# SAKKS



# Supporting Aussie Kids with Kabuki Syndrome Inc.



## Who is Supporting Aussie Kids with Kabuki Syndrome?

We are a registered not for profit charity who support families/care givers who have a child with Kabuki Syndrome.



#### What is Kabuki Syndrome?

Kabuki Syndrome is a rare genetic condition that occurs in approximately 1:32000 births. There are many features which can occur in Kabuki Syndrome but not all are seen in every child. Some of the features include:



- Arched, interrupted eyebrows
- Long palpebral fissures
- Large and low-set ears
- Depressed nasal tip
- Short stature
- Skeletal abnormalities such as short fingers, loose joints
- Intellectual disability
- Cleft lip and palate
- Cardiac abnormalities
- Urogenital and kidney problems
- Anorectal and intestinal problems
- Immune abnormalities
- Ear infections and hearing loss
- Hypotonia



### Our Key Objectives:

- To celebrate the achievements of all children with KS
- To support families/caregivers by offering information, friendship and contact
- To provide information to the public; raise awareness
- To provide information to the educational and medical sectors to increase awareness and aide in earlier diagnosis
- To support the siblings of KS children giving an opportunity to talk with other siblings in a similar situation

and to professionals who seek information to better help children with Kabuki Syndrome and facilitate information sharing.





The SAKKS website offers instant contact and information to families newly diagnosed

If you would like further information or to make a donation please visit our website www.sakks.org or post: SAKKS—PO Box 318, Rundle Mall, South Australia, Australia, 5000