

# WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY 2018

SOCIAL MEDIA TOOLKIT



Co-funded by the Rights, Equality and Citizenship programme of the European Union

# WHAT IS WSBHD?

The World Spina Bifida and Hydrocephalus Day (WSBHD) has been established and designated by IF's General Assembly in Guatemala in 2011 with the aim of raising awareness and understanding about Spina Bifida and Hydrocephalus. It serves also a means to advocate and promote the rights of persons with these conditions. The WSBHD was held for the first time on 25 October 2012 at the European Parliament in Strasbourg.

Read more about our story [here](#)

## 2018 TOPIC: SPINA BIFIDA AND HYDROCEPHALUS THROUGHOUT THE LIFESPAN

- Despite the improvements achieved in healthcare, rehabilitation and social services for people living with this SBH, there are still misconceptions and presumptions with regard to SBH and what it means for individuals living with these conditions and for their families.
- In addition, we need to take into account the lack of knowledge with regard to ageing with SBH, as older people with SBH are the first generation to reach their 50's and 60's so further awareness is needed on this topic.
- **OBJECTIVE:** to collect **25 testimonies** both from parents with children with SBH and from people with SBH themselves. The aim is to show what living with SBH means from birth into adulthood.

# WHAT DOES THIS TOOLKIT CONTAIN?

- Within this toolkit, you will find key links, an infographic, posters, hashtags, logos, banners for your social media channels and suggested messages.
- A PDF document with suggested questions to collect testimonies from people with SBH and their families.
- A survey for parents of children with SBH launched by EUROlinkCAT and information about their event on October 25th.

START EXPLORING THIS TOOLKIT AND JOIN THE CAMPAIGN

LET'S GO! 

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# SOCIAL MEDIA CHANNELS

In order to engage with us for the WSBHD campaign, remember to follow our social media channels. We will publish the testimonies, messages and our members' activities through our different channels.

All the materials are available at:

[www.worldspinabifidahydrocephalusday.com](http://www.worldspinabifidahydrocephalusday.com)



@ifsbh



International Federation for Spina Bifida and Hydrocephalus



IFglobalorg

## HASHTAGS

#mySBHlife  
#WSBHD18  
#SpinaBifida  
#Hydrocephalus

## SUGGESTED ACCOUNTS TO TAG

Your national association's account  
@ifsbh  
@IDA\_CRPD\_Forum  
@iddcconsortium  
@SustDev  
@UN  
@WHO

# KEY LINKS

We have different materials related to WSBHD 2018 and its topic “Spina Bifida and Hydrocephalus throughout the lifespan” for you to publish on your website, share through social media channels, and to distribute within your network.

[Website WSBHD](#)

[Guidelines and questions for testimonies and one infographic](#)

[Leaflet ‘To grow up I need to plan...’](#)

[Leaflet ‘What every woman needs to know before becoming pregnant’](#)

[Banners for social media and website](#)

[EUROlinkCAT survey](#)

[IF’s statement at the 11th Conference of States Parties to the CRPD](#)

[Youtube playlist WSBHD18](#)

From **October 1st**, IF will publish 1 or 2 testimonies per day so do not forget to check both our social media channels and our YouTube channel!

25 OCTOBER  
WORLD  
SPINA BIFIDA &  
HYDROCEPHALUS  
DAY



# KEY MESSAGES

Feel free to adapt, use and share the example messages below and spread the word on #WSBHD2018

## GENERAL

- Today, October 25, I support the #WSBHD18 campaign and share #mySBHlife testimony: *(tell your testimony) + photo*
- I support the #WSBHD18 and want to share this testimony about (add topic) because (add reason) #mySBHlife + *add link to testimony*
- Art. 24 #CRPD and #SDG4 focus on Access to #Education, which is key for people with #spinabifida and #hydrocephalus in #Africa to become independent #WSBHD18
- Paediatric care is improving in most countries in #Africa, but we can't forget about transition to adult care services: the role of the community, home visits, support groups are key to ensure lifelong care #WSBHD18
- There are at least around 1.5 million people globally living with neural tube defects. People with #spinabifida and #hydrocephalus need timely and affordable access to appropriate, specialised and multidisciplinary care throughout their lifespan. Let's celebrate #WSBHD18 and keep working together for an #integratedcare system for all!
- The #SDG3 highlights the need to "ensure health and well-being for all, at every stage of life". In connection with #Agenda2030, @ifsbh is celebrating the #WSBHD18 and takes the opportunity to raise awareness on the importance of a healthy life for people living with #spinabifida and #hydrocephalus throughout the lifespan.

- Happy #WSBHD18! @ifsbh has achieved its goal: to collect 25 testimonies that tell the world about #spinabifida and #hydrocephalus throughout the lifespan. Watch the movies in their Youtube channel from October 1st! *(add link)* Which one caught your attention?
- Up-to-date information and international guidelines are needed for the treatment and care of #spinabifida & #hydrocephalus from before birth to adulthood, these should be accessible to healthcare providers, to people with SBH, and to parents(-to-be) worldwide #WSBHD18
- Raising awareness on the rights of people w #disabilities will help to remove stigma and attitudinal barriers in order to achieve a real inclusive society for all! #WSBHD18 #spinabifida #hydrocephalus
- How to become more and more independent? Take a look at this leaflet: *(link to 'To grow up healthy I need to plan...')* - Your healthcare is a lifetime job that starts at childhood #WSBHD18

## CHILDHOOD & PRE-TEEN YEARS

- #Spinabifida is a congenital disability, children are born with it & #hydrocephalus is a brain condition usually acquired after an untreated neonatal infection. With proper treatment and support, #children with these disabilities can live their lives equal to others #WSBHD18
- IF's statement at the 11th Conference of States Parties to the #CRPD highlights the importance of children with #spinabifida and #hydrocephalus being registered immediately after birth and having access to healthcare. Birth registration is a fundamental right! #SDGs #WSBHD18 + *(add link)*
- Local support groups working together with multidisciplinary clinics can offer training and support for children with #spinabifida and #hydrocephalus on #continence management. #catheterisation #CIC Learning to be independent contributes to self-confidence. #WSBHD18

- Preparing for independent living starts at childhood and it involves parents encouraging their child and giving the same chances as any other children - Check the 'To grow up Healthy I need to plan...' leaflet here: *(add link)* #WSBHD18
- Treatment for children with #spinabifida and #hydrocephalus needs to be personalized, avoiding unnecessary expensive and time consuming treatment. Especially in #Africa, this is only possible through participation of families, communities and devoted health care providers #WSBHD18

## ADOLESCENCE & YOUNG ADULTHOOD

- There are taboos around the sexual life of people w #disabilities such as #spinabifida & #hydrocephalus. Young people w SBH, together with IF, are working on a survey to know what is important for young people with SBH on sexuality #WSBHD18
- #Women of childbearing age need to take #FolicAcid, a B-vitamin preventing 50% of Neural Tube Defects when used in #fortification: more and more countries in #Africa fortify staple foods with FA #WSBHD18 + *(add link to 'What every woman needs to know before becoming pregnant')*

## ADULTHOOD

- Adults with #spinabifida and #hydrocephalus have the right to participate independently in all aspects of life. However, lack of adaptive equipment, education, accessibility and social acceptance creates barriers. #WSBHD18 Do you want to share your experience? #mySBHlife + *(link to guidelines)*
- The current generation of adults living with #spinabifida and #hydrocephalus often consider themselves as "pioneers", as there is a lack of medical research into ageing with SBH, for instance the long-term effects of childhood procedures. #WSBHD18

THANK YOU FOR BEING PART  
OF THE WORLD  
SPINA BIFIDA AND  
HYDROCEPHALUS DAY 2018,  
SPECIALLY TO THOSE  
WHO HAVE SHARED THEIR  
TESTIMONY!

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