



Erb's Palsy Group
024 7641 3293

Erb's Blerb 123

Magazine of the Erb's Palsy Group Summer Issue 2023

Hello everybody,

welcome to our late summer newsletter

As usual we have a packed issue for you – with a lot of interesting articles for you to read.

As this issue reaches you, we are finalising everything for our **Celebratory Anniversary Ball**, I can hardly believe the Charity is celebrating it's **30th Anniversary** – time really does fly when you are having fun!

If you are joining us at our ball- it will be lovely to see you there, if not then hopefully we will see you at our 2024 Fun Day, we are planning a fabulous event, with a wide range of fun activities for young and not so young.

As ever we have something for all ages and all abilities as well as a lovely selection of craft activities for those who enjoy more sedentary activities !

We hope to see you there!

Karen Hillyer

DADS SPEAK OUT

We have often printed letters and stories from Mums whose child has an Erb's Palsy, but not many Dads share their thoughts. We are delighted to feature some articles written by Dads in the group, we are very grateful to them for sharing their thoughts with us. If you would like to have your story in an issue please email us at info@erbspalsygroup.org.uk and we will be happy to print it.

NEW TRUSTEE

Those of you who are regulars on our Social Media platforms will probably know by now that we have a new Trustee – the lovely Stacey Prichard, mum to Mia and Sophia has joined the Board as our Fundraising Co-ordinator – Stacey has already raised a LOT of funds for us- you can read about some of her exploits later in this issue, but she is a whizz at coming up with ideas to raise money as well as Awareness for the Charity and she is already putting together Awareness packs for our Awareness Week in October. So if you want to raise Awareness and some funds – you can e mail her; stacey@erbspalsygroup.org.uk

BACK TO SCHOOL

Just a reminder that as we come towards the end of the summer holidays, when your child moves to a different class and teacher, you may want to offer them some information about the injury.

We have several leaflets available to e mail for Teaching staff.

Nursery & Primary, Middle and Upper and Secondary school leaflets – you can e mail info@erbspalsygroup.org.uk or any of the Trustees and we can send you the appropriate leaflet – just make sure you put which leaflet you are after in the subject line.



Donations

Many thanks go to **everyone** who has raised much needed funds for us recently. We are still trying hard to catch up with raising funds since lockdown, so every donation, large or small is much appreciated.

We would very much like to thank two of our families for their ongoing financial support – we very much appreciate it, our thanks this time include **June** and **Jim Gaw** and **Faiyaz** and **Sheda Bashir**

Ben Haines good friend of the Tripp family recently ran the Manchester Half Marathon on behalf of the Charity and raised a whopping **£623** - **Many thanks Ben - you are a star!**

Lynn Flynn mum of Roisin recently sent a significant donation, we **very much appreciate** it Lynn.

Stacey and **Hayden** recently climbed a mountain for the Charity - **well done** both of you – you can read more about their adventure and how much they raised later on in this issue!

Maxine Goodall recently ran in the Royal Sutton Fun Run on behalf of our charity and raised a brilliant **£345** – **well done Maxine**

We received a further **£280** plus Gift aid in memory of Henry B's grandfather **Simon Butler**, we are so grateful to Jan and the family for thinking of us at such a sad time.

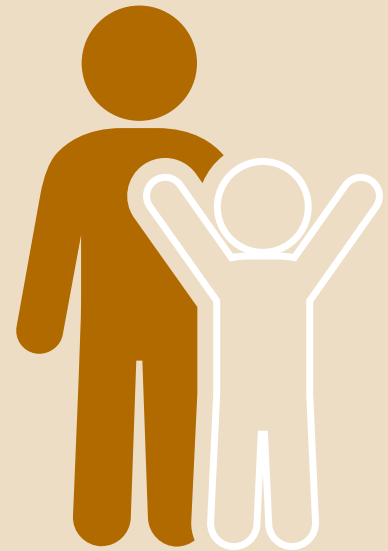
Ceri Richards Mum of Bobby recently nominated our Charity for a donation, her employers Nviron have a small tuck shop and every 6 months they donate the profits to a charity and this time it was us – a lovely donation of **£50 PLUS £12.50** in Gift Aid – **Thank You Ceri!**

Also another lovely donation on behalf of **Bobby** was from his **Nan Anne** who sent another **£75** donation to help us with our work – **Thank you Anne**, your wonderful support is very much appreciated.



What About The Dads?

Hi, I'd like to introduce myself to those who don't know me. My name is Gary Hillyer, I'm a Trustee of the Erb's Palsy Group CIO, husband to Karen Hillyer, and Dad to Gavin (right Erb's) and Mike. I thought it was about time I wrote an article for the Blerb, and the topic I chose is a Dad's perspective of an Erb's birth, and after. The article is based on my own experience and that of other Dads I've spoken with.



When a family's latest addition is a new baby there's a lot of fuss and congratulations, everyone wants to see Baby, and everything's rosy; Mum may have some issues following the birth – after all, she's done all the work to bring this little wonder into the world – so she deserves a little time to herself to get over the pain, exhaustion etc. Dad may have to be the 'hero' for a while and look after Junior and any siblings, all to the praise from family and friends.

BUT – what happens if the birth doesn't go to plan, and baby (maybe Mum too) is injured? The happy event suddenly takes a downturn and the atmosphere in the birthing room turns from bright expectation to a sense of foreboding as hospital staff react to the emergency unfolding. A Shoulder Dystocia is diagnosed; more staff and perhaps a doctor enter the room making the space so crowded that Mum and her birth partner – probably Dad – start to panic at the intense activity as Baby's condition is checked, and Mum is manoeuvred into different positions to make the delivery less traumatic.

So after a time Baby is delivered, battered, bruised and fighting for life; Mum is upset by all the manhandling by Midwives and the sense of panic still in the room, though this eases as everyone realises Baby is alive, and Baby is rushed off for tests – Apgar score and Moro reflex. Mum is tended to, and Dad is mostly ignored.

In my personal experience, I didn't realise that I had gone into shock at the brutality of Gavin's birth. My memories were of watching things happen but a feeling of detachment, like watching a video on TV. To cut a long story short, I didn't get over the birth, and the damage done to Gavin and Karen. I was eventually diagnosed with PTSD, and among other things I was retired from my job. The psychiatrist who diagnosed the PTSD identified the root cause as the actual birth; I was an experienced serving Firefighter and was used to taking charge in emergency situations, being the expert at the scene. But in this instance, although I wanted to jump in and help, I knew the situation was a medical emergency and I should let the experts (midwives) do their job; unfortunately they did a poor job resulting in two injured people. My brain had had to deal with conflicting choices, exacerbated by the emotions from watching things happen to my wife and child but having to hold back whilst others tried to deal with the emergency.

I wonder whether any other Dads had similar experiences, suffering mentally and emotionally from witnessing an Erb's birth. It would be good for others to write into the Blerb with their experiences. I look forward to reading those letters / articles.

Gary Hillyer.



What About The Dads?

We all hear about Mental Health; we all see it on the News. But do we really talk about it? Do us men really talk about it?

My name is Hayden, and my daughter Sophia was born in September 2020. I have a step-daughter but Sophia is my first born and the labour was as the Midwives called it 'text book' until it wasn't. Until my partner was rushed to theatre, emergency buttons pressed. I remember pacing up and down a room for what felt like eternity – not knowing what had happened, not knowing what was happening. Suddenly I had scrubs thrust in to my hands and I was told to change, quick.



Hearing screams from my partner Stacey from across the hall, not knowing if she or our baby were ok, or even if they were going to survive because the screams were so horrific. I entered Theatre my eyes searching for Stacey only to find a room full of so many faces, too many faces. I started counting them, I don't know why but I must have got to over 20 if not 30 before I could finally see Stacey on a bed. Her eyes rolling back in her head, I panicked, I'm losing her now too.

When Sophia was born, there was absolutely no sign of life, her tiny body grey and floppy. Stacey couldn't see. Thank god she couldn't see. I was unable to cut the cord and I felt cheated. I then watched as doctors and nurses performed CPR, attaching tubes to my baby. Was she alive? Was she going to survive?

Stacey kept asking where our baby was and was she ok. What else could I say other than everything will be ok. I didn't know that; I couldn't know that. Sophia was rushed away from us and for two hours we didn't know where our baby was, what was happening to her, was she even alive?

We hadn't held her let alone touched her. I felt confused, upset, stressed.

When we finally saw Sophia in her incubator with wires and tubes everywhere, it was heartbreaking, soul destroying. The next day when they finally explained that Sophia had sustained a birth injury leaving her with Erb's Palsy in her left arm, I felt angry, confused, shocked – how could this happen? How could she have been injured?



The first few months after Sophia was born, I just felt rage. I wanted someone to blame and I wanted someone to be held accountable. The hardest part of all of this looking back is that rage consumed me, I was so focused on being angry, rather than being a father. Every morning I would wake to see my beautiful daughter and I felt angry, hurt and guilty. Guilty because it is my responsibility to protect her. I felt there was more I could have done. Even though deep down I knew there wasn't any more that could have been done by either myself or Stacey.

But seeing Sophia every day was a constant reminder of her birth, the trauma, the fact she was injured and left with Erb's Palsy. I felt like I had let my baby down because I was so focused on being angry and being consumed with having someone held accountable. I was focused on something else and felt like I had been a bad dad.

I wanted to talk to Stacey about how I was feeling and what was going through my mind – but how could I? After everything she had been through both physically and emotionally how could I add more stress? I bottled up my feelings for a long period of time with them slowly eating away at me. I would have outbursts of anger, frustration, shouting and then being silent. Taking it out on the one I love and not handling any of my emotions in the right way.

Looking back over the last two years I should have sought professional help for how I was feeling. Perhaps if I had spoken to a professional, they could have helped me better understand my emotions, the anger, the guilt.

I have a beautiful, bright, smiley little girl who adores life and is so stubbornly strong, fierce and independent. All traits which will serve her well in life and with her Erb's Palsy. I look at her every day and although the emotions surrounding her birth will never likely go away, I look at her with pride and love and admiration of how much she has been through, continues to go through and her resilience and bravery.

I write this article in hope that if even one dad is reading this, that they know they are not alone. I stand with them and always will. We have to talk; we have to tell our partners when we are struggling or when we need extra support. It is ok for us to feel the trauma of our children's injury and it is ok for us to talk about it. How can we be strong for them if we are not strong for ourselves?

After Sophia was born Stacey was the first of us to start fundraising for the Charity, my step-daughter followed suit and then together we began fundraising further. More recently myself and Stacey climbed the North Lee Mountain in the Outer Hebrides to fundraise and raise awareness of the Charity. Although I live with my emotions surrounding Sophia's birth and injury every day – pouring my pain, anger and frustration into something meaningful such as fundraising has been a powerful way of not only giving back to the Charity who supported us, loved us and encouraged us but it has enabled me to focus my mind, remind me of what is important and is slowly helping me to let go of some of the anger. Even writing this article and just putting pen to paper has allowed me to pin-point and establish what my struggles are.

It's not easy to talk about our emotions, but finding a way to cope and move forward is essential.

Hayden



What About The Dads?

The day my youngest son Max (right Erb's) was born was very stressful, the labour room was full of medical professionals whilst I was in a mess due to all the drama that is happening around us.

We were never told that Max had Erb's when he was born, we had to learn about this condition after we sought legal advice in relation to the traumatic birth. I have always felt an element of guilt that I was such a mess that day as I didn't see the doctors' actions which caused his injury which I have been told would have been helpful to his legal claim.

Since Max was a baby, he has amazed me with how resilient he is and how he has been able to adapt to make sure he can do most things that kids his age can do.

With the help of the Erb's Palsy Group charity we have found that we are not alone and that there is a great community.

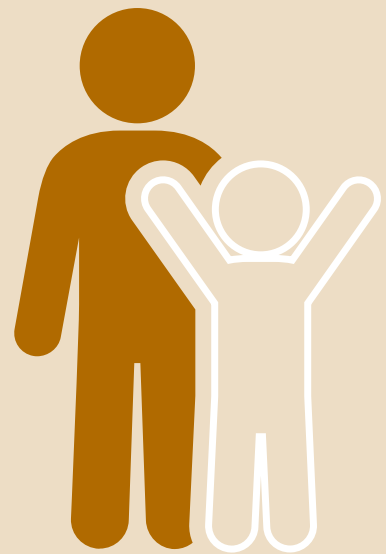
Unfortunately, Max has a grade IV injury so this means he will never get full functionality in his arm, but I am sure with the help and support of family and friends he will be able to achieve everything he wishes.

I have suffered badly with anxiety all of my life and sadly since his birth it has become worse. I have managed to control this by using meditation and medication, my main take away from this is to make sure you reach out to people as there are always people who are willing to help.

My best advice to parents who have an Erb'ling is this - although this is an injury that can be avoided, this has made your child and family very special. Make sure that your child is aware of this as they should be proud to say that they are a warrior.

Although I am not on Facebook if anyone would like help and advice, especially fellow Dads as I know it can be hard to reach out, please contact one of the trustees who would be able to pass your details to me and we can have a chat any time!

Steve



BOOKING FORM FOR 2024 FUN DAY

SATURDAY JUNE 29th 11AM – 4.00PM

Heart of England Conference & Events Centre, Meriden Rd, Fillongley, Coventry CV7 8DX

NAME

ADDRESS

POST CODE

NAMES OF ALL ADULTS ATTENDING

****Have you enclosed your entry fees? Adults £10****

Remember – Adults and Children with Erb's are FREE

PLEASE LIST THE NAMES AND AGES OF ALL CHILDREN ATTENDING

Ages are required as this information is vital for insurance purposes.

Name

Age

Please list here any special dietary requirements:

Do you give permission for any photographs taken at the Fun Day to be used in the newsletter or on the EPG website?

YES

NO

Do you require acknowledgement of your form?

(Please enclosed a stamped addressed envelope)

All cheques or postal orders should be made payable to the ERB'S PALSY GROUP or you can pay via our 'Donate' button at www.erbspalsygroup.co.uk stating payment is for this booking.

Please send completed booking forms with your payment to:
KAREN HILLYER, 60 ANCHORWAY ROAD, COVENTRY CV3 6JJ.

To arrive **NO LATER THAN JUNE 1st 2024**

Dudley...



Dudley our travelling bear is back on his travels and can't wait to go exploring.

Dudley our travelling awareness bear has been a very good bear who has stayed at home for the past couple of years but now he's raring to get back out and meet our members.

Dudley can go anywhere and everywhere. Maybe you can take him to school for show and tell, or on holiday. I know he loves to build sand castles on the beach, or ride on a train.

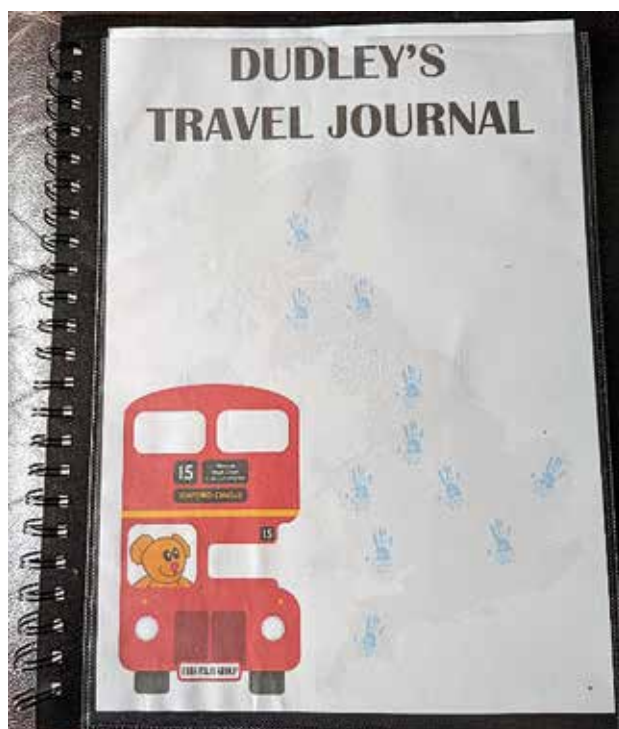
Dudley also likes to keep a diary of all the things he has done and places he has been to with his friends.

Dudley's diary will also feature in the Blerb so remember to take lots of photos of him along the way and remember to fill in his diary.

If you would like a visit from Dudley, please email me at

jackie@erbspalsygroup.org.uk

I'm sure there will be a waiting list of visitors so please be patient Dudley will arrive shortly x





Activities will include:

- Climbing Wall – closed toe footwear required
- Fencing – please bring a long sleeved top!
- Laser Tag
- Bhangra Dancing
- Drumming
- Gong Bath
- Henna
- Velcro Olympics
- Whack-A-Mole and other Side Shows
- Bucking Bronco
- Play Bus and Bouncy Castle
- Crafts
- Face Painter



Saturday 29th June 2024
11am-4pm

Heart of England Conference and Events Centre,
Meriden Rd, Fillongley, Coventry CV7 8DX



£10 per adult

Children and Adults
with Erb's - FREE

It's time to start planning your fun day out!

2022 saw our last fun day held in Harrogate so 2024 is moving to the Midlands and a fabulous venue we have used several times before – it has a great outdoor space for our use with toilet facilities located adjacent to the field.

Whilst seating will be provided, we encourage you to bring along your own picnic blankets (and chairs if you prefer).

Grab bag lunches will be provided to include a sandwich, soft drink, bag of crisps, piece of fruit and a treat. A mobile café selling soft and hot drinks and a small selection of snacks will be available on the day.

Unfortunately we have had to increase our adult attendance fee to £10 but all children and adults with Erb's go free and we do feel this is still a very reasonable and competitive cost for the activities on offer for a day.

We hope you can join us – please book your place by completing the booking form in this edition of the Blerb

We look forward to welcoming you to our fun filled day!



I have no idea how to start this,
but with a

hello...

...to my fellow erbians and non-erbians, I am Sam, or Samuel as my parents named me on the day I arrived into the world. I'm 19 years old and about to enter my second year at The University of Salford. This is an article about my first year at university living with Erb's Palsy, and some may say superpower, so I'll try and be funny even though some would say I am not... but let's see where this goes! Oh, and before you start drifting off to sleep and saying you are "resting your eyes", I could waffle, some bits may not make sense, so bear in mind that as I get lost in my world.

Anyway, without further ado, let's attempt this and see how this article goes...

Moving In Day Sept 2022

Some of you may know me and some of you may not so let me introduce myself, I'm Samuel Dewdney or Sam, as my friends call me and I have finished my first year at the University of Salford! It went incredibly quickly, I'm studying a Bachelor's Honour Degree in Television and Radio Production or as my fellow course mates would say, BARTAP! I have to study from September to May, for three years, two semesters each 13 weeks long, each week consists of one day off during the week, 4 days of lectures and seminars online and in person. I have my lectures away from the campus at Media city next to ITV and BBC studios buildings.

I'll structure this as a timeline from way back at the start of the year in 2022.

Lets set the scene, I am in college around about November 2021 picking my university courses and where to study and deciding etc., but that's a bit too far back; fast-forward to March 2022, I've submitted all my details to UCAS by the January deadline and have decided on which course I wish to take, when I have to do the all-important and extremely exciting (not!) student finance. (This is



where the timeline begins) So all details filled in saying who I am, and showing the government that I am, who I say I am. Me being me, and not listening to anyone ,didn't realise there was a section for people with disabilities called the "Disability Student Allowance" I know it sounds boring. Still, once you fill in all of the information there stating that your disabilities and giving them proof it gets interesting... after emailing back and forth with help from my mum , I had an online meeting with someone who works with the student finance team, She went thoroughly through everything she felt I would need to help with my studies.

I will not sugarcoat it and say how amazing it is; yes, you get free property, but the quality of some was not. On the other hand... 1 of the items I got is by far the best item I got was a chair specially made for me as it was tailored and fitted to my needs, I have to add the day the chair arrived the poor delivery guy had to climb a lot of stairs as I was on the 6th floor and the lift had broken. I also received a fancy printer with ink and paper [I also get a budget for extra ink and paper supplies] which meant that I didn't need to go down to the library every time I wanted to print something out, and I could also print without getting out of bed! Safe to say that the printer got good use throughout the year as I used it a lot. Another of the items I got was a keyboard which I could attach to my laptop, sadly keyboard was unusable due to the keys being so big for every letter and I was unable to adapt to it. That is also

the same with the mouse, it was very confusing to use, and because I have small hands, it wasn't fun to use. With this being said, I didn't use them, but as my mum would say, it's always good to have a spare. Some of the equipment that I got was split between suppliers, so I got the chair delivered to my student accommodation but somehow had to get the printer amongst everything else I was taking into a small car (Ford Fiesta).

Luckily, it all got up to Salford, Manchester in 1 piece in September.

The attention now jumps to September; I said so long farewell to my friends back home, 2 of my mates from college also achieved places at Salford, with 1 of them being on my course (not the same classes unfortunately) and then some of my other friends all studying in the dreaded south of the UK. No offence to the audience/readers reading this, but the North is better than the South.

I said goodbye to my family with a fun day out at Shuttleworth.

With the car packed, a long 3-hour car journey without cruise control we arrived and let the unpacking commence and said hello to my new flat on the university campus. I moved in with no hassle; the chair arrived along with other equipment, but some of it I disapproved of, as when I got it, it made me feel like I wasn't "normal"; so I never used it.

Luckily, I got two weeks' worth of shopping paid for by my parents, which was amazing (more money to spend on going out!), but when the parents left, I had mixed emotions, we were all fine until someone (MUM!) set everyone off crying. I was homesick during the first week in my shared kitchen flat; I wanted to return home and drop out of the course without attending the welcome assembly! Looking back on it now, I ruined freshers week for myself... but not the nights out!

Nights-out in Manchester deserve their very own paragraph! This was 1 of the only things that kept me going. I won't dwell on my feelings, but the city's nightlife is class! I went out every other night to experience the different clubs in Manchester, and 1 of the highlights was going to a foam party! One massive foam cannon booming out foam to music! There was also a party dedicated to the legendary band ABBA! This was the only music throughout the night, and it was class! The order of the night out was having a couple of drinks in the flat, then meeting up and going to the legendary pub chain I call Heave, Wetherspoons! As a young adult, I definitely "drank responsibly," my mum is laughing in the background as I write this !!!! Where I am from in Bedfordshire, there is nothing to do when you want to go out for the night as there are no busses after 8pm into Bedford where all the best pubs are. Of course, I was very safe when drinking and going out... (Just the words my parents want to hear, hehe) Anyway, back to university, freshers' week ended, and my university year officially started.

The day came to attend my first-ever university meeting/assembly. So I got the dreadful stagecoach bus number 50

service, which is even more unreliable than the government. I am telling you because I got the bus to MediaCityUK to study for the whole university year! Oh, and if you didn't know what MediaCityUK is, well, I describe it as "The Hollywood of television in the UK." This place has television studios, broadcast studios, offices, radio studios and the infamous Blue Peter Garden. You also see many famous people here, and they make shows like Match of The Day, Blue Peter, Children in Need, Comic Relief, Who Wants to be a Millionaire, Britain's got talent, countdown and many more television shows! So I was a tad excited but also nervous to start university. Even turning up to MediaCityUK every day was so surreal and fantastic as you never know whom you could bump into or what to do when you get there.

I had welcome to the course assembly with everyone on the course attending in the studio theatre. It was saying who the lecturers are, what group you are in, and what subject you will be doing first, video production or radio production. At this point, I knew exactly what I wanted to do: video production. But unfortunately, I was doing radio production first in semester 1, which I wasn't fussed about, but in the end, there were things I could improve on. For example, I was a bit too ambitious with my assessment as for it I had to interview someone on a relevant topic; I chose to interview the mayor of Greater Manchester, he still hasn't got back to me. One thing I enjoyed about the semester was that I got into the university's state-of-the-art BBC equivalent Radio Studio! The University has four radio studios similar to those in the BBC buildings. I went in there quite a few times but not as much as I would like to; luckily, I can book it out right the way through until I graduate in 2025. One of my assessments was to produce our very own radio programme. The date was set when we all had to be in the studio and present it live to the world, but it clashed with something... I had an appointment for my upcoming surgery that day!

During the pandemic, I was due to have surgery on my right wrist, sadly this got postponed. It was to extend my tendon transfer and tighten it up so my wrist would hopefully stop bending down and keep it straight. It finally happened on the 21st of November, 2022. When I came out of the surgery, I was so high on anaesthetic that I came out and had some tablets; because I was so high, I presumed the nurse said I was given cocaine! I was (sadly) given codeine. I told everyone I knew that I was on cocaine and that it was legal until a couple of days later, I got told it was codeine. I was very embarrassed. I was discharged the next day and was casted for two weeks; I only went home for a week as I missed Manchester too much, so I was doing everything with only one hand effectively; it was pretty challenging, but I was very proud of myself doing it, but I didn't go to any lectures as I found that too tricky unfortunately. The cast did start to fall off halfway through the second week, and if I let gravity take my arm, it would slowly fall off, and I could even turn my cast around in circles. It even fell out at one point, which was scary, but I got it back on. The day came to take the cast off in Leeds General Hospital, and I was so relieved I could do the usual stuff again! I also got given a splint and had exercises to do with it; it was on for 6-8 weeks, with check-ups in between. Also, within that period, I could cut my food up, which I have never been able to do without



a handed knife and fork, and I can also type much better on a laptop/computer. I met with Mr Bains who did my surgery, and he was a bit disappointed with it all; I am not, though, I think it was a little bit of a success, but it didn't do what I wanted it to do and that was for it to be straight, but there are small goals out of it so I guess it's a glass half full situation.

Jumping forward in a time machine or a DeLorean, January 2023 we are back to university. Now it is semester 2; I am starting video production; I am so excited to do this, and there are things I can take away from this module. One of the things is that my video production lecturer is my favourite lecturer, and we have a nice friendship. One thing I should not do is forget equipment, I forgot to book one

piece of equipment called a reflector, and my lecturer bullied me for it. He is someone I will look up to in the television industry and throughout my university journey. One of my assessments was to run from the shopping centre back to my student accommodation for a recording of a podcast I created with my friends. This assessment only got me a 2:1, which is impressive, and I was only two marks off of a first (this is why I wanted to do video production first); the second assessment isn't the greatest but was much more fun. For the second assessment, I did a documentary on the Blue Peter Garden, and I was the presenter; this was fun to do, and people thought I was with the BBC, which was pretty humorous, but I did fail this assessment. Still, regardless of the outcome, I did pass year one and am now off into year 2 in September!

On set at the Blue Peter Garden at Media City

Well, the year is over; I have completed year 1 of university; it went so exceptionally quickly that I don't get where the time has gone! There is a lot I would change if I could do this all again. I would go out, get drunk, go to more clubs, and I don't think I could've done it without my family and friends. I was so homesick at the start and wanted to go home straight away, but now, in the end, I didn't want to leave Manchester. If they weren't there for me and telling me to keep going, I don't know what my life would've been like, but I know for a fact it would've been much worse than it is now, so thank you for telling me to keep going and for pushing me to keep on going over the first semester.

Tip for students starting university: Don't be scared, don't be nervous, and enjoy every second you have there, as it will go so quickly, and you won't know what has hit you. Do eat food; you will need all the nutrition you can get, as studying is hard work and takes a lot of energy. Oh, and go out and have fun with your friends. You only live once! Go drinking, go clubbing, join societies and remember your parents don't know what you are doing and can't keep control of you!



Moving Out Day June 2023

Tip for parents if their child is starting university: Everything will be ok; let them fly the nest; they are not your baby anymore; let them live their life, let them do what they want to do in life and check up on them even if they say they are fine at least once a week as they are still your child even if they are grown up. Oh, and there is also one less person in the house, don't forget...

That is my first year of university living with Erb's Palsy, and onto year 2, where university starts as my grades go towards my degree. If I do this again next year, hopefully, it won't be as long, and I would've done stuff I didn't get to do the year just gone.

This is Samuel Dewdney signing off.



Hello again!

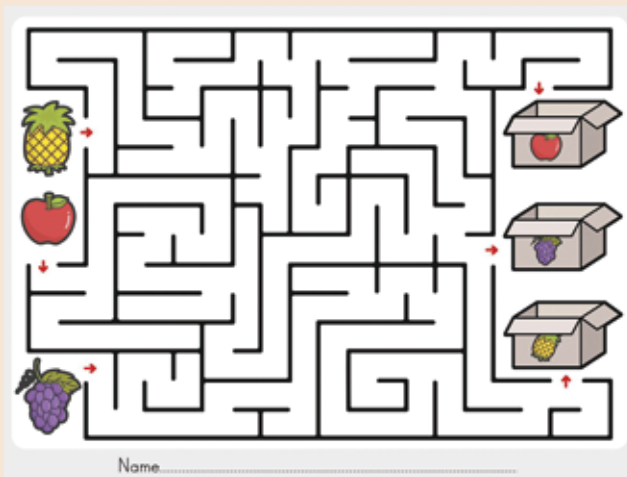


Hi everyone!

How are you? I hope you have been having lots of fun and adventures since my last Herbie page? I have been so busy. I have been cycling lots, and meeting up with friends and family. I love the sunny days!!

Fruit Maze:

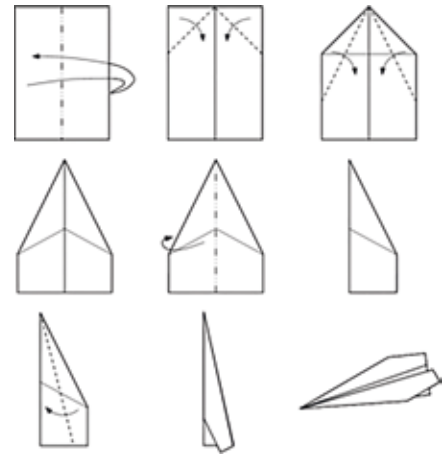
Can you find your way through this crazy maze to pack the fruit into the correct box?



Paper Aeroplane Races

Have a go at making a paper aeroplane using the instructions below. Don't forget you can colour and decorate your aeroplanes any way you like! If a friend makes one too you can race them against each other to see whose can fly the furthest. I would LOVE to see your creations and hear how you got on. Please feel free to email me a photo at info@erbspalsygroup.org.uk and I will include your photo in the next Blerb!

Good luck and happy flying!!



JOKE CORNER

I have some animal jokes for you to try out on your friends:

Why did the robber jump in the shower?

What instrument does a skeleton play?

What did the farmer call the cow who had no milk?

Why is the obtuse triangle always frustrated?

He wanted a clean get away!

A trom-bone!

An udder failure

Because it isn't right!

Ha Ha Ha
Ha Ha Ha
Ha Ha Ha





Will you join us to help fundraise for The Erb's Palsy Group this summer?

Ison Harrison Solicitors have teamed up with the Erb's Palsy Group to shine a light on fundraising and as a show of gratitude we will be running a competition over the coming months.

Anyone who raises funds between 10th July and 31st October will be entered into a prize draw for the chance to win a fantastic Merlin Entertainment Experience worth £300!

All you need to do is get your thinking caps on, decide on a fundraising idea, have some fun, raise some money and let Ison Harrison know what you've done!



Think of a fun fundraising idea & get as many people as you can involved to spread the word!

Get a plan of action together – when will you start / finish fundraising? What will you do to raise money? How much are you aiming to raise?

Set up a Just Giving page to keep track of donations or simply donate the total amount raised directly on the Erb's Palsy Group website.

Take lots of photos throughout your fundraising journey and send them in to Ison Harrison via this special fundraising page on their website: isonharrison.co.uk/erbs-palsy-group-big-summer-fundraiser



Once you've completed your fundraising, tell Ison Harrison all about your efforts & how much you raised so we can promote how wonderful you are & enter you into the prize draw!

Keep visiting isonharrison.co.uk/epg-fundraiser regularly to submit your fundraising updates and see how much money has been raised!

Will you be one of our Top 5 Fundraisers?

Every person that takes part in The Big Summer Fundraiser will automatically be entered into a prize draw to win a fantastic Merlin Entertainment Experience worth £300!

Remember: You must visit the Ison Harrison web page to submit the form and tell us about your fundraising efforts, or we can't enter you into the prize draw!



The Prize

Merlin Entertainments power some of the most magical and memorable experiences across the world, with UK attractions including Chessington World of Adventures, Alton Towers Thorpe Park and Madame Tussauds (plus many, many more to choose from!)

You will receive a voucher for £300 which you can use at any Merlin Entertainment experience!

Top Tips

Set a goal, share your story, track your progress, share your success!

1. Make it personal - Share your story and include pictures – people engage more when they know what the charity means to you.
2. Set yourself a realistic goal and track your progress.
3. Share your goal and progress on a regular basis
4. Remember to say "Thank you"



Visit isonharrison.co.uk/epg-fundraiser for fundraising ideas and terms and conditions.

If you need support with your fundraising you can contact Stacey at stacey@erbspalsygroup.org.uk



Call Ison Harrison Solicitors today on

0113 284 5000

or email clinneg@isonharrison.co.uk

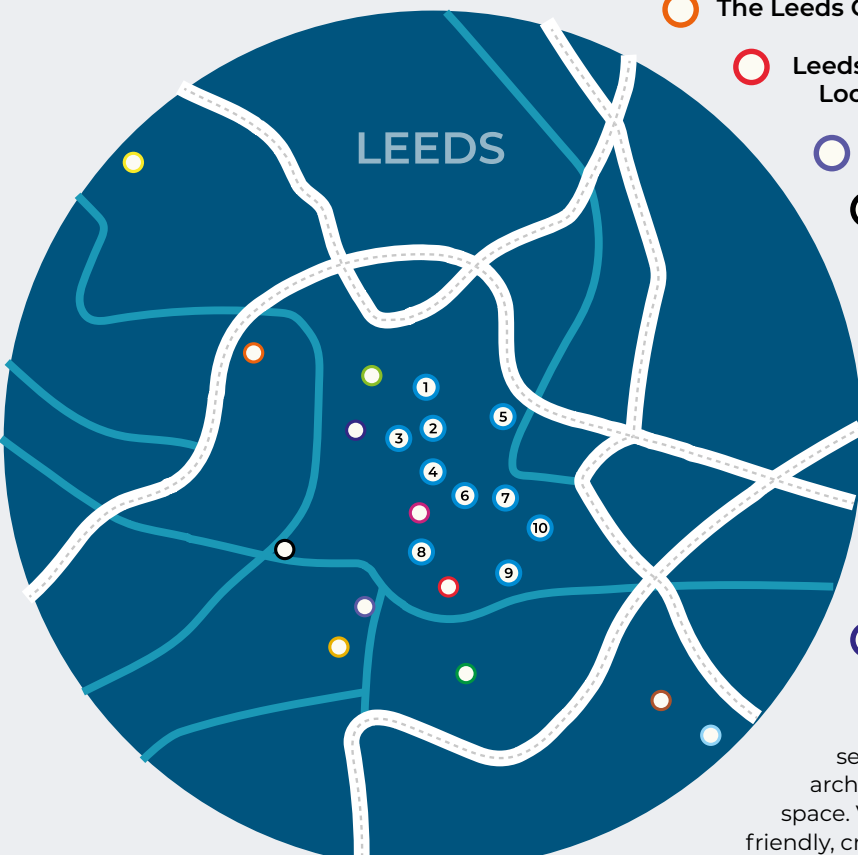









Things to do in Leeds


In anticipation of the Celebratory Ball taking place on Saturday 30th September 2023 at the Leeds Marriott Hotel, we felt it would be a good idea to give you a taste of what our great city has to offer.

The best thing about Leeds city centre is it's beautifully compact, so you can park up or hop off the train and easily spend a few hours exploring everything from tourist attractions and shops to places to eat.

Whether you're in Leeds attending the Ball or at the Leeds General Infirmary for an appointment, we hope you get the opportunity to do some exploring.



-  **The Leeds General Infirmary (LGI)**
-  **Leeds Marriott Hotel – Location of the Ball**
-  **Leeds Train Station**
-  **Ison Harrison Solicitors (Duke House)**
-  **Leeds City Museum**
Free admission - See the famous Leeds tiger and get close to amazing animals, uncover buried archaeological treasures and discover the incredible story of Leeds history.
-  **Leeds Art Gallery**
Free admission - Explore the permanent collection and temporary exhibitions set amongst the stunning architecture of this unique gallery space. Visit Artspace a relaxed, family friendly, creative space in the heart of the gallery.
-  **Henry Moore Institute**
Free admission - With galleries, an extensive sculpture research library and archive of sculptors papers, visit the Henry Moore Institute to experience, study and enjoy sculpture from around the world.





Leeds Library – Public Library

Leeds Owl Trail

You can download a map for free or purchase one for £1 from The Leeds Visitors Centre and Art Gallery shop. You'll have to keep your eyes wide open as some owls are not in the most obvious of places and some are at the top of some very tall buildings.

Leeds Canal

Download a free waterfront trail map from www.visitleeds.co.uk and enjoy a walk along the canal.

Water Taxi

Enjoy a scenic round trip on a yellow water taxi. To pinpoint the boats' location visit www.taxitrak.co.uk

The water taxis run every 15 minutes from either stop. £2 per person, per journey.

Children under 5 can ride for FREE and dogs are welcome too!

Royal Armouries

Free Admission. Explore the UK's national collection of arms and armour, featuring over 4,500 objects across 5 floors. Discover how arms and armour have shaped society, art, and culture throughout history.



Kirkstall Abbey (*Off map, 3.2 miles from City Centre*)

One of the best preserved Cistercian monasteries in the country, founded over 800 years ago. Please see the website for admission prices.

Shopping

- | | | | |
|-------------------|-----------------|--------------------|-----------------|
| 1 Merrion Centre | 4 The Core | 7 Cross Arcade | 8 Trinity |
| 2 St Johns Centre | 5 Grande Arcade | 7 Victoria Quarter | 9 Corn Exchange |
| 3 The Light | 6 Queens Arcade | 7 Victoria Gate | 10 Leeds Market |



Call Ison Harrison Solicitors today on

0113 284 5000

or email clinneg@isonharrison.co.uk



Our North Lee

Where do I start? We started fundraising for the Erb's Palsy Group a month after our Daughter was born- it quickly felt like a purpose to me and is something that has helped me tremendously with my emotional struggles surrounding Sophia's birth. It's given me a great comfort to be able to give back in any way possible to a charity who has stood by us and supported us in more ways than one.

Last year we quickly made the decision that we would be climbing the North Lee Mountain in the Outer Hebrides for our next fundraiser. We set ourselves a target of £300 and with the support of our family and friends we managed to raise an amazing £650!! Now to say we are just two average Joes who have never done anything like this is an understatement. Although the North Lee Mountain wasn't quite Snowdon or Ben Nevis it was a 10 mile walk/climb reaching heights of 863ft. It takes around 4/5 hours to complete and we were thrilled to complete it in just over 4 hours- weather conditions leading up to our climb were not the best and we battled through boggy ground where we literally almost lost our boots and were knee deep in water- it was wet, muddy and most of all slippery and of course there was the odd slip and tumble. But together we did it and watching donations come through was a huge motivation. Every time we thought we were close to the top we'd look up and think what on earth were we thinking haha! But we'd stop, catch our breath and think of the charity and the families we were helping and we pushed forward quite literally.

2 years ago to the day of our climb we travelled to Leeds with our daughter Sophia for a final assessment as to whether they would go ahead with a Nerve Graft Surgery- the decision was made and the day after she went in for Surgery. 2 years later for us to be able to give back as we have been able, has been tremendous.

Fundraising isn't just rewarding or vitally important to the survival of charities but by doing so you spread awareness, you teach and you educate and you can make a difference.

Stacey

Mountain Climb



Jacob won a trip to
Alton Towers

with Ison Harrison
Solicitors for being an
Erb's Palsy hero.

This was a couple of years ago! but due to 2 surgeries since he won the tickets he has been unable to go. Well yesterday was finally Jacobs long awaited special day! We had a wonderful day and would like to thank Ison Harrison Solicitors for making it possible. Jenny, mum of Jacob - 13 years old - Left Erbs Palsy.



We'd like to urge any family to have a go at Ison Harrison competitions – the prizes are great and we had fun doing the entry and using the prize.

The Wood family

Achievements



Ellie, has right Erb's and has proved it won't stop her driving towards success as she has passed her driving test! Congratulations!!



Cody, after a rocky start with swimming Cody has pushed himself and has passed his first grade at the pool. You should be really proud of yourself Cody!



Steven is smashing down barriers and proving that his Erb's won't get in his way. He has been awarded a Headteachers award for the progress he is making with his handwriting. Well done Steven!



Dillon competed in a triathlon and did fantastic especially with the 50m swim Everyone is proud of you Dillon!



Coen has been awarded his 100m swimming award. You should be really proud of yourself Coen for all of your hard work!



Amelia took part in her 3rd national cheerleading competition in Manchester. Well done Amelia!



Aimee has shown how determined she is yet again by being awarded another medal for her footballing. Nothing stops her getting stuck in, keep it up!



Elana has won 3 gold medals for 100m freestyle, 100m backstroke and 200m individual medley. Keep making a splash, Elana!



Kate Snape is pursuing her dream career, she graduated from Newcastle University with a Bachelor of Science with Honours degree in Speech and Language Sciences and is currently working for Bart's Health NHS Trust in the Community Therapies Team as a Speech and Language Therapist in Primary and Secondary schools.



Awareness Week

16th October 2023

From new Trustee Stacey

Let's talk Awareness Week!!

For myself Fundraising and Awareness is hugely important - not only because I feel it saved me after Sophia was born but over the years I've seen first hand how important those funds truly are to a charity run solely on volunteers. So this October I challenge YOU to help us help you!!

Firstly we've had two successful launches thanks to the wonderful Jodie and Wayne on our LIMITED EDITION BLUE TEE'S. I always loved my white EPG Top and myself and my partner have worn them at every opportunity. Even just out doing the shopping. I quickly got in touch with Jodie who is so dedicated to helping support the charity and shares my enthusiasm. Herself and her partner have juggled the ordering, making and posting of these Limited Edition Tops all around work and family life and there are no amount of thank you's that will ever be enough to them both. As we go to print and I write this (mid July) we have made an outstanding profit from the first



two pre-orders of our tops of £320.77 - so a huge thank you to all members, family and friends who have ordered. We will be having only two more pre-orders prior to Awareness Week therefore keep your eyes peeled on our Facebook page!

These fantastic tops are now being worn all over the UK- from the Outer Hebrides to Ireland!! Let's paint the UK Blue for our Erb's Warriors. Let's make a change and let's make a difference and educate people of who we are and by doing so one day we may just implement change. Knowledge is power.

EPG Walks 10,000 steps per day in October.

Now let's just say I am not physically fit but challenging myself has always been beneficial to my Mental Health. I cannot stress enough how a small charity such as ourselves can only run on the support of its members and fundraisers such as these. This is a community fundraiser - which I hope and aim to get a minimum of 100 participants signed up!! You don't even have to leave your house you just get stepping in any which way possible.

By doing so YOU are raising awareness and YOU are raising those vital funds for us to support you!!! Anyone of any age can join so why not sign up your family and all get stepping together.

The whole process is so easy! To sign up and for more information please email me at stacey@erbspalsygroup.org.uk

If you would like an Awareness pack with pens, balloons, ideas for raising awareness, please don't hesitate to e mail me; stacey@erbspalsygroup.org.uk



 Join us 

**THROUGHOUT OCTOBER FOR
10K A DAY**

The aim of the game is SIMPLE!
All members, family and friends can join, so encourage as many people as possible.

There is a £5 joining fee for all participants to be paid via our Just Giving Page.

All participants will receive a Medal and Congratulatory Post Card at the end of the Month.

All Sponsorships MUST be made via our Just Giving Page.

Get Active and help raise vital Funds in this Community Fundraiser.

- TEAM EPG -





Young Achiever 2023

The last few years have seen the Trustees consider the achievements of our members shown on social media and in the Blerb, with a view to selecting an annual Achiever for our prestigious award. Winners the last few years have included Teigan Woollett, Elana Kotei, Bobby Richards.

This year has seen some wonderful achievements and it is always a difficult task to choose just one group member and we are always amazed at how our younger members continue to throw themselves in to their interests and hobbies, having fun along the way whilst showing their determination to succeed.

We are delighted to announce that our Young Achiever Winners of 2023 is Jacob Wood.

**CONGRATULATIONS
JACOB.**

**ENJOY YOUR
AMAZON
GIFT VOUCHER!**



If you would like your child considered for this prestigious award, don't forget to post their achievements on our Facebook page or send them in for inclusion in the Blerb.

WELL DONE JACOB!



Despite 3 surgeries in recent years, 13-year-old Jacob was recently awarded Coaches Achievement of the Year.

Jacob started playing football aged 4 and has played for his team, Marshalls Rosemount, for 10 years now with only short breaks when undergoing surgery. We were told that he improves with every game.

We also understand from several Facebook posts that he has a positive attitude to everything he undertakes and always aims to improve himself.

Adult Disability Payment replacing PIP in Scotland

In the last issue of the Blerb there was an article about Personal Independence Payment (PIP).

One of our members in Scotland has contacted us to say that PIP is no longer available to new claimants in Scotland. Instead, it has been replaced by Adult Disability Payment (ADP). ADP is administered by Social Security Scotland whereas PIP is administered by the Department of Work and Pensions (DWP) as mentioned in the PIP article.

All the general advice given in the PIP article is relevant to ADP but there are different details for applying for the benefit.

You can find details of ADP on the **mygov.scot** website (<https://www.mygov.scot/browse/benefits/adult-disability-payment>)

You can also find a lot of useful information about ADP on the Citizens Advice Scotland website

(<https://www.citizensadvice.org.uk/scotland/benefits/sick-or-disabled-people-and-carers/adult-disability-payment-s/adult-disability-payment/adult-disability-payment-s/>)

Or just go to <https://www.citizensadvice.org.uk/scotland> and search for **Adult Disability Payment**.

PAYMENT RATES

The current payment rates for ADP are:

| Daily living component | Weekly amount |
|------------------------|---------------|
| Standard rate | £68.10 |
| Enhanced rate | £101.75 |

| Mobility component | Weekly amount |
|--------------------|---------------|
| Standard rate | £26.90 |
| Enhanced rate | £71.00 |

Like PIP, ADP is not means tested.

How to apply for ADP

You can apply:

- **online** - by completing an application form on <https://www.mygov.scot/adult-disability-payment/how-to-apply>
- **Phone and paper**

To apply by phone and paper:

Phone Social Security Scotland free on **0800 182 2222** (8am to 6pm, Monday to Friday) to start an application.

Give your details so they can complete part 1 of the application for you over the phone.

Social Security Scotland will send you a paper application form and a return envelope.

Complete and return the form within 8 weeks - you can ask for more time if you need it.

Getting help with the application

Our member in Scotland says it may be better to ask for a paper copy of the application form and contact your local Citizens Advice Bureau for assistance in completing the form. The paper form is 96 pages long and the online application is similar.

Citizens Advice have experience in completing the forms and help clients with them on a regular basis.

Child Disability Payment

Adult Disability Payment is for those aged between 16 and State pension age. For those under 16 the relevant benefit (in Scotland) is Child Disability Payment (CDP). You can find out about CDP and how to apply for your child on the Citizens Advice and mygov.scot websites. CDP is the equivalent benefit for Child DLA.

Citizens Advice

<https://www.citizensadvice.org.uk/scotland/benefits/sick-or-disabled-people-and-carers/child-disability-payment-s/child-disability-payment-s/child-disability-payment-s/>

Or go to <https://www.citizensadvice.org.uk/scotland> and search for Child Disability Payment.

Mygov.scot

(<https://www.mygov.scot/child-disability-payment>)

Again, assistance with applying for CDP can be provided by your local Citizens Advice Bureau.

Jim Gaw



I'm Josh...

...I'm 15 years old and I was born with a right Erb's Palsy birth injury.

I have been playing brass instruments since I was 7 years old in year 3. I started off with a baritone, which I really enjoyed, then I moved onto a trombone and in the past 18 months I've played a bass trombone which is a bit trickier. I have weekly 1 to 1 lessons for this at school. Playing an instrument is great physio for me, and something I love!

In early 2021 during the Pandemic I joined Army Cadets, I've loved learning new things and the social side of it.

In 2022 I joined my local Salvation Army brass band. We do a lot of events and I play with people of different skill levels and instruments.

I've always been interested in the Army and when I found out there was an Army Cadet Band nearby, I just had to join that one too! My only issue was that the instrument I was using was on loan through my school music service, which was only meant for use in school or at home. Buying a new or used trombone wasn't something we could afford.

My mum told me about the Tim Dyde Fund, with the Erb's Palsy Group, so I researched this and began to apply. While I awaited the outcome I made some paracord keyrings and sold them amongst friends, family, cadets and Salvation Army members. I'd managed to raise 1/3 of the cost. I was so lucky to have been awarded the funds towards my instrument. In January I received my shiny new Bass Trombone in a lightweight carry case, ideal for me to carry.

My new instrument has allowed me to join the Army band and in late July I am travelling to London with the cadet band to a 'job' at The Royal Chelsea Hospital for a week. I cannot wait!! This also means I will pass off some of my music qualifications with them.

Having my own instrument means I don't need to worry about being without when I leave school next year and can continue driving my mum crazy

One day though, I'd love to be part of a competition band!



THE TIM DYDE FUND FOR GIFTED INDIVIDUALS

It has been 8 years since we established the Tim Dyde Fund for Gifted Individuals. For those new members who are not familiar with the background, this was set up in 2015 following the very sudden and sad death of our dear friend and supporter Tim Dyde in the Autumn of 2014.

Tim was a highly respected clinical negligence lawyer with Tozers solicitors and he acted for many families and supported the Group from the early days right up until he died, a period of over 20 years. He knew many of the members and supporters on a personal level and was a compassionate man with a great sense of humour. Following Tim's death, we received a large number of donations from group members, his family, friends and colleagues and we thought it fitting to use these funds to establish a memorial to Tim and his work, to recognise the immeasurable support that he gave to the group over the years.

Tim was very enthusiastic about sport and music and with that in mind the fund was set up to provide financial assistance to gifted or talented individuals with Erb's Palsy to help them along the road to achieving their sporting, artistic or musical aims. The pursuit of such aims requires both dedication but also financial commitment and this can often prove to be a barrier to success. Travelling around the UK and even into Europe to participate in competitions to gain experience and achieve the necessary accreditation or classification, comes with a hefty price tag. We wanted very much to support those deserving young people, and hopefully see many more pioneering individuals like Joe Hughes in the future.

Since the fund was set up 8 years ago we have made several grants and awarded over £4,000 to group members. You will have read about these grants in past editions of the Blerb, most recently we made a grant to Josh to enable him to purchase a Trombone (see Left). Other previous grants include payments to assist with:

- Gripping Aids to assist with gym work out
- Musical instruments and accessories
- Mountain bike competition entry fees
- Golf competition fees and accommodation
- European orchestra competition fees
- Sports Tour
- Video equipment

It has been fabulous to support these individuals over the years but with funds dwindling we naturally thought we would have to close the fund soon. However I am delighted to confirm that we have received a further donation from Tozers Solicitors and also very kind permission from Tim's family, who were really touched both to hear about all the deserving recipients and that we were keen to continue with the fund.

The application form and guidelines are on the website. But in a nutshell the fund is available upon successful application to those aged between 12 years – 25 years and who have been recognised as progressing in or having a talent in sports, the arts or music. All we ask is that the applicant demonstrates their own efforts to contribute or raise funds to show a level of commitment, and if successful with their application to promote the Erb's Palsy Group.

So please do apply.

With thanks to Tim's family and Tozers solicitors.



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information

We have a wide range of fact sheets and leaflets available – please check the website for full details www.erbspalsygroup.org.uk all of our leaflets can now be e mailed to you for ease of sending. All requests should be sent to Karen Hillyer (details as above)

In addition to these fact sheets we have a wide range of Information booklets available to post to members or health care professionals. These include the following;

- **Erb's Palsy, A comprehensive guide for professionals and parents on the prognosis, treatment and support of Erb's Palsy**
- **Care of a baby with Erb's Palsy**
- **Rights in the workplace and education – a guide to your rights under the Equality Act 2010**
- **All About Me book – a booklet for you and your child to complete for use in school and other external settings**

These can all be obtained by contacting Karen Hillyer.

Bye for now!
x

