



Growing up with 22q11.2 Deletion Syndrome!



HELLO FRIEND!

Have you ever noticed how people are so different from one another? Do you ever wonder why?

Some people are tall, while others are short. Some people have blue eyes, while others are brown or green.

Some people like to read, while others like maths or science.





Some people have lots of friends, while others have two or three close friends.

There are some people who hardly ever get sick and then there are people like me who have 22q.

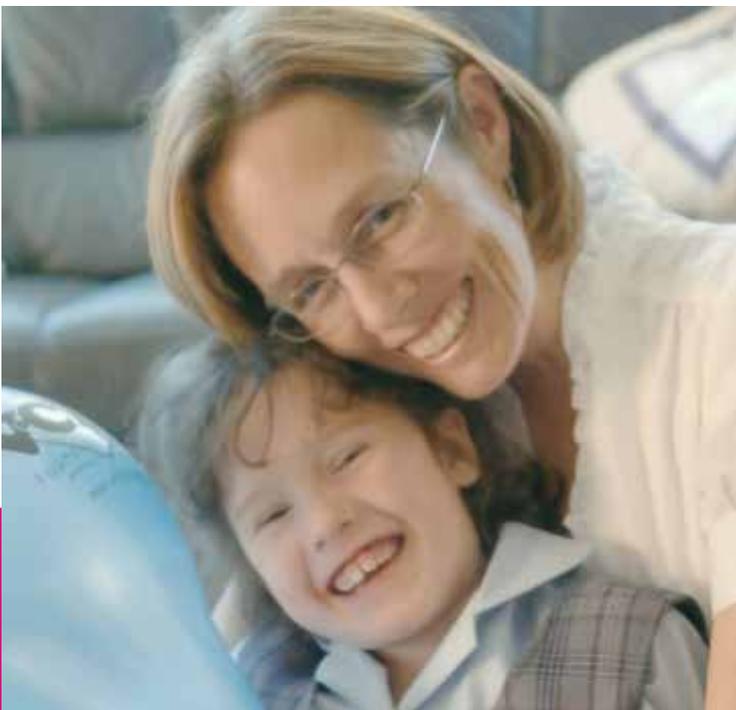
22q stands for a long medical word
called:

22q11.2 Deletion Syndrome!

But we just call it 22q

Some people also call it :

**Velo Cardio Facial Syndrome (VCFS) or
Di George Syndrome or Sequence**



Having 22q means that we may go to the doctor or hospital more often than most kids.

Some of us have special doctors that take care of our hearts.

Some of us have had surgery, sometimes lots of surgeries.

We have scars from all the operations. People often ask us about them.



Some of us get sick more often than other kids.

Some of us talk a little differently and we have to see speech therapists to help us.

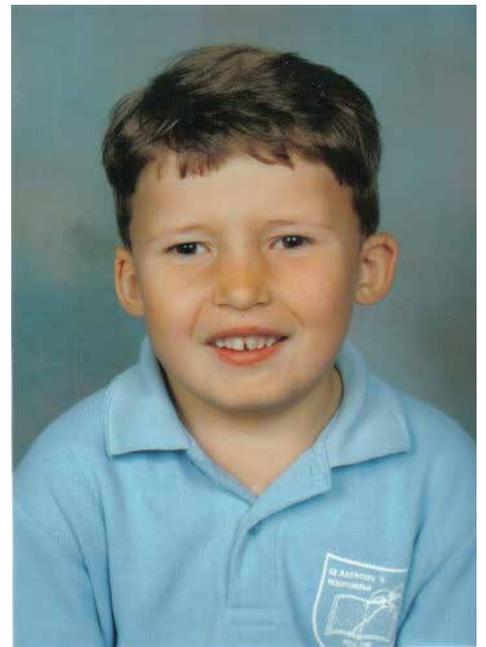
Some of us cannot hear very well and we have to wear hearing aids.





We like going to school and learning, but sometimes it takes longer for us to learn than other kids.

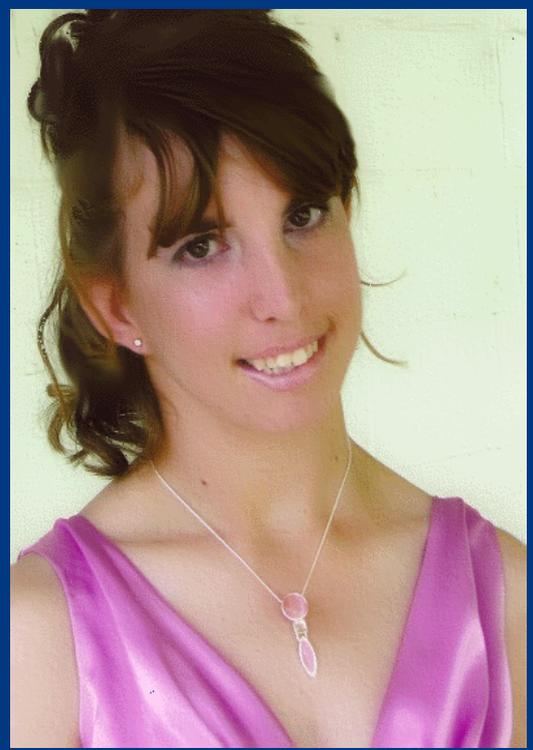
That can be really frustrating!



We are really just like any other kid and we like to do lots of fun stuff as well.

We like to dance, go canoeing, play sport and be just like everyone else.





When we first found out about
22q, we were not sure what to think!

Sometimes we were angry because we felt different.

We would ask things like:
Why do I have to go to the doctor all the time?
Why do I need extra help?
Why aren't I like everyone else?

But most of the time we did not really think about it.



We know our families and friends will always be there for us when we need them.

They are always there when we have questions about 22q and how it will affect us.

If you want to know more about 22q ask your parents or doctor or go online to www.vcfs22q.org.au

Quick Facts

- 22q affects approx. 1 in 2000 - 3000 persons making it the second most prevalent genetic syndrome after Down syndrome.
- 22q is the most common genetic syndrome associated with cleft palates.
- 22q is the second most common genetic syndrome associated with congenital heart defects.
- 95 - 99% of the 22q population will have a learning difficulty or disability.
- 22q has more than 180 anomalies or symptoms associated with it.



**For more information about
22q11.2 Deletion Syndrome
Visit: www.vcfs22q.org.au**

Thanks to the North Carolina 22q
support group (USA) and Childrens Miracle
Center for allowing us to use their ideas
and words for our booklet.

Thanks to all the Australian 22q Families
who have let us use their photographs.

