



FINDING OUR WAY

Finding Our Way Preliminary program (allowing for changes)



		Friday, June 15	
TIME	FOR EVERYBODY	MISCELLANEOUS	CULTURE
8:00 am	Registration & coffee		
9:30 am	Opening ceremony with Cariola Rosdotter-Eriksson , artist, Agnetha Mbuyamba , pres of RBU, and Pierre Mertens , pres of IF. The 2012 IF award will be presented		
10:15 am	Basic knowledge about children and adults with Spina Bifida today Dr Sven Mattsson , Sweden, and Andrew Wynd , CEO of SSBA, the Scottish Spina Bifida Association		
11:00 am	The genetics of Spina Bifida as we know it today Dr Margo Whiteford		
11:30 am	Folic Acid as a preventive measure Physiotherapist Carole Sobkowiak , Folic Acid spokesperson for SRHSB, Society for Research into Hydrocephalus & Spina Bifida Dr Margo Whiteford and the President of IF, Mr Pierre Mertens		
12:00 LUNCH			
13:30 pm	ETV, Endoscopic Third Ventriculostomy – treatment of hydrocephalus without shunting Dr Benjamin Warf	13:30 Basic perspectives on sexuality Ellinor Isfors and Pelle Ullholm , Sexuality Educators	13:30 Parent chat for parents of adult sons and daughters with Spina Bifida. Facilitator: Social worker Charlotte Holmberg (coffee break included) FOR PARENTS ONLY
14:15 pm	Hydrocephalus and shunts Dr Kai Arnell	"Our Voice for the Future" – workshop led by Eli Skattebu , leader of the Norwegian Spina Bifida Association and Helen Healy , occupational therapist. FOR YOUNG PEOPLE AND ADULTS WITH SPINA BIFIDA ONLY	Music Workshop för everyone Songs & Rythm with Cariola Rosdotter-Eriksson (coffee break included)
14:45 pm	Panel discussion about Hydrocephalus and Spina Bifida Drs Sven Mattsson, Benjamin Warf and Kai Arnell		
15:15 pm COFFEE BREAK			
15:45 pm	Presentation of the Elektrodress Fredrik Lundqvist , Doctor of Chiropractic/DC, Founder/CEO Inerventions	Global Friends – creating an interactive internet based website Helen Healy, Ciara Hughes, Danny Lamb, Rebecca Opetsi and Staffan West	The IF projects in Africa. IF's president Pierre Mertens will introduce the work of IF in some African countries. A BBC Channel 4 film will be shown
16:15 pm	"To spend a penny" independently – a multidisciplinary project Gunilla Glad Mattsson , urotherapist, on independence in the toilet situation		
16:30 pm – 16:50	Rounding off the day with participants from the Music Workshop and Cariola Rosdotter-Eriksson		
17:15 pm		17:15–18:15 General Meeting for IF members	
19:00 pm		Reception at The Vasa museum, a warship from 1628	

Saturday, June 16					
TIME	FOR EVERYBODY	MISCELLANEOUS	CULTURE		
9:00 am	The development of the brain in people with Spina Bifida Neuropsychologist Maureen Dennis				
9:45 am	BBB – Basics about Bowel and Bladder Dr Elisabeth Farrelly				
10:15 am	Pain in people with Spina Bifida Dr Per Ertzgaard				
10:45 am	COFFEE BREAK				
11:15 am –12.30 pm	Skin Care Intervention Madeleine Stenius , nurse Adult life situation, bladder and bowel management Magdalena Vu Minh Arnell , urotherapist What children with Spina Bifida know about their condition Lina Strömfors , psychologist How do you get things done? Marie Penny-Dahlstrand , occupational therapist	12:00–13:00 pm Urology workshop BBB – Basics about Bowel and Bladder Dr Elisabeth Farrelly , Magdalena Vu Minh Arnell , urotherapist, Madeleine Stenius , nurse	Adult life with Spina Bifida and Hydrocephalus: Sharing experiences. Sex and relationships. Eli Skattebu , Norway, Kerrie Duff , Australia, Staffan West , Sweden, and Christina Isaksson , Sweden FOR ADULTS WITH SPINA BIFIDA ONLY 14:00-14:30 pm Poster Presentations by D Riedel , H Gabrielsson , A Rajaratnam and L Westbom . Location to be decided.	Parent chat: for parents of children under the age of 15. Facilitator: Christina Renlund , psychologist FOR PARENTS ONLY	1. Film workshop 2. Photo workshop: bring your own mobile phone 3. Painting workshop 4. Pimped wheelchairs and keeping a neat look Margo Whiteford demonstrates inspiring strategies
12:30 pm –13.00	POSTER PRESENTATIONS: The Spina Bifida team for adults at Spinalis about their work & research on cognitive functioning of persons with SBH & how they experience bedoming adults Dorothee Riedel , occupational therapist, and Hanna Gabrielsson , RN Learning interventions for individuals with Spina Bifida Alice Rajaratnam , occupational therapist MMCUP, a Swedish national follow-up program for best treatment of Spina Bifida Dr Lena Westbom				
13:00 pm	LUNCH				
14:30 pm –17:15 pm	Employment for people with Spina Bifida – good examples (coffee break included) 1. TRS – a Norwegian Resource Center Heidi Johansen 2. A project at the police authorities in the city of Umeå Mats Bruhn and Petter Feuk	Cognitive challenges. Workshop with Maureen Dennis , neuropsychologist, Lina Strömfors , psychologist, Marie Penny-Dahlstrand , occupational therapist	The European Structural Fund for Disabled People Organizations Stefania Pirani , IF coordinator, talks on how to apply for funding together with Simona Giarratano from EDF, European Disability Forum	Make a performance in creative dance and mobile art Cilla Colt , musician and artist/dance pedagogue Mats Lindberg , Funkisbyrån Make up artist for everyone	All the way from 11:15 am until 16:00 pm, lunch included.
16:00 pm	COFFEE BREAK				
	Employment workshop to be continued until 17:15 pm: 3. A da Vinci project in three countries A Tontsch , Romania A Nobs , Germany Inés Boekholt Switzerland, M Künemund Germany		Swedish follow-up program for Spina Bifida and Hydrocephalus. A national registry for quality treatment. Lecturer: Dr Lena Westbom A computerised "Patient record system" and the Scottish way of using tele-medicine will be presented by Andrew Wynd , CEO of the Scottish Spina Bifida Associationproject		
17:15 pm	Next year's IF conference in Turkey is introduced.				
17:20 pm	Music Funkisbyrån				
19.00 pm	Banquet Dinner in the hotel				