SAKKS

Supporting Aussie Kids with Kabuki Syndrome Inc.



www.sakks.org

SAKKS—Supporting Aussie Kids with Kabuki Syndrome was established in 2004 by the parents of a child with Kabuki Syndrome who were faced with the isolation that can be associated with this rare syndrome. Since its inception, SAKKS has grown into a Non Profit Incorporated Association with representatives in most states.

Our mission is to support those affected by KABUKI SYNDROME by offering:

- Information, external links to genetics departments and research as well as links to medical information.
- Contacts page—a link to families
- Story pages written by parents as well as photograph pages displaying many of our special members and their journey so far.
- Forum and stories page exclusively for siblings.
- Regular newsletters with the current activities of SAKKS.
- Professional membership; a forum for professionals to aide in information sharing.
- Annual family days in each state and Nationwide Retreats biannually.

To contact one of our team members go to our " contact us " page at www.sakks.org - we look forward to hearing from you.

My friend has Kabuki Syndrome



www.sakks.org

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l have..... Kabuki Syndrome

I am a lot like you.



Even though | have Kabuki Syndrome, | am a lot like you.

I love to watch TV. I love

listening to my favourite

music. I love books. I love playing on

the play equipment. I love to talk to my friends. I like chatting on the phone too. I love singing. I love going to the movies. I lo



going to the movies. I love horse riding. I love dancing. I love magic. I

love drawing and colouring.



l love my friends and

family.

What is Kabuki Syndrome

Kabuki Syndrome is very rare, not many kids have it.

Not all kids with Kabuki Syndrome are the same, they often have different problems, some problems include:



- Arched eyebrows
- Long shaped eyes,
 - Long eyelashes
 - Larger ears
 - Shorter height
 - Learning disability
- Cleft lip and palate
- Heart problems
- Kidney problems
- Intestinal (tummy) problems
- Immune problems
- Ear infections and hearing loss
- Weak muscles



Some kids with Kabuki Syndrome spend a lot of time in hospital





We have a lot in common.

Some of the things I don't like are when people stare; I would rather they treated me like everyone else. I get sad sometimes when I cant do things my friends can; but my good friends can make me feel happy.



Sometimes I need some help, and it isn't always easy, but with help from my friends I CAN do it.



