



Erb's Palsy Group
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Erb's Blerb 121

Magazine of the Erb's Palsy Group Winter Issue 2023

Hello and welcome,
to the first newsletter of 2023.

How quickly time is flying past these years. The Trustees are delighted to be celebrating 30 years of the Erb's Palsy group being a registered Charity, and are delighted to celebrate our **30th Anniversary** with a Ball to be held at the end of September in Leeds.

You will find details of this event further on in the newsletter – we last held such an event for our 25th Anniversary and it was so well attended by members and their families and we received so many requests for another, we decided what better way to celebrate this wonderful milestone.

We have lots of excellent articles and reports in this edition. We hope you will enjoy them, but we are always keen to have YOUR thoughts and experiences, so get those fingers to the keyboard and let us know what is important to you and your family!

Items for inclusion can be e mailed to: info@erbspalsygroup.org.uk

Karen Hillyer

MOVING HOUSE ??????

If you are moving house and wish to continue receiving your newsletter through the post, **PLEASE** can you message us and let us know your change of address? It costs well over £2.00 to print and post your newsletter to you and if it's being thrown away by the new resident at your old address, it is literally a waste of funds - so please let us know if you are on the move!

We previously were able to e mail a copy of the Blerb to members, however we had literally hundreds of undeliverable messages and the cost of sending e mail via a delivery service was prohibitive so we had to stop sending electronically.

If you prefer NOT to have a paper copy sent- you can check out our latest issue online at our website
www.erbspalsygroup.org.uk



SUBSCRIPTIONS & DONATIONS



We would like to extend our Thanks to all the families who made donations and paid subscriptions recently. Those funds are invaluable for helping keep the Charity running and being able to support families and members affected by the injury.

We are still trying hard to recover from the two years fundraising opportunities we lost during lockdown and our funds are extremely low currently. So if you are a whizz kid at fundraising, or have a brilliant idea of how to help us make money, or are in a position to nominate our Charity for sponsorship or a donation from your employer, we'd love to hear from you!

All ideas are discussed and considered thoroughly by the Trustees, so please let us know if you have any thoughts. You can e mail info@erbspalsygroup.org.uk or amy@erbspalsygroup.org.uk.

Thanks in advance!



Donations

Many thanks to our members who asked their relatives and friends to make donations to the Charity instead of receiving Christmas presents. Some have been anonymous and some not, but we **THANK YOU ALL**.

Higgs LLP in Brierley Hill, West Midlands very kindly donated **£500** towards us after we were nominated by an anonymous supporter – **Thank you who ever you are!**

Mairead and **Declan** – thank you and please thank Laura for her donation.

Sharon Corrigan – please say thanks again to your lovely **Dad Dave** for his donation - he is very kind doing it every year.

Louise Cheshire – it was so kind of you to ask Victoria for a donation instead of a present - Karen spoke with her on the phone and thoroughly enjoyed their chat - please let Victoria know.

The Bissex Family, The Bashar Family, Blackford Family, McDermott Family,

Karen Forster-Pearce and her **Dad Bernard Gilhespy** sent a lovely donation of **£60** from their collection of small change - thank you both SO much for your constant support of the Charity.

Shaku-Ntala Limbu and **family**- thank you so much for your kind donation and LOVELY card and words.

Ges Quarmby, thanks to the Dufton Coffee Group for their **£50** donation.

Hannahs Kitchen in Coventry sent a lovely donation of **£153** to the Charity. Sadly we have no information about who nominated us for this lovely donation, but we are VERY grateful to them.

Ecclesiastical Insurance sent a **£200** employee nominated donation, thanks to **Paul Brooker** for organising this for us.

St Thomas Church in Marske, Redcar- once again we were very lucky to receive a donation of **£25** from them – we do appreciate it, especially with so many other demands on their finances.

A wonderful surprise donation of **£240** came from **Charleigh Breslin's** parents **Dawn** and **Charles**, they sent us **£240** which they raised by raffling two Easter baskets off – thank you so much.

Thank you to the family of **Brian Hughes Jones** from Wales who kindly nominated us to receive donations in lieu of flowers at his funeral, Marie Jones sent a donation of **£10** – thank you for your kindness at this sad time.

The family of Errol Menzies of Sheffield also asked for donations to our organisation in lieu of flowers at his funeral, we received a total of **£116.22**. You are so kind to support us at such a sad time.



Harriet Frobisher (right Erb's) was Prestatyn and Meliden Town Council Mayors Consort to her mother Cllr Sharon Frobisher when she was Mayor from May 2021 to May 2022. During the limited events during the year because of coming out of the Covid Regulations, a total of **£310.74** has been donated to The Erb's Palsy Support Group from Cllr Sharon Frobisher's Mayor's Charity Fund. Out of 94 Civic Engagements attended by the Mayor, Harriet was able to attend 49 as The Mayor's Consort.



We were delighted to receive this feedback from one of the delegates at our Study Day- Daizy is a Physiotherapy Apprentice and took time from her busy schedule to send us this.

Erb's Palsy Group Study Day - Best practice to Achieve Best Outcomes

September 2022

Daizy McCulloch – Physiotherapy Apprentice – St Mary's Hospital Isle of Wight

I was very excited to be able to take the place of my team lead's spot on the Erb's Palsy conference when she was unable to make it. My travel was easy with just one train from Portsmouth to Coventry and then a short taxi to a lovely bed and breakfast country looking pub. The Erb's Palsy Group put me up in a room for the night and took me out to dinner! The group was brilliantly welcoming, and I felt very comfortable straight away when having dinner with them all.

In the morning I was driven to the venue to be greeted with a fantastic Erb's Palsy Group pack which had notebooks, pens, various info leaflets and all the PowerPoints printed out for the upcoming speakers of the day. I was glad in the way they started this conference with a physiotherapist talking about the first signs to look out for, the Toronto test and when we can refer on to the specialists. I found this immensely helpful as we recently had a baby referred to our service who had a humerus break during a difficult birth via c-section and my team lead physiotherapist and I were thinking in the way of ERB's palsy.

Throughout the day we had lots of speakers from different backgrounds and specialities that gave us a rounded picture of Erb's Palsy and who is involved at what stages. I particularly found the two surgeon speakers interesting, and the procedures modern medicine is now able to achieve and how this can affect the patient's life. My favorite speaker though was OT, Kim Hawksby, who's personal experience of living with Erb's Palsy was exceptionally explained and her humour was incredible!

Thank you for a brilliant and educational day Erb's Palsy Group (and thank you for all the food and tea through out the day!) I will be presenting this back to my team so we can all learn from this.



Becoming a Mum, with Erb's Palsy

In 2021 I fell pregnant and for me the world of 'motherhood' was all very unknown. Although I have a wonderful Mum myself, not many of my close friends have children and I have no siblings; so, for me, babies were a bit of an unexplored territory! Nevertheless, I was excited (and apprehensive!) about having a baby and becoming a Mum.

During my pregnancy I came across a post on the Erb's FB page by another new Mum who was struggling with breastfeeding positions. This post sparked my interest as obviously it was something I may face once baby was born. I also started to wonder how my Erb's might impact life as a new Mum.

I have about 60-70% movement in my Erb's arm (left), and throughout pregnancy performing day to day tasks continued as normal and my arm didn't cause any additional bother. However, purchasing a pregnancy U-pillow to help while sleeping on my side really helped. Upon the suggestion of a friend, I also invested in a breastfeeding pillow in anticipation that this would make holding and feeding baby a little easier (which it did!).

Fast forward to August and happy, healthy baby is born - Hurrah! Like most Mum's the feeding was initially very challenging for us, but I do believe this was partly worsened by my inability to hold and get baby in to the 'common' feeding positions. However, after some time, follow up care from the nurses and internet research, I was able to find positions (although unconventional) that worked well for us. I found sharing my challenges with my partner, friends, family, other Mum's and medical professionals really helped me to navigate our way to success.

My baby, Penny, is now three months old, it's so amazing to see her grow and it does make me reflect on the challenges my own Mum would have faced working through my Erb's diagnosis as a baby. My Erb's definitely creates some additional challenges and I've noticed increased discomfort in my non-Erb's arm, as there is so much over compensation and over-use. I've learnt that nearly all Mums (not just Mums with Erb's) end up with some kind of repetitive strain injury usually in their arms or wrists from carrying and holding baby, bottle feeding and carrying the cars seats. I've made an extra effort to try to relieve the overuse of my arm, and sometimes wear a wrist support on my non-Erb's arm to help it.

On reflection, I wish I had been clearer in the hospital as to my limitations surrounding my arm; this was something my partner ended up doing for me, speaking to the nurses about what I physically could and couldn't do. The maternity nurses, doctors and midwives are absolutely amazing at what they do, and once they understood our situation fully, I had so much support and a variety of creative feeding positions for us to try. I've learnt that motherhood is challenging for everyone, but the challenges are totally eclipsed by the rewards and cuteness! I am proud of the way that I've adapted with my arm - I may not do things the 'normal' way but it's our way.

Charlotte



Save the Date!

JUNE 24th 2023

For families in SURREY and surrounding area
Fafa and Alistair Young have offered to host a get together
at their home in the KT22 postcode area.

They have told us they are lucky enough to have a swimming pool and would like to invite up to 10 families to their home and have a great day chatting and swimming or even just a splash around!

They will provide LifeGuards and families can bring their own snacks or lunches to share

They have son Lochlan who is aged 7 and would love to meet other families if they can attend

Contact Info@erbspalsygroup.org.uk for further information.



Evelyns Awareness Week

Evelyn Catling aged 9 really wanted to make a difference for Erb's Palsy Awareness week in October 2022!

She had a wonderful idea to sell Erb's Palsy merchandise at her Dad's Health and Well-being clinic to raise some money, although her main aim was to raise awareness.

Evelyn came into the clinic one evening after school to set up her little stall with the merchandise and information leaflets.

She worked very hard to make sure everything looked neat and inviting and even had a chance to talk to some clients about Erb's Palsy, and even had her photo taken with a famous footballer!!

Evelyn's Dad, Lee Catling and his Co-owner Lenny Pack and the rest of the team at For You Now, which also includes Evelyn's Mum Charlotte Catling, all had so much fun during the week talking to so many of their clients about Erb's Palsy, spreading awareness and handing out leaflets with a bonus of lots of merchandise being sold and some extra generous donations from their lovely clients.

Evelyn felt the clinic was a good environment to raise awareness as clients come to see us injured or in pain, so were all keen to hear about Erb's Palsy and how the money raised can help the charity and the families it supports.

It wasn't surprising though how many people had never heard of the condition before, and we were all glad to enlighten people and asked them to pass the leaflets on to a friend or family member.

At the end of the week Evelyn came into the clinic to pack away the stall and count up the money in the donation tub. She was surprised at how heavy it was! Evelyn had managed to raise a whopping £400!!!

She was shocked and so happy and grateful to everyone for their support. Evelyn's parents and the team at FYN are incredibly proud of her efforts and think she's an amazing young lady!

And the cherry on top was that Evelyn won the Ison Harrison's competition and is looking forward to a family trip to the cinema after all her hard work.

Well done Evelyn Catling xxxx



Sign up and see brands donate towards our 2023 fundraising target



You shop, brands donate to us

During January 2023 the Charity received the news from Smile.Amazon that they are closing the programme as from 23rd January.

Obviously this is a blow to many smaller Charities like ours, which gained a substantial amount of donation from our many members via Amazon, but Amazon now wish to work with larger Charities rather small grassroots organisations such as ours.

If you are an avid online shopper, you can STILL generate donations for us by using the EasyFundraising app or tool bar for PC's. This handy tool will remind you that a donation is available when you are shopping online with one of their designated partner retailers.

The system works the same way as Smile.Amazon did- with donations being paid by the retailer at no extra charge to the customer and donations are paid directly into our bank account by EasyFundraising.

All the major retailers such as Argos, John Lewis, E Bay, M&S, Tui, Viking, Hello Fresh, H&M and a raft of others offer a donation on your purchases.

SO if you COULD register with them- it would be fabulous – and help us to get money for nothing!

You can find our easyfundraising page here: www.easyfundraising.org and search for Erb's Palsy Group,

Another way of helping us raise much needed funds is by recycling your printer cartridges.

Keith Bissex kindly signposted us to this great way of saving the planet and raising money! All details are available at their website – why not see if your rubbish can raise money!

Recycle 4 Charity Recycling your ink cartridges with Recycle4Charity is a simple way to help the environment whilst raising money for your charity of choice!

How It Works

- 1 Select Your Charity**
Select which charity you would like to support
- 2 Post Us Your Ink Cartridges**
Pack your cartridges up and send them to us for free
- 3 We Send Money To Your Charity!**
Your charity gets paid for cartridges received from the wanted list

Start recycling now at www.Recycle4Charity.co.uk

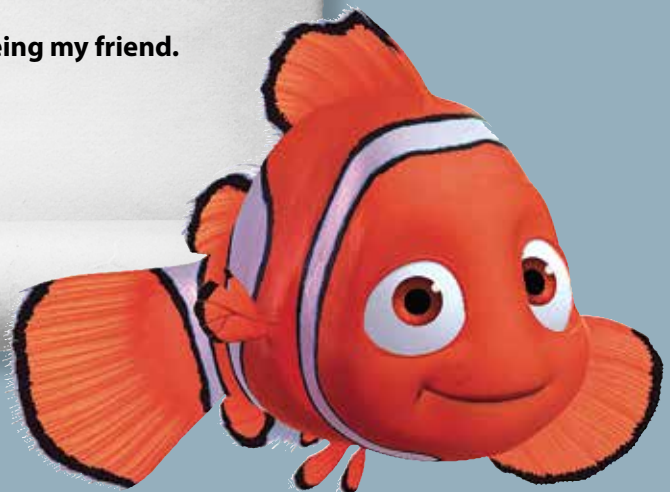
'Just like Nemo'.

When Ava Gilbertson had surgery recently, Mum Sophie and Ava, wrote this fabulous poem to help explain to her classmates why she would need some help.

Well done Ava and we hope you are recovering well.



**Just like Nemo, I have a special fin,
And so I'm going to have a little operation,
I'll be ok, don't worry about me,
But my arm will be in a special cast, which you're going to see,
Can you be gentle to help me get better?
And sit and colour with me when outside it gets wetter,
For a while I will have to watch PE,
But there's plenty you can still do to play with me,
There's Lego and drawing,
Singing and talking,
Painting and sticking,
But not hopping or skipping,
If I am careful, my arm will get better,
Then we can go outside and play together,
Until then, my arm is on the mend,
And I thank you for understanding and being my friend.
Thank You Reception
Love from Ava Gilbertson**



Can discussions with Mother's prior to the birth of their babies prevent injuries to them and their children?

A recent Research Study, conducted by Professor Dimitrios Siassakos and his team in London, a well-respected expert in the field of Obstetrics and Gynaecology, investigated how well a mother is consented for interventions during labour, and whether sufficient discussions were taking place during ante-natal reviews to allow mums-to-be to make an informed choice about their and their baby's treatment.

The rights of women to share in decisions concerning their care during labour and birth were highlighted in the landmark case of Montgomery v Lanarkshire Health Board in 2015. Nadine Montgomery's claim centred around the Obstetrician failing to offer her a c-section, ultimately causing her son to develop cerebral palsy. Now, following this case and as a matter of law, a doctor has a duty to '... take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment and of any reasonable alternatives or variant treatments'.

Prof. Siassakos' research study focussed on an expectant mother's ante-natal care and the discussions that took place during those consultations with her. 16 individual Consultations were analysed.

The findings were essentially that medical professionals were not fully understanding of a mother's legal right to consent to intervention during the birth of her baby, and the discussions that should be taking place during consultations to ascertain the wants and needs of individual mother's when delivering their babies.

Prof. Siassakos and his team found that consultations with mums-to-be, and the obtaining of their consent to intervention during labour, centred around medical risks and procedure rather than an individual woman's preferences. Whilst it is acknowledged from a medical point of view that the safety of Mother and baby is paramount to any decision-making process, the study reflects that a woman's thoughts, ideas, concerns and preferences should also be considered in tandem to allow

for a mutual discussion and understanding of decisions that are made about how an individual woman may give birth to her baby.

"Consultation dialogues should ensure that patients understand the options available and are supported in making meaningful choices by being provided with information on alternatives and risks relevant to them"

Prof. Siassakos' Study concluded that simply asking the mother "what matters to you most?" could improve the medical professionals' understanding of the needs of mums and so greatly improve their birth experience.

A link to the full study can be found here <https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-021-03574-2>

As a legal firm representing Mother's and children who have suffered injuries related to their labours and births, we would expect all expectant Mother's to be given the opportunity to discuss their concerns, fears and expectations regarding the delivery of their baby, including how their baby might be delivered in various scenarios. Therefore, in answer to our own question, 'can discussions with Mother's prior to the birth of their babies prevent injuries to them and their children?': whilst the Study does not go that far we believe, based on our experience of birth injury cases and the results of the Study, that there are indeed injuries which could have been avoided had appropriate discussions taken place with mums-to-be in the antenatal period.

If you believe that you or your child may have suffered an injury as a result of the labour or birth, then do please contact us as we will be only too happy to discuss matters with you. It really is so important that children and their families are compensated for the injury caused to them to allow them to overcome the effects of that including access to any care, treatment and equipment they might need throughout their lifetime, and in order to be able to live a full life free of concerns over the cost of treatment and care.

Rebecca Callard

Associate



Fundraising Raffle

The Erb's Palsy Group has given me strength, knowledge and power. Power to make change and make a difference. It is not a government funded charity - we don't have huge influxes of thousands of pounds. It is run solely on the work of amazing, wonderful volunteers who give up their own time to raise awareness and provide advice, knowledge, compassion, love and support.

When Sophia was born she suffered a birth injury - this left her with a life long disability. We were led to believe it would all be ok and by 9 months old she should regain movement, only in small cases was that not possible. We were led to believe that everything was going great it was just a weakness in her left arm that would be made better over time. We were told we didn't need specialist intervention.

At 4 months old two of the Trustees encouraged me to fill out a self referral to a specialist. I'm not ashamed to admit I was scared, I was in denial and I dragged my feet a little - but I did it and at 5 months old Sophia had a nerve graft surgery where we had to sign over consent for the specialist and his team to do what they felt necessary to give her the best chance and best possible function of her left arm. This surgery is time sensitive. If I waited another day, another week it would of been a lot harder.



I check in regularly now with those two trustees, we chat about milestones, life and everything else in between. They've become like family to me and I will love, honour and appreciate them every single day for what they did for Sophia and what they continue to do...from hearing me blubber down the phone that my baby needed surgery, to keeping me calm during those hours that we waited for Sophia to come out of surgery. Karen Hillyer and Jackie Dewdney thank you for being our real life superheroes!

Since we found the charity it has become my mission to fundraise and support them where I can. To be a part of something bigger than myself.

With Awareness Week approaching I knew I had to do something to support in any way that I could. I reached out to Debbie and some of the other Trustees and asked if I could raffle off a Hamper filled with Erb's Palsy Merchandise. Immediately they agreed and supported me massively!

Together as a community and with the support of family and friends also, we managed to raise an outstanding **£745 + £130.75** in gift aid! Absolutely smashing the £500 target in which I had set.

I would like to take this opportunity to thank Debbie, Karen, Jackie and Amy for supporting me and encouraging me! I would also like to say a very special thank you to Jodie who makes our wonderful T-Shirts and Hooded Jumpers, for her donation and support of the Fundraiser.

To everyone who donated and shared - thank you from the bottom of my heart!

Together we can achieve wonderful things!

Stacey Prichard



Editorial Note:

Thank you so much Stacey – we know you worked extremely hard during Awareness Week on this initiative and for that we are extremely grateful. We hope the lucky winners, 1st Prize: Natalie Atkinson and 2nd Prize: Anne Leonard, enjoy their prize.

If anyone would like any of our merchandise, please go to www.erbspalsygroup.org.uk and search our shop.

T-shirts and Hoodies are available from Jodie Gardiner at her Etsy shop: [@purplepandabearco](https://www.etsy.com/shop/purplepandabearco)



GET YOURS NOW

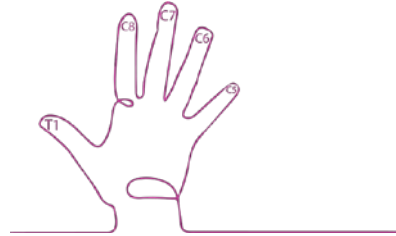
100% of proceeds will be given to the Erb's Palsy Group so they can continue with their great work

Now being sold on our Etsy Store
[@purplepandabearco](https://www.etsy.com/shop/purplepandabearco)

Find a list of prices, sizes and variations

TOZERS

Cost of Erb's Palsy



It seems such an obvious thing to say but having a disability comes at a cost.

Some (although not all) of the physical costs may be obvious, but there are other non-physical costs which are less obvious and even some which are hidden. The consequences of Erb's Palsy are wide ranging, and the "cost" is born in the main by the individual but also by the family and even by society. The costs are:

- Physical
- Psychological
- Financial

In support of the Erb's Palsy Group and during Erb's Palsy awareness week Tozers published a series of articles and case studies highlighting the "Cost of Erb's Palsy" based on our experience, and exploring these areas in more detail.



The Physical Cost – Harry

When Harry was born his brachial plexus was severely damaged, with all 5 nerve roots being affected (C5,6,7,8,T1). Harry has a grade IV injury being the most severe injury possible. Initially he had no movement in his right arm at all. At only 16 weeks of age Harry had exploration surgery at a specialist centre at Leeds General Infirmary. The surgeons discovered that the nerves were so badly damaged, there was little that could be done to repair them. Nerve transfers

were performed but unfortunately this proved not to be successful.

Harry's disability was immediately obvious by the paralysis of the arm but also because the arm was held in an internally rotated position known as the "waiters tip". He also has a Horner's syndrome. When he was 3½ Harry had more surgery - a free gracilis muscle transfer and a shoulder release. He was in a bulky plaster cast which surrounded his waist and arm for 6 weeks. Since he was born Harry's family have had to do daily physiotherapy exercises with him to maintain the muscle strength and range of movement he has and to avoid deterioration. He has also had hydrotherapy.

Despite his young age he has seen many specialists; surgeons, occupational therapists, physiotherapists and attended multiple appointments.

Harry struggles with balance greatly and often falls or bumps into things. He struggles with everyday tasks such as zips, opening wrappers, putting on socks, and tying laces. But what is most frustrating for Harry at the moment, is not being able to climb on the playground equipment like his friends.

Harry is only 7 years of age and will remain under specialists for many years and is likely to require further surgery. Despite all of this Harry is described by his parents as a lively boy who will give anything a go with a huge smile on his face, and although he has moments of sadness when other children make negative comments, these are short-lived. His attitude (re-enforced by his parents) is that it is not an arm that makes you amazing – he is what makes him amazing.

The Psychological Cost

Not everyone will have an emotional or psychological consequence as a result of having Erb's palsy, but many do, and it can be hidden below the surface. As an individual with Erb's palsy the impact will differ to a greater or lesser degree and is not always proportionate to the severity of the disability. Psychological issues can significantly impact upon health and wellbeing, education, relationships and employment.

Matthew aged 20 years

Matthew has a grade II injury to his right side at birth affecting C5,6,7,8. As a teenager Matthew was diagnosed with a chronic Generalised Anxiety Disorder with significant post traumatic elements associated with low mood.

This undermined his concentration and caused distraction and so had a significant impact on his attainment in the educational setting. Matthew had the constant reminder that he could not do things the same way as his peers, and it was the school environment which really brought this home to him and reinforced his sense of difference. Tasks at school took longer, caused self-consciousness and considerable apprehension due to fears about whether he would be able to do a task. Although Matthew's underlying intellectual ability was not affected, the injury had affected his ability to put this to good use.

Contact our legal experts

Ready to talk?

01392 207 020

enquiries@tozers.co.uk

www.tozers.co.uk

TOZERS

Things came to ahead for Matthew after his GCSEs and although he started his A Levels, he completely lost motivation. Matthew reported that he felt like he had hit rock bottom, he did not want to go out of the home, he wasn't eating or sleeping and even had suicidal thoughts. Matthew had these feelings for the best part of a year but somehow, he was able to push through and regain his motivation. He realised that school was not for him and through his unyielding determination and the support of his family he was able to secure an apprenticeship in manual work. This presented its own obstacles given his physical limitations and pain but with the help of a therapy package, he not only managed but is making great progress in his chosen career.



The Financial Cost

Erb's Palsy has a **financial cost** to the individual and their family and an economic cost to society.

As an individual with Erb's palsy the impact will differ to a greater or lesser degree, but **the financial cost** of the disability to the individual and their family can include:

- Travel and parking expenses
- Private medical treatment/therapy
- Lost Earnings
- Aids & Equipment
- Assistance with childcare, home maintenance, domestic chores

To society the financial cost of Erb's Palsy can include:

- NHS Treatment
- State benefits
- Legal costs of litigation

Tom aged 17

Tom has a grade III brachial plexus injury to his left side at birth affecting C5,6,7,8.

Tom had good specialist NHS treatment in the early years. His parents had to take time out to drive him to appointments at a specialist centre and to care for him following surgery. As he got older, due to limited resources important therapy and equipment was simply not available on the NHS so Tom's parents funded what he needed themselves, including physiotherapy and massage, aids and equipment, and CBT.

In the future Tom will leave home and will probably have a family of his own. When Tom has his own home he will find difficult the everyday tasks that his parents currently take care of. Such household chores like peeling and chopping vegetables, laundry, taking out the rubbish. Doing DIY/decorating, cleaning windows and doing the gardening. Whilst he may be able to do some tasks – it may take him longer, may be too physically demanding or cause him pain.

So that he can manage to work full time he may need to pay for a cleaner or a laundry service, buy specialist equipment and pay for additional service: such as chiropody and grocery deliveries. He will need an automatic car and adaptations to drive without relying upon his left arm.

Tom's career choices are more limited. Although he hopes to have a professional career, he will be limited even in this by the pain he experience: when using a computer and carrying a bag and it will be important that he has a suitable package of support in place.

Unfortunately, despite anti-discrimination legislation in the workplace – having a disability can place you in a vulnerable position in employment. In general terms rates of unemployment are higher for those with disabilities.

Tom's parents brought a legal claim for compensation against the hospital where he was born. The damages which Tom has been awarded are to compensate him for the physical, psychological, and financial cost which he has experienced and will continue to. It will support and enable him to enjoy an independent and normal life.

How can Tozers help?

For any further information, or for advice on bringing a claim please contact our dedicated medical negligence legal experts.

enquiries@tozers.co.uk

01392 207 020

www.tozers.co.uk/personal/medical-negligence/erbs-palsy-claims



Contact our legal experts

Ready to talk?

Q&A With Amy Swift, Erb's Palsy Group Trustee

As part of Erb's Palsy Awareness Week, Ison Harrison have interviewed Amy Swift, a trustee of the Erb's Palsy Group.



Q: Hi Amy, please tell us about your background and how you got involved with the EPG, what does the charity mean to you?

I am a children's mental health nurse and a Lecturer at Northumbria University. I am a mum of two and my oldest child has a brachial plexus injury. I became involved with the EPG when my first child was born with a very severe brachial plexus injury. A consultant in the hospital told us about the group and I joined. I became a trustee of the charity a few years ago and have relished the opportunity to support families, individuals and health professionals and to help them navigate what can be a very tricky pathway.

The charity, to me, are a breath of fresh air. They enable parents and support them at the most difficult times. They enable individuals to live life to the fullest and the publications they have made for those living with the injury are great evidence to support that. They campaign tirelessly for understanding and awareness of the condition in the hope that babies will be born safely without an injury and that those who do have the injury can access adequate therapy and treatment.

Q: Please tell us about the Erb's Palsy awareness week and why it is important.

Erb's Palsy week is a week we dedicate as a charity each year to raise awareness about our charity and what we can do

to help others. Not only that but to raise awareness of the condition itself and what the prognosis actually looks like. It is important as through this outreach members find our charity who have previously had no support, we ensure these individuals can access the correct treatment pathway, it enables individuals to tell their story and educate others on what life is like with Erb's Palsy. It can also raise some much-needed funds so we can continue to support those affected by the injury.

Q: What do you wish the general public knew about Erb's Palsy?

Erb's Palsy is so much more than a 'broken arm.' What these individuals have to overcome and live with on a daily basis is tantamount. It affects every aspect of their lives from social to functional, enduring long hours of therapy and operations. Just because someone may look okay does not mean that they are.

Q: If you could offer one piece of advice to parents of a child who has Erb's Palsy what would it be?

I would say 'see the child, not the injury.' As a parent you can get caught up in worry, countless appointments, operations etc and sometimes miss the beautiful human being who is staring up at you. Once you begin to realise their arm does not define

them as an individual can begin to appreciate the wonderful gift you have right before you.

Also, apply for DLA. Those long journeys to see specialists can become quite costly. We also use ours for 1-1 swimming lessons which is great physio!

Q: If you could offer one piece of advice to a child or young person who has Erb's Palsy what would it be.

Don't let it hold you back!

POSITIVE THOUGHTS



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Living With Erb's Palsy – How Physical Exercise Helps My Self-Confidence



Written by Flossie England, an Erb's Palsy Group member who is eighteen years old.

I have a grade 3 Erb's Palsy injury which means that I have limited range of movement so I can't reach above my head or move my arm out in front of me. My elbow doesn't fully extend or flex. I have ulnar drift at the wrist and the range of movement used to be very limited but when I was 7 I had a tendon transfer which gave some extension past neutral. My grip is normally very good but lately it has been getting worse due to cubital tunnel syndrome. So at the beginning of September I had an ulnar nerve decompression which should reduce the pins and needles and over time improve my grip. I also suffered some brain damage at birth as a result of oxygen not getting to my brain which causes me to struggle with processing information. Both of these massively affect my life but I

try not to let them dictate it.

As a teenager with right Erb's Palsy I have witnessed how the opinions of others can affect my own confidence. However, I am lucky that if I ever doubt myself I have an outlet in the sport I participate in.

Show Jumping and Dressage

Competing in para showjumping was great as I felt, for the first time, I was on a level playing field with my fellow competitors. However, as I got older and bought a new pony, Freddie, I gravitated more towards eventing. There is no para eventing so I have to compete against able-bodied riders. The first couple of seasons were fantastic and I was selected for the East Midlands under 18 team and

qualified for both the pony club national championships and the grassroots national championships.

As I moved up the levels I struggled more because in the dressage phase the picture needs to look 'right' which isn't always possible when your arms aren't the same length! This year I missed out on qualifying for the pony club champs by 1.5 marks (the test was out of 250) because I had 2 marks deducted for not making a give and retake of the reins clear enough (when you move your arm forward to give away the contact on the rein – something I can't do due to my limited range of movement). This was gutting and really made me conscious of the limitations that my Erb's causes.



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I am very critical of my position when riding and all photos I like are from the left side, which looks a better 'picture' than the right side does due to my arms and posture. I try not to let this affect me as I know that as long as my aids are effective it doesn't matter what it looks like in the jumping phases! Even though this season may not look the most impressive on paper I have enjoyed getting to know my young horse Orla who has been campaigned lightly alongside Freddie.

The event season ends on the last weekend of October but mine was cut short due to my recent operation on my Erb's arm. I have been reflecting on the positives from our performance this year and any aspects that we need to focus on in winter training before coming out in the spring ready to be more competitive at the higher level next year. I tried to view this time off riding as a positive allowing me more time to focus on my application to university and starting back at school. In reality I have probably spent just as much time up at the yard and can't wait to get back on!

Physiotherapy

Physio is a big part of anybody's life with Erb's and luckily my parents made it very clear to me at a young age that there was no option about doing it or not. I could probably count on one hand the number of days I didn't do physio between being first told to do them as a baby to being 13 when they said I could start to do less as I was doing so much sport. At the time it wasn't great fun but it is something I will always be grateful to my parents for. I used to do physio every night before bed and it was just part of the routine. I even remember standing at the top of the stairs shouting down asking for someone to come and do my exercises because I was the youngest of 4 siblings so I used to like the time with mum or dad to myself!

Dream Big

I struggled at school to keep up with the work and the high standards I set for myself. Year 11 is a difficult year for most teenagers, but with a significant lack of

sleep and increased aches from sitting at desks for prolonged periods, I really struggled. I remember coming home from school and going straight to bed as I was both physically and mentally exhausted. With my grades being teacher assessed we had up to 5 exams a day which made revising effectively impossible. This caused me to feel as though I wasn't living up to my high standards so I saw myself as a failure. Luckily as an outlet I ride horses and even just going up to the yard and seeing the horses after a long day at school helped me appreciate that there is more to life than just getting high grades.

I achieved grades that meant I could continue my studies in the sixth form at my school. When I expressed my love of



science in school I was always faced with people saying how it was a shame I would never be able to become a doctor due to my Erb's. As a result I spent most of secondary school unsure of what I wanted to do next. As I grew older I began to pay less attention to other peoples' opinions and decided to ask my surgeon, who said I was definitely physically able enough to study medicine! Now I have just finished my application for university and have applied for medicine.

My Advice

My advice to anyone would be to focus on the things you are in control of. There is no point worrying about something that is out of your control but if you enhance any aspect you can it will only make the situation better. If you have done your best what will be, will be. This is better deduced by Jimmy Dean who says "you can't change the direction of the wind, but you can adjust your sail to always reach your destination".



POSITIVE
THOUGHTS



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Hello again!

I hope you have all been making lots of lovely memories! Have you done any new and exciting things? Feel free to tell me about them. I would love to hear from you. I rode my bike lots, I played with friends and I've done some baking.



My Gratitude Jar

I have been taking some time to think about how my Erb's Palsy makes me feel. Some days I feel happier than others. Sometimes it can be hard and I don't want to do my physio, even though I know it helps.

I made a gratitude jar which is just an old jam jar which I have written and drawn pictures of things I am grateful for. Things like family, friends, pets, hobbies, and my favourite teddy. I also included things like having pizza for dinner, cuddles from my Nanna or when someone gives me a great chocolate bar as a treat. I even put in memories, a nice holiday, a friends party, my school play and the time I was able to ride a pony. It can be anything!! I decorated the jar too to make it nice.

What is great about it, is when I have a day where I am not feeling so happy, I can pick anything out of the jar to remind me of all the great things in my life. I know every single thing inside the jar is something which makes me happy! It really helps me to smile again on tough days.

If you have a day where you would like to get your smile back, you could try making a gratitude jar, or even just think quietly to yourself about something which you are grateful to have in your life. I know you will be smiling in no time!

Acrostic Poem challenge

I challenge you to write an acrostic poem about Erb's Palsy. Send me your poems at info@erbspalsygroup.co.uk I will try to include some in the next issue of the Blerb!

What is an acrostic poem?

Making acrostic poems is fun! We start by having the word Erbs Palsy down the side, and then each letter creates the first letter for that line. I have done one to give you some ideas to start you off.....

Every day is a physio day

Really lovely people help me at hospital

Brave new friends

Special equipment can be used to help

People often don't know about Erb's Palsy, so I tell them!

All of the fun days are so much fun

Life with Erb's Palsy is challenging but great

Super proud of myself

You are all amazing too!

JOKE CORNER

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

What did one toilet say to another toilet?

How do you get a squirrel to like you?

What did one plate say to the other plate?

You look a bit flushed!

Act like a nut!

Dinner is on me!

Ha Ha
Ha Ha
Ha Ha



#ThisIsMe

Campaign Celebrates Body Positivity



Ison Harrison Solicitors recently ran a fantastic campaign to help support Erb's Palsy Awareness Week.

#ThisIsMe was aimed at promoting body positivity and self-empowerment for individuals with Erb's Palsy. It was designed to encourage positive mental attitudes and showcase an unbreakable spirit in the face of disability.

As part of the campaign, Ison Harrison and The Erb's Palsy Group joined together to start a search for nominations for #ThisIsMe prior to the Awareness Week taking place.

All entrants needed to do was to send a photo and tell us what makes them feel body positive.

With fourteen entries received, we were delighted to see so many getting involved with the campaign and helping us to promote this very important message of body positivity.

Each individual entry was featured across social media and we had some lovely feedback and comments from friends and family who saw their child taking centre stage during the Erb's Palsy Awareness Week.

Here are all our wonderful entries:



POSITIVE
THOUGHTS



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We also ran a competition where one lucky entry would be chosen at random to receive a family cinema ticket with popcorn and treats!

The winner was Evelyn – well done!

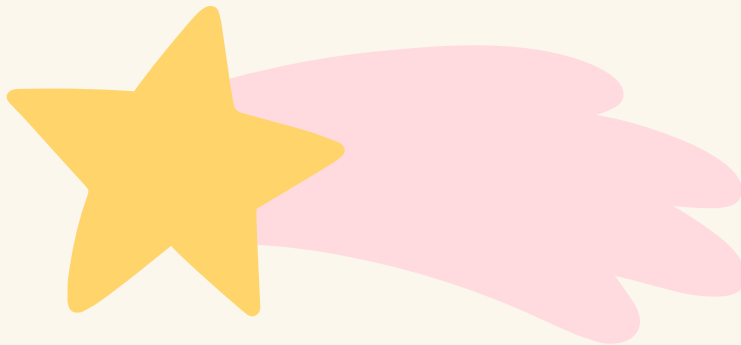


Debbie Robinson, Deputy Chairperson at the Erb's Palsy Group, commented:



We were delighted to collaborate with Ison Harrison on the #ThisIsMe campaign and help to promote body positivity around Erb's Palsy.

As the Erb's Palsy Group is the only UK based organisation offering advice, information and support to families affected by Erb's Palsy, we appreciate the unwavering support from Ison Harrison in raising awareness through creative campaigns such as this.



Ison Harrison would like to thank everyone who entered the #ThisIsMe campaign.



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Erb's Palsy Group Christmas Card Competition

We were very excited to run the Christmas card competition for the Erb's Palsy Group members again last year.

All of the entries were fantastic and we were overwhelmed with the amount of effort that had been put in. Everyone who participated should be extremely proud of themselves.

We loved receiving the entries and the emails telling us how much the children enjoyed taking part. It was extremely difficult to pick the winners and it was very close once all of the votes had been counted.

The winners were **Zion aged 10, Sam aged 9 and Ella aged 14**. We were very happy with how the designs looked once they were printed onto cards and we hope you enjoyed sending them to your family and friends.

We would like to thank everyone who took part they all did an amazing job and we hope they had as much joy making them as we did receiving them.

We hope each of the winners enjoyed their prize and we look forward to running the competition again this year.

Ison Harrison are proud of our longstanding affiliation with the EPG, and look forward to our continued relationship in the years to come.

We hope you all had a lovely Christmas and we wish you all a Happy New Year.

The Yorkshire Law Firm



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ANNIVERSARY BALL SATURDAY 30TH SEPTEMBER 2023



Leeds Marriott Hotel, 4 Trevelyan Square, Boar Lane, Leeds LS1 6ET.
Dress Code: Black Tie/Cocktail Dress and Pearls!



£50 per person

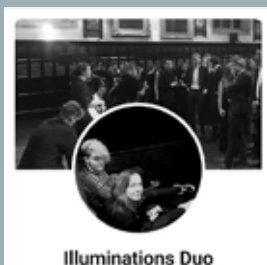
7.30 – 8pm: Drinks Reception with acoustic accompaniment by
Illuminations Duo

8 – 9.30pm: 3 Course Dinner with wine, followed by teas and coffees
9.30pm – 1am: Entertainment including Casino Tables, Photo Frame and
Music

PLEASE NOTE: This is a ticket only event and MUST be pre-booked.

Over 18's Only!

Tables will be in rounds of 10 so please feel free to book a full table or
simply a ticket for yourself and be allocated a table amongst Trustees and
other guests.



TO BOOK TICKETS: Please go to www.erspalsygroup.org.uk and order from the 'BALL TICKETS' Tab (It is very important to use the allocated tab and not the donate button to ensure we don't sell more tickets than available).

You must then complete the appropriate Booking Form available in this edition of the Blerb and forward it as soon as possible to Debbie Robinson via Email at Robinson.debbie@sky.com or debbie@erspalsygroup.org.uk or by post to 26 Browning Hill, Coxhoe, Durham, DH6 4HB.

Tickets will only be confirmed once payment is confirmed and booking forms are received.

Bookings will close when tickets are all sold or our deadline of August 1st 2023 is reached, so please don't delay!

Accommodation: Rooms are available at a discounted price .. please use the link to book this independently
<https://www.marriott.co.uk/event-reservations/reservation-link.mi?id=1665409948480&key=GRP&app=resvlink>



With thanks to RWK Goodman for
sponsoring the Photo Frame



ANNIVERSARY BALL BOOKING FORM

Saturday 30th September 7pm - 1am

Leeds Marriott Hotel

Email Robinson.debbie@sky.com or debbie@erbspalsygroup.org.uk or Post: 26
Browning Hill, Coxhoe, Durham DH6 4HB

Full Name:

Address for correspondence:

.....

.....

Email Address:

Telephone:

Number of Tickets Purchased:

Date of Online Purchase/Payment:

Menu choices **MUST** be listed at time of booking unless following a vegan, gluten free, dairy free, nut free, halal, etc. diet – please then indicate dietary requirements and the venue will cater accordingly.

Starters: Goats Cheese, Heritage Beetroot, Basil Starter OR Roast Tomato and Red Pepper Soup

Mains: Roast Fillet of Pork, Air-Dried Ham, Apple and Sage Compote, Roast Leeks OR Spiced Butternut Squash, Sweet Potato, Ginger, Coconut Milk and Jasmine Rice

Dessert: Milk Chocolate Cheesecake with Vanilla Sauce OR Lemon Brulee Tart with Berry Compote

TABLE ALLOCATION: Where tickets are booked in Groups of 10 we will allocate you to the same table. If purchasing as individuals or couples, please indicate below if you are planning on attending with other guests and wish to be seated with them. We will endeavour to arrange table plans to suit your wishes but this is dependent on final numbers. Table plans will be available on entry to the event.

PLEASE NOTE: This is a Ticket Only Event and Tickets will only be issued once full payment and this form have been received. Thank you.

OVER 18'S ONLY



Who Can Help?

As we start a new year, most families are struggling with keeping up with paying bills and the rising cost of living. With this in mind we have scoured the internet and discovered some Organisations who offer help and support to families who have a child or young adult with additional needs

Here are some which you may not know about

Driving ambition

www.familyfund.org.uk

What can we apply for?

Family Fund offers driving ambition grants to help your child or young person get started as a driver.

Whilst we cannot help with ongoing driving lessons our grants help get your child started, with their:

- Provisional licence
- Theory test
- Learning materials, such as the Highway Code or Theory test booklet/DVD
- First taster lesson
- Funding towards compulsory basic training (CBT) for moped riders.

Grant conditions: driving ambition grants need to be used within 12 months of the date that your Family Fund award letter was sent.

Disability Grants

www.disability-grants.org

Are you a parent or carer of a Disabled child or adult?

If so, use this website to save time finding Disability Grants.

Charities and Trusts provide funding towards the high cost of disability equipment, holidays, housing, days out.....in fact anything above and beyond the normal costs of everyday living.

Searching for extra funds takes time - in between work, hospital appointments, caring, therapies.....

And the hundred and one other things we all have to juggle every day!

That's why Disability Grants is here to help YOU, your family or anyone you're supporting with a disability.

Discover what's available nationally and in your local area by searching the individual sections.



Searching for ideas for toys?

We provide a free loan of specialist toys for 12 weeks to families who have a disabled or terminally ill child.



www.newlifecharity.co.uk

This Charity offers a range of Play Therapy pods suitable from birth to 5 years and above

Each pod has a different theme and is self contained and delivered directly to your door

The website has this to say;

Children learn about the world around them through play, and families can often learn a lot about their child's needs through use of specialist toys. They can also encourage learning, improve relaxation, give enjoyment and distract from pain.

87% of families report the specialist toys improved relationships.

82% of parents had a better understanding of their child's needs.

77% enjoyed quality time as a family though play with appropriate toys

There are different categories of play pods to choose from, depending on the child's age, physical and learning abilities, and medical needs.

PLAY
THERAPY
PODS

Achievements



Eva – Beep Beep! Eva has right Erb's and passed her driving test on her first attempt! Well done Eva!



Bobby is a big football fan and he was recently awarded Man of the Match. Keep working hard on those ball skills Bobby! We love to see your achievements.



Dillon recently joined his local Scouts group. He has already been presented with his first 2 badges for first aid and an overnight away from home. He is over the moon! We look forward to hearing how you get on Dillon.

Cody has suffered a few knock backs with his footballing but has fought through them and is now part of a great team. They must appreciate how much of an asset he is as he was recently awarded player of the team! We all hope this gives you a great boost to carry on with the sport you enjoy, Cody!



Mia: Despite initially struggling with some aspects of rugby, Mia has got to grips with it and is really starting to enjoy the game. She even scored her first Try in a recent match. **Keep it up Mia!**



Max recently changed schools and has settled into his new school really well. He took in his Herbie book to explain to his new friends all about his Erb's. Max was even awarded the Head Teacher's award on his first week. **Keep it up!**



Sam was asked to carry the Cub Scout flag during an Armistice Day parade. He had to carry it a long distance but managed it brilliantly. **Top effort Sam!**

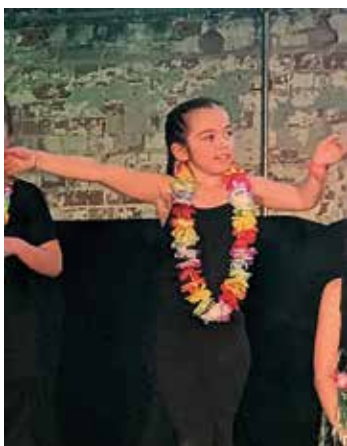


Indi attended the World Championship Disco Kid 2022 in the world famous Blackpool Tower! She danced all weekend to reach the final and came 6th. Your hard work has paid off, Indi!

Harry, 11 with left Erb's has saved some of his pocket money to give to a local charity youth group he used to enjoy attending to help with their costs. He is unable to attend now as he is busy with his dance career. He popped over to see his old friends and drop off some cards and funds for the group. What a kind gesture, **well done Harry!**



Lyla aged 5 with a right Erb's has recently changed schools and has been awarded the Best Learner award, she was presented with this at school where Mum and Dad watched. Keep up the hard work Lyla!



Faith's Mum sent us this about **Faith's** achievements;

Faith is a member of the Colchester Phoenix Amateur Swimming Club, a swimming club for people with disabilities. In 2022, she won their 'Young Achiever Award' and in December took part in the annual swimming gala. For the heats Faith was in (front crawl, back stroke and breast stroke) she was mainly competing against boys who were much older than her and quite literally double her height, but despite being very nervous she was enthusiastic and took home both silver and bronze medals. Faith absolutely loves swimming and it's great physio for her - she works so hard every week, always listening to her teacher really well so that she can learn new techniques and increase her ability in the water. She even won a head teachers award at school for her efforts in swimming.

She is also a member of the Starz Performing Arts Academy and performed in a showcase in December. She rehearsed singing and dancing for the show for several weeks and she even learnt sign language to go along with one of the songs (This Is Me from The Greatest Showman). She performs with a smile and is a brilliant dancer!



Family Fun Day 2024

Saturday 29th June 2024

You know how we like to be organised! So here is the date of our 2024 event for you to add to the back of your new dairies and calendars!



Sponsorship Opportunities

- ▶ As always, we are on the look out for sponsorship and funding. As a charity run by volunteers with no government or lottery funding, we send many hours completing lengthy funding applications to cover the costs of activities, venue hire, raffle prizes, etc.
- ▶ Do you own a company and would like to sponsor an activity at our event? In return, we will advertise your business details in the Blerb, and on all our social media challenges - Facebook, Instagram and Twitter. A small advertising banner can also be erected at the event. Please get in touch and we will happily supply activity suggestions and quotes.
- ▶ Do you own a company or business who could kindly donate a prize for use on the raffle or tombola stall?
- ▶ If you can help in any of the ways suggested please get in touch with Debbie or Karen at debbie@erbspalsygroup.org.uk or info@erbspalsygroup.co.uk
- ▶ THANK YOU!



Awareness week 2022

What did you do?

From cake sales to raffles, personal stories to newspaper stories, our Awareness Week was as busy as ever. Lots of our members got involved in sharing their Erb's journey, whether they have Erb's themselves or have a child with Erb's. Social media was ablaze with our members stories.



Lyla, with her mums help, made some very yummy cupcakes for the family.

Amelia and her mum Jodie wore their t-shirts to work and nursery.



Ellie Gunn had an article in her local newspaper about growing up with Erb's. Ellie now works as a laboratory analyst for a chemical manufacturing company.



Josh's mum, Sarah, recreated a picture that we have used for several years.

Josh was only 5 when the first picture was taken. He's now 15 and stands over 6ft tall!

Thank you to Bech Schofield and Sharna Lochlan-Adams who created our wonderful 2022 posters.

All the Trustees would like to say one big Thank you to all those who participated this year x



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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

