

A close-up photograph of a woman with dark hair and blonde highlights holding a baby. The baby is crying with its mouth wide open and eyes closed. The woman is looking at the baby with a concerned expression. The background is a blurred green, suggesting an outdoor setting.

**An introduction to
Down's Heart Group**

Penny Green - Director



Who am I?

- Bereaved parent of baby born with Down's Syndrome, congenital heart defects and Hirschsprungs
- Director of Down's Heart Group who I've been involved with since 1990
- Parent representative on the Steering group of Down Syndrome Medical Interest Group
- Strong links with Down Syndrome Foundation Nigeria





Who are we?

- Founded in 1988 to address the specific needs of these families. Became a registered charity in 1992.
- Trustees are primarily parents, grandparents or siblings of someone with Down's Syndrome and cardiac conditions.
- They have a range of personal experiences with family members of different ages and having different medical needs – bereaved families are also represented.
- To access a wider knowledge base, our Constitution also allows for the appointment of trustees without these personal links, but limits their representation to 25% of the board to ensure the focus remains parent led .

What do we do for families?

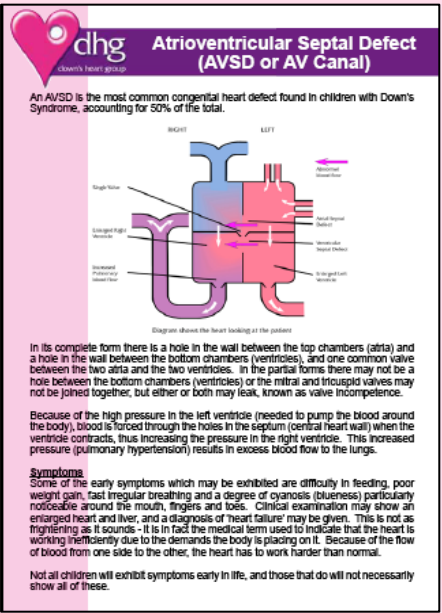
Provide information and support in parent friendly language via:

- Website
- Newsletters
- Information Pack
- Telephone Helpline
- Email & Social Media
- CD's & DVD's
- Conferences



(DHG has Information Standard accreditation for providing quality evidence-based health and social care information)

- Individual sheets
 - Simple diagrams
 - Parent friendly language
 - Info on main heart defects and normal heart
 - Info on other topics, travel advice, teeth etc.
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- All available to view or download on website
 - Also available on a CD



dhg down's heart group
Atrioventricular Septal Defect (AVSD or AV Canal)

An AVSD is the most common congenital heart defect found in children with Down's Syndrome, accounting for 50% of the total.

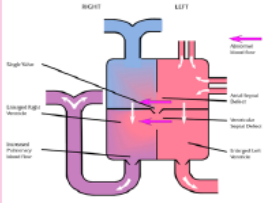


Diagram shows the heart looking at the patient.

In its complete form there is a hole in the wall between the top chambers (atria) and a hole in the wall between the bottom chambers (ventricles), and one common valve between the two atria and the two ventricles. In the partial forms there may not be a hole between the bottom chambers (ventricles) or the mitral and tricuspid valves may not be joined together, but either or both may leak, known as valve incompetence.

Because of the high pressure in the left ventricle (needed to pump the blood around the body), blood is forced through the holes in the septum (central heart wall) when the ventricle contracts, thus increasing the pressure in the right ventricle. This increased pressure (pulmonary hypertension) results in excess blood flow to the lungs.

Symptoms
 Some of the early symptoms which may be exhibited are difficulty in feeding, poor weight gain, fast irregular breathing and a degree of cyanosis (blueness) particularly noticeable around the mouth, fingers and toes. Clinical examination may show an enlarged heart and liver, and a diagnosis of 'heart failure' may be given. This is not as frightening as it sounds - it is in fact the medical term used to indicate that the heart is working inefficiently due to the demands the body is placing on it. Because of the flow of blood from one side to the other, the heart has to work harder than normal.

Not all children will exhibit symptoms early in life, and those that do will not necessarily show all of these.



E-learning package

Link on our website homepage

Our child



Loving and learning with a child with Down's Syndrome &
a Congenital Heart Condition

When do we help?

We use knowledge gained from personal experience and interaction with our membership to assist families on every stage of their journey

- ante-natal diagnosis facing decisions
- diagnosis after birth
- through open-heart surgery
- inoperable conditions
- bereavement



Our support and advice is non biased and available regardless of ethnicity, belief or any other factors

We cover all the UK and Ireland and try to help beyond when we can



Support

Until it's your baby's turn you don't know how you will feel. Imagine being in a bubble of what if's and why me? DHG helps families move out of that bubble and move on.

“Our surgery did not require a stay on ICU. The ward nurses were very busy and not sympathetic or particularly helpful. We were still worried that he had heart surgery even though to them it was a more routine procedure, but it was serious and upsetting for us.”

*“We contacted Down's Heart Group just after * was born after finding about the group on the internet. We were put in touch with another family who had a young lad with Down's Syndrome and a heart condition. Just knowing that there were others with similar experiences was a great help. The Down's Heart Group were a big help to us and I would like to thank them for their much needed and appreciated support - thank you.”*

Recent call examples

- 4 week old boy – large hole, needs surgery soon but needs to gain weight, leaving hospital

Worried as not been told what to expect, what to do if baby unwell etc – should he be going home?

- 2 week old girl – vsd and small asd feeding well, check up with NICU started on diuretics, given open access

Been given open access to ward immediately after diuretics prescribed, wondering what they are not being told.

What else do we do?

Raise awareness by:

- Working with other groups, schools and the media
- Social networking
- Involvement in training of medical professionals

Provide representation and advocacy:

- At conferences and events
- Working with various organisations such as DSMIG, Down Syndrome International and Children's Heart Federation
- By working with staff from the various heart units in the UK





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