

Frequently asked questions

- Information about grants and loans that are available
- Equipment – where can I get it, and what is available?
- Alternative educational opportunities

We are not medical experts but we have practical experience of living with these conditions and can share our learning and signpost you to appropriate help.



Our website

You can read more about our association on our website, which also has information about our holiday chalet at Brambles Chine in Freshwater.

 www.iwasbah.com

Contact us

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*My life
a full life*


**Isle of Wight
Clinical Commissioning Group**

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Spina Bifida and Hydrocephalus

Isle of Wight local support



As a child I was encouraged by my parents to believe I could achieve anything, and that attitude has never left me. I find it hard at times to think of myself as disabled, I just do things differently. Spina bifida need not limit a child's opportunities to progress and excel in life.

*Baroness
Grey-Thompson DBE*



What is Hydrocephalus?

Hydrocephalus literally means 'water on the brain'. Excess cerebral fluid accumulates and if untreated can cause brain damage. Since the early 60s it has been possible to insert a valve to drain the fluid and prevent the build up of pressure.

Both abnormalities can occur independently but often occur together. Until 1960 most babies with Spina Bifida or Hydrocephalus died soon after birth, but surgical advances have enabled many born since then to survive.



How can we help?

You can talk to someone living with the condition or other parents who have the same experience as you.

We are all local, living on the Isle of Wight, and can offer practical advice.

We offer practical information about living with a child born with either condition.

Who are we?

We are an Island Group who can help answer your questions about Spina Bifida and Hydrocephalus.

We are not medically qualified but we do know what it is like to live with these conditions, or to be parents of someone with the conditions.



What is Spina Bifida?

Spina Bifida is a congenital abnormality resulting in the bones of the spine not joining properly, exposing the spinal cord leaving it liable to damage and infection.

Surgery shortly after birth lessens the risk of infection but inevitably some disability results. Some are more severely affected and are confined to wheelchairs while others less severely disabled can walk with the aid of calipers and crutches.

Some become expert athletes!