



INVITATION FOR PARTICIPATION OF FAMILIES OF EUROPEAN SBH ASSOCIATIONS

Collaboration of the International Federation for Spina Bifida and Hydrocephalus with the European Association of Urology on person centred paediatric urological guidelines for spina bifida

Deadline September 30, 2023

Background

There is a unique opportunity for the spina bifida and hydrocephalus associations to have a direct influence to improve the European Association of Urology Paediatric Urology Guidelines for care for children with urological problems.

This survey study is a collaboration between the International Federation for Spina Bifida and Hydrocephalus (IF) together with the EAU-ESPU Paediatric Urology Guidelines Panel.

It is a unique collaboration whereby we actively involve persons with spina bifida and/or hydrocephalus and their families to improve the existing guidelines in making them more patient centred. In this way, the spina bifida and hydrocephalus community is actively involved in the development of this survey study from the beginning onwards.

The International Federation for Spina Bifida and Hydrocephalus distributes this survey internationally for only a limited number of countries. Hereby European countries are important.

Your cooperation to complete this survey (which takes 15 minutes) is of great value! With your contribution, we are able to obtain a better understanding on the needs for urological care and specific differences between countries. The results will be used to improve the current European Association of Urology Paediatric Urology Guidelines.

Survey

Children and adolescents until the age of 18 years old and their families are invited to complete the survey. The results of the survey are collected online and will be handled anonymously. **The first round of the survey will finish September 30th 2023.** Following the results, IF will invite her member associations to take part in a members meeting for discussion of the results and outcomes. Furthermore, the results will be published in a peer reviewed scientific journal and presented during the upcoming IF 30th International Conference on Spina Bifida and Hydrocephalus.

Please find here the link to the survey in the following languages:

English: <https://www.surveymonkey.com/r/7WSB9S9>

Greek: <https://www.surveymonkey.com/r/5TDFNQQ>

French: <https://www.surveymonkey.com/r/5TJR5PH>

Turkish: <https://www.surveymonkey.com/r/5TWWNXT>

Spanish: <https://www.surveymonkey.com/r/JGXLRYC>

Italian: <https://www.surveymonkey.com/r/JGNRG2P>

Danish: <https://www.surveymonkey.com/r/5TT58N9>

German: <https://www.surveymonkey.com/r/JGB9XT6>

Dutch: <https://www.surveymonkey.com/r/5ML5SVV>

Contact details

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