

NATIONAL FAMILY DAYS

Providing support through shared experiences.

Friendships

Fun

Future

National Family Days are organised for caring, sharing information and having fun.

This event has provided the only forum, in Australia, for families with this rare condition, to come together to meet another family with a child with Kabuki syndrome. The children and young adults respond to meeting new friends who are "just like me", have an enjoyable time and look forward to further contact at the next event.

The need for families to have contact with other persons who have similar problems / understanding of Kabuki syndrome, is so great that they will travel the breadth of Australia to attend the annual National Family Day.

This is also a time for professional educational input to enhance the wellbeing of persons with the condition of Kabuki syndrome.

As Kabuki syndrome is little known to both medicals persons and the general public, the parent / guardians gain great strength making use of this valuable time for networking, sharing their child's achievements, exchanging health and child management, whilst generally supporting and encouraging one another.



EDUCATION FORUM and WORKSHOPS



This is a one day event, supported by professional bodies who have an interest in the condition of Kabuki Syndrome. These sessions provide psychological and educational support with interaction pertaining to the improvement of the wellbeing of the person with Kabuki syndrome and family issues. Held in conjunction with the annual National Family Day.

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MEMBERSHIP

Membership is open to all persons with the condition of Kabuki syndrome, interested persons or groups who wish to support the persons with this condition to reach their full potential. For a small annual fee you can be involved in caring and sharing with a group of pro-active families, supporters and professional bodies.

For further information and Membership Forms, visit our website:

www.kabukisynndromeassoc.com.au

or contact the Membership Coordinator at:

kabukisynndromeassoc@gmail.com

AUSTRALIAN KABUKI SYNDROME
ASSOCIATION INC.

C/. 13 Lockwood Road
Erindale SA. 5066

This document was prepared by
the Management Committee of
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AUSTRALIAN KABUKI SYNDROME ASSOCIATION INC.

Established 2006
ABN 63 186 247 884



ASSOCIATION INFORMATON



The Association is a registered, not for profit
Organisation.

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AUSTRALIAN KABUKI SYNDROME ASSOCIATION INC

The Association is a registered, not for profit organization. Managed by volunteers, from across Australia, with the aim of bringing together, the persons with the condition of Kabuki Syndrome and their family, for support.

OUR MOTTO

TO SUPPORT AND MAKE A DIFFERENCE



Jos Vergouwen, a Dutch parent of a child with the condition of Kabuki syndrome, designed the logo which is now used throughout the world to represent Kabuki syndrome. The character 'K' represents the word Kabuki and illustrates two outstretched arms symbolic of the invitation to network with one another.

HISTORY

The Australian Kabuki Syndrome Association Inc. was officially formed in September 2006, holding the inaugural Annual General Meeting in Geelong, Victoria, preceding a National Family Day celebration.

A South Australian mother of a daughter with the condition of Kabuki syndrome, organized the first National Family Day in Adelaide, South Australia in 2001.

This was the beginning of Australian families, meeting for the first time, forming friendships and supporting one another through their shared experiences. Two guest speakers from the Women's and Children's Hospital spoke to the occasion.

From this small group of five families, the number of families attending the annual National Family Day has increased each year.

At the third get together in 2005, held in Sydney NSW, three mothers decided there was a need for a formal organisation to help support one another and to make an awareness of the little known, rare condition, Kabuki syndrome. The organisation would also focus on supporting the National Family Day.

One year later the Association was formed with a constitution and registered as an incorporated body.

Within twelve months of the Association's existence, word had spread of the benefits gained by families interacting at the National Family Days. This gave rise to fifteen persons with the condition of Kabuki syndrome, their families, friends and supporters attending the Associations National Family Day at Varsity Lakes, Queensland in September 2007. This was approximately 50% of the known persons with Kabuki syndrome in Australia.

The original name of the Association was the Australian Kabuki Support Association Inc. As this resulted in much explanation of what Kabuki meant, the word Support was deleted and replaced with the word Syndrome. This now describes who we are and promotes awareness of Kabuki syndrome.

The annual National Family Day held at Collaroy Beach, New South Wales, September 2008 brought change by the Management Committee with the introduction of a second day for an Education Forum.

Each year a different range of topics are introduced to the Education Forum. Information on improving/maintaining good health, social issues, how to choose the right education for your child, workshops with families working together creating magical art, giving rise to concentration and rivalry between the family groups. An educational session, learning maths through music, proved to be a great success with the children.

Session on Creative Education aimed at the younger child, a workshop for siblings and a siblings workshop for parents are just some of the activities planned.

Time for respite, improving the future, friendship, and above all some fun .



AIMS OF THE ASSOCIATION

- To provide support to persons who have the condition of Kabuki syndrome and their family.
- To provide a contact point for the families
- To provide a forum for the exchange of information on and expression of concerns
- To provide an annual National Family Day
- To share information pertinent to the well-being of the persons with the condition of Kabuki syndrome and their family.

