

## Supporting Aussie Kids with Kabuki Syndrome



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# SAKKS NEWS

[www.sakks.org](http://www.sakks.org)

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What does the term New Year mean; well literally it is the beginning of the year, for some of us it is a fresh beginning, for others it means making new resolutions to change some bad habits and improve ones life. For many it may mean we are a little closer to dealing with our grief and coming to terms with our challenges, and then for some who don't know it yet, it may be the year that they first hear those words Kabuki Syndrome. What ever way you see the new year it holds the potential for us to look forward, become wiser, and find happiness in all that we have.

Try to let go of all your grief, and step forward and as a wise person once said to me: use those rocks that fall in your way as stepping stones. Peta.

Something important our SAKKS Team has been discussing is our new group "Sibling Voice". We already have the foundations of the group on the website, but would like to encourage our young siblings to have their voice; please see the attached Sibling Voice Newsletter and print it and pass it on to your kids. Let them know that there is a surprise for all members.

Janelle from NSW; has been working hard getting details together for the Weekend retreat being held in September at Camp Breakaway, she has informed me that 10 families have confirmed their attendance and there is only room for 5 more families. If you are considering the weekend or would like to find out more please email [janelle.cameron3@bigpond.com](mailto:janelle.cameron3@bigpond.com)

We have also put together some information on "Talking to your child about their disability". Each family and child is unique and there is no right or wrong time, but parents are usually made aware of the need by their kids at some stage. Please read attached article and let us know if you would like more information.

The SAKKS Team wishes you good health and happiness in 2008.

We have put together some O.T. Information. Most of you would have seen some of them at some stage but there are some really great ideas, that can be trialed at home. Let us know if you would like a copy.

We have recently enrolled some help from Amber and Stephen from California. We have 17 members from the USA and would like to be able to support them more. Stephen and Amber are the proud parents of 6 year old Elena. Stephen after learning about Kabuki Syndrome is researching Multiple Congenital Anomaly/Mental Retardation Disorders to understand more about the genes that are likely to cause KS. As a graduate student in biology. Stephen is well versed in the Medical aspects of Kabuki Syndrome. Amber is a stay at home mum with great experience in dealing with education and therapy options for Kabuki Syndrome.

As part of their role they will act as a liaison for Family Days in the USA and offer initial support and information for newly diagnosed families. Time permitting they will also contribute information for the site and our newsletter.

Please take a minute and introduce yourself and welcome them in their new role; their contact details are on the "Contacts Page".

Next month: Our KS kids begin their school journey—read about some of the first day experiences of our KS kids.

### Happy Birthday

Connor-1st January

Michaela-1st January

Jennifer-1st January

Charlotte-3rd January

Elena-6th January

Jerome-8th January

Luke Henri-18th January

Chloe-26th January

Jamin-30th January



# State Family Day—New South Wales

Kelly—our NSW Representative for SAKKS is hosting a State Family Day.

It is being held at the Woodcroft Community Centre, on the 29th of March, 2008.

State Family Days which are organised by the SAKKS State Representatives allow families to attend without the hassle of long distance travel. Interstate families are, of course, welcome to attend.

The State Family Days are a more informal get together for families also allowing for extended family and close friends to attend. These days are an extra get together, and do not replace the annual Aussie Nationwide Family Days.

We have 17 families registered with SAKKS from NSW, so we are expecting a great turn out.

The SAKKS Team encourage Family Days; they are an excellent way of sharing ideas, making life long friends, and they offer support and comfort for many.

The venue is: Woodcroft Community Centre  
Address is : Woodcroft Drive,  
Woodcroft NSW

The start time is 10.30am

The venue, (which was used for the 2005 Family Day) has an indoor play area and outdoor play ground which is fully fenced. There is also a lake and, time permitting, children can feed the ducks. Kelly is in the process of organising a few surprises for the children.

Kelly will notify you on more of the details a little closer to the day.

If you would like to attend or have any questions please email Kelly at [kelly@sakks.org](mailto:kelly@sakks.org) or telephone her on: 0402 000 776 .

Look forward to seeing you there



## SAKKS Sibling Voice Newsletter

Being a sibling to a brother or sister who has Kabuki Syndrome is different for each person.

Every family is different and many of the challenges will be unique to you, but many of your experiences may be the same as other siblings who have a brother or a sister with Kabuki Syndrome.

But like every family, siblings can argue or fight and that is absolutely normal.

Sometimes you might feel embarrassed or annoyed, other times you might feel proud and happy which are all very normal feelings.

Sometimes it might seem that your sibling with Kabuki Syndrome is given more attention and you might feel jealous – that's okay, it is perfectly normal to feel jealous sometimes.

Children with Kabuki Syndrome may find it harder to do everyday things and when they finally achieve their goals parents or carers might make a fuss; this doesn't mean that your achievements are any less important.

Being part of a support group like SAKKS Sibling Voice is a great way to share experiences and make friends from all around the world.

Some kids have said:

*"I remember being jealous of the fact she was getting so much attention. I remember my mother telling me that she was not well and that I asked her if she had a cold. I didn't understand until later."*

*"Going to see my brother in the special care baby unit after his birth and seeing him in an incubator. He was so tiny, they were not sure at first if he was going to live, but he did. It was quite scary seeing all the equipment that was keeping him alive."*

*"Once when I told someone my brother had Kabuki Syndrome, they replied with "I'm sorry to hear that". I was uneasy at their response because, to me, he is just my brother and I don't want anyone to feel sorry for him, I guess people just don't know what to say."*

What effect does having a sibling with KS have on you and your family?

We would love to hear your experiences both positive and negative, please email us at [petal@sakks.org](mailto:petal@sakks.org) with your story.

On the Sibling Voice page there will be an extra section for contacts. This will be a password protected section that only siblings of kids with KS can access. On there you can look up names and email addresses of siblings just like you, please email us a little about yourself and we will send you your membership pack.

We look forward to hearing from you - you are going to  being a member of SAKKS SIBS.

Til next time; The SAKKS Team.

## Doing Disability Awareness with Kids

Kids like grown-ups have a need to know the truth whether it's about them or about the classmate sitting next to them. However, also like grown-ups, lots of mini-discussions will have more impact and be a better solution than one "big talk".

Remember the steps of this response system:

- (A) Awareness
- (E) Education
- (AC) acceptance

And your goal: Helping your child or another child in their world make the leap from confusion & fear to acceptance & understanding.

Let's talk about some practical ways to move through this process with your child and your child's classmates or peers.

### 1. Your Child

Parents go through a range of emotions when given their child's diagnosis. Your child also needs to be given information about their diagnosis and support for understanding and coping with this new information. Adults who are successful have learned who they are, and accept and use that information to help themselves become the best they can be in life.

Try setting a positive tone and focus on the fact that every family member has unique characteristics that make him or her special. Emphasizing that has their own likes and dislikes, strengths and weaknesses, and physical characteristics makes uniqueness just a matter of course. The ongoing use of positive concrete examples of contrasts among familiar people can make it easier to talk about other differences related to your child's diagnosis with him or her.

#### **Practical tools:**

(A) Read simple stories

(E) Check with your state Parent Training & Information Center, many have a library of videos that can be checked out for viewing by your family.

(AC) Talk with your child one-on-one. If your child is very visual, videotape them and watch the video together as a conversation starter. Consider your child's ability to process information and try to decide on what and how to tell. Remember it doesn't all have to happen in one big session. A series of conversations may meet both your needs better.

### 2. Your Child's Classmates

Just as you come to rely on your co-workers as an extended family so your child will see his/her classmates at school as a primary source of interaction and support. Time spent ensuring that this group is well informed and supportive when they are young, will make the road easier as your child grows.

(A) Volunteer to do a disability awareness presentation for your child's class as soon as school starts. Use strategies and conversations you have already developed with family and friends to explain a complex diagnosis in child-friendly language. And just as important as disability awareness is "ability awareness". Make sure your child's classmates understand all the ways your child is just like them. By talking about your child's favorite games, subjects, or areas of interest you help classmates see areas of common interest. Another good tactic can be pointing out that "being different" is actually a normal condition. Have the group look around and notice that everyone has something that is unique and special about them....and point out what a boring place this world would be if we were all just the same.

(E) Work with your child's teacher to integrate disability awareness into the class's regular curriculum through stories, simulation activities, and reports.

(AC) Discuss ways to encourage peer friendships for your child through the use of Peer mentors or friendship groups such as a "circle of friends" at <http://www.inclusive-solutions.com/whatisacircle.asp>. Add these items to your child's individualized education program to make them a priority or select specific social goals for your child to work on. One caution, relationships built in this way won't be of the same quality as a naturally occurring friendship, but they can offer your child a supportive environment to learn and practice key social skills. Some extra effort can help this "planned" friendship develop into a real friendship if the kids have an opportunity to spend time together away from school.

Written by Lisa Simmons, Lisa is a family advocate and director of the Ideal Lives Project.

Find more tips on effective

advocacy and inclusion at her website: <http://www.ideallives.com>

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