

Registered Charity Status

Our biggest aim for the first year of Kabuki UK was to become a registered charity. We have now achieved this and our charity number is 1150972.

This is important to the charity for several reasons; We can now apply for Gift Aid which will make donations from UK taxpayers worth 25% more to us, it means that we can now use websites such as justgiving.com for fundraising and we can now apply for corporate giving schemes.

In order to become a registered charity we had to hit a fundraising target and we would like to say a huge thank you to everyone who has held a fundraising event, made a purchase from the online shop or made a donation. We now need to keep up the momentum in order to achieve all of our other aims!

Upcoming Fundraising Events

Bag packing ASDA, Holt Road, Wrexham 15th June

The "Skinny Chimp" team will be completing the Tough Mudder Assault Course. They are a team of 10 and hope to raise a lot of money for Kabuki UK.

Jo Hare is running the 2013 Brooks Paddock Wood Half Marathon. She says "This is my first half marathon and the furthest I have ever run before is 10k. Finding the time & energy to train is my biggest challenge as I am a Mum to a 4 & 6 year old, whilst volunteering at their school & working. I have known Lisa Johnston for approx 25 years and have followed her and Kitty's Kabuki journey for the last few years. Kitty is adorable & has given me the inspiration and motivation to challenge myself and I know just thinking of Kitty on the day is going to be enough to keep me going!"

Kabuki Blues Night will be on the last Saturday in October (28th). More info in the next newsletter.

If you have any fundraising ideas please email tommy@kabukiuk.org.uk for more information and sponsorship forms.

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 Beth Allen, mum to Charlie, 4.

Beth writes, "One of the most obvious side effects of Kabuki Syndrome for our gorgeous Charlie is the never-ending stream of dribble that would quickly soak through his tops if left. This is where Bubba Bibs steps in. I

found this website after being astounded at the high prices certain well-known internet retailers were charging for bandana bibs and have ordered twice from them so far. Not only do they have a range of over 120 colours and funky designs suitable for both boys and girls to choose from, but they are incredibly reasonably priced. I have just ordered a pack of four (with one free - you can choose the bibs too) for under £9 and they arrived just two days later. They also provide larger bibs for older children and the bibs themselves wash really well. Highly recommended - I know I will be ordering again!"



Bubba Bibs are available to order from www.bubba-bibs.co.uk. The owners of Bubba Bibs have kindly offered a 10% discount to Kabuki UK members. Just enter the word KABUKI in the discount code box at checkout.

Kabuki UK Regional Contacts

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



Welcome to the Spring issue of the Kabuki UK Newsletter.

Big things have happened since our last newsletter.

We are now a fully registered charity! Our charity number is 1150972 and there is more on what this means for us inside.



In this issue we hear from Emma Bond, whose brother Matthew was diagnosed with Kabuki at the age of 20, and have exciting news about the next family day.

We hope that you enjoy the newsletter and we look forward to meeting as many people as possible at the family day.

Best wishes



Sally & the Kabuki UK Trustees

Next Family day

Kabuki UK Family Day – June 22nd 2013

Following the huge success of last year's family day which was held at the home of Lisa and Jason Johnston we have big plans for this year's event. We would love to get as many families as possible together to share experiences and enjoy a great day out.



We have booked Hatton Adventure Farm, Dark Lane, Hatton, Warwickshire, CV35 8XA. Saturday 22nd June 2013, 10am onwards. Tickets are £5 per adult, children free. This includes entry to the farm, lunch, drinks and entertainment.



Set in the beautiful Warwickshire countryside, Hatton Adventure Farm offers a wonderful family day out with a fun packed programme of farm-yard animals, adventure play, fun fair rides, children's shows, falconry displays and tractor rides.

If you would like to come please email beth@kabukiuk.org.uk before 31st May

We have found a venue which is central so that as many people can get together as possible. As we know that most people will be travelling, we have negotiated a preferential rate of £55 per room per night including breakfast at the Holiday Inn Express Warwick, Stratford Rd, Warwick, CV34 6TW which is 10 minutes drive away. If you would like to book a room please call the hotel on 01926 483000 and quote the reference KABUKI saying that you are with the Kabuki UK party before 31st May, after that date the cost will return to their standard rate.

Matthew's story, as told by his sister Emma

Matthew Bond was born on December 14th 1984 in Ascot to my Mum Kim and Dad David. He has an older brother Stephen and a younger sister: that's me, Emma.

Matthew weighed just 5lbs 13 at birth. Both my parents thought Matthew looked different but nothing was suggested by any medical staff. Everything was fine at home for the first few weeks; he was a slow feeder but Mum just put this down to his small size.

When Matthew was six weeks old he had a temperature and started to convulse. He was taken to hospital and was kept in for observation. On his chart at the end of his cot the letters FLK were ringed. When my parents asked what this meant they were told it stood for 'Funny Looking Kid'!

Matthew had a lumbar puncture & chromosome test but all results came back clear and my parents were allowed to take him home. Matthew was still a very poor feeder, he had little weight gain and was always crying (probably due to being hungry) it would take up to an hour to get two ounces of milk into him, he didn't sleep and would just cry continuously. At 9 months old Matthew's health visitor advised my parents to take a week away and arranged for Matthew to be looked after by a local lady who offered respite care. She introduced a lot more solid foods to Matthew and helped him with his sleeping routine. At this point he really turned a corner and became a very content happy baby!



My parents were later referred to a paediatric nurse who said Matthew had a 'bizarre' pallet and possibly a heart murmur, but again this came back negative.

At two years old Matthew was seen by the geneticists at Great Ormond Street hospital and the Wolfson Centre to try and diagnose his condition as he wasn't developing at the normal rate.

After all the tests came back negative my parents felt that as Matthew was such a happy young boy there was no benefit of continuing with the tests, and thought it would be best to leave it here and if Matthew wanted further tests when he was older they would revisit this at a later date.



Matthew grew up with all the, now recognized, signs of Kabuki Syndrome - fine and gross motor skill difficulties, lax joints which affected his coordination, visual perceptual difficulties, speech problems with pronunciation, etc.

He had a Statement of Special Educational Needs and went to a school with a unit for special needs children. He loved school and singing, he found it hard to write so used a keyboard. He had lots of friends from the unit and loved being in a routine.

He went on to a secondary school with support in place to help him with his poor organisational skills and achieved low grade GCSEs in a couple of subjects and was awarded a certificate of achievement. From here Matthew went onto college and did a life skills course.



Mum received a letter when Matthew was 20 from Dr Blair of John Radcliffe asking if they could do some tests on Matthew as genetics had moved on a great deal since the early days. As a family, we agreed it would be interesting to see if we could find a name for his condition and see if it would have any knock on effects to any children born into the family by Stephen or myself.

Doctors initially thought Matthew had a form of Down Syndrome; they used old photographs and new blood samples in their research.

In 2005 Dr Blair contacted my Mum and revealed that it was in fact Kabuki Syndrome. Matthew was delighted he had a name for his syndrome and took great pride in telling people.

Matthew has since gone on to live independently. He lives with two women of a similar age with Down Syndrome and has some supported care. He gained an NVQ Level 3 in childcare and works full time voluntarily in a pre school nursery for children with learning difficulties, where he is a valued member of the team.

He enjoys an annual ski trip with 'DSUK', is shortly off to California and has been to Las Vegas. He attends clubs and goes out on a Friday to a local bar and club with carers and other adults with learning difficulties.

He is a wonderful, inspirational young man who is loved by everyone he meets, he hasn't a harmful bone in his body and would do anything for anyone. This does mean he is a vulnerable young adult, but he's well loved and we look out for him. The first nine months were tough on my parents but the rewards have all been worth every second.