Disorders in Children with Neural Tube Pathology

TALK 14 *M. Koshmaniuk* - Multidisciplinary Care for SBH; Experiences from the Parent Organization in Ukraine

TALK 15 *S. P. Kaiser* - Ponseti Idiopathic and Non-Idiopathic Clubfoot Correction and Implications for Spina Bifida

TALK 16 *K. Zewdie* - Developing a Multi-disciplinary Team and Aftercare Program for Children with Spina Bifida and Hydrocephalus at Zewditu Memorial Hospital

DISCUSSION

5.10 - 5.20



DAY 3

SEPTEMBER • 16 • 2021

Chair: Prof dr Jacques Scheres

Co-chair: Dr František Horn

HOURS IN PM (CEST)

WORD OF WELCOME

2.50 - 3.00

SESSION 5

PARENTING AND TRANSITION

3.00 - 3.50

TALK 17 *C. Alves* - Responsibility Sharing, Family Conflicts, Parental Overprotection and Adolescents' Quality of Life: Perspectives from the Dyads

TALK 18 *F. Dominick* - Challenges of Parenting Spina Bifida Children at Moshi Northern Part of Tanzania

TALK 19 *V. Giudice* - Description of Contextual and Personal Factors in the Transition Process in Patients with Myelomeningocele

TALK 20 *Z. Toefy & R. Bihl* - Multidisciplinary Care - An Outpatient Clinic Perspective

TALK 21 *E. Adefris* - Assessment of Clinical Pathway of Children with Spina Bifida and/or Hydrocephalus in Gondar, Ethiopia

DISCUSSION

3.50 - 4.00

SESSION 6

HOURS IN PM (CEST)

AGEING WITH SPINA BIFIDA

4.00 - 4.45

TALK 22 *K. O' Donnell* - Ageing with Spina Bifida and/or Hydrocephalus: Findings from Focus Group Discussions

TALK 23 *J. Jasien* - Cognitive and Motor Function in Adults with Spina Bifida Myelomeningocele: A Pilot Study

TALK 24 *I. Z. Arusoglu* - A New Multidisciplinary Scoring System (Union) for the Clinical Assessment and Follow-up of Spina Bifida Patients

TALK 25 *I. B. Lidal* - Adult Spina Bifida Care in Norway

DISCUSSION

4.45 - 5.00



DAY 4

SEPTEMBER • 17 • 2021

Chair: Dr Andrea Manunta

Co-chair: Dr Giovanni Mosiello

HOURS IN PM (CEST)

WORD OF WELCOME

2.50 - 3.00

SESSION 7

KEYNOTE 4 *Marinus Koning* - Building Capacity for Spina Bifida and Hydrocephalus Care in Ethiopia, a 12 Year Perspective, Lessons Learned and a Way Forward

3.00 - 3.20

MULTIDISCIPLINARY CARE NEEDS & EXPERIENCES

3.20 - 4.00

TALK 26 *H. M. Lekuya* - Factors Associated with Early Age Mortality of Children with Spina Bifida in Uganda

TALK 27 *L. Madrid* - High Burden of Neural Tube Defects in Eastern Haraghe, Ethiopia: Initial Findings from Child Health and Mortality Prevention Surveillance

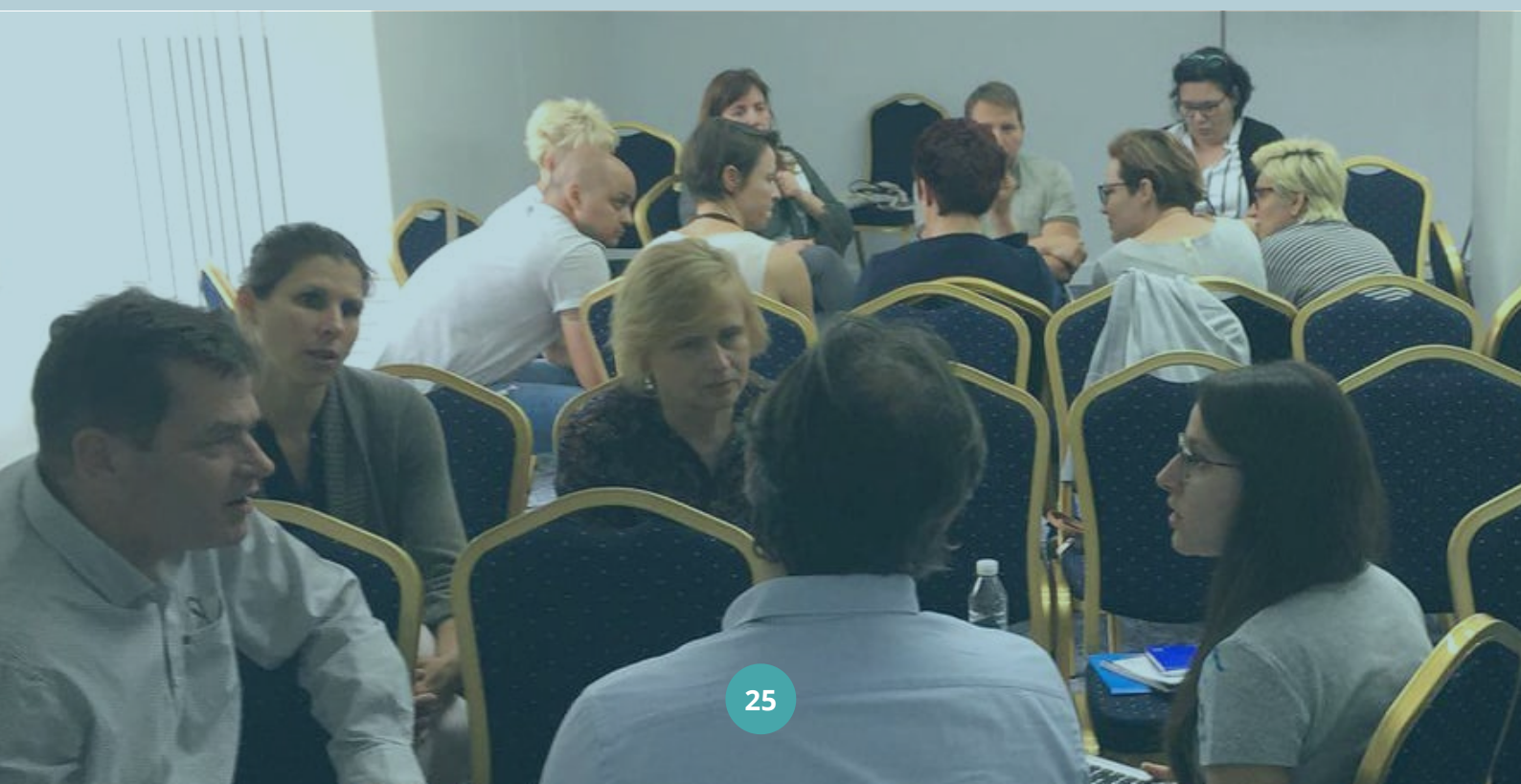
TALK 28 *V. Sutkus* - Inpatient Day Centre for Children with Spina Bifida in Lithuania: a Single Center Experience

TALK 29 *S. Ivanov* - Multidisciplinary Treatment of Children with Spina Bifida in the "Spina Bifida Center"

DISCUSSION

4.00 - 4.15

SESSION 8	HOURS IN PM (CEST)
TALK 30 <i>M. Ward</i> - Perceptions about Mental Health Among Youth with Spina Bifida and / or Hydrocephalus	4.15 - 4.30
TRAINING	4.30 - 5.00
TALK 31 <i>E. Tanil</i> - Patient and Parent Perspective from a Spina Bifida Patient Congress	
TALK 32 <i>F. Shala</i> - An Educational Electronic Health Record with a Configurable User Interface: Gaining a Better Understanding of the Health Management of Spina Bifida and Hydrocephalus	
TALK 33 <i>C. Ondoma</i> - Application of the PRECEDE-PROCEED Model to Scholarship about Individuals with Neural-Tube Defects and their Families	
KEYNOTE 5 <i>Santosh Karmarkar</i> - Multidisciplinary Care for SBH in India: An Orchestra with Many Players	5.00 - 5.20
DISCUSSION & CLOSING CONFERENCE	5.20 - 5.45



ABSTRACTS

In order of presentation



Wladimir Wertelecki*OMNI-NET, Ukraine*

Background: The care and prevention of developmental anomalies, including Spina Bifida and related neural tube defects (SB-NTD), pose a considerable challenge to new parents. The notion “care”, when enriched by those in “sister-words” in other languages, conjure concurrent notions: “caution, guard, preserve, defend, protect” and “conceal, hide, bury”. These notions, at times, can become contradictory and can best be clarified by empathetic others.

It is self-evident that the core mission of SB-NTD organizations (SB-NTD-PO) is the advocacy of optimal care. This ideal is tempered by notions of practicalities and local realities. In any case, a fetus or infant with SB-NTD is a fact that forces mothers and fathers to adapt to their new reality. Their “I am” will become “I am I and my circumstance”. Such process is often clouded by bewilderment and solitude. However, experienced members of SB-NTD-PO as well as professionals, can significantly alleviate this process by pairing with such parents and providing empathy and sharing their knowledge of facts. Most likely, such gestures are likely to enhance the development of new parents as core care providers.

Methods: Regarding practicality, we explored the above notions, to some degree, during a series of 10 webinars dedicated to SB-NTD care and prevention. These webinars were jointly organized by experts from OMNI-Net programs and the “Siavo Dukhu” parental support organization. OMNI-Net conducts population-based surveillance of malformations, including SB-NTD in several regions of Ukraine.

Results: Analyses have repeatedly demonstrated that SB-NTD frequency and associated mortality in these regions are the highest in Europe. The webinars featured native speakers engaged in dispensing various aspects of multidisciplinary SB-NTD care. The audience was nationwide and included a spectrum of health care providers, educators, students, parents, patients, as well as directors of hospitals and academic departments, among others. The rationale for the large scope of themes with a compressed timetable reflected our wish to maximize memorization and opportunities for novel liaisons to arise. From 2222 registrants, 1154 participated live, and 1387 individuals viewed recorded webinars posted on the Internet (this number rises with time). Currently, a contact list includes 953 individuals who sustain an ongoing dialog to test perceptions and their translation into viable eventual initiatives.

Conclusion: Obviously, the optimal SB-NTD care is prevention. Mandatory fortification of flour by folic acid is, perhaps, the only proven method to reduce the impact of these malformations as amply demonstrated in many countries over two decades. OMNI-Net forwarded a project-law to the Council of Ministers proposing that Ukraine implement public health measure. Letters of support issued by webinar participants residing in every region of the country had a significant positive impact. The Council of Ministers agreed to forward the proposal for consideration by the Parliament.

Regarding care needed by mothers and fathers confronted with a fetus or child with SB-NTD, the dialogue with experienced parents and others is ongoing. One core issue is the extent to which such care represents a task for a novel, national SB-NTD care network, distinct from concurrent SB-NTD-PO organizations.

In summary, multifaceted dialogs are to our opinion the first step toward successful change. In this regard, the strategy of intense, multiple, consecutive webinars delivered and attended by nationwide participants was effective. Our hope is that the ongoing dialogues will translate to better care and prevention of SB-NTD patients.

Bizzotto G.

Associazione Spina Bifida Italia (ASBI), Lombardy, Italy

Background: The main purpose of the study was to map the Spina Bifida Centers on the Italian territory in order to understand their territorial distribution, the extension of services offered and the identification of clinicians' équipe employed as well as to investigate the best practices and challenges for a full attainment of an integrated care for people with SBH.

Methods: Both quantitative and qualitative analysis have been used, through surveys and interviews to clinicians, people with SBH and family members of persons with disability.

Results: It is well known that the level of regional healthcare conditions in Italy could determine a remarkable differentiation in the management of the care within SB Centers. People with SBH perception is that the system is fragmented and untangling the yarn falls back into families. For example, family should keep track of the frequency of medical visits and follow-ups and collect information to understand the procedures to follow for the provision of mobility devices and other assistive technologies. Moreover, people would prefer to be followed-up by the same clinician or group of specialists, because different doctors at each visit do not allow to build an open patient-doctor relationship. Last but not least, people find that SB Centers are specialised only in relation to some aspects (usually urology), while the downside clinicians reported is a scarcity of experts on the pathology and a dispersion of skills. Besides these aspects, it has been contested the medical-assistance approach in which the social context in which the person lives is totally overlooked and the focus is mostly on the care of the pathology in itself.

Conclusion: The surveys and the interviews broadly showed the different perceptions that clinicians and people with SBH and their families have on the various aspects related to care and treatment of SBH. The research pointed out several opinions and experiences that are all part of a larger issue: the problem of unaccredited SB Centers. Being an accredited Center means that also a protocol could be developed and parents-to-be could finally be addressed to specific Centers and/or clinicians without navigating the system to search for the best option. Therefore, their missed recognition creates a series of issues among which an increased amount of dispersion of patients, of skills as well as of clinicians. Indeed, a scarcity of specialists on the pathology does not allow the patient to properly perform all the tests he/she would need. Moreover, there is a poor connection between SB Centers especially in the sharing of expertise and skills, in the uniformity on protocols and modalities for the development of a real multidisciplinary. These issues could be solved in several ways: from pushing for SB Centers accreditation, to establishing scholarships for some post-graduation courses in order to train doctor on SBH-related issues. Also, a new position of "mediator" should be created and trained in order to orient families to navigate the system and learn about national and regional regulations on disability as well as procedures to follow. Moreover, a beforehand planning of systematic follow-ups and medical visits in the entire lifespan of the person would help to understand aspects related to adults and elderly with SBH. Additionally, a new consultant positions such as the uro-psychologists should be established and the human rights approach on disability should be integrated and intensified through the help of DPO's by means of out-of-hospital initiatives in which also SB Centers should be involved. Last but not least, one of ASBI Italy future plan is to organise a sort of "promo tour" within the SB Centers in which young and adults with Spina Bifida could take their testimony and their experiences, letting the clinicians know their specific needs.

Pech M.-H.

Fédération Française des Associations du Spina Bifida (FFASB), Lyon, France

Background: The main purpose of the study was to map the Spina Bifida Centers on the French territory in order to understand the practises and challenges of an integrated care for people with SBH. Its objective was to expose existing practices in the country, and to provide the perspectives of individuals with Spina Bifida and or Hydrocephalus and their families on the difficulties encountered in the field.

Methods: First, publications were reviewed to provide an overview of multidisciplinary care settings for SBH in France. Secondly, interviews were conducted with specialists to shed light on the organisations and the reality of care pathways as well as recommendations for improvement. In the same way, interviews of families of SB patients and SB patients allowed to collect their experiences on their care path, and also on their journey in a competence centre when it exists.

Results: Competence centres have been labelled in France under the impetus of the general health organisation. The established Spina Bifida competence centres are registered under the National Rare Disease Health Sector called "NeuroSphinx". This network coordinates different stakeholders working in the field of rare diseases, specifically congenital disorders. Observed are there is a need to strengthen collaborations between Spina Bifida specialists, patient organizations, general practitioners, and the "NeuroSphinx" network.

Conclusion: In France, there remains an urgent need to strengthen the availability and quality of multidisciplinary care for persons with SBH and their families.

The national health network "NeuroSphinx" plays an important role in the growth of the current Spina Bifida network in France. We observed the network allows for better communication between specialists, referrals of patients, and sharing expertise. As such the SB centers are currently in the process of developing National Diagnostic and Care Protocols (PNDS). These guidelines in turn can inform other healthcare professionals on the diagnostic processes and pathways for management and care.

For individuals with SBH as well as their families the availability of integrated care approaches covering all aspects of health are important. Special attention needs to be given to the transition from childhood to adulthood.



Madaj-Solberg D.*Fundacja Spina, Katowice, Poland*

Background: Presenting the current situation regarding multidisciplinary care for children and adults with Spina Bifida and Hydrocephalus (SBH). Identifying the strengths and weaknesses of the Polish SBH care system. Focusing on stall points, solutions and possible development paths to create at least one Spina Bifida reference point That would conducts interdisciplinary coordinated care.

Methods: Firstly based on a qualitative study conducted in 2019 with parents of SBH children and youth, we conducted a process map with the needs of those families. Secondly based on the results, the project SOS for Spina Bifida Poland was conducted. Funding was obtained in cooperation with hospitals and clinics, recommendations from institutions and decision-makers as well as health and support from experienced volunteers.

Results: A qualitative study conducted on parents of SBH children and adolescents showed that the most difficult moment was when the parent was informed of the diagnosis. The respondents indicated that being left stand alone in the first phase of facing their child's illness caused an accumulation of stress- searching to find appropriate doctors, exposing children to unnecessary examinations and in consequents delaying proper childcare and effective treatment. All respondents emphasis that although there were many difficult moments no other moment was as traumatic as the moment of hearing the diagnosis and the period immediately after. Thus accordingly, Spina Foundation (Fundacja Spina) created the SOS for Spina Bifida project, which supports parents of children with SBH from the very beginning and the first period of life. The program enables entry into all gynecology and obstetrics hospitals in Poland along with installing an information board on the premises and providing an SBH guide. The program will also launch a network of volunteers (which are parents of older children and youth with SBH) throughout the regions. Besides supporting the parent at the very beginning of life and directing the child to the proper specialists, the project also allows close cooperation with hospitals all over Poland and very importantly a feeling of control over the situation. The program received a recommendation from the Ministry of Health, the Patients' Rights Ombudsman, the Polish Registry of Congenital Malformations (PRCM), the Medical University of Silesia, EUROlinkCAT and was introduced in several hospitals all over Poland (12 hospitals at the moment).

Conclusions: Due to the fact that no leading centre with multidisciplinary care for SBH has yet to be introduced in Poland, The Spina Foundation decided to build a support network by introducing the SOS for Spina Bifida to hospital wards, where the child and his parents begin their battle. The hope is that if the family will receive support at the start, it will be easier to start effective treatment and help the families "get back on their feet" sooner. The annual program operation shows that it fulfils its role on many levels. Supports parents and their child from the beginning, builds a good relationship between the family and our organisation, as well as engages family members to use their unique skills and therefore draws attention for the need to create a Spina Bifida multidisciplinary centre. Thanks to the support of two university hospitals from the Katowice region participating in the program allows for children and adults managed by the Medical University of Silesia, and the fact that the Spina foundation runs urotherapy laboratories at one of those establishments, there have been promising discussions regarding creating a reference centre for Spina Bifida in collaboration with the above-mentioned establishments as well as with EUROlinkCAT and the Polish Registry of Congenital Malformations (PRCM).

Ashagre Y.¹, Koning M.², Koning J.³

¹ College of Medicine and Health Sciences , Bahir Dar University, Bahir Dar, Ethiopia

² ReachAnother Foundation, USA

³ ReachAnother Foundation, Netherlands

Background: Tibebe Ghion Comprehensive Referral Hospital has a catchment area of more than 5 million people, and is teaching hospital under Bahir Dar university. It is the location of a ReachAnother Center of Excellence for Pediatric Neurosurgery program with a focus on Spina Bifida and Hydrocephalus (SBH), established at Tibebe Ghion hospital on Dec.1, 2021. The hospital provides care for over 200 SBH cases per year. Care for Spina Bifida and Hydrocephalus has long suffered from being disorganized and ineffective, and suffering from lack of equipment and supplies with implications for treatment and survival.

Objective: To showcase the possibility of creating and running a sustainable Center of Excellence for Spina Bifida and Hydrocephalus in a resource limited country.

Methods: Qualitative assessments of the changes in practice and process as well as literature review on the importance of these centers versus traditional fragmented care provision.

Results: The primary aim of the Center is to provide a multi-disciplinary comprehensive patient centered care in a sustainable manner. The college has changed its structural form to accommodate the Center of Excellence in its governance and human resources structure and allocation. We have also changed the fragmented clinical service in to a multi-disciplinary comprehensive clinical service. The clinic will provide access to a multi disciplinary team of physicians during a single visit, thus improving efficiency and reducing cost for the patients. An SBH Team was established: including pediatric nurses, neonatal nurses, physiotherapists, social workers, pediatric surgeon, pediatrician, neurosurgeon, pediatric orthopedist and administrative staff. The ReachAnother Pediatric Neurosurgery Training Curriculum was used to train 12 nurses and other team members. The training created a remarkable transformation to form a cohesive and committed SBH Team that committed to staying for at least 3 years to build continuity of care. The multidisciplinary out patient clinic was established and 50 patients were operated and enrolled in the after care program. RAF has also helped us equip our wards and operating theater with state of the art instruments. A database was established to provide better patient care and follow-up and a create focus on evidence based medicine as research studies are being conducted regularly to guide our future practices.

Conclusions: The establishment of the Center of Excellence for Pediatric Neurosurgery has significantly improved the care being provided, enhanced the practice environment and inspired different research projects. It is our hope that the ReachAnother – Tibeb Ghion Center of Excellence with its exemplary host-partner relationship and best practices will serve as a prototype for establishment of such SBH care facilities in other low income countries and ultimately serve in changing the fate of these kids.

Levy S., Wynd A.

Spina Bifida Hydrocephalus Scotland

Background: Research findings, concerning integrated approach to supporting people with a range of neurological conditions, affirm that the continuity and quality of such care help prevent the development of more severe health and social problems, resulting in fewer hospital admissions and emergency care attendances. In Scotland, our collaborative work with a range of stakeholders found that people living with Spina Bifida and Hydrocephalus (SBH) benefit from a coordinated and multidisciplinary approach to their care. Yet, all too often they experience fragmentation between health and social care services, leading to reduced outcomes and poor patient experience. The National Neurological Frame (2020 – 2025), which we helped to shape, is set to achieve a collective vision of a coordinated multidisciplinary care that seamlessly crosses entrenched geographical and professional boundaries.

Methods: To help the work of the Scottish Government, we signposted our users and participated in a range of opportunities to shape a comprehensive national framework for neurological care and support. We engaged in collaborative work on a core dataset with the NHS Information Services Division (ISD) and liaised with other organisations, across the neurological community, as well as researchers and industry. Throughout the period of consultation, we emphasised the need to create the conditions that help people make informed choices and express their views about their treatment and care options.

Results: The framework recognises that many people with SBH do not need or want access to hospital based care and support. Indeed, many people living with these conditions are self-managing their condition effectively, within their communities, accessing our resources to promote self-management and enhanced wellbeing.

Some of our service users do need care and support delivered within the local community by paid care workers from the local authority or a social care provider, personal assistants, social workers, speech, occupational or physiotherapy and district nursing. The integration of health and social care services is critical to addressing the holistic needs of the individuals and their carers.

There are people who require specialist services available regionally or nationally. Such individuals may require complex, highly tailored packages of care and support. The fact that there is only one specialist adult SBH clinic, based in London and servicing the entire UK population, is an issue that we are lobbying hard to resolve.

Conclusion: The report that the International Federation published last year included a section on Scotland, which offers further insights to the state of our affairs. We included several recommendations, which should be considered in a wider global context:

1. Improve communication and shared data exchange between primary and secondary care and third sector organisations to enhance multidisciplinary care and facilitate an open dialogue.
2. Include service users in information exchanges, using terminology that could be understood by all.
3. Use technology to remind service users/carers of appointment and cancel appointments if admitted to hospital.
4. Standardise a national pathway for transition to adult services and referrals to specialist services and provide concise, linkable, and reliable evidence on which guidance is based.
5. Include third sector organisations within the referral and transition pathways so that excellent resources could be used to enhance multidisciplinary care.
6. Consider annual review for SBH service users to cover their entire lifespan.
7. Create a learning framework for multidisciplinary teams so that shared understanding could be built on the correct knowledge, skills and values.

Drdul A.

Slovenská spoločnosť pre spina bifida a/alebo hydrocefalus (ASBH), Slovakia

Background: All concerns of people with SBH are often strictly understood as medical care only. There is no equal drive for the system including education, accessibility in all forms (for example living places, rest zones, work & school places, transportation), the transition to teenage, to adulthood and to seniority, the survey of life with SBH (any disability), financial independence, improving chances for employment and building career path and its supporting skills but also including social relations, sexuality, nutrition advice, improving physical condition, feeding psychological health and many more aspect of life which makes it full and reasonable. In the presentation, we have no intention to store all aspects of life with SBH in Slovakia, rather we prefer to touch medical care and besides that, we try to show that there exist many other important aspects of human life that are not systematically treated, often not even considered.

Methods: Firstly, a survey has been submitted to various members of the Association from different sides in Slovakia. Secondly, interviews with clinicians and family members with children with SBH have been arranged to get as much as possible a full picture.

Results: Firstly, we may conclude that the quality of the medical approach for SBH differs from county to county. In Slovakia, there exist experienced clinics however whose quality varies in assisting the people with SBH. BUT there does not exist even one place where from the medical point of view we may call it the multidisciplinary approach. The place where people with SBH are at one time checked by different experts. Usually, clients are checked at a different time with different experts, which causes no small time and financial effort from parents, assistants, and people with SBH. Also, we may conclude that the quality of care for the people with SBH is from a medical point of view much better while they are children and teenagers as are with adults. Sometimes it's a very big challenge for adults with SBH to find a doctor or an expert for the consultation and the treatment. Secondly, we may identify a lack of personal approach to fulfill needs as a person with SBH with special needs as they grow up. There is no systematic inclusion policy to the schools, hobbies, sports activities, and transit policy concerning the unique age needs. There is no systematic accessive philosophy regarding transportation, schooling, and job finding. Usually, people with SBH adjust to conditions, not choosing from the options. This package including the systematic development of a person with SBH is what we call a Multidisciplinary approach and that is an area where the SBH Association substitutes official policy. It networks information providing the best available option regarding hospitals, doctors, cares. Furthermore, advocate for children and provide support for inclusion and healthy mental growth.

Conclusion: Results from our survey showed that although some – especially medical aspects of treatment with SBH are good and providing hope for the future we are still in the beginning and if we want to provide a better quality of life we should speak in wider terms and options than medical only which by the way has also a lot of area for improvement itself. BUT the life with SBH did not consist only of medical care and we tried to show up for systematic inconsistencies which should be set up if we want to transform a person with a disability into a person with the ability, independence, and meaning of life with purpose and joy.

Höglin R.*Spin-off, Sweden*

Background: Spin-off is for adults and their relatives and friends, not for children. All members in Spin-off used to be active in RBU, an overall organisation for children with mobility challenges in Sweden. They were categorised in specialized groups, and obviously children with Spina Bifida in one. Now there is a new policy and children are mixed in one, overarching group. On top of this, children with Spina Bifida become rarer every year. In 2020 only three children were born in Sweden with Spina Bifida, according to the annual registry of newborns in The National Board of Health and Welfare. A lot were aborted. Due to lacking knowledge and poor classifications, there is no real knowledge of how many fetuses that were taken away during pregnancy. Some migrant families who come to Sweden bring along children with Spina Bifida, they are not newborns but add to the total but still very low number of new children with Spina Bifida in Sweden.

Methods: Interviews were held with several stakeholders.

Results: Multidisciplinary care for adults in Sweden does not offer a clear and evident path. It varies a lot and both members of Spin-off and non-members say that they far too often must tell their local doctor what to do to help them in their predicaments. Doctors in the local health centres play a vital role. When an adult with Spina Bifida has the opportunity to develop good relations with his or her personal doctor, there's a good chance that the patient may get good treatments. Too often the contrary is the case. Doctors come and go and move to other clinics.

Conclusion: There are seven university hospitals for the ten million inhabitants of Sweden. In those hospitals they usually have the various specialities needed for the treatment of people with Spina Bifida, but not grouped together. In consequence some hospitals are better for the community of Spina Bifida than others. Locally you may find a nurse, or a urology therapist or an occupational therapist that has become a kind of center person for adults with Spina Bifida. They keep track of the individuals, remind them of checkpoints and forward them to the right experts when they are sick.

In Stockholm it works fairly well with the help of Spinalis. It's a clinic shaped mostly for trauma injury patients, but they also receive adults with Spina Bifida annually or every eighteenth month. The team there has good relations with doctors in the nearby Karolinska University Hospital. In Gothenburg it's functioning rather well, as in Linköping and Malmö-Lund. In Växjö too, as in Umeå and Uppsala. Not perfect but nearly acceptable. The MMCUP plays a pivotal role for medical, para-medical experts and others to learn and search information about Spina Bifida. Spin-off members participate in their annual two-day conferences in September when all leading experts meet and report to each other. Adults from Spin-off share their own experiences of the care they receive or want to have.

Seliner B., Wattinger A., Padden B., Mazzone L.

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

Background: With the increase in prenatal Spina Bifida repairs and thus the rising number of children in our multidisciplinary Spina Bifida clinic, the role of an Advanced Practice Nurse (APN) dedicated exclusively to caring for patients with Spina Bifida was established in 2018. The aim was to provide integrated family-centered care and the coordination of multiple services during visits. Additionally, the goal was to support families and their children with managing health issues and symptoms in between visits.

Methods: Based on literature and clinical evidence, the profile of the APN (N=1) was developed by the medical (N=2) and nursing (N=1) management. Feedback rounds with the multidisciplinary team (N=16), reflective clinical practice within the nursing team, and systematic coaching of the "junior" APN over two years by an experienced APN (N=1) refined the profile.

Results: After three years, a catalog with assigned areas of responsibility for the APN was established. The profile developed into that of a clinical nurse coordinator. Today, the APN, supported by the senior APN, cares for nearly 200 families and is the main contact person for medical, psychosocial and nursing issues at our center. She connects the multidisciplinary team, coordinates clinical meetings and ensures that all relevant information is available for patient visits. She supports and accompanies discharges, readmissions, or transitions of patients to adult care. Her work prevents unnecessary consultations, treatments, and emergency admissions and creates a caring environment for patients and families.

Conclusion: The APN provides orientation and support with everyday life issues for patients and their families related to Spina Bifida. She coordinates the needs of the families with those of the medical professionals involved and enables smooth transitions and efficient clinical processes. To facilitate integrated transdisciplinary care, the APN must possess specialized and in-depth clinical knowledge and a high level of communication and coordination skills.



Giovanni Mosiello

Bambino Gesù Children's Hospital, Rome, Italy

Background: Neurogenic bladder and bowel dysfunction (NBBD) in children are commonly related to Spina Bifida patients. For NBBD, guidelines in Europe and the USA exist. With these guidelines there are at present some concerns.

Methods: Existing guidelines have been evaluated, in order to define major points to ameliorate, considering daily clinical practice and the role of patients and families.

Results: Actual guidelines are generically defined for NBBD, not specific for Spina Bifida. Other causes of NBBD are common to observe in daily clinical practice, sometimes in Spina Bifida patients too. Current guidelines are not discussed with families and patients, and some difficulties exist in order to apply them. Patients with Spina Bifida require a multidisciplinary care approach and high specialistic treatment. Standards are not always well defined. Guidelines are mainly thought for western countries. Applying these guidelines in limited resource settings is subject to restrictions. Transitional care is another critical point, and there is the need to ameliorate this process. Some topics need to be better specified as fertility and sexuality.

Conclusion: This presentation reflects on current pediatric Spina Bifida urological guidelines, limitations, and opportunities for improvement.



*Gavrilova E., Belova N., Tishchenko G., Pasechnik I., Ivanchenko D., Kotov V., Berdichevskaya E., Zinenko D., Bulat Y.
CIP, GMS Clinic, Moscow, Russia*

Background: Spina bifida is a complex congenital disease that requires multidisciplinary approach. The Center for Inborn Pathology was organized in 2006 for the multidisciplinary help for patients with congenital and hereditary pathology, initially with bone diseases. In 2018 MDT for SB was organized. At the moment, there is only one multidisciplinary team in Russia. Routinely patients with SB and others complicated inborn diseases are examined by number of specialists in different clinics, in majority of cases there is no “road map” and serious, sometime life-treating pathology may be missed. The purpose of the study is to identify the main problems faced by patients who have not received comprehensive medical care for a long time, and to develop programs for examination, counseling and further management of such patients.

Methods: A total of 100 children with severe forms of Spina Bifida (62 boys and 38 girls, aged from 6 months to 18 years) were reviewed. These are children from the regions of Russia with different living standards, accessibility of environment and quality of medical care. Of the 100 children, 28 were adopted and 4 were orphans, living in orphanages. 6 patents were after intrauterine correction. 85 patients were hospitalized for 3-4 days for the complete evaluation. All patents filled out questionnaires. Then they were examined by following specialists: Pediatrician (head of SB MDT), Neurourologist, Orthopedist, Neurologist, Neurosurgeon, Orthosis specialist, Ophthalmologist, Psychologist, Speech pathologist/ special teacher, Physical therapist.

Following examination was performed during 3-4 days of hospitalization: Spine and Head MRI, Urinary Tract US, Urodynamic Investigation, CBC, Urea, Creatinine, Urine test, Urine culture, Vit D, Spine, Hip and Leg X-ray. If necessary: Renal Scintigraphy, Excretory Urography Cystography, Head CT, EEG. Others: 130 patients were examined by one or two specialists of the MDT by the request of parents.

Results: All patients (100%) had never received comprehensive evaluation or treatment by MDT; 30% of children have never had an MRI; 90% have never had a complex urodynamic investigation, didn't take appropriate medicines and wasn't catheterized; 15% of children underwent meningomieloceles surgery after 1 month of age or later or not at all; 7% were diagnosed with osteoporosis, requiring bisphosphonate treatment; 50% had vitamin D deficiency; 10% had shunt dysfunction; 85% did not have required orthoses; 60% have never visited school, kindergarten, pool or other activities; 30% have never been vaccinated.

Conclusion: The main medical care provided to children before seeking help at the Center was the treatment of hydrocephalus, orthopedic surgery and frequent or constant antibiotic therapy. The plan of examination, hospitalization and rehabilitation was usually worked out for the children by their parents themselves, often on the advice of parents' groups. Orthopedic operations were often performed without correction of osteoporosis, urological and neurosurgical complications, even life-threatening.

Poor accessibility of medical care, especially in remote regions of Russia, a lack of quality sources of information for patients and doctors lead to a low quality of care for patients with Spina Bifida. It is necessary to carefully prepare programs for multidisciplinary management of patients with SB for organizing the work of Spina Bifida centers in different regions of Russia.

Albaugh J., Sheehan L., Gartley C.

Simon Foundation for Continence, Illinois Institute of Technology

Background: Incontinence is a condition that impacts millions of people on a daily basis. It creates challenges in a wide variety of situations including the demands of the workplace, fear when traveling or at family events or while doing activities of daily living. Patients are confronted with occasions when they may question what to tell and who to tell it to. In addition, situations arise that may lead to an unwanted disclosure. The goal of this research and project was to develop a kit to help people with incontinence navigate disclosure.

Methods: Individuals who experience incontinence (n=25; 60% male) participated in focus groups about disclosure of incontinence. A community-based participatory research (CBPR) team, consisting of researchers, health care providers, and people with lived experience of UI developed the research design and focus group questions collaboratively. Participants completed a brief demographic questionnaire and then responded orally to questions within the group setting. Questions were open-ended and asked participants to share their experiences with disclosure and expand upon perceived risks and benefits therein. Transcripts were coded with MAXQDA 12 using inductive thematic analysis. Information gathered from the study was used to develop a navigation tool for people with incontinence.

Results: Participants reported a range of incontinence types including urge, stress, enuresis, overflow, and mixed/other. The perceived benefits of disclosure included: 1) helping others gain understanding or awareness about UI, 2) getting relief from telling the secret, 3) obtaining support and accommodations, 4) strengthening relationships with others, 5) getting treatment for UI, 6) taking control and feeling empowered. The perceived risks of disclosure were: 1) gossip, 2) prejudice and discrimination (stigma), 3) embarrassment, 4) ignorant reactions from others, 5) unsupportive reactions from others, 6) others using your UI against you.

Conclusion: People with incontinence struggle with disclosure. Our team used information gleaned from our research to develop a tool to navigate incontinence disclosure that can be accessed by anyone with incontinence. The tool was designed by our expert team to provide people with incontinence information to help them determine if, when and how they might disclose their urinary incontinence to others while maximizing benefits and minimizing risks.

Karmarkar S.

Department of Pediatric Surgery, Lilavati Hospital and Research Centre Bandra Reclamation, Bandra West in Mumbai, India

Background: Our department is a recognized centre for management of Urinary and Bowel incontinence – especially that related to Spina Bifida.

Method: In our clinical practice over the past 25 years, we have accumulated a large experience in the area of SBH continence management and treated several hundred cases.

Results: In this presentation salient points regarding management of incontinence, including the medical and surgical options, techniques, complications, and results will be discussed.

Conclusion: The conclusion focuses on key take home messages regarding how a Spina Bifida individual can achieve good social continence, thus improving their quality of life significantly.



Masnata G.¹, Dessì S.¹, Corona L.²

¹ Pediatric Urology and Urodynamics-Spina Bifida Centre- Brotzu Hospital- Cagliari, Sardinia, Italy

² School of Pediatrics, University of Cagliari, Sardinia, Italy

Background: The current pandemic has forced health practitioners to meet the clinical needs of each patient and to provide efficient assistance, while also adapting to mitigation strategies and containment measures. Telemedicine has become an effective strategy to achieve this goal, as supported by the increasing literature reports concerning remote patients monitoring.

In our reality, as we represent the local referral center for Spina Bifida and Neural Tube Defects, we follow patients with neurogenic bladder sphincter dysfunction (NBSD) and neurogenic bowel dysfunction, thus needing procedures such as Clean Intermittent Catheterization (CIC) and Trans-Anal Irrigation (TAI). To better adapt to this time of pandemic, we have started a transition to virtual visits for our outpatients' appointments, assessing a remote follow-up. Brief day hospitals or hospitalizations were guaranteed to previously unknown patients requiring diagnostic investigations or in case of acute complications. Even in these cases, a telematic follow-up and remote monitoring was ensured afterwards.

Materials and Methods: The clinical activity that was switched into a "telematic approach" included remote patient monitoring, remote patient training for specific procedures (CIC, TAI) and remote logistics management. Telephone clinic appointments and patient training were performed via mobile and web-based platforms that allow remote viewing, in the presence of the Urologist and the Urology Nurse. Imaging and laboratory records were shared via mail. Voiding charts were administered and shared via mail by our Urology nurse to assess the adherence to the procedure. Emergencies, complications and diagnostic investigations in recently admitted patients were all performed in wards, with brief hospitalization limiting person-to-person contacts.

Results: Among the 78 patients currently admitted to our clinic for Neural Tube Defects, there are 30 patients performing CIC, and 25 patients performing TAI, who were supplied with catheters, delivered directly to their pharmacy. Follow-up of 40 patients were performed via mobile and their clinical records were updated and sent via mail to patients and to their family doctors. During the past 14 months there have been 13 hospitalizations for infective complications or diagnostic investigation. Two patients with cystostomy needed two and three hospitalizations respectively because of Urinary Tract Infections. There were four patients who were firstly admitted to our Unit during the pandemic and were briefly hospitalized to perform specific investigations. One of these patients was then trained to perform CIC using a telematic approach with web-based platforms.

Conclusion: Compared to an equally lasting period of time before pandemic, telephone clinic and telematic management have guaranteed a good clinical practice: the number of hospitalization and complications during pandemic are coherent with those recorded before pandemic. Based upon the feedback of our patients during virtual appointments, the telephone clinic approach during a dramatic moment of health crisis, contributed not only to their overall physical but also psychological well-being. The comfort of a virtual appointment and the possibility of a real-time assistance increased their perception of a trusted source of support.

Andrea Manunta, Benoit Peyronnet

Centre de Référence Spina Bifida – Dysraphismes, Rennes, France

Background: 90% of children with SB are born with normal upper urinary tract but 50% will undergo upper urinary tract damage if untreated, hence the importance of a strict and effective urological follow up. Spina Bifida used to be considered a pediatric pathology but at present 61 to 75% of patients born with SB will live into adulthood and their life expectancy is increasing in parallel with improvement in care; SB has become a pathology of adult age, nevertheless urologic disorders are still the leading cause of death in patients with spinal dysraphism. Even when life expectancy is not threatened, lower urinary tract and sexual dysfunction severely impact the quality of life of SB patients. There are no specific guidelines widely available in English language on this issue. The Guidelines published in 2018 by the SBA (Spina Bifida Association of America) are very broad, encompassing all aspects of care of spinal dysraphism at all ages; the chapter dedicated to adult urological management is therefore quite short and synthetic. The European Association of Urology issued guidelines on adult urological management of neurological bladder at large (including traumatic spinal cord lesions, multiple sclerosis, Parkinson's disease) again very broad based and not sufficiently detailed for our purpose.

Methods: Systematic review of the literature published in English on adult urological management of SB patients in the Embase, MEDLINE and Cochrane SRs Databases, followed by redaction of the guidelines by a panel of European Experts and Patients' Representatives.

Conclusion: The aim of this project is to establish a common European reference for urological care of SB based on available scientific evidence. This should facilitate harmonisation of clinical practices in different European countries and help to structure a multidisciplinary approach and a decision making for clinicians and carers in their daily management of this condition.



Gonchar V.V.

Department of Pediatric Surgery, Shupyk National Academy of Medical Sciences of Ukraine

Background: The pathology of the neural tube has been known to mankind for long time. Only in the 20th century, due to the development of qualitative radiology, computer and magnetic resonance imaging, it became possible to determine the relationship of congenital vertebral dysplasia with disturbances in the functions of the anorectal zone.

Neither assess the degree, depth and, most importantly, the possibility of restoring lost physiological functions. This study assess anorectal dysfunctions among children with Neural Tube Defects and Spina Bifida in Ukraine.)

Methods: Within a period of 2008-2021, 276 patients turned to us concerning manifestations of anorectal dysfunction. All children underwent standard X-ray examination - irigography.

Based on the standard procedure of examination of patients of this group developed in our clinic, they were treated computer and magnetic resonance imaging with subsequent 3D modeling. We obtained the results of the examination in 117 patients. The most important factor in the choice of further treatment tactics was the evaluation of the obtained CT and MRI data. The first thing to notice was the condition of the roots in the S1-S5 area. Taking into account the peculiarity that a pudendal nerve is formed from them, it was important to assess their structure, diameter.

Results: Within a period of 2008-2021, 276 patients turned to us concerning manifestations of anorectal dysfunction. The main complaints related to chronic constipation in 235 people, fecal incontinence found in 172 children, and in 38 of this group it was the only complaint. The prolapse of the rectum was revealed in 21 patient, and in three of the children this was also the only complaint. It should be noted that we found two pathological manifestations in 139 children, and three in 13. An important point was that all children with three pathological manifestations of anorectal dysfunctions had an operative intervention because of the congenital malformation of the spine and spinal cord - spinal hernia.

All children underwent standard X-ray examination - irigography. An important feature of the survey was the preparation of patients. Especially it was expressed in children with chronic constipation. The goal of the preparation was complete cleansing of the intestine and its degassing. In 189 patients, signs of Spina Bifida were revealed. Spina Bifida occulta was detected in 158 patients, and in 31 cases it was confirmed as a pathology after Meningomyelocele.

Conclusions: From the current study several recommendations can be made:

1. Primary radiological examination of children with anorectal dysfunction of any kind and any combination should be conducted with the obligatory study of the condition of the lumbosacral spine.
2. Having the slightest data on the possible presence of a congenital malformation of the spine and spinal cord, it is necessary, in order to establish the diagnosis, CT and MRI of the lumbosacral spine and perineum must be made.
3. In the presence of data on the violation of the symmetry of the perineal function, estimating a degree of damage allows to recommend in time and precisely the necessary method of treatment.
4. Control execution of CT and MRI in a year allows to reasonably estimate the results of the proposed treatment.

Koshmaniuk M.

Association of Parents of Children with Spina Bifida and Hydrocephalus «Lights of spirit», Ternopil city, Ukraine

Background: The organisation “Association of parents of children with Spina Bifida and Hydrocephalus “Lights of Spirit”, was established in Ternopil in May 2017 to improve the quality of life of children and people with spinal fissures and hydrocephalus. Leading principle is to allow a child with a pathology like Spina Bifida and Hydrocephalus to live a normal happy live and don't leave the family alone dealing with the challenges. The dedicated care of parents for their child need to be supported by proper medical care and government support.

Methods: The activities of the association for improving multidisciplinary care will be described from the beginning until now involving our partners.

Results: In particular focus will be given to the series of 10 webinars dedicated to SB-NTD care and prevention that were organized in collaboration with experts from OMNI-Net programs. The webinars were held in collaboration with the OMNI-NET International Charity Foundation and leading physicians and professionals working to improve patients' quality of life and prevent birth defects. The 10-webinar series included key issues of multidisciplinary care: prevent birth defects, prenatal diagnosis of congenital malformations, neurosurgical treatment, the concept of a multidisciplinary approach and continuous care, physical and social rehabilitation of children and adults with complex problems. Webinar videos are available on the organizers' websites. At any time, parents or specialists can view them and get additional information about treatment and care, as well as contact information of expert speakers.

Conclusion: However, we have to admit that the whole set of implemented activities is only the beginning of large-scale work aimed at preventing congenital malformations, eradicating prejudices about the doom of such patients, overcoming physical and social barriers that prevent their active social life. Because, despite the complex condition caused by dysfunction of various systems and organs, such children and adults are intellectually and emotionally developed, their conscious worldview is fascinating. They are full participants in public life on an equal footing: they go to school, get a higher education, do sports and work, and at the same time, throughout life they need individual and comprehensive care. That is why it is so important to educate and inform, join meetings of parents, professionals and government officials to share experiences and address current issues at the state level of prevention, care and socialization of children and people with Spina Bifida and hydrocephalus.

Kaiser S. P., Ishizuka T., Hung Y., Weintraub M. R., Williams M. L.

Kaiser Permanente Oakland Medical Center - Regional Spina Bifida Program (National Spina Bifida Association Clinic Care Partner), Oakland, California, USA

Background: Talipes equinovarus (clubfoot) in the United States is diagnosed in approximately 1 in 1000 live births, but the incidence varies worldwide. The Ponseti method of serial casting is the gold standard first line treatment for idiopathic clubfoot. There are less data pertaining to the success of the Ponseti method in patients with Spina Bifida. We hypothesized after the Ponseti casting method, patients with non-idiopathic clubfoot, including our patients with Spina Bifida, would have a higher rate of secondary foot surgeries compared to patients with idiopathic clubfoot.

Methods: The Kaiser Permanente Northern California (KPNC) Electronic Health Record (EHR) database was searched for children under the age of 3 who received an ICD-9 clubfoot diagnosis between 01/2007 and 12/2015 with minimum 3 year follow up. Our Coding strategy was validated.

Surgical procedure codes were used to quantify additional foot surgery in both the idiopathic and non-idiopathic cohort. The initial Ponseti Achilles tenotomy was not included as a surgical procedure. Secondary chart review was performed to confirm association of all secondary surgeries.

The clubfoot incidence rate was calculated by using the number of KPNC liveborn babies from 01/2004 to 12/2014 as the denominator. Comparisons involving categorical variables were performed using the chi-square or Fisher's exact tests. Normally distributed continuous variables were compared using Student's t test. Data analysis was conducted using SAS 9.4 (SAS Institute, Cary, NC). A logistic regression analysis was run to assess the adjusted association between surgery status and clubfoot type.

Results: 375 children received an ICD-9 clubfoot diagnosis between 2007-2015. Most of the clubfoot cases were idiopathic (n=334, 89%) compared to non-idiopathic (n=41, 11%). Patients with non-idiopathic clubfoot were a heterogeneous population in terms of comorbidities. Meningomyelocele or Spina Bifida was the most common comorbidity (20 patients; 33%).

In the total study population, 82% (n=309) of the patients treated with Ponseti method, maintained correction without the need for secondary surgery. Additional foot surgeries were performed on 17 patients (41.5%) with non-idiopathic clubfoot as compared to 49 patients (14.7%) with idiopathic clubfoot. In the logistic regression model adjusting for demographic characteristics, non-idiopathic clubfoot patients had a higher risk of undergoing surgery as compared to those of idiopathic etiology.

Patients with non-idiopathic clubfoot were younger (mean 2 years of age) at the time of their first surgery ($p=0.04$).

Conclusion: Children with Spina Bifida represent 1/3 of all non-idiopathic clubfoot treated with ponseti method. Secondary surgical treatment is performed in a larger proportion of these children at a younger age. However, over ½ of children with Spina Bifida treated with Ponseti method did not need surgery for their clubfeet, and Ponseti treatments should be recommended for children with Spina Bifida and clubfoot deformity.

Zewdie K., Bizuneh Y.

College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia

Background: Zewditu Memorial Hospital is a district hospital in the center of Addis Ababa. It was established in 1963 and has a current catchment population 1.2 million, it is also one of the affiliated hospitals for the Addis Ababa University College of Health Sciences. It is the only referring hospital for handling babies with hydrocephalus and neural tube defects. Currently the neurosurgery department at Zewditu Hospital sees 1500-2500 cases of neural tube defects, especially Spina Bifida and hydrocephalus (SBH), at its outpatient clinic and admits 800-850 cases annually.

Children with SBH require timely intervention along with long-term management by a highly trained multidisciplinary team. Our past experience in managing SBH patients was focused on surgical intervention (and training of neurosurgeons) with almost non-existing after care management. A large part of SBH mortality is from non-neurosurgical aftercare complications. Improving patient care in pediatric neurosurgery is the major concern of the institution as well as ReachAnother Foundation.

Objective: To describe recent developments in SBH nurses training, aftercare, development of a multi-specialty outpatient program, and highlight the role of the Program Coordinator. Describe challenges and plans for improved patient care.

Methods: In 2020 we have operated 435 cases of neural tube defect and 247 cases of hydrocephalus. We improved our database to better track surgical results and improve patient follow-up care. A qualitative analysis of current program accomplishments and challenges with emphasis on direct benefits to patients and families.

New era: In 2020 we trained 16 clinical nurses with the ReachAnother Pediatric Neurosurgery Training Curriculum focused on developing a specialized SBH Team that will provide comprehensive aftercare to SBH patients. We also launched our multidisciplinary SBH clinic consisting of (neurosurgeons, pediatricians, pediatric surgeon, pediatric orthopedic surgeon, and physical rehabilitation, CIC nurses, along with nurse care coordinators).

Results: Several challenges were observed including for example a high caseload, poor coordinated care, lack of awareness among the general population. The nurse coordinator plays an integral role in providing ongoing, comprehensive and coordinated care throughout the patient life span.

Conclusion: Developing a multi-specialty SBH Care Team and a multi-specialty outpatient clinic where patients can be seen by all needed specialists in one visit is not only a major improvement for the patients and families, but also creates efficiencies that will allow for an increased number of patients to receive surgery and aftercare. It also facilitates follow-up, data collection and scientific studies. Shortages of equipment and supplies are a major obstacle to realization of these goals.

Alves C.¹, Gomes A., Brasil R.¹

¹ ASBIHP – Associação Spina Bifida e Hidrocefalia de Portugal, Portugal

²Faculty of Psychology, University of Lisbon, Lisbon, Portugal

Background: Earlier studies have shown that parents and adolescents with Spina Bifida (SB) share tasks related to SB management, and it is expectable that adolescents' autonomy and independence regarding their self-care increases with their growth. Although there is a tendency of parents to overprotect their adolescents with SB, the relationship between this dimension and the sharing of responsibilities related to their medical condition is not yet clear. It is also important to understand how the family discussion about general and SB issues and sharing of medical responsibilities, and parental overprotection behaviors are associated with adolescents' perceived quality of life. We aim to i) characterize parent-adolescent with SB dyads, regarding the sharing of medical responsibilities, the family conflicts, parental overprotection, and adolescents' quality of life; ii) explore the differences between parent and adolescent's perspectives about the sharing of medical responsibilities and family conflicts, and, iii) explore associations between the sharing of medical responsibilities, family conflicts, parental overprotection and adolescents' quality of life.

Methods: We asked a convenience sample of 28 Portuguese parent-adolescent dyads to complete an evaluation protocol with the following questionnaires: *Parental Anxiety and Overprotection Scale* (Pereira, Barros & Beato, 2013); *KINDL* (Ravens-Sieberer & Bullinger, 1998; Portuguese version: Ferreira, Almeida, Pisco & Carvalheiro, 2006); *Sharing of Spina Bifida Management Responsibilities* (Psihogios, Kolbuck, & Holmbeck, 2015); and *Parent-Adolescent Conflict Scale* (Psihogios, & Holmbeck, 2013). Both parents and adolescents answered similar versions of the questionnaires regarding sharing responsibilities and family conflicts. Quality of life was assessed by adolescents, while parental overprotection was evaluated by parents. Most adolescents who answered the questionnaires attended high school and 53.6% were girls; their ages ranged from 13 and 19 years ($M=16.04$; $SD=1.99$). Most parents were mothers (96.4%) and completed elementary school (53.8%); their ages ranged from 37 to 56 years ($M=45.59$; $SD=5.41$).

Results: The medical responsibilities were perceived by both groups as being shared in a balanced way. In family conflicts, the issues related to SB were more discussed than general issues (that are typically addressed in adolescence). Parents showed moderate scores on overprotection and anxiety/concern behaviors; low scores were verified in parental support to confront behaviors. The adolescents' quality of life dimensions showed overall values above 75%, except for the self-esteem dimension. We found no significant differences between parents' and adolescents' perceptions considering the sharing of medical responsibilities and family conflicts. From parents' and adolescents' perspectives, the more responsibility the young person has in tasks related to the SB, the more these tasks are discussed within the family. More concerned/anxious and overprotective parents, who reported arguing about more SB-related tasks, had adolescents reporting lower disease-related quality of life. The adolescent overall quality of life was positively and significantly correlated with emotional, self-esteem, friends, and disease dimensions of quality of life. Higher scores on parental overprotection were associated with higher parental anxiety and concern.

Conclusions: Despite being an exploratory study and with a small sample, the results seem to point to three main cues. First, both parents' and adolescents' involvement in SB tasks and the higher scores on adolescents' quality of life can be interpreted as good indicators regarding effective SB family management and respect for the developmental tasks of adolescence. Second, a shared responsibility or even a major assignment of the SB tasks to the young person might be challenging and demand more discussion and articulation of the family to better manage the disease. Third, the relationship found between higher parental anxiety and overprotective behaviors, the family discussions about more SB tasks as perceived by parents, and lower disease-related quality of life can be explained both as a parental negative coping response towards a less adequate psychological adjustment to adolescents' disease or as a negative adolescent response to an over-monitored, conflicted familiar context. These initial conclusions highlight the importance of working with families of adolescents with SB about the sharing of responsibilities, discussing with parents suitable alternatives to parental overprotection behaviors, and helping adolescents to develop their autonomy regarding SB management in a safe and collaborative context.

Dominick F.

The Tanzanian training center for international health, Ifakara, Tanzania

Background: Parenting children with Spina Bifida disabilities in Tanzania needs parents or caregivers time, knowledge and resources in order to provide the important needs of the children. This study aims to explore the challenges of parenting children with Spina Bifida and support needs.

Methods: A total of 30 parents were interviewed by using a developed interview questionnaire checklist designated and it was filled in by the researcher. The questionnaire included, challenges and support needs of parents parenting children with Spina Bifida attending at CCBRT Moshi center northern part of Tanzania.

Results: Parents attending at the CCBRT rehabilitation center expressed their thanks fullness and happiness feeling towards the services and improvements of their child's health. All parents reported to cope with the previous stress that was high before attending the clinic and receive psychological counselling.

Children who received rehabilitation services early with VP shunt in were able to study and only 8% presented with hydrocephalus 50% were female and also male was 50% all with good performance in class. Common reported challenges was the ability to use clean intermittent catheterization, bowel management, cost of attending and receiving rehabilitative services, low household income, bad tradition believes and having support from another parent in taking care of the child, highly support need suggested by parents upon their challenges were provision of national of free national insurance fund card, sustainable economic help like domestic keeping, education to the community and use of peer educators in community sensitization and case finding.

Conclusion: Parents of children with Spina Bifida experience a lot of challenges during their daily life of parenting their children. The challenges are much influenced by poverty, low education on provision of care to the child and high cost of assessing care services. Generally Spina Bifida disability does not affect the future of the child if he or she may get a good supportive environment to fulfill their dreams and may become helpful to both their family and society at large. Rehabilitation services should be expanded to many areas of our country in order to reduce the burden of cost for transportation that leads to failure in attending follow-up visits. Also special boarding schools with a friendly environment to Spinal Bifida disabled children should be built in many areas across our country.



Giudice V., González A., Gomez S., Vazquez J. A., Capmany L., De Castro F., Bernardes L., Norton E., Sager C., Mato R., Rodriguez E.

Pediatric Hospital 'Prof. Dr. Juan P. Garrahan, Buenos Aires, Argentina

Background: Since 2005, the clinical approach of patients diagnosed with Myelomeningocele (MMC) is in charge of the Multidisciplinary Myelomeningocele Team (MMT), in which different specialties participate according to each case (Pediatrics, Urology, Gastroenterology, Learning Psychology, Traumatology, Physical Therapy, Neurosurgery, Ophthalmology, Traumatology, Psychology, Spine Pathology, Nephrology, Nutrition, Renal Nutrition, Adolescence). Consultations are received from the neonatal period to adolescence. To date, more than 900 patients from all over the country have been assessed, 75% of which still receive care in this center. The aim of this study is to describe which factors guide intervention strategies in the transition process with patients over 12 years of age with a diagnosis of MMC during 2019. The results obtained will allow the team to optimize the formal transition protocol to be implemented in 2022.

Methods: Retrospective descriptive observational cross-sectional study.

Results: Of the 58 patients diagnosed with MMC seen in 2019 in the Learning Psychology Unit, 50% (29) were in the target age group with whom specific transition interventions were performed. More than 65% of the sample has a low socioeconomic status, 3.4% of which present extreme poverty. Regarding the family educational level, in terms of the average years of schooling of the adults in the household, 65.5% have a medium level (from 7 to 11.99 years) and only 31% are high (≥ 12 years). Regarding the neurocognitive assessment, 14% present average cognitive skills, 42% present a diagnosis of Intellectual Disability, 25% borderline intellectual functioning and 19% learning disabilities.

Conclusion: The majority of our population deals with socioeconomic deficits, which interferes in the transfer process due to lack of access to the health system. Our study suggested that beside these factors, interventions implemented during the transition process were regulated according to two main variables: intellectual level and degree of autonomy. The goals setted range from addressing the personal level to functioning in the community, depending on each patient. Based on this, it is planned to take these variables into account in the formal protocol that the MMT is creating. In addition, the analysis of the strategies implemented so far with the transition guidelines has allowed us to identify aspects that have not yet been addressed in the transition of this population.

Toefy Z., Bihl R.

Red Cross Children's Hospital Spinal Defects Clinic, South Africa

Background: Children born with Spina Bifida and Hydrocephalus (SBH) face a lifetime of medical care and follow up. Long term management includes the expertise of a wide range of medical professionals, including Neurosurgeons, Urologists, Radiologist, Orthopaedic Surgeons (with the help of the Orthotists), Physiotherapists, Occupational Therapists, Social Workers and the clinic Nurse/Stoma therapist.

Care is best offered in the context of a Multidisciplinary Clinic to avoid fragmentation in the management of this condition. In South Africa, individuals with Spina Bifida and Hydrocephalus and their families are confronted with challenges especially in the transition phase from childhood to adulthood. Therefore there is a need for specialized and integrated care. This presentation will share experiences from the multidisciplinary clinic at Red Cross Children's Hospital in Cape Town, South Africa.

Methods: The Multidisciplinary Clinic at Red Cross Children's Hospital was established in 1967. The multidisciplinary team includes several specialists. Complicated cases are discussed between the various health professionals to plan the correct treatment.

The Clinic Nurse who is also a stoma therapist is the first person the mother sees with her baby on arrival at the clinic. Here the baby is weighed and urine is tested. The nurse has the opportunity to observe the baby holistically for any skin conditions and developing pressure sores. In discussion with the mother, the nurse can identify any delays, physical or mental, and timeously refer them to the correct medical specialist. This has a significant impact on survival and long-term quality of life.

The nurse also teaches the management regime of 3-hourly catheterisation and bowel washout, and re-enforces the importance of regular clinic attendance. More importantly educate them about prevention with preconception folate.

Medical complications (high fever coupled with lethargy and breathing difficulties) are immediately referred to the medical emergency department.

Results: A group of dedicated parents work together with the healthcare professionals. As a result, in 2014 the Association for Spina Bifida and Hydrocephalus (ASBAH-SA) was established. One of the successful partnerships included the establishment of the ASBAH-SA Training and Caring Centre (ATCC). In our team, we have a lot of experience and in this presentation we will talk about the experiences we have with the multidisciplinary team of healthcare professionals at the Red Cross Children's Hospital.

Conclusion: We have a positive experience of working together with the outpatient clinic for individuals with Spina Bifida and Hydrocephalus and their families. Our journey shows a fruitful collaboration between parent associations and clinical centers. Experiences as well as lessons learned will be shared during the presentation.

Adefris E.¹, Nigussie K.¹, Hoeven L.², Rouwen S. G.², Overvelde A.², Koning M.³, Koning J.³

¹ College of Medicine and Health Sciences, University of Gondar, Gondar, Ethiopia

² Radboud University Medical Center, Scientific Institute of Healthcare, Nijmegen, The Netherlands

³ Reachanother Foundation, USA and The Netherlands

Background: Comprehensive and effective care of children with Spina Bifida and hydrocephalus (SBH) is essential in high prevalence countries like Ethiopia. Since 2009 the ReachAnother Foundation (RAF) has been investing in better health care for these children. Neurosurgery in Gondar started in 2017, including a strong focus on physical therapy.

Objective: To detect gaps in the clinical pathway (CP) in the care of SBH children compared to the ideal clinical pathway (ICP) and develop a concept implementation plan based on the findings.

Methods: We conducted a qualitative study, which included semi-structured interviews with parents and health professionals. Respondents were asked about the CP of children with SB(H). The interviews were recorded, transcribed, translated, coded, thematically analyzed and compared with the ICP.

Results: Twenty-one semi-structured interviews with parents and 30 interviews with healthcare professionals were conducted. The care system for children with SBH appears to fail in several aspects such as use of folic acid, diagnostic skills, sufficient knowledge and experience regarding the care of these children. Additionally, both parents and healthcare professionals identified several essential and practical suggestions to improve clinical care. One immediate result was the video: "What parents can do" to preserve mobility of their Spina Bifida baby, a physiotherapy training film for babies with Spina Bifida and Hydrocephalus

Conclusions: Based on semi-structured interviews with parents and health professionals, this study provided information on the gaps in the CP of children with SBH. Major gaps were encountered in communications, prenatal care, home care, and the knowledge and skills of healthcare professionals. Based on these gaps a concept implementation plan has been developed to improve the pathway of SBH children. The application of this implementation plan can have a significant impact on the improvement of care of these children and will address most of the impairments, if not all.



O'Donnell K.², Sel M.³, Dijk T.⁴, Pereira F.⁵, Toft E.⁶, Thibadeau J.⁷, McGeough H.⁸, Duff M.⁹, Lie C.¹

¹ Ryggmargsbrokk- og hydrocephalusforeningen, Norway;

² Spina Bifida Hydrocephalus Scotland;

³ Vlaamse Vereniging voor Spina Bifida en Hydrocephalus, Belgium;

⁴ SBH Nederland, the Netherlands;

⁵ Associação Spina Bifida e Hidrocefalia de Portugal;

⁶ Spin-off, Sweden;

⁷ Spina Bifida Association, USA;

⁸ Spina Bifida Hydrocephalus, Ireland;

⁹ Australia

Background: Spina Bifida and Hydrocephalus (SBH) are complex health conditions leading in many cases to disabilities involving cognition, behaviour, and neurological dysfunctions. These are the most common NTDs, which affect over a quarter of a million annual birth outcomes worldwide. However, rapid developments in medical science, advancement of technology and improvement in healthcare practices have seen a significant increase in the life expectancy of babies born today with these conditions. For persons with SBH life expectancy is on the rise. Whilst the knowledge base concerning neonatal and paediatric care is growing, there is little known about the impact living with SBH has on transitioning to old age. There is a need to explore and expand our knowledge and gain insights into current health and wellbeing status of older people with SBH. To address these, the IF Working Group on Ageing with SBH, involving members from IF member associations aims to improve our understanding of the lived experience of older persons with SBH.

Methods: Several actions have been undertaken by the IF Working Group on Ageing and SBH to advocate for the rights of persons with disabilities also on behalf of IF members. For example, in 2019 the IF Working Group on Ageing with SBH conducted a Europe-wide explorative study using an online survey. The report described results from 650 persons with SBH and their lived experiences. Not unexpected, the results from the survey revealed different lived experiences which clearly shows there is no one true lived experience that we unearthed. There is a clear need for qualitative investigations to adopt a more in-depth approach to data collection and affirm overall findings from the previously conducted survey.

Following these recommendations, this presentation will describe outcomes of recent focus group discussions to better understand lived experiences for persons with SBH with respect to mental and physical health.

Results: In this qualitative approach, focus group discussions were used to capture lived experiences with SBH. The findings from the explorative study showed and second the general concepts important to those living with SBH while ageing indicated in the quantitative study conducted in 2019, including: lack of support, isolation, the need for a multidisciplinary healthcare system, a better communication between doctors, the need from doctors to take Mental Health among adults with SBH more into considerations and the fear of becoming dependent.

Conclusion: The advancement in medical science, improved public health and rapid development of technologies had a significant impact on longevity. Those growing older with the added complexity of living with a chronic condition, are more vulnerable to risks that may adversely affect their health and wellbeing. The concept of transition, in the context of the older adults with SBH, involves a human response to change and associated needs. Results from the Focus Group Discussions show that whilst progressing along the ageing pathway, people with SBH are becoming more isolated and they are more anxious and depressed. The results demonstrate that there is a need to support and enhance lived experiences of people ageing with SBH, especially with respect to the topic of mental health.

Jasien J. M.¹, Mikati M. A.¹, Kolarova M.², Smith B.³, Thera S.¹, Lee P.⁴

¹ Department of Pediatrics, Division of Pediatric Neurology and Developmental Medicine, Duke University, Durham, NC, USA

² Duke University, Durham, NC, USA

³ Division of Neonatal-Perinatal Medicine, Duke University Medical Center, Durham, NC, USA

⁴ Duke University School of Medicine, Durham, NC, USA

Background: Despite improved longevity in the Spina Bifida myelomeningocele (SBM) population and a number of studies addressing cognition and motor function, there is still a need to identify a specifically tailored battery of tests that could be utilized clinically to follow the cognitive and motor status of adults with SBM over time. To address this gap, we conducted a pilot study of adults 18 years and older seen in our Duke SBM multidisciplinary clinic to achieve the following goals: (1) to identify if it is feasible for adults with SBM to be consented and to complete a battery of cognitive, functional activities and motor assessments that are commonly utilized in the typical adult population; (2) to identify the spectrum of their abilities and which tests detect this spectrum by comparing the results of the battery to normative sample means; and (3) to provide cognitive and functional ability data and tools necessary for future long-term prospective follow-up studies of SBM patients.

Methods: Prospective study in which 15 participants (mean age 28.7 ± 8.7 years, range 19–45 years) completed the targeted battery of tests (n 5–15/test) previously standardized to the general population. Results were compared with normative data.

Results: Statistically significant differences with normative means were noted in the following tests: Montreal Cognitive Assessment (MoCA), Functional Activities Questionnaire (FAQ), and NIH Toolbox Fine Motor (Dexterity and Grip Strength) tests. Cohort means for NIH Toolbox Fluid, Crystallized, and Cognitive Composite Scores and Timed Up and GO (TUG) were not different from normative means.

Conclusion: All tests were successfully completed by cohort. Whereas many aspects of cognition were normal, tests assessing visual-constructional, calculation, motor, and fluency functions did show differences from population means. Numerous tests assessing multiple domains are needed and can be used in future aging studies to appreciate the spectrum of cognitive and motor abilities in adults with SBM.



Arusoglu I. Z.¹, Ulman I., Tiryaki S., Cayirli H., Avanoglu A., Gunay H., Turhan T., Capaci K.⁴

¹ Ege University Faculty of Medicine, Pediatric Surgery, Pediatric Urology, Izmir, Turkey

² Ege University Faculty of Medicine, Orthopedics and Traumatology, Izmir, Turkey

³ Ege University Faculty of Medicine, Brain and Nerve Surgery, Izmir, Turkey

⁴ Ege University Faculty of Medicine, Physical Medicine and Rehabilitation, Izmir, Turkey

Background: Efficacy of specialized clinics for Spina Bifida have been documented. But a scoring system for overall evaluation of these patients for different specialties is lacking. The objective of this study was to develop, to test clinically, and to validate a new scoring system easily applicable and reproducible in the follow-up evaluation of Spina Bifida patients.

Methods: In this prospective study; different specialists designed a simple, objective, convenient assessment tool to evaluate Spina Bifida patients during their clinic visits. Five systems and functional status ; urinary, neurologic, intellectual, orthopedic, and nutritional states (UNION Score) were separately scored in four different grades of clinical severity by different specialists and the parents. The scores obtained from various evaluators were compared statistically using Cronbach's alpha reliability and Pearson correlation test.

Results: One hundred twenty two patients were scored by evaluators and total scores demonstrated a high correlation (Alpha=0.966). The highest correlation was noted between pediatric urologist and neurosurgeon (Alpha=0.941). The correlation between family and healthcare givers was also noteworthy (Alpha=0.804-0.917). When subclasses were compared, urologic status scores were not consistent between specialties but showed significant correlation except neurosurgeon (0.278-0.495).

Conclusions: The new scoring system was easy to use and it was convenient among evaluators. Changes in the scores during follow-up of Spina Bifida patients may help warn patients, parents, and health care providers. It also may ease evaluation of Spina Bifida patients between different specialties. Acquaintance of scores between family and medical group may be important to motivate the patients socially, and increase their compliance during follow-up.



Lidal I. B.^{1,2}, **Lie C.**³, **Larsen K. L.**¹

¹ TRS National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Oslo, Norway

² OsloMet – Oslo Metropolitan University, Norway

³ The Norwegian Association for Spina Bifida and Hydrocephalus, Norway

Background: This presentation aims to describe how Spina Bifida care is organised in Norway, and specifically the role of a National Resource Centre for Rare Disorders (NRCRD). The purpose is also to present results on perceived health problems and health care usage collected in a study of middle-aged and older adults with Spina Bifida conducted by the NRCRD in 2017 in collaboration with the users. Norway, with 5.4 million inhabitants, has a very strong welfare system with universal rights to citizens. About 800 people with Spina Bifida live in Norway. Their experiences with the Spina Bifida care are diverse, commonly characterised by little knowledge among professionals and society – and often forced to be their own experts and information bearers. A recent study (chart review) from a university hospital at the western coast of Norway concluded that persons with Spina Bifida have a need for continuous, life-long multi-specialized follow-up and rehabilitation, and suggested systematic follow-up together with rehabilitation to be established.

The NRCRD is not a part of the “traditional” health-services, but works in cooperation with clinicians and users to ensure easy access to holistic, multi-professional, individually based care from cradle to grave. Among the main tasks are knowledge dissemination and counselling, cooperation and involvement with users and professionals, and research. Historically, the user organisations participated actively in the modelling of the NRCRD, and are still valuable informants in building up the staff’s competence and knowledge.

Methods: Narrative information on health-care and welfare systems, and the role of NRCRD. Cross-sectional study based on questionnaires collected in 2017 from thirty persons with SB aged 50 years or older.

Results: Eighteen women and twelve men participated in the study. They were residents from all over Norway. Since they were born prior to 1967, most did not have hydrocephalus. Thus, the study group was a selected and well-functioning group. Most (83%) reported an early deterioration in ambulation, 30% reported pain to be their main health problem, about 60% used medication for hypertension, and 43% were obese with BMI above 30. Fatigue and distress were also common. Still, multidisciplinary follow-up was seldom. Two-thirds saw their primary physician the past year, less than half of them had contact with a local physiotherapist, while about 60% had follow-up by urologist.

Conclusion: The study indicates multiple secondary health problems among well-functioning adults with Spina Bifida as well as relatively infrequent health-care usage. Based on the findings, we underline the need for systematic multidisciplinary follow-up.

The user organization was a driving force on the topic “middle-aged and older age”, and also an important part when communicating the results.

In a small country such as Norway, without specific Spina Bifida clinics, the role of NRCRD is very important. The NRCRD is dependent on a strong collaboration with the users to fulfil its mandate and to help Spina Bifida care move forwards.

Marinus Koning,¹Jan Koning,²Patricia O'Neill,¹Marjan Tervoort,²Hagos Biluts,³Mersha Woldemariam,³Yordanos Awoke,⁴Kibruyisfawe Zewdie,³Addisalem Belete,³Esayas Adefris,⁵Dagnachew Yohannes,⁶Anteheh Tadesse,⁷Nebiyat Tesfaye,⁸Abdi Ermolo,⁸Lola Madrid,⁹Vijaya Kancherla,¹⁰Godfrey Oakley¹⁰

¹ ReachAnother Foundation, USA

² ReachAnother Foundation, Netherland

³ Addis Ababa University, Ethiopia

⁴ University Bahir Dar, Ethiopia

⁵ Gondar University, Ethiopia

⁶ Hawassa University, Ethiopia

⁷ Mekelle University, Ethiopia

⁸ St Peter Specialized Hospital, Addis Ababa, Ethiopia

⁹ London School of Hygiene and Tropical Medicine, England

¹⁰ Institute for Spina Bifida Prevention, Emory University, USA

Background: Spina bifida is a non-specific term that refers to neural tube defects which are the most common and severe birth defects to affect the human nervous system. As such, they are one of the greatest causes of childhood mortality and disability-adjusted life years globally. Worldwide, it is estimated that there are approximately 300,000 babies are born each year with Spina Bifida and related defects, resulting in approximately 100,000 deaths. Spina bifida and hydrocephalus (SBH) disproportionately impact low- and middle-income countries (LMICs). Mortality in children affected by SBH is 10-fold higher than in nonaffected children. There is a very high incidence of SBH in Ethiopia. Recent data show 40,000 pregnancies are affected each year. Neurosurgical capacity for treatment is a relatively new development. ReachAnother started work in Ethiopia in 2009 and has been instrumental in developing clinical services both for training neurosurgeons and improving treatment. The objective is to assess ReachAnother's work in Ethiopia developing clinical care capacity for SBH surgery, aftercare and prevention. Identify programmatic and ethical challenges encountered, solutions developed and implemented, and evaluate effectiveness and impact of these interventions. Provide a road map for successful collaboration and program development. Identify successful strategies and projects and their related improvements in care.

Methods: Review of historical data, interview principals of the organization, review of the Ethiopian and international medical literature regarding treatment development and capacity. Identify ethical challenges, proposed solutions, and assess effectiveness.

Results: Ethical dilemmas encountered formed the impetus for targeted action that led to improvements in care. Neurosurgical capacity expanded from 2 to 50 surgeons during the studied term. RAF provided equipment for neurosurgeons in new locations to immediately start operating on SBH. A Center of Excellence program was designed to provide multi-specialty care with "one stop shopping" for the families. A training curriculum for pediatric neurosurgery nursing was created and implemented forming highly competent SBH Teams that provide long term follow-up of patients and their mothers'. Call Centers are being established to improve communication and follow up. A high-risk prevention program has been developed to track SB mothers and avoid further SB pregnancies. Surgical care increased from inception to a capacity for over 2,000 cases per year by 2020 and is expected to grow to 6,000 cases per year by 2025. Fundraising and an innovative surgical instrument recycling project significantly aided in the program's success. In 2018 RAF formed an international coalition to propose folic acid food fortification of wheat and iodized salt to the Ethiopian government and a possible timeline for implementation.

Conclusion: ReachAnother Foundation was able to leverage its resources to significantly contribute to improvement of care for SBH children and their families in Ethiopia.

Lekuya H. M.^{1,2}, Nantambi R.¹, Mbiine R.¹, Kamabu L.¹, Ssenyonga P.²

¹ Makerere University, CHS, Department of Surgery, Kampala, Uganda

² Mulago National Referral Hospital, Neurosurgery, Kampala, Uganda

Background: Spina Bifida (SB) is one of the neural tube defects that is a group of congenital malformations of the central nervous system due to the lack of closure of the neural tube during the 4th week of pregnancy. It frequently results in various levels of neurological deficit and may be part of the Chiari Malformation type 2 with Hydrocephalus (HC). It leads to children's vulnerability in society due to associated morbidity and mortality. Sub-Saharan African (SSA) reports high mortality among children with SB. The objective of this study was to identify the factors associated with early age mortality among children with SB in Uganda.

Methods: We recruited children with SB admitted to Mulago Hospital in Uganda, born between June 2016 and June 2018, recorded in the neurosurgical database. They were reviewed later between June and December 2019 either by phone call, or physically in outpatients' clinics. Data on the previous in-hospital management were collected from the medical records.

Results: Of the 44,273 children born in Mulago Hospital during the study period of 2 years, there were 102 SB (0.23%), but only 92 patients were fully captured. The Sex ratio was 1. The mean birth weight was 3.06 ± 0.4 kg; the median & mean ages of the mothers = 26 years. A third of those SB children were 1st or 2nd born. Myelomeningocele was the commonest type ($n=88$, 95.65%), and in more than 60% they are ruptured at presentation. The median age at admission was 2 days, and the median time to the initial surgery was 10 ± 8 days. About 72 (79.12%) had SB closure, and 17 (18.68%) ran away from the hospital before surgery. The surgical site infections (SSI) clinically diagnosed were 42.39%. Treatment of SSI of the SB repair was done by wound dressing until granulation achieved in the majority. Among those who developed HC, 33 had VPS, and 6 ETV/CPC for HC, yet the initial neonatal cranial ultrasound has detected ventriculomegaly in only 26. The timing between SB repair and HC definitive treatment was more than 8 weeks for the majority. The median time of the study follow-up was 28 months; there were 28 dead, 27 still alive, and 37 with unknown vital status. The median age of death was 34.5 weeks, and about 19 (67.86%) died at home. Most of the reported events surrounding death are related to the complications of severe HC. The SSI of SB repair and delayed HC treatment were found to be associated with mortality in analysis.

Conclusion: Early age mortality is high among SB children in Uganda and associated with the occurrence of SSI of SB closure and the delayed treatment of HC. Early surgery of SB repair combined with early management of HC should be promoted to reduce early age mortality in SSA.

Madrid L.^{1,2}, Leulseged H.¹, Tesfaye T.¹, Dufera T.¹, Gure T.¹, Alemu A.¹, Edris Y.¹, Assefa N.¹

¹ College of Health and Medical Sciences, Haramaya University, Harar, Ethiopia;

² Department of Infectious Disease Epidemiology, London School of Hygiene and Tropical Medicine, United Kingdom

Background: Neural tube defects (NTDs) can result in fetal loss and early neonatal death and, most of them are related to folate deficiency during pregnancy. The child Health and Mortality Prevention Surveillance (CHAMPS) aims to determine causes of death (CoD) among <5 children (U5) and stillbirth using Minimally Invasive Tissue Sampling (MITS) and advanced diagnostic methods in Eastern Ethiopia.

Methods: CHAMPS was established in a demographic surveillance system (DSS) area in Eastern Ethiopia in February 2019. A notifications system was implemented to detect MITS-eligible deaths (stillbirths and U5 children who died within the last 24 hours and were DSS members). An expert panel assigned the final CoD after analysing clinical information, pictures, microbiological and histopathological findings, and verbal autopsy.

Results: From 4th February 2019 to 3rd February 2021, families of 196 (63.8%) among 307 MITS-eligible deaths consented for MITS. Of these, CoD was assigned for 150; 80 stillbirths, 50 neonates and 20 U5 infants/children. Among them, 15 had a neural tube defect (10%), all identified as the underlying cause of death, 13/80 stillbirths (16%) and 2/50 (4%) early neonatal deaths. The most common type of NTD was craniorachischisis (6/15, 40%). The overall NTDs prevalence in CHAMPS-Ethiopian catchment area was 2.7 per 1000 births and went up to 7.2 per 1000 births when considering just Haramaya site. However, NTDs burden found by CHAMPS is likely underestimated as we are just capturing a proportion of all deaths and it doesn't include alive children. This finding has led to the program's development to prevent NTDs in the area consisting in food fortification.

Conclusion: Mortality surveillance identified that NTDs are common among stillbirths in Eastern Ethiopia. Due to the lethality and disability of NTDs, the role of folic acid fortification as public health intervention to prevent NTDs in Ethiopia urgently needs to be explored.



Sutkus V.¹, **Stulginskaite P.**¹, **Kalibatiene D.**^{1,2}, **Udraite-Mikalauskiene R.**³, **Cerkauskiene R.**^{1,2}

¹ Rare diseases coordinating centre, Vilnius University Hospital Santaros klinikos, Vilnius, Lithuania

² Clinic of pediatrics, Institute of Clinical Medicine, Faculty of Medicine, Vilnius University, Vilnius, Lithuania

³ Lithuanian Spina Bifida and Hydrocephalus Association, Vilnius, Lithuania

Background: Patients with Spina Bifida and Hydrocephalus (SBH) frequently require multiple visits to hospital due to a large number of specialist consultations and various procedures needed. We describe the model of the inpatient day centre in Vilnius university hospital Santaros klinikos (VUH SK).

Methods: Inpatient day centre for patients with Spina Bifida has been established by the Clinical Unit of Coordinating Centre for Rare Diseases in VUH SK in 2019 with the aim to improve the patient care by organizing multidisciplinary team (MDT) consultations according to the Guidelines for Spina Bifida (2018) in a single day and providing patients with a coordinated care plan. The visit is planned in advance. Patients are first contacted via email, phone or invited for an outpatient visit to discuss current health problems. The visit is scheduled and an individual timetable is sent for each patient and member of the MDT.

Patients also receive recommendations on how to prepare. On the visit day the patients are examined by the pediatrician and, if needed, the visit plan is modified. After the visit members of the MDT gather to discuss current problems and recommendations for patient's care.

Results: Inpatient Day Centre requires longer preparation times and availability of MDT members for patient consultations on a specific day. Each situation requires a different combination of resources based on presentation of the condition, age and developmental level of the child. Personalized schedules ensure timely consultations and free time for the patients. MDT discussion at the end of the meeting results in consistent recommendations for further care.

Conclusion: This current model of care aims to improve the multidisciplinary care pathway for all SBH patients and families. This allows a more structured approach to SBH in providing comprehensive MDT care, scientific research, education of professionals, patients and community.



Ivanov S.V.¹, Shchedrina A.Yu.^{1,2}, Onufriychuk O.N.¹, Fedoseeva A.S.¹, Solokhina I.Y.¹, Shishkina A.I.¹

¹ FSBI "National Medical Research Center of Pediatric Traumatology and Orthopedics named after G.I. Turner" Ministry of Health of Russia

² Federal State Budgetary Educational Institution of Higher Education "St. Petersburg State Pediatric Medical University" Ministry of Health of Russia, St.Petersburg, Russia

Background: Spina Bifida is a malformation of the spine, accompanied by a variety of clinical manifestations of the spine, spinal cord and lower extremities. Today, the multidisciplinary treatment approach is gaining more and more development, it brings together specialists who work as a single team, their actions are clearly coordinated and this provides a rational approach to the implementation of the tasks of habilitation and rehabilitation.

Aim: to substantiate the use of a multidisciplinary approach in the treatment of patients with Spina Bifida.

Materials and Methods: In 2015, the basis of the "Spina Bifida center" was created. Then a multidisciplinary council was formed including neurologist, orthopedist, urologist, ophthalmologist, psychologist and orthotist. The research is based on the examination and treatment of 144 patients who were observed in a multidisciplinary council in 2018-2019. We have developed a registration card for Spina Bifida patients, which were used when examining and interviewing children and / or their parents were performed. The registration card consists of several modules: general part, orthopedic part, using orthotics, neurological, urological and ophthalmological parts. To determine the nature of neurosegmental lesions in children with Spina Bifida, we used the Sharrard classification, according to were 27 patients with Thoracic; L1-L2 - 13 patients; L3-L4 - 46 patients; L5-S1 - 31 patients; S2 - 27 patients.

Results: All 144 patients with Spina Bifida were examined by a multidisciplinary team. 18 (12.5%) patients required repeated neurosurgical interventions (8 - ventriculoperitoneal bypass grafting, 6 - spinal cord mobilization, 2 - elimination of diastematomyelia, 2 - removal of the terminal filament lipoma). Children with the Spina Bifida have a wide range of congenital and acquired orthopedic deformities. In the research group 114 (79%) patients had orthopedic pathology. The elimination of contractures and deformities of the lower extremities required 54 (37.5%) patients. Surgery on the feet required 17 patients.

In the studied group only 56 (39%) parents of patients were aware of the urological pathology that the child had. Intermittent bladder catheterization was required in 52 (36%) patients with Spina Bifida. 132 (92%) children needed a comprehensive urological examination.

Examination of an ophthalmologist showed decrease in visual acuity in 98 (68%) patients. The main causes were refractive errors, more often myopia and astigmatism; amblyopia with anisometropia, strabismus and nystagmus; optic nerve atrophy, damage to the central neurons of the optic pathways. Most ophthalmic disorders were due to Arnold-Chiari II syndrome. Oculomotor, predominantly unfriendly, as well as pupillary and accommodation disorders were found in 75 (52%) patients and indicated central neurogenic nature of the lesion.

The organized "Spina Bifida council" within the "Spina Bifida Center" allowed to involve all specialists needed for the treatment of children with this severe pathology. Our research showed the validity of attracting specialists (orthopedist, neurologist, urologist, orthotist, ophthalmologist, psychologist). The presented comprehensive approach to the diagnosis and treatment of the patient with Spina Bifida allowed us to develop an individual map of habilitation and rehabilitation of patients.

Conclusion: Our preliminary research showed the need for a comprehensive multidisciplinary examination and treatment of patients with Spina Bifida. The developed individual map of habilitation and rehabilitation allows to determine the sequence of treatment and continuity between specialists.

Ward M.¹, **Dunne C.**¹, **Bukovac M.**², **Garcia de Ceca E.**³, **Albertova P.**⁴, **Hendre P.**⁵, **Adeolu R.**⁶, **Folorunsho O. S.**⁶, **Austin R.**⁷, **Armughan M. A.**⁸

¹ Spina Bifida Hydrocephalus Ireland

² Udruga osoba i roditelja djece sa spinom bifidom "Aurora", Croatia

³ Espina Bífida i Hidrocefalia Madrid (AMEB), Spain

⁴ Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus, Slovakia

⁵ Spina Bifida Foundation India

⁶ Festus Fajemilo Foundation, Nigeria

⁷ Australia

⁸ Pakistan

Background: Often it is said that the youth are the “backbone of any nation” and that they contribute to the development of the country. But today, challenges in the youth community are encountered more and more every day including among the youth community with SBH which generates negative impacts on several aspects of their lives. Being a young adult with a complex health condition such as Spina Bifida and Hydrocephalus brings many issues that impact different sides of their lives such as their mental health, physical and sexual health, their relationships, their self-esteem.

Methods: To achieve their goal, the IF International Youth Group mobilises youth with SBH communities around the world and brings together resources available in order to contribute to actively raise awareness on important topics related to well-being and quality of life; develop tools to support youth of different regions; disseminate information and materials to support the work undertaken by young people in different countries around the world.

Results: The IF International Youth Group conducted a survey including a variety of questions on the topic of mental health. The survey was shared among youth worldwide. The results of the survey will be shared in the presentation.

Conclusion: For youth with Spina Bifida and or Hydrocephalus the topic of mental health is important. There is a need to integrate the important topic of mental health into multidisciplinary care systems across the globe. The IF International Youth Group has several actions planned to promote positive mental health for youth with SBH. Recommendations will be shared in the presentation.



Tanil E.¹, Tiryaki S.,² Tekin A.,³ Ulman C.,⁴ Ulman I.³

¹Division of Pediatric Urology Ege University Department of Pediatric Surgery, Division of Pediatric Urology, Pediatric Surgery, Ege University, Izmir, Turkey,

²Division of Pediatric Urology, Gaziantep Children's Hospital, Gaziantep, Turkey,

³Division of Pediatric Urology, Pediatric Surgery Izmir, Turkey,

⁴ Medical Biochemistry Manisa, Turkish Association of Spina Bifida, Chairperson, Celal Bayar University, Turkey

Background: National Spina Bifida Patient Congress aims to improve the life of patients with Spina Bifida and their families by increasing knowledge, establishing a social event responding to their requirements, and gathering patients and health professionals in a setting out of the hospital. The aim of this study was to determine the perception of patients and families.

Methods: The questionnaire was performed during the annual congress anonymously. It included questions about their intentions, satisfaction, and suggestions about the congress as well as determinants as age, gender, and their incidence of congress attendance. Both the patients and families were invited to participate in the study.

Results: In total 51 questionnaires (35 patients, 16 parents) were answered. The median age was 30 (14-59) and 61% were female. 24% attended the congress for the first time, 35% attended more than 5 congresses. Only one respondent said that he won't consider attending again. 78% said the congress changed their point of view, 39% specified that this was because of understanding that they were not alone. 59% said the training sessions they attended during the congress helped to improve their continence. The most frequent answer to an open-ended question about what they like the most was the attention of the doctors (31%). Increasing knowledge about sex was another favorite answer (20%), all participants giving this answer were patients and between age 18-40 (p=0.026). None of the other answers had a specific distribution about age or gender.

Conclusions: Patients with disabilities and their families require social support. These events shall also focus on providing a supportive social network and increasing the perception of being cared for as well as increasing knowledge.



Shala F., Wagner E., Zhao Y.

University of Victoria, Victoria, BC, Canada

Background: Proper educational training and support are proven to be major components of Electronic Health Record (EHR) implementation and use. However, the majority of health providers are not sufficiently trained in EHR use, leading to adverse events, errors, and decreased quality of care. In response to this, students studying Health Information Science, Public Health, Nursing, and Medicine should all gain a thorough understanding of EHR use at different levels for different purposes. The design of a usable and safe EHR system that accommodates the needs and workflows of different users, user groups, and disciplines is required for EHR learning to be efficient and effective. This project builds several artifacts which seek to address both the educational and usability aspects of an educational EHR. The proposed artifacts are models for and examples of a configurable EHR to help students gain knowledge and hands-on experience when treating conditions related to Spina Bifida and hydrocephalus. The design of a usable and safe EHR system that can accommodate the different needs of users involved in the treatment of Spina Bifida and Hydrocephalus can help avoid mishaps before they happen.

Methods: Review literature and gather professional opinions from domain experts on usability, the use of workflow patterns, UI configurability and design, and the educational aspect of EHR use. Conduct interviews in a semi-casual virtual setting with open discussion in order to gain a deeper understanding of the principal aspects of EHR use in educational settings. Select a specific task and user group to illustrate how the proposed solution will function based on the current research. Develop three artifacts based on the available research, professional opinions, and prior knowledge of the topic.

Results: Three artifacts were developed to address the usability aspect of an EHR. The artifacts capture the user task and user's interactions with the EHR for learning. The first generic model provides a general understanding of the EHR system process and its interaction with the end users. The second model is a specific example of performing the task of MRI ordering with a configurable UI. The third artifact includes UI mock-ups showcasing the models in a more practical and visual way.

Conclusion: Due to the lack of educational EHRs, medical professionals do not receive sufficient EHR training. Implementing an educational EHR with a usable and configurable interface to suit the needs of different user groups and disciplines will help facilitate EHR learning and training, and ultimately improve the quality of patient care. In addition, case studies related to Spina Bifida and Hydrocephalus could be included as examples during training for learners to better understand the health management of such conditions as well as provide the highest levels of data integrity, accountability, configurability and convenience.

Ondoma C., Lauver D., Tluczek A., Albers C.
University of Wisconsin-Madison, Madison, USA

Background: We reviewed health-related literature to identify theories and conceptual models scholars had used regarding individuals with neural tube defects (NTDs) and their families. Although theories and conceptual models could be useful to guide scholarship about individuals with NTDs and their families, we did not identify studies where scholars had applied theories or conceptual models to this topic. We proposed the PRECEDE- PROCEED Model (PPM) as one model that could guide scholarship about individuals with NTDs and their families because it is logically consistent and comprehensive in providing guidance for practice, research, education, and policy. Compared to health behavior theories such as the theory of planned behavior and the health belief model, the PPM is more adequate in addressing individual and external factors that influence behavior and is broad enough to encompass disease prevention and management. We proposed the PPM could be useful to guide scholarship about individuals with NTDs and their families because it is more explicit than the socio-ecological model in providing relationships among concepts. In this presentation, relevance of the PPM will be demonstrated to health-related scholarship about individuals with NTDs and their families.

Methods: We searched major scientific databases: PubMed, PsychINFO, Cochrane Library, and CINAHL for selected health-related literature about individuals with NTDs and their families published in English. We included studies published from 2000 to 2019 because we were interested in recent studies. After reviewing the health-related literature about individuals with NTDs and their families, we identified examples from this literature that reflect each of the factors of the PPM. We organized the examples by PPM factors under each phase of the PPM.

Results: We synthesized health-related literature about individuals with NTDs and their families guided by the PPM. Because we easily identified variables that reflected PPM factors and organized our findings by the PPM phases, we demonstrated that the PPM is relevant to scholarship about individuals with NTDs and their families.

Conclusions: The PPM can be helpful to guide scholarship about individuals with NTDs and their families, because (a) it includes a breadth of factors relevant to disease prevention and health promotion regarding NTDs, (b) it is logically consistent, and (c) it is explicit in providing propositions between constructs and across the phases. Applying the PPM phases and factors to such scholarship could enable scholars to describe, predict, and explain the challenges of individuals and families in a comprehensive manner. By systematically applying phases of the PPM to their scholarship, researchers can (a) identify gaps in literature regarding the care of individuals with NTDs and their families, (b) design, implement, and evaluate educational and systems interventions that could address such issues. Guided by the PPM, research scholars, clinicians, and policy makers could collaborate to revise policies that could address issues identified regarding individuals with NTDs and their families. By applying the PPM to future research & scholarship about individuals with NTDs and their families, we could advance our understanding of the breadth of challenges for such individuals and families and how to address them accordingly in a comprehensive and multidisciplinary approach.

Santosh Karmarkar

Department of Pediatric Surgery, Lilavati Hospital and Research Centre Bandra Reclamation, Bandra West in Mumbai, India

Spina Bifida Foundation India, India

Spina Bifida is a condition which affects several body systems and structures. Primarily, this involves the Central Nervous system, The muscles, and Bones of the Lower Limbs and Back and it affects the Urinary tract. Accordingly, several specialists are to be necessarily involved in the care of these children. Additionally, the complete rehabilitation requires the timely involvement of the parents, the extended family, the schoolteachers, the orthotists etc.

Thus, the holistic care of Spina Bifida is like an orchestra with many players – but for all of them to work and create a wonderful symphony and be successful – they need an experienced Conductor.

The talk will highlight the roles these players play – what they should and should not do, and why the role of the Conductor is so crucial. In addition, the needed qualifications and qualities that a successful Conductor of this Multidisciplinary care Orchestra must possess will be further elaborated upon.



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