

AUSTRALIAN KABUKI SYNDROME ASSOCIATION INC.

The Association is a registered, not for profit organisation. 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 MOTO

To support and make a difference

THE LOGO



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.

Kerrin Windsor, 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 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 Associations 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.



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 and expression of concerns
- . Aim to provide an annual National Family Day
- . Aim at providing a newsletter to keep families in touch

Visit our website for more information at

www.kabukisynndromeassoc.com.au

NATIONAL FAMILY DAYS

Providing support through shared experiences

National Family Days are organized for caring, sharing and having fun. They are usually held in a different State or Territory each year depending on where the kind and energetic person / people live and offer to host the day.

National Family Days are supported very generously by the general public, service clubs and businesses by way of providing for the day and monetary support for families to be able to travel and have accommodation whilst attending the function.

From these National Family Days the persons with the condition of Kabuki syndrome and their family form bonding friendships and look forward to the next meeting. Often, for some families, this is the first time they have contact with another family who has a member with the condition of Kabuki syndrome.

As Kabuki syndrome is little known to both medical 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.

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.

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.



EDUCATION FORUM

This is a one day event, supported by professional bodies who have an interest in the condition of Kabuki Syndrome. This day is held in conjunction with the annual National Family Day.

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.

It provides a venue to support the person with the condition of Kabuki syndrome and their family to have contact with other families and to meet annually at a National Family Day held in a different part of the country each year.

For a small annual fee you can be involved in caring and sharing with a group of pro-active families, supporters and professional bodies.

There are three categories of membership.

Consumer: Open to all persons with the condition of Kabuki syndrome.

Full Membership: Open to all persons with a common interest in supporting the persons with the condition of Kabuki syndrome and their Family.

Corporate: Open to all organisations with ideals which are parallel to those of the Association.

For further information and Membership Forms, visit our website:

www.kabukisynndromeassoc.com.au

Or contact the:

MEMBERSHIP COORDINATOR

AUSTRALIAN KABUKI SYNDROME ASSOCIATION INC.
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This document was prepared by the Management Committee of the Australian Kabuki Syndrome Association Inc.

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AUSTRALIAN KABUKI SYNDROME ASSOCIATION INC.

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ASSOCIATION INFORMATON



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