

Laurie Taylor

Projects Manager

VCFS and 22q11 Foundation

Annual General Meeting

The Children's Hospital at Westmead

Sunday 28 August 2011

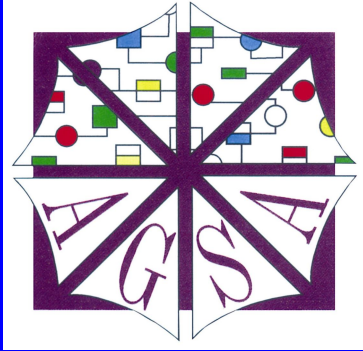
Overview

AGSA

FTV

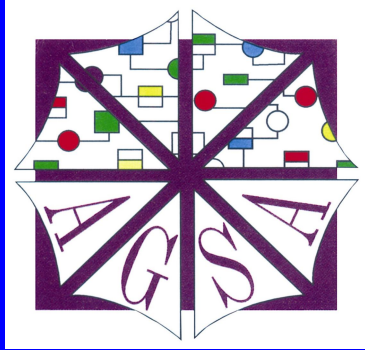
Siblings

Resilient families



AGSA

- **Established in 1988 to lobby genetic services and as a voice for support groups**
- **Database of over 900 mostly rare conditions as well as a chromosomal abnormalities database**
- **Funded by the New South Wales Health Department and ADHC**



AGSA

- **Advocates for those affected by a genetic condition**
- **Facilitates contact between people**
- **Raises community awareness**
- **Supports increased level of genetics education for General Practitioners and Paediatricians**
- **Alerts government to social policy issues eg Patent Act 1990, Better Start initiative, NDIS, Rare Diseases, PBAC**

Collaboration

- International Genetic Alliance
- Australasian Genetic Alliance
- National Organisation for Rare Disorders
- Steve Waugh Foundation
- SMILE **Australasian**
- APSU **Genetic Alliance**
- Support Groups



Ways to access support

AGSA can provide:

- **Peer support & Information provision**
- **Tips on self care**
- **On line support**
- **Activities**



What will I/We gain from the project?

- Meeting others in the same or similar position.
- Sharing stories and strategies.
- Learning about services currently available in the area.
- Accessing specialists in a non clinical setting.
- Opportunities to discuss future options.

AGSA aims to:

- Provide a contact point for families who are affected by genetic conditions so rare that they do not have their own support group.
- Facilitate access to individual support groups for those families with particular genetic disorders.
- Provide a forum for the exchange of information between support groups regarding available community services.
- Educate the medical and allied health professionals and the community about genetic disorders.
- Consult with government bodies, both Federal and State, for appropriate funding for genetic services.



AGSA

The Association of Genetic Support of Australasia Inc.

Reg Charity CFN15481 ABN 83 594 113 193

66 Albion Street

Surry Hills NSW 2010 Australia

Telephone: +61 (0) 2 9211 1462

Facsimile: +61 (0) 2 9211 8077

Website: www.agsa-geneticsupport.org.au

Email: projects@agsa-geneticsupport.org.au

Funded by

NSW HEALTH

Under the NSW Carers Program

Printed July 2005

Ready Set Design (02) 9922 4924

Printed by PR Print (07) 3205 1235

Frog illustration by Annabel Craighead

Supporting people living in isolation who are caring for someone with a genetic condition.

Filling THE VOID



AGSA

The Association of Genetic Support of Australasia Inc.

To facilitate support for those affected directly or indirectly by genetic conditions throughout Australasia.

FILLING THE VOID

Quality support for families through:

- **Seminars**
- **Sibling Workshops**
- **Telegroup counselling**



Telegroup Counselling (TGC)

- 1 hr phone call, once per week for 7 weeks
- Between 4-6 participants per group
- Topics vary but generally include: grief & loss, sibling issues, communicating with your partner, accessing services
- Newsletter each week



SUPPORTING SIBLINGS



Sibling issues

- Pressure to be perfect
- Grief and sorrow
- Independence
- The future
- Jealousy



Sibling issues

- **Most siblings of a person with extra needs say there were good and not so good aspects to their experience**



- **Support for siblings enables them to feel less isolated and helps build resilience**

Some points to consider

- **Some sibs are more tolerant and understanding of individual differences**
- **Some sibs take great pride in their brother or sister's achievements, and go on to work in helping professions**



Supporting Sibs

- **Communicate openly with Sibs**
- **Help Sibs to feel connected**
- **Give Sibs opportunities for 'headspace'**

Taken from Association for Children with a Disability

In their own words....

What is it like to be a sibling?

“Sotovf harde (sort of hard)”

“My brother makes me happy”

“They get all the attention”

“Good sometimes”

“I wish I was the only child”

“Fun”

Siblings Workshop

- Car of emotions
- Bean bags
- Drawing the family as animals
- Decorating a cut out doll as their sibling
- Fun



RESILIENT FAMILIES



Perspective



“...it is not the child’s disability that handicaps and disintegrates families; it is the way they react to it and to each other”

(Dickman & Gordon, 1985, p. 109).

Build a Resilient Family through:



Communication

Making time a priority

Keeping perspective

Building support networks

Seeking professional assistance

Respite

Play!

© Original Artist
Reproduction rights obtainable from
www.CartoonStock.com



“Your car broke down? Oh, my. Well, don’t panic. Just be there for it. Listen and try to be supportive.”

AGSA

Thank you for your time today

Any questions?

www.agsa-geneticsupport.org.au

