



WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY 2022

To celebrate the 10th edition of the **World Spina Bifida and Hydrocephalus Day**, the **International Federation (IF)** has proposed “**Elevate Your Voice**” as general campaign theme.

ASBI supports IF vision of a society that **guarantees fundamental human rights** of children and adults with Spina Bifida and Hydrocephalus and therefore intends to remain by their side towards achieving full autonomy and independence in every aspect of social, working and community life.

For this reason, the theme of the **Regional Side Event Europe** is precisely **to raise their voices** and allow all children and persons with Spina Bifida and Hydrocephalus **to be heard**.

Four appointments are organized during the month of October **to go through some key stages together on the path towards autonomy and independence for people with Spina Bifida and Hydrocephalus**.

ELEVATE YOUR VOICE! A PATH TOWARDS INDEPENDENCE

WEBINAR ON ZOOM

Realized in collaboration with



WEDNESDAY 5 OCTOBER 2022

TITLE: TRANSITIONAL CARE: STATE OF THE ART IN ITALY

Moderator: *Dr. Giovanni Mosiello*

TIME	SESSIONS	SPEAKERS
15:30-15:40	Words of welcome and introduction	<p>Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH)</p> <p>Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)</p>
15:45-16:45	Transitional care according to experts	<p>Dr. Giuseppe Cretì - <i>Medical Director of the Pediatric Urology Department at the Hospital for Relief of Suffering. Head of Spina Bifida Center in San Giovanni Rotondo - Puglia. President of the Italian Society of Paediatric Urology.</i></p> <p>Dr. Claudia Rendeli - <i>Director of Spina Bifida and Congenital Uropathies Department. Head of the Pediatric Nephrourology and Spina Bifida Outpatient Clinic Gemelli Hospital - Rome.</i></p> <p>Dr. Paolo Gelli - <i>Clinical Psychologist and Psychotherapist, ASBIN Consultant at Spinal Unit Niguarda Hospital - Milan</i></p> <p>Dr. Adriano Ferrari - <i>Surgeon specialized in neurology and physical medicine and rehabilitation, formerly full professor of physical medicine and rehabilitation at the University of Modena and Reggio Emilia - Director for the rehabilitation of disabilities of developmental age department of the IRCCS Arcispedale S. Maria Nuova in Reggio Emilia. Currently lecturer at the University of Modena and Reggio Emilia.</i></p>
5 MINUTES BREAK		
16:50-17:30	Transitional care according to patients and families: testimonies	<p>Ilaria Guidotti - <i>ASBI Italy Youth Group</i></p> <p>Luigi Russo - <i>ASBI Italy Youth Group</i></p>
17:30-17:50	Discussion	All the participants
17:50-18:00	Closing & Greetings	<p>Dr. Sylvia Roozen – <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH)</p> <p>Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)</p>

FRIDAY 14 OCTOBER 2022

TITLE: THE SPINA BIFIDA REGISTRY: A RESEARCH TOOL FOR A BETTER QUALITY OF LIFE

Moderator: *Dr. Domenica Taruscio*

TIME	SESSIONS	SPEAKERS
15:30-15:40	Words of welcome and introduction	Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH) Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)
15:45-16:45	The Italian Spina Bifida Registry: an increasingly clear picture of the pathology	Dr. Paola Torreri - <i>III level researcher - National Center for Rare Diseases (ISS) - Rome</i> Dr. Tiziana Redaelli - <i>Chief emeritus of the Unipolar Spinal Unit of Niguarda - Milan</i> Dr. Paolo Salerno - <i>Surgeon at the National Rare Disease Centre - Higher Health Institute - Rome</i>
5 MINUTES BREAK		
16:50-17:30	Patients experience in Europe The point of view of local associations	Benoit Fourcroy - Association Nationale Spina Bifida & Handicaps associés (France) and representative of the ERN ITHACA working group Mario Orgiana - ASBI Italy Vicepresident and President ASBI Sardinia
17:30-17:50	Discussion	All the participants
17:50-18:00	Closing & Greetings	Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH) Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)

TUESDAY 18 OCTOBER 2022

TITLE: THE PATH TOWARDS INDEPENDENCE: FROM THEORY TO PRACTICE

Moderator: *Dr. Alessandra Leo*

TIME	SESSIONS	SPEAKERS
15:30-15:40	Words of welcome and introduction	<p>Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH)</p> <p>Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)</p>
15:45-16:45	Independent living and welfare: the full citizenship	<p>Dr. Giampiero Griffo - <i>Graduated in philosophy and trained in the field of law, Co-director of the Robert Castel Center for governmentality and disability studies of the "Suor Orsola Benincasa" University of Naples, and Italian member of the European Academic network on disability.</i></p> <p>Dr. Mirko Grauso - <i>Occupational therapist at Policlinico Gemelli - Rome</i></p> <p>Patrizia Ferroni - <i>Professional Urorehabilitation Nurse - Perugia</i></p>
5 MINUTES BREAK		
16:50-17:30	Testimonies: the meaning of independent living for people with disability and their families	<p>Pierpaolo Innaimo - <i>ASBI Italy Youth Group</i></p> <p>Elide Bruna - <i>ASBI Italy Youth Group</i></p> <p>Alessia Varesi - <i>Parent and member of the Board of ASBI Italy</i></p> <p>Laura Rosillo Beneyto - <i>IF Youth Group</i></p> <p>Kevin O'Donnell - <i>Wellbeing Counsellor at SBH Scotland and representative of the IF working group on ageing</i></p>
17:30-17:50	Discussion	All the participants
17:50-18:00	Closing & Greetings	<p>Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH)</p> <p>Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)</p>

WEDNESDAY 26 OCTOBER 2022

TITLE: DISABILITY AND SPORT: LIMITS AND INTENTIONS FOR THE FUTURE

Moderator: *Roberto Bof*

TIME	SESSIONS	SPEAKERS
15:30-15:40	Words of welcome and introduction	Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH) Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)
15:45-16:45	The importance of sport activities as a means to generate autonomy	Luca Pancalli - <i>President CIP - Rome</i> Dr. Maria Taverna - <i>Medical Director of Urology</i> <i>Department, Head of Urology at the Tuscany Spina Bifida Centre</i> Federico Mancarella - <i>Paralympic athlete</i> Sofia Brunati - <i>Paralympic athlete and member of ASBI Italy Youth Group</i> Cillian Dunne - <i>Paralympic athlete and member of IF Youth Group</i>
5 MINUTES BREAK		
16:50-17:30	Testimonies	Nicola Busata - <i>Ski teacher specialized in the teaching to people with disability - Freerider Sport Events - Varese</i> Castorino Emanuele - <i>Parent and member of the Board of ASBI Italy</i> Roberto Gerevini - <i>Parent</i>
17:30-17:50	Discussion	All the participants
17:50-18:00	Closing & Greetings	Dr. Sylvia Roozen - <i>Secretary General</i> International Federation for Spina Bifida and Hydrocephalus (IFSBH) Maria Cristina Dieci - <i>President</i> Associazione Spina Bifida Italia (ASBI)