



Erb's Palsy Group
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Erb's Blerb 119

Magazine of the Erb's Palsy Group Late Summer Issue 2022

Hello and welcome,

to our late summer issue of the Blerb, we hope that you are enjoying some down time and recharging your batteries!

This issue is full of lovely photographs from our recent **Family Fun Day** – it was such a joy to be able to finally have an event which we could welcome you all to – it was terrific to see old friends and meet new ones, it is amazing how much the children have grown since we saw many of them last in 2018.

We hope the event was as wonderful for families as it was for us – maybe if you haven't had the chance to attend one yet- you can come to our next one which hopefully will be in 2024.

Karen Hillyer

NEW TRUSTEES

The Trustees are delighted to welcome two new Board members to their ranks – well one completely new one and a familiar face is re-joining the Board, much to our delight!

We welcome Trudi Hole who is mum to the gorgeous Max and his brother Theo and lives in lovely Devon with husband Steve. Trudi has been supporting the Charity for a good few years with lots of fundraising events and also producing our children's page more recently. We are delighted to welcome Trudi and look forward to working with her on a more formal basis.

And our much loved long standing member Kim Hawksby has found the time to re-join the board in a more formal role. Kim has been a Trustee previously before she went to work in her beloved India. Kim is a long-standing member of the Charity and has been a massive support to the Charity for over 20 years. Since returning from her travels Kim regularly shares her experiences of life with Erb's Palsy with delegates at our study days and she and her Mum Julie have hosted some lovely coffee mornings in Yorkshire where they live. Kim works in her professional life as an Occupational Therapist and this is certainly an added bonus for our members as she can share her professional skills alongside her personal experience to support families.

I know you will join me in welcoming them to the Board.

FORTHCOMING STUDY DAY



We are also pleased to announce that now Covid restrictions have been lifted we are able to commence our much praised Study Days for Professionals, This year we are running the event for Physiotherapists and Occupational Therapists on September 30th.

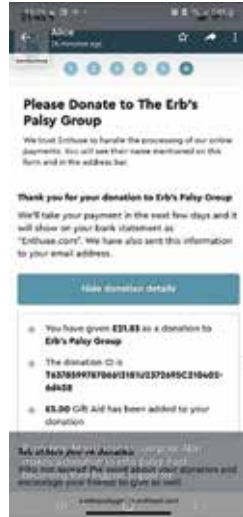
We have an excellent array of guest speakers from both Leeds General Infirmary and RNOH and the event is a wonderful learning experience for delegates.

Could you ask your local Physio or OT if they would be interested in attending? We can supply information you can forward on to them – lets get them properly up to date with Best Practice Techniques in treating Children! Contact Karen Hillyer at **info@erbspalsygroup.co.uk** for further information to pass on to your local therapy team.



Donations

Flossie England's elder sisters boyfriend **Alan**, makes a donation to our Charity each time Manchester United football team lose a match to Liverpool – we are delighted that we have received **£22** so far – lets hope the losing streak continues!! (or is that the wrong thing to say?!!)



Last issue we mentioned that we had received donations in memory of **Mr John Randall, Isla-May's grand dad** – we have since had further donations made at his funeral and afterwards. We are so grateful to have received a further **£1080.84**. I think you will all agree that this is a tremendous amount for us to have received and we are immensely grateful to the Randall family for all their support, and especially would like to mention that we think John would have been very pleased to know what high regard he was held in. **Thank You.**

Our thanks to **Christina Bailey** who nominated us for a donation from **The Inner Wheel Club of Wellington** (Shropshire) we were delighted to receive **£50** from them – **thank you all.**

Huge congratulations to **Flossie England** who completed her first ever 10k Run in the searing heat at the Asics London 10K - so far Flossie has raised a fabulous **£420** and completed the course in 1.07.13 - **well done Flossie what a great result!**



Kim Hawksby gave a talk to "**The Open House Ladies**" which as ever, was wonderfully received the ladies donated **£40** to the Charity – thanks ladies and Kim of course!

Matt Griffiths has been compering Wrestling Matches and his wrestling club, Royal Imperial Wrestling from Port Talbot in Wales held a collection for our Charity and raised **£40** well done Matt and everyone involved.

Our thanks also go to **Tyndale Vets** in Gloucestershire for their generous donation of **£37.50** which Director Ben donated on behalf of Jess Hemmings and her daughter Poppy – **thanks guys**

Karen Bartlett very kindly thought of the Charity when her father Keith William Bartlett passed away and asked for donations in lieu of flowers at the funeral. We received a lovely donation of **£315**. **Our thanks go to the family for thinking of us at such a sad time.**

In addition to this **Karen** sent donation from the collecting tin she has at their **Butchers shop Hoptons** in Chester this time we were staggered to receive **£462** - **thank you all** so much we really appreciate the kindness of your customers.

Our lovely member **Henry B** who regularly helps at his Nans sweet shop Sweet Thoughts in Gloucester, and once again Jan has been fundraising for our Charity by raffling this gorgeous Easter bunny which was won by Olivia – Jan sent a lovely donation of **£80 plus £20 Gift Aid** Thanks so much for your ongoing support!





Hello everyone...

...I thought it was about time to update you all on the big baby trial.

Firstly, a little bit of background of the trial. The big baby trial started in 2017 as a collaboration between Warwick Clinical trials unit at Warwick university and the Perinatal institute in Birmingham. The aim of the trial is to see if the incidents of shoulder dystocia can be reduced if the mother is induced at 38 weeks, or is it better to let the mother go full term with the baby and start labour naturally?

The mother is asked if they wish to take part in the trial and if they agree their details are placed into a computer algorithm and then randomly selected for early induction or left to go to full term. The trial is aimed at mothers with babies measuring over the 95th Centile at 35-week scans.

In the last 5 years we've recruited over 2 thousand women, still a way off our estimated 4.000 that we were hoping to get by July 2021, but thanks to Covid and a few other factors we're a little bit behind and have requested a couple of extensions that have been granted thankfully.

We've also held a couple of seminars, one face to face and one online, both of which were very well attended and, on both occasions, I was able to give a more human side to the trial by telling them about my son's birth. We also had to stop the trial through the first lockdown as hospitals were very busy and a lot of midwives were posted elsewhere in the hospital.

So fast forward to 2022, we're still meeting bimonthly remotely, strangely I miss travelling to Warwick CTU and meeting face to face with the team as well as being able to sing along [all be it very badly] in the car to my music on the journey

One of the team members has also been very busy with her studies and has had a paper published in several different medical journals and due to the groups help and participation we have been mentioned in the papers so its helped spread awareness of our support group with in the medical practices in the UK and Europe.

We've also started a 2 up programme as we wanted to see there's any long-term conditions including Erb's Palsy that the child has been diagnosed with or is in the process of being diagnosed. We are hoping to eventually follow them until the leave school, but at present that's a long way off.

Recruitment is also picking up; we have lost several hospitals but have gained new ones so were getting back on track slowly.

So onwards and upwards and carry-on recruiting.

Jackie x



Hi everyone,

I just wanted to write a little something about my weekend takeover for an Instagram account called 'behindthescars'

The whole idea of the account is to encourage conversation and provide a platform for individuals to tell their stories whilst unintentionally raising awareness of little-known conditions.

As someone with Erb's Palsy, I know all too well the importance of raising awareness of conditions people haven't heard about in everyday life. I guess that's one reason I took the opportunity, so if one person learnt something it might just go on to help someone in the future. Another reason I chose to take the opportunity to tell my story was to show other people that these scars on my body are nothing I will be ashamed of anymore.

Growing up, I really struggled to accept my arm as part of me and I was anything but proud of my scars. I avoided questions about my arm and lived most of my childhood in denial about my injury. I felt angry that my life revolved around surgeries, physio, occupational therapy, hydrotherapy, splints, more physio, specialist equipment, support in school, legal assessments, court visits etc. I felt embarrassed and a failure for not being able to do things like everyone else. On top of that I was autistic but wouldn't go on to receive a diagnosis until I was 15 following a mental health breakdown.

Fast forward to today. I am 26 years old. I have had many operations (both related and unrelated to my arm) and I have many scars as a result. Some from surgeries, some from the lowest points in life when I ended up self-harming and others from just being generally quite clumsy! My most unique scar- that Prof Kay told me to always be proud of is the one on my inner elbow; a harry potter shaped scar. At the time I thought he must be joking to think I'd ever be proud of it but now I can see his point. Embrace what life throws at us because the weight of feeling constantly embarrassed by my arm was so much more draining than the effort it took to work on changing my life for the better.

My scars are a reminder of where I have been and the journey in life that I have had to travel. Some I wear with more pride than others and some of my scars get more judgements than others, but I've learnt to accept that they are and always will be a part of me now. They don't define who I am and I have the ability now to tell people why they are there and what they are from. If



I could talk to the younger me, I'd tell myself that I'm okay. I'm perfectly fine the way I am and it's not for me to compare myself to others. There really is no such thing as 'normal'. Participating in the Instagram takeover gave me a chance to prove to myself I could embrace the things that are slightly different about me and nothing awful would happen.

A little message for anyone else struggling to come to terms with their injury or scars or anything else in life, be proud of all that you are because each of us with Erb's has a similar but yet unique story to tell. And even though we might not have two working arms, we have something so much stronger than that; a community that understands and reminds us, we aren't ever alone.





First Fun Day!

This was our first Fun Day with the Erb's Palsy Group and to be honest we didn't know what to expect.

We were eager to attend to meet some of the trustees and personally thank them for everything they have done for us and our family and most importantly our little Sophia. The activities set out were outstanding, absolutely everything was so well thought out and we were quite honestly overwhelmed with how much there was on offer! After a long drive we felt really nervous walking in but we were greeted by Jackie who was as lovely as she has always been in every conversation I've ever had with her (and there's been a lot ha-ha) she immediately made us feel like we'd come home and we were amongst family.

Having never met anyone other than our Sophia with Erb's or any other parents/carers with a child with Erb's, we felt a bit overwhelmed. We were finally somewhere where everyone knew how it felt, what Erb's meant and that was a very emotional experience for us. Beautiful but emotional. We were in awe of children climbing the rock wall and watching their determination. We were amazed by the strength, courage and bravery of so many individuals all with huge smiles who gave us comfort and joy.

I'm not ashamed to admit the journey home we reflected and I shed a few tears. We were filled with such love, such comfort, such knowledge and compassion. We felt humbled to be in the presence of so many amazing people. We felt we could learn from their courage, their determination. We needed a day like this having buried a lot of our emotions and feelings surrounding the trauma of Sophia's birth and her injury. We just went into autopilot and this fun day woke us up.

Thank you to everyone involved for making a day so special it will remain with us always. Thank you for allowing us and encouraging us to be a part of a huge special day. We can't wait to attend the next and the next and the next ha-ha. We hope that as Sophia grows these will be memories she will cherish forever. We will never forget our first Fun Day with you all.

Thank you for being our Superheroes!



With love from
Stacey, Hayden,
Mia-Ella and
Sophia x



Narakas 2022

Berlin May 2022

This year I was fortunate enough to attend the Narakas conference as one of the Erb's Palsy Group attendance.

Unfortunately given the issues surrounding Covid for the last few years and some of the planned presenters falling ill with Covid 19 this meant that there wasn't the usual number of delegates present in Berlin.

Similarly there were a number of different pieces of work that were not able to be completed, which resulted in a number of presentations that focused around more technical aspects of Managing Brachial Plexus injuries or statistical work, rather than the usual studies of actual physical aspects of managing the injury.

Because of this a lot of the presentations did not focus on break throughs in technique, but rather designing mathematical approaches to analysing Brachial Plexus injuries the same way across different countries and clinics, or reporting on the statistics in their area.

However there were a few interesting pieces of work around the technology that can be used to work try and support the surgical side of treating Brachial Plexus Injuries. One piece of work was based around attempts to try and use MRI imaging to map the Brachial Plexus so that it can be examined without needing surgery. Sadly it was not completely perfect but with the research still ongoing it is possible that this might become a

more viable option in the future in order to examine the nerves without needing surgical means. However one problem that they found during their research is that Brachial Plexus injuries are not common.

From our perspective this is a good thing, but medically it can prove to be a problem when you are looking at performing research. One of the speakers was a Medical Student from America who looked at the previous studies of Erb's Palsy, and found that all of the studies have very small numbers of patients, which makes it hard to get concrete outcomes from. They also used different methods to assess and grade the injuries which meant that it's not a simple matter to simply group different studies together. This is one of the reasons why a lot of the work this year was designed around a project to try and unify the grading systems into one international standard, as it would allow the different studies going forward to pull upon patients from different area and increase the information that can be taken from them. That and the Fact that statistical work was more appropriate over the last couple of years.

This was my first ever Narakas Symposium and I was very intrigued by the level to which this injury is studied and by the number of countries around the world working on trying to achieve the best outcomes for people injured. It is clear that surgeons are now working in collaboration with a range of other fields within the medical world to ensure that they can capture meaningful data and help both them and families of those affected to achieve the best outcome possible.

I am sure there will be much more to report after the next symposium in Turin in 2025!

Gavin Hillier





Harrogate Pavilions 25 June 2022

This was the first family funday the group had held since 2018. The event had been postponed for the last 2 years due to COVID. The sun shone and it was a great turnout with 200+ people attending. It was lovely to see so many familiar faces after such a gap – but also to welcome lots of new members we had not met before.

From our perspective, and from the comments we have received so far the event was a great success. We always ask for feedback, both positive and negative because we want this to be an enjoyable event for our members, and to improve it year on year. So please do contact us and let us have your thoughts.

However we thought it might helpful for you to know what goes on behind the scenes, in terms of the practical and financial considerations which guide the decisions we make.

The main purpose of the event is to get people in our community together. Erb's Palsy is a rare condition and without these events many would never get the opportunity to meet others with the condition. Families hopefully will forge friendships – share experiences and support each other.

Whilst we ask for a small donation from those attending – this is only a nominal contribution. When we begin the planning, we cross our fingers that charitable grants and external funders will cover the majority of the costs which can run into several thousands of pounds.

A huge amount of organisation goes into the event – which is normally at least a year in the planning. Location wise we rotate between the North, Midlands and the South so that within reason, we can reach people all over the Country and minimise their travel.

Finding a venue however is not easy – it needs to be the right size, with easy transport links and parking, have suitable facilities, accommodation close by and of course come within budget! But with a new venue (even having visited it at least once, spent hours on the phone with the venue management and the activity providers, drawn up several versions of plans), you never can really tell if the space and layout will work until the event goes ahead. Even then the weather will often thwart you – as you can never reliably predict that!

A lot of thought, research, planning and budgeting goes into the activities. We want to keep it fresh and so we try new things. We also really do try and include a range which will appeal to all interests and all age ranges, but you will appreciate that we do have limited funds and we won't know the demographics until the members actually book. By that time it is too late to make changes. We are often asked for more activities for older children and teenagers and we do organise these but often find that we just don't get enough by way of numbers. A lot of these activities are then not suitable for the younger ones.

Incidentally we have tried to organise a separate teenage only event but unfortunately there was very little support for it.

A frequent comment made at previous events is that people would like more encouragement or facilities to bring people together and mix, teenagers particularly, other families and the Trustees. So for some years now we had sessions where you can "Meet the Trustee", we have also had "care and share" sessions where teenage members can chat informally/confidentially with young adults with Erb's, and this year we also had a "Teen only area". We also tried a personal treasure hunt this year. Those wanting to participate were given the name of another family and they had to try and "hunt" them down during the day with the hope that they would make new friends.

Unfortunately these ideas seemed to have had limited appeal on the day – perhaps people were having too much fun!

All things being well it is our intention to hold next Family Funday in 2024 and this is likely to be a Midlands located venue. This is of course subject to getting the funding and support that we need, and we very much hope that you will join us again.

But in the meantime please do let us have your thoughts and suggestions – these are always very welcome.

Finally a very special thanks to Debbie Robinson – Deputy Chair and Funday Co-ordinator – without whom this event would not happen, and of course all our 2022 Funday helpers supporters and our funders.

The Board of Trustees



What is financial planning and why is it important?

Financial planning involves thinking about your current financial situation or funds that may be available to you/a family member (i.e. a legal settlement) and determining and defining the short term and long-term financial needs and goals.

In determining these needs and goals individuals will be required to think about why the need/goal is important to them, the level of funds that will be required to meet this goal and the timeframe within which the funds will be needed.

A short-term need/goal is defined as those which will occur within approximately 5 years from the plan being defined whilst long term needs, and goals are those which are likely to happen after 5 years. A good financial plan will often involve apportioning the funds available between these short- and long-term financial needs.

An individual's financial plan will be unique to them as everyone has different financial needs and goals and often these can change overtime or new needs/goals may become more of a priority and it is therefore important that any financial plan is regularly reviewed and updated to ensure that it remains on track and any changes to the objectives for the financial needs/goals are taken into account.

Whilst it is often possible to construct your own financial plan it is typically recommended to develop a plan with the use of an independent financial adviser. A financial adviser will spend time with you to understand your needs, define your goals and assess and explore your attitude and tolerance to financial risks and situations to underpin your approach to risk that you are prepared to take in order to meet those longer-term financial needs. This will then underpin the strategy for the overall financial plan outlining the suitability of how it can meet your needs and goals. Any good financial adviser will usually undertake these initial steps without obligation or fees so that you are able to consider the services being provided and why they are suitable to you and your situation.

How to establish a relationship with a financial adviser?

Ask for recommendations: usually many of our clients are referred to us for advice via professional connections (solicitors, accountants etc) or via existing client and friends and family.

Ensure that they offer the services you require: in relation to legal settlement financial planning are the financial advisers specialists in this area of advice, how many other clients do they work with and can they give examples.

When you have received recommendations for financial advisers and firms that you wish to consider engaging with it is important to ask the following information:

- What are the qualifications held by the individual that would be advising you?
- How much experience do they have and how long have they been with their current firm/company?
- What are the services they offer and how do these meet your needs?
- What are their fees/charges and how is the fee structure applied?
- What is their investment approach and how does this meet your needs?
- How does the initial advice and on-going relationship/service work? (i.e. frequency of meetings/engagement etc).
- What is the succession planning should the financial adviser leave the firm or no longer be able to advise you as a client?

The above information will provide transparency on the advice process and help begin to build the foundations between you and the adviser which should be designed to be a long-standing relationship.

CONTACT US

- 21-27 St Paul's Street, Leeds LS1 2JG
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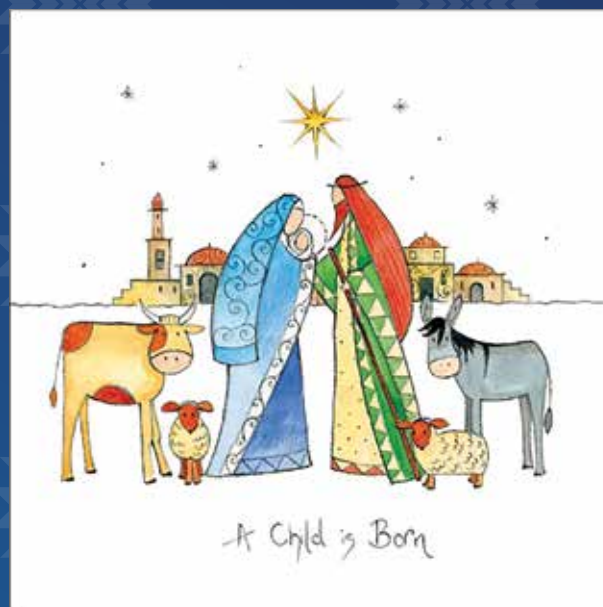
CHRISTMAS CARD SNEAK PREVIEW FOR 2022!

Yes we know, we've just had blistering hot weather and we are featuring our 2022 range of Christmas cards!

Here we have a quick preview of those we will be selling on behalf of the Charity this year

They will remain fantastic value for **10 cards** all cellophane wrapped with envelopes and featuring our Charity information for **£2.50 per packet**.

Keep an eye on the website -they should be for sale from Mid September on a first come first served basis!



Case study:

RWK Goodman have successfully settled liability on behalf of a 15 year old girl who sustained a right sided brachial plexus injury at birth. The hospital trust have admitted that negligent force was applied by the midwife in delivering our client, such that it caused her Erb's palsy injury. As the case is ongoing, the facts have been anonymised.

The Claim

The first thing you will note is that our client is now 15 years of age. It was not until our client was 10 years of age that her mother contacted us to see whether or not her daughter's injury was something that could have been prevented. Parents have many reasons for waiting to investigate a case, usually in the hope that the injury will get better of its own accord, but in reality for many parents there are diverse and complex reasons relating to not only the circumstances of the birth, but their own family circumstances which hold them back from investigating a potential claim.

After the initial approach from our client's mother, we obtained an expert report from a consultant obstetrician, which was critical of the management of the shoulder dystocia that our client experienced at the time of her birth in light of an awareness that she was going to be a larger than average

baby. The opinion was that the damage to the brachial plexus occurred during excessive traction applied by the midwife after shoulder dystocia was recognised, without the use of any of the recognised manoeuvres designed specifically to deal with shoulder dystocia. It appeared that rather than using the trialled and tested formula of various positions and manoeuvres, they simply tried to achieve delivery with increasing amounts of force.

A causation condition and prognosis report was then obtained from a consultant in plastic surgery with a specialist interest in obstetric brachial plexus injuries, which confirmed the injury as a direct result of excessive force and confirmed that sadly the condition would be permanent.

A formal letter of claim was sent to the Hospital Trust setting out the breach of duty of care as is required under the Pre-action Protocol for Clinical Disputes. Despite there being a four month time frame within the protocol, it actually took almost 18 months to get a full letter of response due in part to the delays caused by the Covid-19 pandemic.

The Outcome

Fortunately the Letter of Response admitted breach of duty on behalf of the hospital trust for causing our client's injury and we are therefore now in the process of valuing her claim.

A formal letter of apology was also sent to our client

and her mother from the Trust.

Whilst this is excellent news for our client, in that we will be able to get her the compensation she needs to provide her with help, aids and equipment and anything else she will require for the remainder of her life, it was also incredibly important for her mother.

The Unexpected Outcome

Whilst it is not unusual for mums, in particular, to unnecessarily blame themselves for what happened, in this particular case I was unprepared for the reaction from my client's mother to the admission and the apology from the hospital.

In the first instance, she burst into tears, which she then said she was not expecting to do. She then revealed to me that it had been like a great big weight had been lifted from her as she had blamed herself entirely for her daughters' injuries for the previous 14 and a half years. This sadly came about from some very unthinking and untrue comments made by the doctors at the time of the delivery and when the injury was discovered.

My client's mother had a high BMI, and was told that her daughter's injury would not have happened if she had not been so overweight and had been more cooperative during the delivery! This was compounded by when she had read her medical notes, which she felt were untrue.

To put the blame on the mother in this situation was completely unacceptable and she has carried that guilt for far too long. She went on to say that every time her daughter cried because she couldn't do something with her arm/hand, or cried when she was having injections to ease her condition, she struggled mentally to deal with the guilt. This in turn made her quite depressed.

I was horrified to think of the affect those few sentences have had on her for such a long time. I immediately advised her that what had happened was never her fault and now it has been set out in

black and white for everyone to see, that the blame lay with the Trust.

Since that admission has been made and the formal apology received from the Trust, the wider benefits of investigating the claim has been palpable for both mum and daughter.

Next Steps

We are now in the process of getting an interim payment to help with our client's immediate needs whilst the psychological benefit and recovery continues.

I look forward to updating you in due course about settlement of damages in this case and sharing the findings of the experts we have now instructed to help us with valuing the claim.

Erb's palsy cases are very varied in terms of experiences of mothers during their delivery and the injuries incurred by their children. Whilst the injury in some respects is the same, the degree of injury is always different and the needs of the person with the Erb's palsy will always be different. It would be my view that each case should be considered and investigated by specialist solicitors as they can be complex and technical. It is also good, for both the person with the Erb's palsy and their family to really understand what happened and to experience the benefit of knowing one way or another whether anything could have been done differently to prevent that injury.

If you believe that you or your child may have an Erb's palsy claim or a linked maternal injury claim, then do please contact us as we will be only too happy to discuss matters with you.

Lucy Norton

Senior Associate



Gender Dysphoria, Transition and Erb's Palsy

Background

Gender dysphoria is currently a very hot topic and I write this article based on my experience of gender dysphoria and transitioning in the context of practicing as a solicitor specialising in clinical negligence claims for Erb's Palsy.

This article will firstly provide a definition of the condition of gender dysphoria together with some background to the treatment available. Secondly, we have a very open and personal account of a mother of a child with Erb's Palsy who is currently going through the transition process. Thirdly I will set out my experience of dealing with this issue in the context of Erb's Palsy Claims, including the challenges this presents in quantifying the claims.

Definitions

When I first came across gender/body dysphoria it was in the context of a clinical negligence case and, as I had not come across the term before, I initially confused it with "body dysmorphia". I have since discovered that I am not alone as this is a common mistake and I have even seen the terms incorrectly used interchangeably by medical experts within their reports.

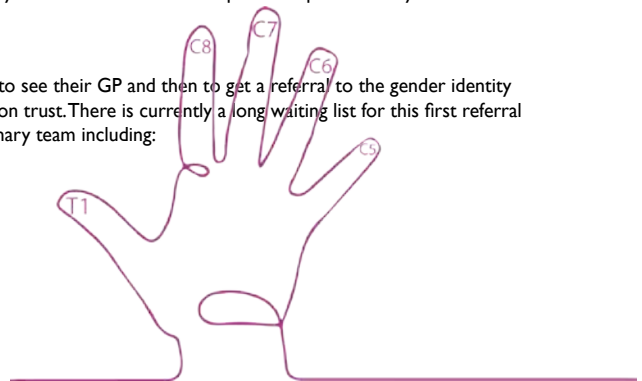
Body dysmorphia is a mental health condition and is defined as a sense of dissatisfaction with one's body and the perception that it is flawed or defective. This can manifest in perceptions of "bad" skin or hair or most commonly the perception that one is "fat" despite evidence to the contrary.

Gender or body dysphoria is defined on the NHS website as "a term that describes a sense of unease that a person may have because of a mismatch between their biological sex and their gender identity". It applies to both males and females. This sense of unease or dissatisfaction may be so intense that it can lead to depression and anxiety and can have a harmful impact on a person's daily life.

Treatment

For a child experiencing gender dysphoria the first port of call is usually to see their GP and then to get a referral to the gender identity development service (GIDS) at the Tavistock and Portman NHS foundation trust. There is currently a long waiting list for this first referral (see below). Once referred the child will be dealt with by a multidisciplinary team including:

- child psychologist
- child psychotherapist
- child and adolescent psychiatrist
- family therapist
- social worker.



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TOZERS

This assessment takes place over a period of 3 to 6 months. There is:

- family therapy,
- individual child psychotherapy,
- parental support counselling,
- group work,
- regular reviews,
- referral to local Children and Young People's Mental Health Services for more serious emotional issues,
- referral to specialist hormone clinic for hormone blockers for children.

At this stage most of the treatment is psychological rather than medical as for some young people this may not be something that they want to take further. Once that assessment has taken place then the first medical intervention is puberty blockers. The purpose of puberty blockers is to halt the physical changes of puberty such as breast development and facial hair. Previously it was thought that this was like pressing a pause button and up until June 2020 the NHS website referred to the effect of puberty blockers as being "considered to be fully reversible so treatment can usually be stopped at any time". Following a recent court case this narrative was changed so that since June 2020 the NHS website now says "although GIDS's advised this is a physically reversible treatment if stopped, it is not known what the psychological effects may be. It is not known whether hormone blockers affect the development of teenage brains or children's bones. Side-effects may be hot flushes, fatigue, mood alterations".

By way of background puberty blockers were first used in a Dutch clinic in the 1990s. Up until 2011 in the UK puberty blockers were only available to over 16s but from 2011 they have been prescribed to 12 to 15 year olds and are also considered for under 12's if they are considered to be in established puberty.

From age 16 teenagers who have been on hormone blockers for at least 12 months may then be given cross sex hormones also known as gender-affirming hormones:

- for those born male (natal males) this is oestrogen which causes breast development
- for those born female (natal females) this is testosterone which causes breaking or deepening of voice. Further treatment may then be undertaken in relation to double mastectomy – hysterectomy and genital reconstruction.

Long-term testosterone may cause temporary or permanent infertility and there is uncertainty about the risks of long-term use of sex hormones. The cross-sex hormone treatment is for life and there will need to be continuous hormone monitoring.

Prior to natal females starting on testosterone treatment a discussion needs to take place, often at a young age, regarding the harvesting of eggs. If this option is taken, then this may cause a delay in treatment.

Young people aged 17 or older may be seen in an adult gender identity clinic or be referred to one from GIDS. In terms of treatment for adults this includes psychological support, cross sex therapy and speech and language treatment.

An interim report of a review commissioned by NHS England in 2020 has reported that the available treatment service is now very oversubscribed with the wait for a first assessment at a gender identity disorder clinic as being up to 2 years. This is due to a marked increase in referrals to GIDS. In 2010-11 there were 138 referrals whereas in 2020-21 this had increased to 2,383. In 2011 there was a 50/50 split between referrals of natal girls and boys whereas in 2019 76% referrals were of natal females. Interestingly a significant proportion of those referred had received a diagnosis of autistic spectrum disorder. It has been reported that this increase in referrals has left staff at the GIDS feeling overwhelmed and left young people "at considerable risk" of distress and deteriorating mental health.

This is obviously incredibly difficult to navigate not only for the young person themselves but also for their family as described below from a mother's perspective.

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Parental Perspective and EPG Support

We've often referred to the 'Welcome to Holland' Poem in terms of how you may feel with regards to an Erb's diagnosis - for me, this isn't too dissimilar to the feeling I am experiencing today ... sat on a train to London for our first top surgery consultation. This was not where I had envisaged myself 23 years ago but here I am!

When X was born, ironically wrapped in a blue blanket as she was whisked to SCUBU, grandparents in the waiting room thinking we'd given birth to a boy only to be told hours later that no, in fact, we had a daughter ... maybe we should rewind and say actually the midwife got that bit right with the blanket!

For the next few years, we focused on our beautiful, curly haired daughter and her medical needs for Erb's Palsy not thinking there may be other needs to deal with in the future of a different nature.

Of course there were signs along the way but not in our case until secondary school – prior to this we had the love of dolls and all things pink! At aged 12 this changed to what we believed was a self expression of fashion and no more and it wasn't until aged 21 when our son had the courage to speak to me and tell me he was transgender had this ever crossed our minds – looking back however the signs were there. Had we chosen to ignore them? I don't think so. I consider myself to be very accepting ... if our daughter wanted to wear male trousers and boxer shorts, so be it! When she wanted her hair short from the gorgeous, long, curls, again, so be it – I couldn't deny that it would be 100% easier with Erb's and added another level of independence. Admittedly the distress around periods and the horror at bra fittings should have been a wake up call ... but I am only human. Maybe the late night chats, tears, self doubt, lack of confidence whilst a decline in mental health took hold was another pointer but I took them at face value.

Following disclosure and that is something I struggle with – why should anyone have to 'disclose' who they are in 2022?! - suddenly everything seemed to move very, very quickly ... name changes, referrals, telling everyone – I wanted to scream ... wait ... I'm not ready for this. It felt like a bereavement, not one that I ever shared with my son because I was and still am incredibly proud of him, but I very much mourned the loss of my daughter. There are still times when I do – the use of his original name on tv, the recall of a baby memory ... we have however come to a mutual understanding that we cannot erase the past and can only move forward. And as for using the new name and pronouns ...

I do make mistakes and when I do, I get 'the look' – a quick apology is all that's needed though. He knows we cannot change a habit of 21 years overnight but we're trying and that's what counts.

Welcome to Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel.

It's like this.....When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy!"

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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The navigating of friends and family ... in reality that should not have been an issue. This was my child and no matter what I stood alongside him and always would and anyone who cared would do the same. Luckily, for the most part, we both had a very supportive network and their love poured out to both of us.

I admit I wanted to press pause and believe this would be many parent's natural instinct – this is difficult when you have an adult child who we have to remember has dealt with this for a lot longer. Just because it was new to me, it wasn't to him! WE needed to play catch up!

So, to find the waiting list for services was months was such a relief to me initially ... we could take time ... pause for breath ... get things right ... allow the mental health of gender dysphoria to take hold further ... see the evidence of self harm appear ... this was not good! And continues not to be. What started out as an 18 month wait for adult services is now at 36 months plus for a first appointment, there is then a further 24 months for the second appointment in our area. No wonder suicide rates amongst the trans community is so high. This changes your perspective as a parent massively!

And that is why I am sat on the train today on my way to see a private consultant for top surgery with my son. He is in a 'fortunate' position – I use the term lightly – to have the funds from a successful Erb's legal case years ago that we were able to approach a private provider for support, medication and referral. Again, this didn't come without concern – surely the NHS provision and the support/counselling service was preferable than a service you can choose to opt in and out of?! Surely we shouldn't have to pay for a service that is available on the NHS?! What if who he has picked from the internet is someone random?! Yet again, the mental health side kicked in and the improvement in attitude, behaviours, and general outlook made me confident that this had been the best option for ourselves. 12 months on Testosterone has certainly been good and everyone can see how much happier he is. The smile opposite me as we travel to London is priceless.

Please do not think through these ramblings that I am not understanding nor that I know everything ... I know I don't! But I do try ... I also know we live in a world where inclusivity is key and things have changed greatly for the better but there is always more that can be done ... I know I was biased by the conformities of blue or pink, male or female, when I was pregnant and there is so much more ... I have a healthy, loving child (adult now!) whom I love unconditionally, who has taught me so much throughout his life and I know I get it wrong at times – he tells me so! I am however prepared to listen and learn. Not everyone is so willing and it was (and can still occasionally be) quite a lonely experience to begin with – wondering who I could/should talk to ... the LBGTQ+ community is one huge positive strength as my son has never lacked others to talk to, confide in, ask advice of but in my area the support available to parents isn't as good but as we navigate this journey together I know the Erb's Group will extend that support partly because being trans with Erb's has come with some additional considerations ...

*Shaving ... facially this isn't yet a problem but will be new territory. Underarm is no longer an issue though!
Hair styling ... a shorter style has been a Godsend as there is little to no styling involved and washing is so much easier.*

Binders ... oh my goodness! These are clearly problematic purchases without Erb's to ensure the correct fit and with companies refusing returns for such items, can be an expensive product. Clothing has in the past been bought with ease of putting on and therefore loose rather than tight fitting – this defeats the purpose for a binder and is consequently very difficult to put on. Many a tear from us both has been shed having had independence taken away as I attempt to get it on and off! There are some available with zipped fronts but these aren't much easier and again don't give the desired fit but can be sourced. As with a number of things, time and determination has found a way for the binder to be worn and removed with no intervention. Our recommendation for binders would be: Spectrum Outfitters.

Top Surgery ... with breast tissue being close to the nerves/muscles leading to the Erb's arm concerns have arisen as to the effect this surgery could have on that area ... I needn't have worried and my concerns were put to bed by the consultant. He was however interested in and took on board the concerns regarding blood pressure and cannulas not being taken from the Erb's side and has noted that assistance may be needed from this angle during the hospital stay.

For now, that is all that has come to light in terms of Erb's and whilst this is my first time of approaching the subject with the Erb's Group I have every faith that their usual love, friendship support and advice will extend to issues relating to transgender if required – so please, if you need to reach out please do. I can be contacted via the Trustees and am happy to speak/email in confidence if wanted.

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Gender Dysphoria and Erb's Palsy claims

As referrals for gender dysphoria have increased, unsurprisingly, I have found that this is increasingly a factor in clinical negligence claims that I am conducting.

Recently in my caseload I had three adult Erb's Palsy clients all of whom are natal females and gender dysphoria was a feature in each of them. Each of these clients were at different stages of their transition journey.

One of the first issues faced in relation to the claim was the instruction of an appropriate expert psychiatrist. Various specialities and subspecialities exist within psychiatry but the most challenging issue was to determine whether I needed an adult or child & adolescent psychiatrist. The Claimant was now an adult but obviously gender dysphoria does not "develop overnight", and feelings of unease as to identity can start in childhood and adolescence.

I also had to consider the potential effects of gender dysphoria treatment in the long term in the context of the claim, but also taking into account that some clients were currently undergoing that treatment and therefore it was a delicate subject. For example, reduced bone density is now known to be a possible side-effect of puberty blockers.

It was very difficult to consider the long-term implications as treatment is still relatively novel and the information available is limited. However, it was crucial to do so given that damages are usually paid by way of lump sum and on a once for all basis taking into account long term prognosis.

Other issues thrown up by gender dysphoria relate to quantum. This is because when calculating damages we use gender specific data. For example, male and female life expectancy is different with females on average living longer than males. I had to consider what was the best approach. Also, data suggests that in modern society generally speaking males still tend to earn more than females – how should this be approached in a loss of earnings claim?

Another issue to consider was how gender transition would affect a claim for the cost of future childcare. This proved a little thorny in one case where my client had decided not to harvest eggs prior to transition.

I have navigated these difficult issues with my clients and with the help of experts and concluded 2 cases thus far, achieving very good settlements for my clients.

One thing that I have found to be invaluable in cases where gender dysphoria has been a feature is to say to my clients from the start that I am learning about this – and as a result I may unintentionally say things that are wrong or tactless. However, it is important that we work in a safe space where I am not afraid of making mistakes and they should not be afraid of setting me right. As a result we have been able to have very open and frank conversations which has been vital to me in informing the way I have been able to present the claim. I am very grateful to my clients for their patience and openness with me and for the education that they have given me on this topic both from a work and life perspective.

How can Tozers help?

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

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Kate Stone

Solicitor

k.stone@tozers.co.uk
01392 207 760

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Erb's Palsy Awareness Week

17-23 October 2022

Some ideas of fundraisers can include:

Cake sales, raffles, sponsored walk/runs, facebook fundraisers, gameathons, coffee mornings, sports challenges, sponsored silence, challenges plus many more!

Awareness week is a great time of year to raise much needed funds and awareness for the charity. Whether you share stories and facts on social media or commence your own fundraiser the support and efforts are great appreciated by all here at the epg.

We run annual fun day events for our members as well as local outreach days. In addition, we run annual conferences for health professionals such as midwives, physiotherapists and occupational therapists to educate and provide guidance on best practice procedures. We cannot continue to do this without your help and support!

Please contact amy swift – **ahopper16@yahoo.co.uk** for a free fundraising pack to assist you with your fundraising. Included are sponsor forms and leaflets plus merchandise such as pens, balloons, ribbons and wristbands.

Contact us: 02476 413 293 info@erbspalsygroup.co.uk

Find us on Facebook, Instagram and Twitter

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Erb's Palsy Group Fun Days of Past and Present

Age: 9. Year: 2009. Destination: Rugby. Current location: car. Estimated arrival time: as quick as legally possible.

From the CD player Kate Bush sings sweet melodies, and my mother echoes every note, every harmony, every verse, every chorus, every bridge, every backing instrument, every backing instrument she thinks is there but isn't, every outro, every... and so on. She smiles warmly at the empty road, and I can't help but wonder why Miss Bush would choose to run up a hill?

In fact, why would anyone choose to run anywhere? I've never been allowed to run so there must be something dangerous about it. What if as soon as I pick up speed my legs disappear, and I never get to wear light up Lelli Kelly's again? Or worse, what if as I begin to run my toes blast out tiny rockets that fire me up into space like a mega bounce on the trampoline? Then I'd be stuck, living in the stars forever, which could be kinda cool, sitting back watching the earth spin and catching the occasional shooting star. But they don't have apple juice in space, and that is most definitely not cool.

"Are you excited for the Erb's Palsy Fun Day?"; Mum calls from over her shoulder.

"Yes!"; I call back. I've never been to one before, but Mum says there'll be kids with arms like mine there, even some grownups too. Maybe they can tell me why I'm not allowed to run.

Age: 22. Year: 2022. Destination: Harrogate. Location: Harrogate. Arrival time: yesterday.

The Erb's Palsy Fun Day of 2009 was life changing for several reasons. For example:

1. There were, what felt like, hundreds of super exciting activities, for all ages, with everything from informative talks to snake petting.
2. All these super exciting activities could be adapted to any ability, empowering each person that took part.
3. It was basically a day where if you didn't have Erb's you felt like a weirdo. Which is right, you should feel like a weirdo. Using two hands is SO out of fashion and some people really need to get with the times.

Attending the Erb's Palsy Fun Day of 2022 was no different. Well, slightly.

This time I was one of the grownups I'd watched with awe at my first Fun Day, amazed that someone with an arm like mine had done everything an able-bodied person could.

This time I was the reassurance to parents and guardians that everything would be okay, that their little ones with Erb's would find a way to tie their hair, drive a car, even start a family if they wished – though, I've heard having babies can be extremely expensive so maybe hold off on that one.

At the same time, attending the event was a reminder of my own capabilities. Spending the day shooting arrows, completely off target, and taking embarrassingly long amounts of time to solve an escape game, may have proved I would never be fit for the navy; however, it also reiterated the lesson I'd learnt, at my first Fun Day: adapt the world to suit you, not the other way.

Many years ago, my first Fun Day taught me that I wasn't allowed to run because people were afraid that I'd fall and damage my Erb's arm further. Each event since then has taught me that that was not my problem, but that of others. Instead, I was to sprint through life, overcoming every obstacle, empowered by the incredible individuals I'd met at each Fun Day.



As a disabled person, there will always be battles to fight, but these events provide us with the armour we need to take on those battles. And that is why everyone should go to at least one Erb's Palsy Fun Day.

Rhi x

THEN...



...& NOW!



PEARL ANNIVERSARY BALL

SATURDAY 30TH SEPTEMBER 2023



Leeds Marriott Hotel
Please Save The Date To Join
Us Celebrating 30 Years Of
The Erb's Palsy Group



Whilst all plans are still in the negotiation stage and subject to change, please think posh frocks, casino tables, photo booth, live music and 3 course dinner with reception drink.

Ticket and Pricing Details to follow.

Ways To Raise Funds

Did you know you don't even have to leave the comfort of your home to help us raise funds?

We are much in need of funds to keep working and supporting families, especially as over the past 2 years most fundraising opportunities have been curtailed – we have seen a huge dip in our donations and fundraising efforts!

The Charity is registered with a number of partners who make donations to our funds each time you shop using their app or browser! The donation is made by the retailer and **it doesn't cost YOU anything extra! It really is money for nothing!!**

So how do we do it I hear you ask?



If like most of us you are a regular Amazon Shopper you can register at smile.amazon.co.uk or download the App – select our Charity for support and then shop via the browser or App each time you buy something a % of the spend is directly allocated for our Charity – you don't need to do anything else, the funds are sent through directly into our Bank Account each quarter.



Easy fundraising operates in a very similar way to Smile.Amazon – they have thousands of retailers registered with them from Argos, John Lewis, Tu, Sky TV, Booking.com, Go Compare and lots of others – they also have an App or a toolbar reminder for your PC browser – like Amazon the donation is paid by the Retailer and the customer pays NO extra for the donation – and again all the funds which accumulate over a quarter are sent directly to our bank account- it is so easy!



Pledjar is an App (And a Website) that makes donating to Charity easier. Once you have made an account in the App you can select any number of Charities that have signed up to receive a donation each week.

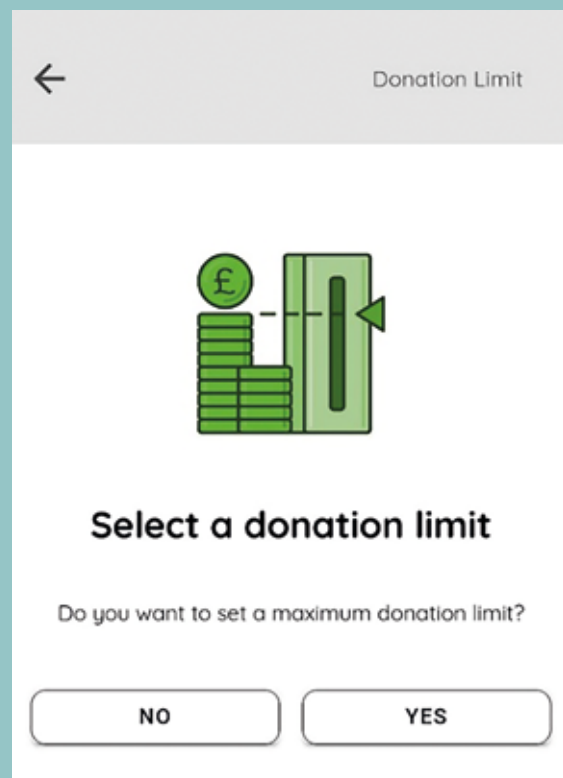
The Pledjar Account links in with your bank account and 'Rounds up' any transactions you make during the week. So if you send £19.50 on your favourite takeaway when you pay, Pledjar will round that up to £20. The takeaway will be paid in full and Pledjar will put the 50p aside in what it calls your Jar, to be donated to the charities of your choice at the end of the week. It might not sound like much, but by rounding up all of your transactions it soon adds up for the charities!

Pledjar also allows you to set maximum limits for how much it will round up each week. Once you have hit that limit it won't round up any more transactions so you can stay in control of your donations. The limit is easy to change so you can change it to suit your needs. Similarly you can easily change which charities you want to support simply and easily by searching for the ones you want and toggling the little switch next to them! This means you can easily support the Erb's Palsy Group only one week then add in other charities as you wish! Of course we would prefer you keep our Charity as your chosen one!

The app also allows you to view reports on how much you are donating, and to who, each month. So you can retain control of who your money is going to, how much, and how often! You can download the app through the Google or Apple stores and set up your donations within minutes.

Remember our code is

EPG001



Why make a Will?

Here are seven reasons why it's important to make a Will:

- 1 A Will is the only way** to guarantee everything you own goes to the people and causes you care about.
- 2 A Will makes it much easier** for your family or friends to sort everything out when you die - without a Will the process can be more time consuming and stressful.
- 3 A Will also enables** you to preserve assets for beneficiaries, by making specific gifts to individuals. These can range from items of jewellery to sums of cash or property and/or business interests.
- 4 Inheritance Tax** - a Will can help reduce the amount of Inheritance Tax that may be payable on the value of the property and money you leave behind.
- 5 Writing a Will is especially important** if you have children or other family who depend on you financially, or if you want to leave something to people outside your immediate family. The absence of a Will can sometimes lead to family disputes. Leaving a Will should remove any doubt about who you want to leave your estate to.
- 6 A Will allows you to appoint** Guardians to look after your children if they are under 18.
- 7 You can also use your Will** to tell people about any other wishes you have, like instructions for your burial or cremation.



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Achievements



Sharna has Erb's Palsy but it didn't stop her completing a 5k Tough Mudder course with 15 obstacles! Sharna reminded us all to "chase dreams and believe in yourself". **Well done Sharna!**

Max has received not one but THREE swimming badges/certificates all at once. With a Grade 4 BPI he struggles but is finding his own way to swim and enjoys being in the water. **What an achievement!**

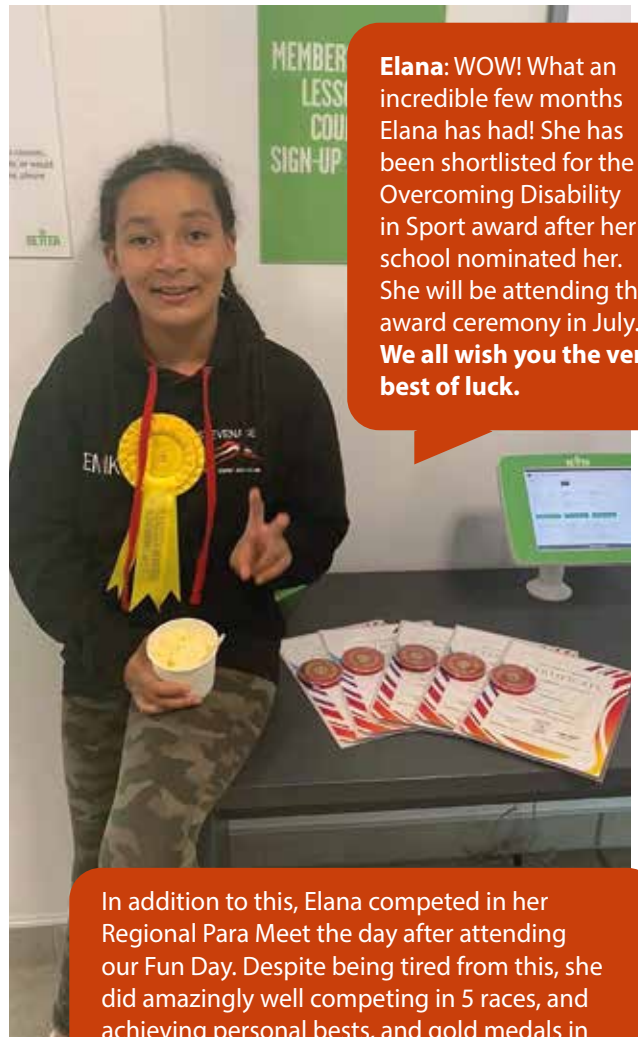


Coen has worked hard every week to achieve his white card skills at skating. Not only that but he has also earned an award in swimming too! **Keep up the good work Coen!**





Amelia danced in her first Cheerfest recently, it looks like you had a great time!

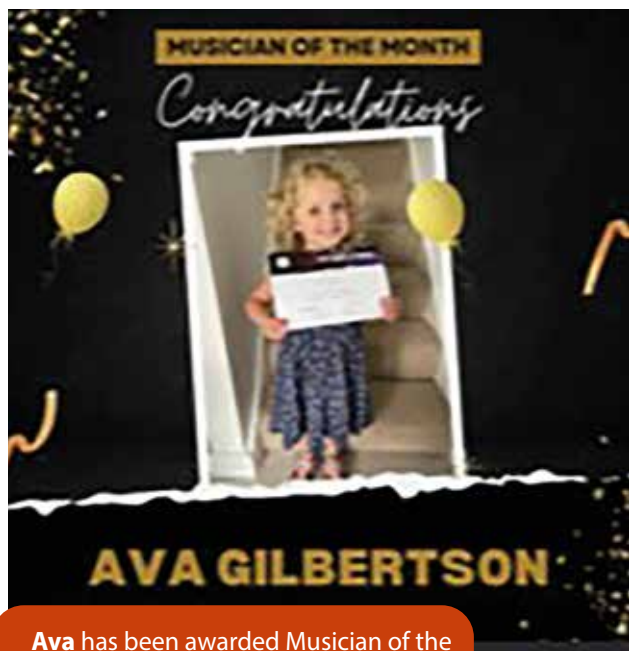


Elana: WOW! What an incredible few months Elana has had! She has been shortlisted for the Overcoming Disability in Sport award after her school nominated her. She will be attending the award ceremony in July. We all wish you the very best of luck.

In addition to this, Elana competed in her Regional Para Meet the day after attending our Fun Day. Despite being tired from this, she did amazingly well competing in 5 races, and achieving personal bests, and gold medals in EVERY race!



Well done Lyla for getting 2nd place in PE at school



Ava has been awarded Musician of the Month! Well done Ava!

Fun Day Reviews

This year's fun day was another astounding success! People travelled from across the country and we are so pleased you made the trip, having everyone come really shows us how far reaching our members are. It was lovely to meet new people, and greet old friends, some of whom we haven't seen for many years.

Thank you to everyone who has provided feedback after the day, which has been so positive. We are all thrilled you had as good a day as we did.

Seeing so many smiling faces really reinforces our belief that we all stand as one Erb's family and that was evident by the advice and support we know was passing between families. This support is essential and it is wonderful that the fun day can provide a catalyst to help as well as being a chance for some fun family time surrounded by like minded people.

Here are a few photos and some feedback received about the fun day.

Sorry we couldn't include everyone's photos, there were simply too many fantastic ones to choose from!

If you couldn't make it to the fun day this year, we would love to see you at the next one!

Praise for the fun day

What a great day...thank you all. He's been buzzing all night and the climbing wall has given him so much confidence to try new things. – **Ceri**

Thank you to all the Trustees and all of the other volunteers who put in so much effort to pull off a fantastic fun day! Your hard work is not taken for granted.

To anyone who missed it this year, hopefully you can make it next time, you'll have a blast! – **Trudi**

To all those involved with the organisation and running of the Fun Day in Harrogate last Saturday....THANK YOU SO MUCH!!!!

We had a wonderful time, meeting people and chatting, getting involved with new activities. But most of all it was just fabulous to see everyone with a smile on their face having a really good time!! – **Hilary**



We had the best time and so grateful to you for everything you've done for our family and all the other families you guys are our superheroes!!xx – **Stacey**

It was absolutely fantastic A big thank you to everybody involved, we had the most amazing time. – **Phil**

Well done guys xx above and beyond as always – **Jenna**



Thanks for a fantastic day at the Erb's Palsy Fun Day, so lovely to see everyone and meet new people. So much hard work clearly goes into these events, much appreciated - **Jenny**



Herbie said he had a lovely day meeting lots of you at the funday, he had lots of hugs and high fives. He even had a go at some of the activities. – **Jackie**



Our first ever EPG Fun Day, and you didn't disappoint. We crafted, made 'splat'

pictures, played crazy golf, did Henna art on our hands, won on the tombola, shot arrows, threw poo, climbed and climbed, bounced and span til we went pale faced, ate yummy lunch and met lots of wonderful people..... What a day - **Kirsty**



Thanks for a lovely day – **Beth**



Our first fun day we loved it. To everyone who made it happen it was amazing and to all the wonderful families we spoke to... so much kindness and knowledge shared. An amazing group of people – **Jodie**

We look forward to the next one. They have already made me promise to take them to it. Thank you thank you thank you – **Sarah**

Thank you for a fantastic day, had a blast and we had the pleasure of meeting some wonderful people. We will definitely be attending the next one – **Kimberley**

What a fab fun day that was! Thank you so much to the trustees and volunteers for making this day so special. Was lovely to see friends again that we have made over the years. – **Sarah**

I just wanted to say a massive thank you to yourself and everyone involved in running the fun day and the charity itself. It's been a lifeline for our family and the fun day was the cherry on the cake.

We weren't sure what to expect, especially bringing a two year old during her tantrum stage of life! But we had a wonderful day.

There were plenty of activities for everyone of every age and the location, the layout and the people were brilliant.

I feel I benefited the most from speaking to other families. I learnt so much from speaking to other mums for 10 minutes round an arts and crafts table than I've ever learnt from any doctor or physio. How crazy is that! The Erb's community is amazing.

Possibly the oddest activity – and one of the most fun for children and adults was this!

Debbie Robinson told us about her conversation with Sarah Taplin – Physio from the Leeds Clinic team.

Sarah Taplin/Leeds Physio: "Is it ok if we're creative and bring some fun activities to the Fun Day for the physio area?"

Me: "Yes of course! Do what you like, I trust your judgement



APOLOGIES to every parent in attendance who is now having to clear up any mess in their bathrooms!!

Never in my life did I expect a toilet and poo (fake I hasten to add)!

Best activity there though and made me wonder why I had booked expensive entertainment providers lol x

Splat machine

As ever Geoff's Splat Machine was in demand the WHOLE day with both adults and children making fabulous rockets and butterfly pictures as a keepsake form the day

We would like to thank the lovely Geoff Johnson for bringing the splat machine and also

Dave Wagstaff at Blowfish Media Coventry for the lovely boards the splats go on and to Raj Reddy at Goldenbox Ltd in Coventry for the brilliant pizza boxes to ensure they make it home safely- thanks so much guys- we really appreciate your kindness!



Yes, we had a LOT of activities – from crafts, to rock climbing, to indoor golf, to an Escape room competition and lots more!

The Trustees would like to say a MASSIVE Thank you to our funders and sponsors for enabling us to run such a fabulous come back event – without their financial contributions we would not have been able to have such a great range of activities;

OUR THANKS GO (in no specific order) to;

Tozers Solicitors LLP

Arnold Clark Community Foundation,

Ison Harrison Solicitors,

RWKGoodman Solicitors,

Magic Grants,

Dune Financial

WH Smith

Notcutts Garden Centre

The National Lottery Community Fund



Erb's Palsy Fun Day 2022

by THEO SWIFT, Aged 7

It started on the Friday when I got out of school early and pretended I was going to Physio. I drove down to Harrogate with my mam, nana and little sister Ayla. We then checked into our Premier Inn for the night and it was lovely! We had an hour to chill and then we got ready for the evening with the Trustee's.

There was a fun dinner on the night time where I got to stay up late and I made new friends with Max and another Theo. I even got to have the adult dessert which was my favourite - sticky toffee pudding! I wanted some wine but I wasn't allowed. My mam said 7 is not old enough and I need to be 18!

The next morning, we were up early for a full English breakfast before heading to the fun day. My mam said not to stress Debbie out but she looked happy I thought and was pleased to see me. I stayed with nana and had a bath while my mam went to set up, but I did get a sneaky look at the set up before it started which was good. I was pleased. Before it started, I got in line for the space ball when there was no one even in yet! I tested it for them and I could have died – but I didn't so that was good. It was so fun I went on it 7 times. Then I went on the rock climbing, it was amazing. The button at the top went oooooooooooooo when you pressed it and I pressed it 5 times as I got to the top every time! The lady helping me was so nice. They were my two favourite things.

I couldn't do VR as I wasn't old enough and I said I was 12 because you had to be 12 but they never believed me. I loved playing the tombola and putting on tattoos. I also got a really cool face painting of a black and white zombie. Herbie loved it too. I loved cuddling Herbie; Herbie is the best.

I also did a mobile escape room and I really enjoyed that too. I loved the dinner; it was very quick, and I didn't have to wait. After dinner me and Max had loads of fun chucking darts at the dart board and poo into the toilet – it was a physio game and not real poo by the way! It was really funny. I also did Archery even though I wasn't supposed to because my collar bone is broken. I asked the man to help me so that made it better and it meant I wasn't really being naughty.

I made two rockets on the splat and they were the best. I loved putting the paint in and I liked the man who helped me.

It was a fantastic day and I cannot wait for the next one.



BY Max Hole, aged 6

Thank you to everyone who organised the fun day. Sorry if you missed out on this fun day, hope you can come next time because it is so fun! It was good to see my EPG friends again.

I really enjoyed throwing the poo into the loo, the coding activity, and splat paint. My brother really liked the gyro spinner and the climbing wall.

I'm glad the escape room was outside as I wouldn't like to be locked in a room in case I need a wee!

The lunch bags were good because I could choose my sandwich. The flapjack was yummy but I didn't want the apple, strawberries are much better!

I liked seeing Herbie but I was too scared to cuddle him.

Please can I come to next fun day?



Hello friends!

I hope you are all enjoying your summer. There is so much to see and do in summer! You can go swimming, ride your bike or scooter, go for walks, play outside, visit the park. The possibilities are endless! What sort of things do you like to do when summer is here? I really enjoy seeing friends for BBQ's and playing in the paddling pool.



Stone Painting

A really fun summer activity to try is stone painting. It is really popular at the moment and people sometimes hide them for others to find. Below is a picture of an EPG stone I have painted which has been in my garden for a couple of years.

You can use felt tips or paints for this activity. If you don't want your design to wash off in the rain some varnish needs to be applied once it has dried to protect it.

I would love to see some of your designs, please feel free to email them to me at info@erbspalsygroup.co.uk and I will include your pictures in my next Herbie Page!



Summer Scramble!

Unscramble the letters to make words relating to summer. Good luck!

Answers are at the bottom of the page.

- ahceb _____
- ramiece _____
- ncssadleta _____
- hdvaloyi _____
- nnshisue _____
- ukbcet _____
- unsrcame _____
- nimgapc _____
- eiesdas _____
- wisnimgm _____

*Herbie's
Page*

JOKE CORNER

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

What is brown, hairy and wears sunglasses? **A coconut on holiday!**

How do we know the ocean is friendly? **Because it waves!**

Where do sheep go on holiday? **The Baa-hamas!**

What did the pig say when laying on the beach? **I'm bacon!**



ANSWERS: beach, icecream, sandcastle, holiday, sunshine, bucket, suncream, camping, seaside, swimming.

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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.co.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

