

## Upcoming events

### Kabuki Blues

A special charity night of great Blues music with the Tommy Allen Big Band, including a 4 piece brass section. Celebrating the 40s/50s swing music of the legendary T Bone Walker. Worthenbury Village Hall, Church St, Worthenbury, Wrexham, LL13 0WA Sat Oct 13th 7.30pm for 8.30pm show. Tickets £10, fully licensed bar, real ales. For tickets call 01948 770215 or 01691 624384 All proceeds go to Kabuki UK



### Christmas Card Competition

Although the school holidays are behind us and the September mornings are getting chillier we are still a long way from Christmas. However we thought it would be a nice idea to have a Kabuki UK Christmas card competition this year, and that means starting early.

The winning design will be made into a Christmas card which will be sold in packs on the Kabuki UK website. There will be information about Kabuki Syndrome and the charity printed on the back as well as the name of the winning designer.

The competition is open to anyone associated with Kabuki UK. If you fancy designing a card with a Christmas or wintry theme we would need to have the designs emailed to [sally@kabukiuk.org.uk](mailto:sally@kabukiuk.org.uk) by October 30th.

### Kabuki UK Regional Contacts

The email address for your regional contact can be found on our website at [www.kabukiuk.org.uk](http://www.kabukiuk.org.uk) If you would like to get involved in any way please email [tommy@kabukiuk.org.uk](mailto:tommy@kabukiuk.org.uk)

## Product recommendations

In each issue of the newsletter we will aim to bring a recommendation of a product which has made life easier in some small (or large) way. This review comes from Paul Trewartha, dad to Harry now aged 4.

"We came across this great little product while visiting a museum in Suffolk. We were visiting with our three year old who has Kabuki and our baby who does not. We were not allowed to take our pram with the buggy board inside the galleries and we were offered a baby carrier to use for the little one and a Hippyck Hipseat for Harry. The Hipseat forms a seat on your hip which the child can comfortably sit on while taking the pressure off of your back. The waist band is wide and supportive with a quick attachment using velcro and a more secure clasp too.



We ordered our own one straight away and it has been kept in the car ever since. It allows you to carry a child who is tired or can't walk very far without hurting your back. The Hippyck Hipseat can be washed and is extremely durable and well made, we can't recommend it enough."

The makers of the Hippyck Hipseat have kindly offered a 20% discount to Kabuki UK members. Just call 01278 434440 with the code HCKAB12 and ask for Vicky or Francis.

If you have a suggestion of a product please email the details to [sally@kabukiuk.org.uk](mailto:sally@kabukiuk.org.uk)



## Welcome to the first issue of the Kabuki UK Newsletter.

Kabuki UK is a newly established charity which has been set up by a group of parents who all have children with Kabuki Syndrome.

In this issue we hear from Jenny Anderson on being an Olympic torchbearer and from Lisa and Jason Johnston on hosting a Kabuki family day.



We hope that you enjoy the newsletter and we look forward to bringing you more stories and information on upcoming events in our next issue.

Best wishes

A handwritten signature in black ink, appearing to be 'Sally'.

Sally & the Kabuki UK Trustees

## Jenny's Olympic story

My name is Jenny Anne Anderson and I'm 20 years old. I was diagnosed with a mild form of Kabuki Syndrome at 5 years old which means I have lax ligaments and I was prone to knee dislocation up until the Summer of 2010.

I have always struggled where other people have succeeded for example I have always struggled with tying my shoelaces and I still today find Maths difficult.

I was brought up in Hadfield near Manchester for 10 years and then I moved up to the Scottish Borders with my parents.

I have had to face many challenges throughout my life due to my Kabuki Syndrome mainly because of my left knee deciding to dislocate first when I was in a Dance Class and then continually on five different other occasions. However after a couple of long trips down to Norwich Hospital they managed to do a major operation in 2010 and touch wood it hasn't done it again since!

I absolutely love being on the stage be it singing or acting and I have taken part in lots of choirs and drama groups over my twenty years –

Kinder Children's Choir Of The High Peak and Inchorus to name a few choirs; Northern Kids Theatre Company and Borders Youth Theatre to name a few drama Groups.



On June the 14th this year I was given the privilege of carrying the Olympic Flame through a town about an hour away from where I live. This was an extremely magical day and an experience I never want to forget. I was nominated via my Mum for all the Voluntary Work I have done in my area. Rainbows – Young Leader, Primary Schools, Nurseries, Playgroup, Youth Group and even Borders Youth Theatre as well as WRVS, Hospital Radio and a local radio programme for young people. I had to be up at 5:30 in the morning to get ready for my Moment to Shine however it was well worth it.

I was rather emotional on the day when I carried the torch as I was still rather shocked that little old me had been chosen to carry it and also how quick the day had come around for me to carry the torch. It was so fast and it left me wanting more and to be able to relive the experience again.

I have made a huge step in my life recently and decided to look further afield for places to study as I had an unfortunate time at a local college. I decided to move out of my parents' home and move an hour up the road to study at Jewel and Esk College on the East side of Edinburgh. I am studying Tourism and Events and loving every minute of it so far.

I was extremely nervous on my first day as everyone knew other people from school, however I have found a nice group of friends now and I am very happy there.



## Family Day

Kabuki UK Family Day – May 5th 2012



Jason and Lisa Johnston hosted the first Kabuki UK family day at their home in Bournemouth, Dorset (with the helping hands of Grandma and Auntie Emma!) 8 Families attended the day traveling from as far as Kent and Shropshire.

The day proved to be a great success and was a fantastic opportunity for all the parents to discuss their Kabuki journeys, offer advice and support to each other.

While the parents enjoyed this opportunity, the children quickly bonded and there were some great comments as to how the siblings really looked after their brothers and sisters.



All together there were 21 children who spent the majority of the time in the garden bouncing on the trampoline and playing with other garden toys. Jason spent most of his time cooking endless sausages and burgers (we won't mention the first batch!) to feed the hungry crowd.

The day rounded up with a large chocolate cake and singing Happy Birthday to two beautiful Kabuki girls, Katie and Thalia who were about to turn 2. Singing Happy Birthday was quickly followed by a rendition of Twinkle Twinkle Little Star, on the microphone, from Harry and Charlie.

A fantastic day was had by all and everyone is looking forward to the next one. Watch this space.