

# KABUKI

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Welcome to the long awaited Kabuki UK newsletter.

We have been very busy over the last few months working on the completely new website. The new site holds lots of information on Kabuki Syndrome and on the charity. If you haven't seen it then have a look at [www.kabukiuk.org.uk](http://www.kabukiuk.org.uk)

Ticket sales for this years Family Day are going strongly and we have a lot of new faces coming along this year. For the first time we have been able to help some families who have a very long journey to make it to the Family Day and we are really looking forward to welcoming members from all over the UK.

We have an exciting film project coming up which we are hoping will be a great tool for raising awareness of Kabuki. There is more information about that in the newsletter.

There have been some great fundraising activities going on, details of which are also in the newsletter. We are very excited about the fundraising gig on May 15th which should be a really great night.

Best wishes



Sally & the Kabuki UK Trustees

Family Day  
Saturday 27th June



Our annual family day is nearly here again and it is great to see that so many people have already registered for tickets.

Hopefully the on-line ticketing system which we have used this year has made things simpler for members as well as for us. There are still tickets available and they can be found here; <https://itrulycare.com/events/kabuki-uk-family-day-2015>

As in previous years we are just asking for £5 for each adult ticket with under 16's free.

We will be sending out a form nearer the time asking for any dietary requirements so that we can make sure that the catering is correct.

This years family day coincides with the East Coast Kabuki Conference at Johns Hopkins Medical Centre in Baltimore US and the West Coast Kabuki Conference in California US. We are looking at ways to connect the three events as it is the first time so many people have gathered in this way across the world.



We have people traveling from all over the country and even a family from Germany so we hope that this will be the biggest family day yet.

If you have any suggestions of things that you would like to see or do this year please let us know.

Fundraising gig

Friday 15th May 2015 7pm  
St Lukes, Penn Road, London N7

For anyone near North London in May we are putting on what will be a really great night.

We Used To Make Things are an 8 piece London band, their sound is layered with big Horns, big harmonies and a healthy respect for a melodic hook and a fat groove. Laced with warm, witty lyrics about dissatisfaction, personal politics and the kind of characters Mike Leigh and Pinter would be proud of. Their journey is in turn: funny, sad and poignant but also very good to dance to.



At St Lukes the band will be promoting the release of their new single Love In A Minor Key. On what We Used to Make Things is hoping to make a memorable night they will be joined by their full live outfit plus the fantastic Volta string quartet.

We Used to Make Things are proud to be playing in the beautiful setting of St Lukes of West Holloway in aid of the Kabuki UK.

Tickets are £10 in advance and all of the proceeds from ticket and bar sales will go to Kabuki UK. Tickets can be purchased through the Kabuki UK website and here; <https://itrulycare.com/events/we-used-to-make-things>

You can find out more about the band here; <https://www.facebook.com/weusedtomakethingsmusic>

## Film Project

Back in 2013, at the first Hatton Farm Family Day, we were able to make the film which have now been seen by almost 5,000 people all over the world. If you haven't seen the film it is on the front page of the new website [www.kabukiuk.org.uk](http://www.kabukiuk.org.uk)

We have had a lot of positive feedback from this film, most often people say how reassuring it is to hear people talking about their own experiences and how uplifting the film is.

We would like to build on this success by making three more films. They will be 5 minute documentary style pieces telling the stories of some people in our community.

We are very fortunate to have Director Sam Strickland on board. He is committed to helping the charity and will be donating his time and kit for free. Sam specializes in making sensitive and thought provoking documentaries. You can see more of Sam's work on his website [www.sam-strickland.com](http://www.sam-strickland.com)

We would like to find three families who would be happy to spend a day with a film crew and talk about their experiences. We are looking for a range of age groups and a range of experiences. We will come to the homes of the people in the films and see their normal day to day lives.

The subject matter will be handled sensitively, the films will be produced by me (Sally) and edited by my husband Paul so all of the key crew have first hand understanding of Kabuki Syndrome.

Filming will take place in late summer and the films will be finished in time for the Kabuki Syndrome Awareness Day in October. The films will be hosted on our YouTube channel and used on the website.

Costs to the charity are minimal as the films will be produced through our production company and all of the crew are donating their time.

If you would like to be involved with the project please contact me at [sallytrewartha@gmail.com](mailto:sallytrewartha@gmail.com) for more information.

## Marathon!

Jill Hookway will be running the Virgin London Marathon on April 26th, raising funds for us in the process! Jill has been running for 20 years and as her 45th birthday approached, she felt the urge to run her first marathon to mark the occasion. She also wanted to use the opportunity to raise funds for a charity. Whilst Jill waited for the ballot for the 2015 Virgin London Marathon, Noah, the baby son of one of her great friends, was diagnosed with Kabuki Syndrome. Jill gave her word that if she got a place, she would run for Noah and the other children like him. The training has been far harder than Jill ever imagined. It has been a real sacrifice to do long runs every weekend since October, and by the time she hits the start line, Jill will have run 700 miles in training! But it will be all worthwhile when she crosses the line. To sponsor Jill, go to; <https://mydonate.bt.com/fundraisers/jillhookway1>



## Run or Dye - 27th June 2015

James Caza says "We will be putting together a team to enter Run Or Dye Cheshire 2015 to raise money for our chosen charity of 2015 - Kabuki UK! With Run or Dye, you become part of the rainbow. As you run/walk/dance through the course, you get showered in safe, eco-friendly plant-based powdered dye at every kilometer turning us into a technicolour canvas of fun! Just when you thought it couldn't possibly be more colourful, we will cross the finish line and find ourselves in the middle of a colour storm at the Finish Festival!" You can support James by sponsoring him here; <https://mydonate.bt.com/fundraisers/runordye15>



## Wow Moments

The new website features a page which we have called Wow Moments. This is an opportunity to share the joy when something great happens. These are things like when Imi Dickinson jumped out of a plane or when Antoni Tarnawska met Mr Tumble.

If you have a Wow Moment that you would like to share please get in touch with a few words and a picture and we will get it up on the website.

## Football Club

Heather Lowe had the great idea of sponsoring a football club to raise both money for the charity and awareness of Kabuki Syndrome in general. They have bucket collections on the touch line and we would like to say a huge thank you to Heather and all of her family for their energy and support.



## Donation

It is now possible to support Kabuki UK with a monthly donation, this goes directly into our bank and supports us in paying for the family days, the website and the grant scheme. If you feel that you would be able to set up a monthly donation you can do so here; <http://www.kabukiuk.org.uk/#!/donate/c1vud>

## Contacts

The best way to get in touch is through the contact form on the new website, you can find that here; <http://www.kabukiuk.org.uk/#!/contact-us/cudb>

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