

# KABUKI

SUPPORT//SHARE//STRENGTH

MOBILITY, EDUCATIONAL & SENSORY EQUIPMENT GRANT APPLICATION PACK

Registered charity England and Wales 1150972



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# Kabuki UK



**Kabuki UK was set up by a group of parents who all have children with Kabuki Syndrome.**

Each of us has been through the confusion, pain and heartache of a Kabuki Syndrome diagnosis.

We have all experienced the isolation that comes from having a child with such a rare and complicated condition.

Until 2012 there was no UK-based organisation to support people with Kabuki Syndrome and their families. Although there are wonderful organisations in other countries, their advice and experiences are often different to what we find here.

Kabuki UK was set up to address this problem. The website ([www.kabukiuk.org.uk](http://www.kabukiuk.org.uk)) has a wealth of information on the health, educational and developmental aspects of Kabuki Syndrome but is written in a reassuring way. There are lots of photographs of children with Kabuki Syndrome having fun with their friends and siblings.

# Grant Scheme

One of the charity's original aims was to establish a system of grants to enable the purchase of specialist equipment for people who have Kabuki Syndrome. We now have that Grant Scheme up and running.

This could include items such as;

- Walkers
- Specialist car seats
- Specialist buggies
- Lycra suits
- Push alongs
- iPads or similar
- Specialist key boards
- Light Tubes
- Reading aids
- Bubble tubes
- Fibre Optics
- Writing slopes

Applicants will be expected to specify the make, model, cost and supplier of the specific piece of equipment.

Applications are limited to one application for one item, per person, per year.

All applications will need to be backed with a letter from a therapist or specialist explaining who they are, what their qualifications are and why this specific piece of equipment is needed. We will also require a copy of a letter from a medical practitioner/therapist confirming the Kabuki Syndrome diagnosis.

The grant scheme is not available to the Trustees of the charity or their immediate family.

# Key Dates

Applications are welcome at any time. Trustees will agree the total size of the grants fund for that year at the start of the Financial Year and once that is allocated the fund will be closed. The amount for the following year will be set at the start of the that year. The size of the grant fund will vary year on year and is dependant on fundraising revenue.

Grants are made at the discretion of the Trustees.

# Procedures

When we receive the applications they will be checked to make sure that all of the required information has been provided and a note will be made of when the application was received.

If the form is incomplete the applicant will be notified once by email and invited to resubmit. Trustees will not chase up applicants. Once we receive the resubmitted application form it will be recorded as received on that date, ie not the date of the original incomplete application.

Applicants will be expected to specify the make, model, cost and supplier of the specific piece of equipment.

Applications are limited to application for one item, per person, per year.

All applications will then be kept securely together until the Trustees meet.

Trustees will meet to assess and consider the eligible and approved applications and grants shall be allocated on a first come first served basis until the allocated funds are used up.

The available grant funds are finite and Kabuki UK intend to make grants to eligible, approved applicants up to the limit of available funds.

The successful applicants will be notified and the process of purchasing the equipment will begin. The charity requires written confirmation of purchase and any further evidence of purchase reasonably required.

The charity may require pictures of the equipment and the recipient for use in promotional material and future fundraising.

Unsuccessful applicants will also be notified and invited to apply again next year.

All applications will then be shredded to ensure security of personal details. However sufficient details of applications, particularly successful applications, will be retained for the purposes of the charity's audit records and accountability. Any retained data will be held in accordance with Data Protection Act.

All grants are made in the discretion of the trustees and no guarantee is given that any particular application will be approved.

The charity will rely on applications for assessment of personal need and of the suitability of the item specified in each application and will have no responsibility for the supply or performance of any grant-funded item.

Grants are given on the condition that if and when a beneficiary has no further use of the item, the charity will be given the option to receive the item for possible provision to another beneficiary.

# Application Form - page 1

Name of person applying for the grant	
Address	
Telephone number (landline and mobile)	
Email Address	
Name of person with Kabuki Syndrome	
Relationship to the person who has Kabuki	
Address if different from above	
Date of birth of person with Kabuki Syndrome	
Approximate date of diagnosis	
Name of therapist (please include their letter with your application)	
Professional Qualifications	
Work address of therapist	
Therapists telephone number	
Therapists email address	

# Application Form - page 2

Name of equipment required	
Cost of equipment required	
Manufacturer or wholesaler	
Manufacturer or wholesaler address	
Manufacturer or wholesaler phone number	
Please explain how this will help the person who has Kabuki Syndrome	



# Application Check-List

Please make sure that you have included the following;

1. Fully completed application form
2. Confirmation of the Kabuki Syndrome diagnosis
3. Letter from your therapist explaining why the piece of equipment would be beneficial. This should be on headed paper and should explain their relationship to the person who has Kabuki Syndrome. The therapist could be an Occupational Therapist, Physiotherapist, Pediatrician or other specialist health professional.

Please email your application to [sallytrewartha@gmail.com](mailto:sallytrewartha@gmail.com)

You will receive an email acknowledging that we have received the application.

## What have we done?

### Fundraising - walk for a walker

Kitty was diagnosed with Kabuki Syndrome at 13 months. Kitty's particular presentation of Kabuki Syndrome means that she is unable to weight bear and therefore cannot walk.

At almost three years old, Kitty was becoming increasingly frustrated at not being able to run around with her friends and siblings. Kitty was assessed for a walker but unfortunately there was no NHS funding available to pay for it.

Kitty's family and friends organised a sponsored walk to raise the money to buy a walker. This was so successful that, due to peoples wonderful generosity, they were able to buy not only the walker but a specially adapted bike as well.

Kabuki UK now hope to do similar, life changing things for other children.



# How to contact us

You can email us through the website by following this link <http://www.kabukiuk.org.uk/#!/contact-us/cudb>

[www.kabukiuk.org.uk](http://www.kabukiuk.org.uk)

Find us on Facebook at [www.facebook.com/kabukiuk.charity](http://www.facebook.com/kabukiuk.charity)