Helping children with upper limb differences live life without limits

within Keach

Meet Reach's New Ambassadors

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OCEAN J-KAYAK

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The Official Magazine of the Association for Children with an Upper Limb Difference

What's Inside

Branch Coordinators





Reach news & events



Welcome to new members



NEW! Editor's Column

Branch meet ups

- 21st - East Anglia

- 22nd - Ireland

Branch meet up

-4th - West Midlands

- 21st - Northern Ireland

Events 2021

- 15th - South London picnic

- 3rd - Virgin London Marathon

- 30th - The BIG Give Christmas

Challenge, Ends 7th December

- TBC - Christmas Parties

- 24th - 31st - RAW

EVEN

For details contact reach@reach.org.uk or the branch

- 23rd - Annual Family Day 2021 (Virtual)

- Limb Loss/Difference Awareness Month

- R5ach Charity Fundraising Challenge

Loen & Lando's Bursary story



From the Editor & Designer of within Reach

We're Max & Tom Swinhoe. We welcome comments, articles, requests, or suggestions for future editions of withinReach. Email Max & Tom at withinreach@reach.org.uk

Reach Membership





#RepresentationMatters

Meet our Wonderful Branch (oordinators

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Branch Coordinators Needed!

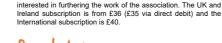
Are you in the South West or Kent and keen to get involved?

Contact Reach Head Office for more info email Reach@reach.org.uk.





All event news is on our website www.reach.org.uk and facebook page www.facebook.com/reachcharity.



Hello!

Reach Insurance

This covers any member aged between 2 and 85 years of age, resident in the UK, with a congenital difference of one upper or lower limb or both upper limbs or who have had one upper or lower limb or both upper limbs or one hand amputated. There is a slight difference in cover for under 16s and those not in paid employment at the time of their accident. Please call Head Office for more details about the schedule of insurance.

Membership is open to parents of children with upper limb

difference, and individuals of 18 years and over who are

Views expressed in withinReach are not necessarily those of Reach and are not intended to reflect or constitute Reach policy, or in any way portray an official view



AUG

SEP

OCT

NOV

DEC

APR

JUL

coordinator.



Happy summer – I do hope the sun is shining with you.

Light seems to be on the horizon for Branch events being able to happen at last. All Branch Coordinators are now looking at how they can make them happen safely.

Webinars

We broadcast and recorded sixteen #NoLimits Insights Webinars from January to May and the response was amazing. We hope you all enjoyed the range of content, from parents talking about their experiences and chats with prosthetic companies, to REMAP telling us all about the adaptations they make free of charge and Paralympians talking about their journey to success. Plus, Cornwall mobility, BOLDKids, Orla Duncan talking about how to handle upsetting situations, drumming with Cornell and Frank Letch sharing his expertise on the Disability Living Allowance. If you missed them, you can find them all on our You'lube channel. https://youtube/F.SxeMPKI70

Events

The restrictions have meant that the Reach North-West family weekend has been postponed unt next year.

We are so pleased that RAW went ahead and the children and mentors had a fantastic time.

Rob and Dawn's Tyn Cae went ahead virtually. Tyne Cae is normally a camping weekend that invites people to camp in the wonderful Welsh hills. We want to say a huge thank you to them (and their family) for putting this on year after year.

Annual Family Day

Plans for the AFD on Saturday 23rd October are forging ahead. Melissa Johns will be leading the arts section, there'll be a story corner, a talk with Open Bionics about the Hero Arm, discussions with our Ambassadors, the Reach Orchestra will be in the studio, Briony will give a cooking demonstration with some of our younger members, and plenty more entertainment for our Reach children.

R5ach (harity (hallenge – August 2021 – Get involved!

We are also really excited about our very first bespoke Reach fundraising challenge that will be happening in August. We hope it will be an opportunity to have some fun and raise some vital funds at the same time. If you would like more information, please go to our web page https://reach.org.uk/r5ach-challenge/



Debs Bond National Coordinator debb@reach.org.uk



Hi there

After so long in lockdown and I-can't-believe-it's-not-lockdown, I think some of us were beginning to wonder whether we would ever get back to normal. I know there is still some way to go, but it is great to see some opening up and the start of some live Reach events happening. Seeing the photos of RAW2021 was a great reminder of how important it is for the children in our community to be able to spend time with each other - here's hoping that a lot more of that will be possible in the weeks and months ahead.

But despite all the restrictions, there has actually been a lot going on in Reach-land, as the pages of this magazine demonstrate.



Chairs Report

The Trustee Board were delighted to appoint Melissa Johns and Briony Williams to join Frank Letch, Claire Cashmore, and Alex Brooker as our Reach Ambassadors, and Ella Dickinson as our Young Ambassador. What a wonderful star-studded cast we have helping to spread the word about our charity!

There is something really valuable about high profile public representation in helping to cement, in the public consciousness, the normality of limb difference, whether that is through TV celebrilies or models or characters in books, and to provides role models for the younger limb different community.

Role models are important to all of us in all aspects of our life. And they were an important factor in why the Reach oRchestRa was successful in winning the 'Excellence in SEND music and drama education' award earlier this year. The judges commented on our 'deeply moving work and astonishing achievements' which they saw as 'a fabulous example of collaboration between children and adults with similar disabilities, with long term impact and real wow factor for the sheer quality of the work as well as their deep commitment to inclusion''.

All of us who were involved in the oRchestRa project were delighted with the award, but the judges' comments about the long-term impact of inter-generational collaboration really struck home for me. One of the oRchestRa players commented that, when she was younger, she had never seen a musician with a disability. The real success of the project is that it shows the world - and crucially shows young budding musicians - that there are lots of wonderful musicians with upper limb differences and that it is possible to make music without limits, just like every other aspect of life.

Clare Salters Chair, Reach Board of Trustees clares@reach.org.uk





Reach was formed in 1979. Inspired by a 1978 Tomorrow's World programme featuring a new myo-electric hand being fitted to children in Sweden, two groups, which focused on upper limb difference, were formed simultaneously before joining together to become Reach.

(ontact Reach

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Annual Family Day 2021

Access for all! This year the Annual Family Day will be virtual once again which means more speakers, more workshops and more fun for and from our wonderful Reach community. Tune in on Saturday 23rd October 2021, from 10am to 5pm.



Lewis Humphreys received his bursary of £329.99 for an adaption for his

The Reach Bursary supports Reach's under 25s to fulfil their potential through the arts, sport, music, mobility or adventure, Discuss your ideas with Reach. Email Reach@reach.org.uk or visit reach.org.uk/apply-reach-bursary/ for more information.

Congratulations...

Keep track of the Paralympics

24th August -5th September

Find competition dates and times and follow the athletes online at reach.org.uk/reach-membersset-to-shine-at-paralympics/

2021 Evening Standard Future Theatre Fund

Reach adult and actor Beth Hinton-Lever's credits include an array of theatre. TV. and film performances and now she's been awarded the prestigious 2021 Evening Standard Future Theatre Fund for Musical Theatre.

Beth says Reach has always been part of her life, especially the RAW events, which gave her an abundance of confidence to know that 'where there was a will there was a way'. She took that confidence from her studies in archaeology to the stage, and she's never looked back ...

'I came to acting a pretty strange way. I had never seen any representation of someone who looked like me on stage, and especially not in musical theatre, which was where my heart lay. Because of that I never truly believed that it was a career that I would be able to pursue.

But whilst studying Classical Archaeology and Classical Civilisations at University College London, Beth says she spent half of her time doing musical theatre and it was there, in her final year, where her life took a different turn.

'I choreographed a musical that I very luckily ended up winning Best Choreography for at the National Student Drama Festival

Congenital upper limb anomalies

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News & Events

which opened the door into the industry for me. I was one of those incredibly lucky people who got plucked out of obscurity by a kind stranger who saw something in me. I left UCL with my degree and started work in the theatre pretty much immediately, and I guess, as the saying goes, the rest is history.

The 2021 Evening Standard Future Theatre Fund grants 12 recipients across the industry £10,000 each to help with their chosen career path and allocates them a mentor from the industry to provide support and guidance.

I've been incredibly lucky to have had the career I have so far, and I do hope it continues, but I also hope that we are heading towards an industry that is far more accessible, inclusive, and has far more accurate representation.

Open Bionics start trial days

Open Bionics, a manufacturer of bionic arms for adults and children, has launched Hero Arm Trial Days to support individuals exploring cutting edge. 3D-printed prostheses options. During the Trial Day, everyone has a chance to tour the Open Bionics HQ where the Hero Arm is made, see the engineers printing 3D parts for the bionic arm and meet fellow members of the limb difference community.

To find out when the next trial day is and to register your interest visit the Open Bionics website: www.openbionics.com/get-a-hero-arm/



11-year-old Ronnie had his dream come true, as he was recently fitted with an Iron Man bionic arm. Ronnie was born without his left arm and wanted a bionic arm so he could feel more confident. Ronnie's Hero Arm was funded by Tej Kholi's foundation. Read what Ronnie had to say about his bionic arm here

www.openbionics.com/11-year-old-gets-ironman-robotic-arm/

Online Webinars

Your online resource when you need it; we have webinars on everything, from learning to drive Allowance and PIP, to expert from our ambassadors and what it takes to

watch now

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reach.org.uk/reach-insights-nolimits-webinar-recordings/

We were featured in July's issue of The Society of Radiographer's magazine Synergy News

Successful Reach Bursaries

News & Events

My Reach Bursary Success

We're so unbelievably overwhelmed to have my Reach Bursary accepted!

By Loen Groom

I have been riding horses on and off since I was little (I am now 15) but in the last couple of years it has become a huge part of my life and upon finding an amazing trainer, Tracey Bateman, and realising that I have a passion for Dressage we started to look for a suitable horse to loan.

Who knew it would be so hard to find the perfect horse, after lots of tears and tantrums of being continuously let down, a beautiful Bay came up for sale at the stables where I learn to ride. He was a young, big, beautiful boy called 'Orlando PX' (Lando or Landy-Pops for short).

Tracev advised us to have Lando for a month to see if we bonded. I fell in love from the first moment I rode him, and it became apparent that we made the perfect team. 3 weeks later. after lots of cuddles, hacking, jumping, and schooling him we decided to go ahead and purchase him.

The following weekend we went to a Dressage show, we all got up early, including my sister Ellie, to go to the yard to get him ready. After a shampoo the night before we gave him a brush and plaited his mane and tail. He looked so handsome. We got him loaded into the trailer like a dream and we were off! I was so nervous but people from my stables Team. Phoenix Stud. helped to keep me calm. After two super tests we came back with a 2nd and a 4th! I was so excited and proud - this was the start of something so special!

As soon as we got home we started to look for more shows to enter. However, we soon realised that the costs would be very high; we were already paying a fortune with his livery, shoes

and of course all the other 'bits and bobs' alongside lessons with Tracey and my dressage trainer Charlotte Drakeley - so we started to think about sponsorship.

Scrolling through Facebook one day we saw on the Reach page about someone that had received a

Bursary payment, which got us thinking. My Mum called the Reach Head Office and they advised that we put all the costings together to figure out the amount we would need. We worked out how much it would be to have extra lessons with a Dressage Trainer, the costing of the shows and travel expenses etc.

The Bursary payment would also help to buy Tack that would make it easier for me. especially things like adapted reins and special gloves. It all totted up quite quickly. So, we sent off our costings to Reach and were so excited to receive an email from Kate at Reach Head Office telling us that the Bursary for £3.000 had been granted. I have never smiled so much!

We have since been to Keysoe twice, where we came back with two 4th places, and then we went back to Keysoe again to get another 2nd and a 4th.

I'm so looking forward to all the Covid restrictions easing so we can get out even more, whether that's for a beach ride or to Thetford Forest for a hack.

We will keep the Reach page updated with our progress and all the fun we have over summer.

Thank you so much Reach!

Follow Loen and Lando's journey on Instagram @LoenandLando

Introducing... Briony May Williams New Reach Ambassador

In 2018 Briony reached the semi-finals of The Great British Bake Off then went on to win The Great Christmas Bake Off. Now, when Briony isn't baking with her daughter Nora she's gracing our screens on shows like Loose Women. Celebrity Mastermind, and presenting channel 4's programme Food Unwrapped. We chatted about baking. TV, her experience growing up with a upper limb difference, and what it means to her to be a Reach Ambassador.

So, Briony what's been going on with you in the kitchen and on the TV screen?

Well, it has been a busy few months and things are picking up after the latest lockdown. I am filming for Channel 4's Food Unwrapped and I recorded some recipe videos for Lorraine which will be coming out soon. I'm also going to be on the show 'Would I Lie to You?' which is really exciting. I am still baking regularly, especially with my daughter, Nora, who is a budding baker herself. And of course, I am delighted to be an Ambassador for Reach, it is such an honour.

When you were growing up, were you confident with your upper limb difference?

My mum always taught me that if I couldn't do something because of my little hand, I needed to find my own way of doing it. It really set me up for the rest of my life really because I never looked at anything and thought, I can't do that, I just thought, how can I do it? The teenage years were tricky because I was very self-conscious about my hand, but I had an incredibly supportive group of friends who would always be by my side.

What does it mean to you to be an Ambassador for Reach?

It means more than I can say! I was a member of Reach as a child and having that support system for me and my parents was invaluable. Being able to talk to other kids with similar limb differences and for my mum to be able to chat to other parents about their experiences was so important

models growing up? Lots of the older kids at Reach were my role models, they

Did you have any limb difference role

showed me that we could do anything if we tried. I never saw anyone on TV and in films with a hand like mine, so it was really important to see other people like me.

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As an adult with an upper limb difference, what advice would you give to Reach parents who might be struggling to know how to best help their child during a low confidence moment?

This is so tough and you can feel so helpless but you have to remember how much it means just to have supportive and

loving family around you when you're growing up with an upper limb difference. I think having books with characters who have a limb difference in will help or to show them videos of people in the media who have a disability, like Paralympians, can be so unbelievably important because they can see that they can achieve amazing things and that it won't stop them from doing anything. Remind them

that they are awesome and that's what people see when they look at them.

How do you deal with people asking about your hand or if you notice people staring?

I've never minded people asking about my hand, even from a young age because 99% of the time it isn't coming from a horrible place, they are simply curious, especially children. I just say that it's my special hand that I was born with, it may look different, but everyone is different and that's a wonderful thing. If people stare I tend to ask if they want to ask me about it, again especially if it's little ones.

If you could go back and tell your 10-yearold self one piece of advice, what would it he?

I would say don't ever think your limb difference will stop you doing what you want to do, and it doesn't make you any less of a person, if anything it makes you more awesome.

Visit https://youtu.be/0Y3xk708kAE to watch Briony and Nora's cooking demonstration from last year's Annual Family Day and make your own homemade pizza and chocolate orange cupcakes!







Melissa Johns New Reach Ambassador

It was wonderful to meet

Reach's new Ambassador, Melissa Johns - actor and disability activist. We talked on Zoom about everything from her toughest moments growing up and cooking for the first time on Celebrity MasterChef, to advice for parents and how Reach is paving the way when it comes to representation.

Welcome to Reach Melissa!

So, why is representation important to you?

Everything we feel as we get older, Reach parents have already gone through. My mum at 25 would sit and cry because she'd look through the Argos catalogue and never see a child that looked like me - it was a constant reminder that her daughter was different. So, representation is important because parents need to see it first to make sure there's the right environment for their child to grow up in, so it can then be embedded in the child's life

What's does limb difference awareness mean?

For me, it's really important that we represent all industries. Acting is one that there aren't many representatives for. Usually, disability is associated with the Paralympics, which is incredible, I have absolute pride when it comes around and I'm so lucky to know so many of the wonderful athletes - I just think that it's important to shine a light on all areas.



People have often asked why I'm not a Paralympian, to which I tell them: 'For the same reason that you're not an Olympian. Because I didn't want to, and there are other jobs for us. Paralympians haven't got to where they are just because they have a disability. People don't always understand the dedication, skill, and experience that it takes. I couldn't do what they do

What do you think needs to change?

We need to elevate everyone's voices, so we can stand next to the Paralympians. For example, Strictly and I'm a Celebrity don't have disabled actors because we're not shown in other areas, all the contestants have been Paralympians, which I think it's brilliant because we're seeing disability on TV even more, but other industries aren't being portrayed. Where are the writers, photographers, models, teachers, and doctors?

Do you think having a range of Reach

Ambassadors helps with this?

Reach is brilliant because they've got the incredible Paralympian Claire Cashmore and comedian Alex Brooker, and now Briony who's an amazing baker, and now me as an actor, and it's so liberating to see that range of different people showing Reach families and children lots of different industries so even if they don't want a job in that area, just knowing they can access it is great!

Talking of different industries, how was Celebrity MasterChef?

Great! But it was one of the hardest things I've ever done. I learned the basics and the processes of cooking - I've cooked pan-friend duck with a homemade plum sauce so much that I've gone off it! But I only started to cook the day after I signed the contract. I'd never cooked a meal from scratch and over the years I had developed a real phobia.

When people say: 'I'm not good at cooking', for me it was a different level, so I knew it was going to be a huge challenge, but it was one I'm so glad that I did. It's true that something can be wonderful, terrifying, and nerve-wracking all at the same time

Why was it important to represent upper limb difference?

We were able to break the mould again, as they did it last year with Amar Latif, MasterChef's first blind contestant.

I had assistance from my best friend Emma; I wouldn't have been able to do it without her because my left hand is extremely weak. I've already had carpel tunnel surgery twice and I get really bad pain and spasms. I've had so many accidents including dropping boiling water over myself and times when my left hand just couldn't keep up with doing the work of two.

How did you find the physical side of it?

If it had been 5 years ago, I wouldn't have done it because I would have known that I would need to use my arm, like holding a bowl and needing to put my arm around it where people could see the end of my arm or the fingers. There's no way a few years ago I would have done that on an international TV show!

I wore a long-sleeved top on one day and I think I did that strategically, not because I was embarrassed but because I was out of my comfort zone. I'm an actor, I get given a script, I'm told what to say and where to stand; suddenly I'm doing a show where no one has told me what to say and people are seeing you as a person. And I'm cooking and I cannot cook, plus I'm surrounded by actual full-on celebrities. I just wonder whether I thought 'I just can't go full arm out on this day'.

I think lots of Reach adults and

children will relate to that struggle.

to cover up or not.

Yes! And some people don't understand, but it's ok not to understand. I think we live in a society that gets defensive if we say that, but it's ok because you haven't had my lived experience. We can't carry the knowledge of every different disability. Just say: "Oh ok I hadn't thought of that, if there's anything you need me to do, just say." That can be more valuable than people thinking that they have the answer.

How was lockdown for you?

I feel lockdown set me back due to the lack of going out and pushing myself every day.

Actually, I was walking to Travis Perkins a couple of months ago, it was really warm, so I just had a t-shirt on, and I was almost there when it suddenly hit me and I went into panic mode. Like when you're swimming, and you realise that you're really deep and far from shore. Suddenly you're saying hello to your teenage-self again. I found myself pulling out the old techniques like walking close to the side of the path so people walked on my left and when I crossed the road I pretended I had an itch on my right shoulder so I could hide my arm.

What's your advice to

friends or family who

You dont have to do anything.

We live in a world where we all

want to fix things or each other but for me. I just wanted to wear

a cardigan. I knew it was hot and

at me funny because it was 27

degrees and I had a massive

cardigan on, but I didn't need

people to keep telling me that. I

already carried the pressure of

knowing I shouldn't have it on.

I knew people were going to look

'want to help'?



What advice would you give to Reach parents

about dealing with people staring?

It's important to check in. I love my mum and dad to bits but if there was one thing I wish they'd done, was not get so defensive about someone staring.

My mum would grab my arm and march me up to them and shove my arm in front of their face and say: 'Would you like a better look?'. Not because she wanted to be mean to me but because in that moment all that mattered was that she was angry and needed to do something about it.

If she'd just turned to me and said: 'I know you saw those people staring, are you ok? Do you want to go back to the car for a bit?' it would have helped. I'm not a parent, nor am I a parent of a child with a limb difference, so I can only imagine the anger and frustration you feel when you see that. But I think it's about channelling that anger and protection. The most important thing is how your child feels.



Did you face any negative situations growing up that knocked your confidence?

When I was 19 I was in a nightclub dancing with a lad, and he hadn't noticed [my arm]. He asked my friend Holly for my number, and I saw him again for another dance but then a few minutes later he'd gone. The next morning, I had missed calls and voice messages and we were so excited, my tummy bubbling away because he'd obviously called, so I listened first. He left an awful message; he called me a freak and said I'd embarrassed him in front of

his mates. I didn't tell Holly because the last thing I wanted was her to feel angry or guilty and selfishly, I just couldn't deal with her feelings because I was already dealing with mine.

You said he hadn't noticed your arm; did that

happen often?

People don't get how anyone couldn't notice but growing up I just became so good at hiding my arm. It's what Snatched (https://www.thealchemisttheatre.co.uk/snatched), my one-woman show is about; how you can become the absolute master of manipulation and if you don't want someone to know, then they won't know.

One of my best friends told me that I have a really animated face when I'm talking, which was just a mechanism I used. Keeping people engaged with my eyes and face so they'd look up and wouldn't need to look below my shoulders. It almost feels like you have a superpower that you don't want them to know about. Nowadays, I talk with my arm, but back then I would craft exactly how I was going to sit, stand, what I'd wear, how to gesture ...

How do you feel about being asked about your limb difference?

I knew someone that had been told that they 'over-share'. To that they said: 'I've had to give too much information all my life so excuse me for choosing when I want to give more. I've spent my life with people asking intrusive questions, feeling like it's their right to have a nugget of my information.

So ves, sometimes we do over-share because we live in a world that's made us explain ourselves from a young age, asking us: 'What's wrong with you, what happened, how do you do this, or that.'

What would you say to your 12-year-old self?

I would explain that there's beauty in being different. When you're a teenager beauty is being like everyone else and when you have a limb difference aesthetically you don't look like everyone else. I'd say: 'You're going to be really

badass because you only have

one arm and not just because of

the way you look, but there are

so many benefits of living your

life differently to somebody else

your life differently to them. But it

will happen when it happens, and

jumper today, then wear it, maybe

because you've already lived

if you feel like wearing that big

tomorrow you can take it off.'

Watch Melissa's Reach webinar here: https://voutu.be/f-SxeMPki70

News & Events

Donations

New Members

Massive Thanks Pamela White £4000 Albert Hodges The Elizabeth and -50 'In support of Clare Salters Prince Zaiger Trust and everyone else who works tirelessly for this wonderful cause Annual donation **Broughton-Herrick family** in memory of Melissa Herrick **Build Base** .205 Reach member Alisha Horne organised a raffle Warwickshire Masonic Charitable Association LTD In memory of member Raph Smith Our (urrent Fundraisers **Pip Wakefield** Four Adaptive Adventure Challenges! Climbing Mt. Everest, Cycling Land's End to John O'Groats, en Nevis Scafell Pike Rowing the English Channel, Walking and wheeling https://uk.virginmoneygiving.com/ AnousheHusain Tom Stafford Chris Perrior Chris is taking on the National Three Peaks Running the Robin Hood Half Marathon Challenge! 1st - 3rd October 2021 2021, on 26 September 2021 https://www.justgiving.com/fundraising/ www.justgiving.com/fundraising ChrisPerrior-Reach tomstafford Fundraise Limb Difference Awareness Month? An upcoming challenge? Sharing a new skill? It's quick and easy to 'add a donate button' to your Facebook posts through so you can raise funds and spread awareness about Reach any time of year. Just post, click 'Add Donate Button' & select Reach from the list. Facebook!

here: https://reach.org.uk/fundraising/







to Reach

Florence Sergeant







Muhammad Jibraar

Amelia, Robbie & Bertie Jackson





Throughout August

Free to enter Every participant gets a Reach #Nolimits medal!

Be as creative as you want, as long as it's connected to the number 5!

Run 5k or cycle for 5 minutes, read 500 pages or sing 15 songs, cartwheel 25 times or be silent for 5 hours. This is your challenge so have fun your way whilst raising funds for Reach. https://runforcharity.com/running-event/r5ach-charitychallenge



Catriona Matthews Eilidh made over 100 pieces of jewellery



Alan Scott's Virtual Land's End to John O'Groats In November Alan Scott, Becca Scott's dad, started his 874mile walk/run, averaging just under 10 miles a day over 100 consecutive days, despite a stuttering start due to Covid-19.



Poochie Pads Shop at https://poochiepads.info/

Stanley's Three-legged 5K with part of his left index finger



100% profit of our 'Bee.Kind' Collection hairbands in a range of Bee print designs..

amazonsmile Amazon Smile

https://smile.amazon.co.uk/gp/chpf/homepage

f.1419

Tamsin Kane's 'Couch to 5K' .652 raise money for Reach!

Manisha's 5 Km Cycle Ride for Reach by doing a 5km bike ride. She also .5128 got a special mention in the school bulletin and

Rueben and Romans 'Month of Kindness' Reach has been a support for both Reuben and Roman Loss/Difference Awareness Month this year, 1284



Julie Detheridge & Mum, Linda Stokes Smarties for her Captain Tom 100 Challenge

> Kate Hoare and sister Helen Thewlis



Reach Parents, You're the experts!

The Transition from Primaru to Secondary School

The move to secondary school is big. Children are faced with a barrage of all things new; new school, timetable, homework, friends, whilst also dealing with new stages of physical, emotional, cognitive, and social development. On top of all of that, Reach children may come up against a unique set of challenges when dealing with an upper limb difference too.

I chatted with Reach mum. South Wales Branch Coordinator and teacher, Melissa Beesley, who says she's felt 'let down by her profession' over the years and that she learned that teachers don't always have the answer but that she had all the tools she needed.

You're the expert!

As a Reach parent you're already equipped with the best tool for the job - experience. 'You and your child are the experts, not the teachers or even the head of the school', says Melissa.

Teachers know how to plan, teach, discipline... But when it comes to upper limb difference and your child - this is where you can take the reins so trust your judgement, have confidence and feel comfortable to share it with the school, if that's what you wish to do.

Empower your child

There's no one size fits all approach; it can be beneficial to discuss the transition with your child to identify any areas that centre around their difference i.e., how other children will react. getting dressed after PE, or opening their crisps at lunch.

- Openly discussing their worries is important so you can work out how to deal with them.
- 'Identifying any 'big no's' helps your child to feel less anxious, knowing they won't be singled out or need to explain reasons for requiring help or not taking part. For Owain it's rugby, by communicating this to the school he doesn't worry about it being an issue'.
- 'Discuss situations that could arise to better prepare them when talking about their difference like how to move a conversation on or how to remove themself from an uncomfortable situation'.
- Encourage conversation. It needn't be a serious sit down, but just a chat on the way to the supermarket about what they are or aren't looking forward to, to identify any areas of worry

https://reach.org.uk/changing-faces-shares-teacher-training-classroom-resources-to-celebrate-embrace-difference/



Seasonal Feature

The teacher doesn't always know best

A teacher that learns they have a pupil with a 'disability' coming into their class may not be equipped with knowledge or experience and may have preconceptions, about where your child may require greater physical help, whether they need more attention than other children, or assistance with day-to-day tasks. They don't know your child vet, or their capabilities, which can lead to uncomfortable situations for your child to deal with.

How to keep the transition smooth

Melissa says 'the key is to have open, honest conversations early on, to set the groundwork and guide the school. Preparation at home is more important as unfortunately, due to Covid, schools haven't had the transition sessions they might have had.'

Melissa's Top Tips:

- Be proactive. Arrange a visit, have a nose around, get a feel for the school and meet the teachers and head of year.
- Make yourself an invaluable resource. Discuss your child's 'big no's' and their capabilities, this will give teachers confidence to handle situations that may arise.
- Trust your experience. You're solving a problem for them by sharing your expertise - they'll know exactly how to proceed which is better than them guessing and getting it wrong.
- Just say it. Teachers may not be confident with what language to use; tell them how your child refers to their upper limb difference. Do they call it their hand, little arm. nub. or stump?

Communication with the school will never be a bad thing. You may not need it but if anything does come up, they'll know they can talk to you and you'll know exactly who to talk to.

Schools do their best to prevent issues of bullying or inequality, but good intention won't always prevent problems. Talking to the school makes them more aware; teachers more capable of confidently dealing with situations, and your child more at ease knowing they'll know how to handle issues or when to step in.

> Remember, you're the experts and it's a personal choice - there is no 'right' answer, there's only what's best for you and your child.

If you're ever in doubt, you can always chat to other Reach parents about their experiences. For Melissa she's gained a lot from the Reach community. 'If I ever need advice or to gage a situation, I share it with other Reach parents - they know where I'm coming from and they'll give me a straight answer.



Parent Corner

Our Limb Difference Journey

Jamie & (hester

On the 5th of September 2019 I joked with colleagues about not coming back in to work as I left to meet Sarah for a scan, what would be our last before the due date of the 17th of Sept. Just 30 hours later, following an emergency C-section, Chester was pulled, limp and quite blue, from the 'sunroof'.

I'll never forget the wait. The very definition of eternity, or so it felt. Eventually the docs got a little yelp out of him and continued to work on him for some time before being happy to bring him over to the table where Sarah lay and I sat paralysed, her by an epidural and me by fear. The doctor showed us his face all scrunched and still quite blue, explained that they needed to get him to the neonatal unit for more help quickly and almost as an aside, pulled back the blanket to show us what we now call Chester's little arm.

His left wrist was folded over and quite a bit shorter than the right with only 2 fingers. Sarah and I just looked in shock as they whisked Chester off to be cared for. We had so many questions and almost no time to process anything. 5 days later we were transferred to Southampton Hospital as his immediate medical needs demanded a tertiary level hospital. We didn't know it at the time, but we'd stay in Southampton, over 50 miles from home, for the next four and a half months, returning home only to pick up post or clothes.

Over the coming days Sarah and I quickly made peace with the fact that Chester would not sudvenly grow any extra digits and agreed that actually, if he survived the following weeks or months with nothing worse than what we now call a limb difference (I had never heard the term before becoming a parent to a child with an upper limb difference), then we would be incredibly lucky. Sarah's mum found out about Reach and put us in touch with the charity who have come to be a fantastic resource since, for both information and importantly, support.

Many questions remain around how we had just so many scans without picking up his limb difference despite being able to see at just 20 weeks that one of his kidneys, which would have been measured in millimetres at the time, was seen to be in the wrong place. Not to mention whether any of his health issues are related by some common diagnosis in any way, but 21 months down the line and we still don't have an answer

However, despite all of this, Chester has done what I imagine all Reach kids do, and that is find his own way of doing things. He never crawled but could bum shuffle at an alarming speed and is now walking, climbing, and causing trouble everywhere he goes.

We feel so lucky to have him in our lives and despite the ongoing health concerns he is an incredibly happy toddler.

Jamie Webb Reach Parent



We're nervous.

Stuart & Kit

We're preparing for potty-training. Not ours, you understand - our son's. Kt is two-and-a-half and has no lower left arm beyond his elbow joint. I think we, like so many parents before us, had hoped this particular change might just pass us by...

And yet, somehow, it's no longer even on the horizon. It's *here. Now.*

So here we go again, fretting and researching and feeling optimistic and then fretting and so on and o on, as with every milestone ve've passed getting to this point.

We worried about him managing to sit up. He sat up. We worried about him being able to crawl. He crawled. We worried about him pulling to stand, and then walking. He pulled to stand and he walked. And now he runs. *Everywhere*. All the time.

His mother and I like to think of ourselves as creative individuals, and the evidence is there to suggest this is true. We've both been fortunate to forge careers and enjoy hobbies in which our ability to imagine and create has been fundamental. We hope we'll be able to pass this thread of creativity on to Kit.

So why do we also, sometimes, fail to imagine what our child is capable of?

Talking about this in terms of a 'failure of imagination' might sound harsh, but it feels appropriate. As adults who have only ever coped with two hands, it's hard for us to conceive how someone might manage with fewer. But that doesn't mean we shouldn't try and imagine it.

Parent Corner

To a limb different adult, or older child, witnessing this kind of unimaginative thinking must sometimes be exasperating, if not infuriating. Assuming that fundamental human developments can only be achieved by very specific types of bodies is not only unimaginative, it's also ignorant. It effectively erases legions of people who were born, progressed through childhood and led perfectly happy adult lives - while living with all manner of differences.

After all, this is the kind of closed-mindedness we hate to witness in other people when they talk about our child. We won't hesitate to correct someone who questions whether KI can climb up some steps in order to go down a slide, or whether he'll be able to ride a bike. But while we correct others aren't we also, sometimes, questioning it ourselves?

All I can put it down to is the fact that whether a child has a limb difference or not, parents worry. The worry is similar to the way a car's daytime running lights remain on while it's 'awake'. Sometimes a parent's worry is low-powered, sometimes it's blinding. But it's always on.

Sure, it's limb difference-related some of the time, and sometimes it's not. Often it's hard to discern what, precisely, we're worried about. And if I'm really honest I think Kit's limb difference is almost incidental to our fears at the prospect of potty-training.

Because we've heard the stories from other parents, you see. We know for sure that in our future there will be poo in places where poo would, ideally, not be found. And the prospect of errant poos is enough to make anyone feel a bit nervous, surely?

Stuart Waterman

Editors & Ella's Column

The 'New' health Professionals Subcommittee **By Ruth Lester**

Reach Trustee and Chair of Reach's Health Professionals Subcommittee, Ruth Lester, tells us all we need to know about the new Reach committee, why they're asking for your help with its upcoming survey and its aims to better inform health care professionals and greatly improve the support available for parents whose children are born with an upper limb difference.

We listened to our members:

One of the biggest concerns that our members tell us is the lack of knowledge that sonographers have about upper limb difference especially in children. Many families tell us that if the limb difference is picked up at their scan, the sonographer often has no

knowledge of limb difference and is unable to support the new parents. Many parents are left feeling alone, confused and isolated.

Reach is governed by a Board of Trustees who employ a National Coordinator and administrators. The trustees have identified areas within the organisation which warrant subcommittees to deal with specific issues who then report back to the Board.

This year saw the development of a new Reach Subcommittee whose aim is to improve the quality and timeliness of information given to families and carers of children and adults born with upper limb differences.

We understand that CULD - Congenital Upper Limb Differences - are very varied and rare. This does pose some challenges for HCPs - Health Care Professionals - who may never have seen these differences.



There is wide variety of HCPs who may encounter new parents including:

Sonographers, Fetal Medicine Specialists, Midwives, Obstetricians, Neonatal paediatricians, Geneticists, Children's Hand Surgeons, Therapists, Psychologists and Counsellors, Primary Care Doctors and Health Visitors

These HCPs can be very uncertain themselves as to how best to deal with the inevitable shock and distress experienced by new parents on their first realisation that their baby has an upper limb difference. Access to specialist Children's Hand Surgeons is limited to a few centres around the country and communication between HCPs is variable from region to region. Reach aims to support new parents: therefore, we need to be able to inform HCPs about upper limb differences and how to signpost parents to get specific relevant information.

How much more powerful would this message be to the NHS of England, Wales, Scotland, Northern Ireland and the Republic of Ireland. if we can find out how parents themselves experienced that shock following the birth or the antenatal scan identifying the CULD and understand from parents what could have been more helpful to them and other new parents at that time.

We are therefore planning a detailed survey of your experiences. ethically approved, and made suitable for publication and presentation to you and a wide variety of HCPs.

UK and Ireland Survey of Parental Experience Aim

1. To assess the current parent experience across the UK and Ireland of first encounters with HCPs following or before the delivery of a baby with an upper limb difference

2. To find out from parents what was helpful and what might have been more helpful

WE NEED YOVR HELP! Look out for the request by email/social media

The committee will also aim to improve the information available to you on the website acknowledging that an individualised approach from a specialist health care professional, is the most important source of information for you and your child.

Members of the committee have a huge range of experience to grapple with these issues.

Chair: Ruth Lester - Retired Admin: Deborah Bond (NC) and Kate Hoare **Trustees: Lorraine O'Farrell** and Alice Gair - both parents of

External advisers:

Wee Lam MB ChB, M Phil, FRCS (Plast), Dip Orla Duncan - Psychosocial Nurse Practitioner Edinburah Samantha Bradnock - Our verv own midwife with an upper limb difference



In April I agreed to help with Orthopaedic examinations at the uncomfortable. I had stepped in as a confident Royal Hampshire County Hospital in Winchester. There were 32-year-old woman feeling brave and unique 10 of us, each split up into our own examination rooms. I was and empowered, but had quickly shrunk into nervous, I took my cardigan off and waited

Minutes dragged and I grew guite anxious. A group of consultants then swept in and spotting my left arm (and upper limb difference) immediately, they proceeded to ask me for my medical history whilst one consultant read a chart: "She's in for a ganglion cyst. On her right hand?" (It had been during that appointment I had volunteered.) I told them about my limb difference then they disappeared.

I heard muffled conversations in the hallway about a bell, then one sounded, and two consultants came in with a new face, that This to-and-fro examination of my left and right hand continued of a nervous looking registrar who promptly introduced himself him he had 5 minutes to 'diagnose' my arm, informing him (and inadvertently me) that he was allowed to ask questions but that I couldn't say too much. It was then that I learned what my role was



The registrar asked if he could examine my arm, so I presented it to him awkwardly. As he looked at whether it was congenital, if I'd had It had been years since I'd seen any professional about my arm, so that first exam was strange and honestly, wholly uncomfortable

I didn't know where to look, how to hold my arm, when to put it

remember the first time someone

held my little arm when holding

hands - no previous partner had

me. For someone not to question, flinch or hesitate to be comfortable around me was the best feeling.

an awkward, nervous child. I felt hot and flustered - I rearetted volunteering.

But, the first exam was soon over. The registrar finally reached the conclusion of 'amniotic band syndrome' (with a fair bit of prompting from the

Until, he was asked to diagnose my right hand, the one with the ganglion cyst and the very reason I had been to see the consultant several months before.

for approximately 4 hours. I mastered my role, understanding what I should or shouldn't divulge and I got used to the dispassionate medical terms being thrown around.

a relationship with for the past year and a half and this weird experience, along with lockdown, had knocked my confidence. Nevertheless, the consultants were very friendly and each time they returned with a new registrar we all became a little more comfortable

When the final bell rang, I felt exhausted and relieved, but the a level of ease. Witnessing each registrar wring out every bit of knowledge and experience they had to reach a diagnosis made me realise how beneficial this process could be for an expectant mother or parents faced with the news that their child will be or has been born with a disability. I knew that these registrars now down; I felt embarrassed and knew a little more, and just knowing that, made it all worth it.

Dating with an Upper Limb Difference Ella's Column When it comes to dating. I prefer meeting people in person rather than online because a lot of pictures



How can you love someone else if vou can't love vourself - I truly believe this.

comfortable with yourself. By no means am I Cupid, I'm just speaking from my own experience because it can be daunting to date when you have a disability, but as long as you set boundaries and you both respect th em, it can be a new and exciting experience.



(everyone knows I don't hide my arm), it's just how they've been taken. So, if I do message someone, I start thinking 'shall I tell them, shall I wait, do they know' and I overthink scenarios that might never happen, but as with everything, it's a personal choice.

it's often worse in your mind. With some people. we've not spoken about my Little Arm until after a about it on the first date. The key, no matter how first date or the tenth. It's your decision, you should never feel pressured to answer any questions - you don't owe anyone any answers.

So, don't stress because you'll find someone who

Reach Buddy Project

Our Reach Buddy project has been a great success: building friendships even when we can't meet in person. Here are a few of our Reach buddies...

Layla & Ella

Buddy Lavla: "

Mum Danielle Ball:

with another Reach member. She is really

Buddy Ella: "I like writing letters to my

Emily & Beth

Mum Sarah Hughes: "It was wonderful to meet Beth - she exudes positivity. Emily found her inspiring and was keen to chat about her hand and Beths arm and challenges she's faced. Emily was surprised by how much Beth could do and has achieved. When we got home Emily pinned a picture of Beth on her noticeboard and a list of things to remember.

The buddy scheme has helped to build Emilv's her self-esteem and worth, showing her there are lots of people just like her, and she's been able to ask questions that she can't ask anyone else, because as she says 'you don't know what it's like to be different and I suppose she is right.









....

Sophie & Freva

Mum Hannah Goldinger: "There have been a couple of positives that have come from lockdown. It's been great for Sophie getting in touch with Freya after so long. It's been really lovely seeing them keeping in touch. Sophie gets a lot from this friendship.... Long may it continue!"

Buddy Sophie: "I've enjoyed talking to Freya because I haven't seen her for so long. It's fun getting emails and photos from her. We made a picture together!

Elise & Sophie

Dad Mark Buttery: "We've exchanged several letters now and Elsie and Sophie are getting to know each other, and it's been really nice for Elsie to chat to someone else from Reach. We've arranged to meet at the Eureka Museum in the summer holidays, and Elsie is really looking forward to meeting Sophie in person for the first time.

Buddy Elsie: "I've enjoyed writing letters to a pen pal and I'm excited when a new letter arrives. We've

got lots of things that we like that are the same, and I'm looking forward to meeting Sophie soon!*

> Mum Jodi Benson: "Our families are all meeting up in a couple of weeks so Sophie is very excited. Reach has really given her the reassurance that she's not on her own and I know it will be a big support to her as she grows, with all that entails nowadays with social media and the like, I know I'm very grateful to have other parents/ Reach-ers to speak with."

> > Buddy Sophie: "I've loved writing to Elsie because she is really nice

and I enjoy getting her letters through the post. I like having a friend who has the same hand as me and I am excited to meet up with her soon. She is 6 like me and her hand looks like my hand. She is very kind and we both like princesses.

Engineer & 'TikTok's 'Bionic Man'

A year ago, 25-year-old Henrik Cox posted his first TikTok video. Little did he know then that he'd soon have a following of 1.3 million.

Henrik proves that you don't have to take life too seriously, sharing videos about life (and misadventures) with a bionic arm. He speaks positively about joining TikTok:

'It's a warm and welcoming community. I've met lots of creators, including others with limb differences - we share ideas and stories. I created short movies as a child, and now that I'm in them, I make sure they're videos that my 10-year-old-self would have appreciated.

I've gained confidence, self-reliance and creativity, and I love being a positive role model; I get lots of messages from parents saying their child watches and loves my videos, which makes it all worth it.

Growing up Henrik says his hand was an insecurity and still is sometimes, but during college he came to an acceptance that 'this is me and I'm different'. Despite being bullied at school, he's turned his experience into a positive one, inspiring and educating people through videos and humour and is always happy to answer questions about his arm, understanding that they come from a place of curiosity not unkindness

To me, representation means growing up and realising that your difference doesn't make you so different after all, that your experiences are shared with others around the world. I share my journey because I remember feelings of isolation when I couldn't relate to anyone around me and hope that at least one person can be more comfortable in their own skin and happy to be themself as a result.

Irish Paralympic Swimmer on the cover of Irish (ountry Magazine

'Being on the cover of a magazine is a 'pinch me' moment. I've only ever seen one other girl with an arm like me on the cover of a magazine and I idolise her. When I got asked to the shoot I couldn't believe it. I've never seen something like this in Ireland: I was so excited to be on the cover for all the little humans and older humans who need more representation. Getting my arm out there gives people the opportunity to look and stare as much as they want. to get used to the sight of disability and normalise disability. We matter, our bodies matter and we deserve to be seen.

'Bionic Bev', Trustee of the Open Bionics Foundation & LimbBo Ambassador

double amputee Tilly Lockey who recently won CBBC's Got What it Takes and appears every weekend on Sky TV. Last year The Witches film caused an outcry because the lead character was portrayed with a limb difference, but a negative suddenly

being portrayed positively and at the time of writing this I'm enjoying the build up to the Paralympics, where new limb different heroes and role models will be given the first time, reflected back through their TV and device screens.



Representation Matters









Did you know?

As well as books and Reach merchandise like t-shirts, hoodies, masks and bags, you artwork and Christmas cards.

Just visit Reach.org.uk/shop



arm, and is a great problem solver and book lover ... '

I use a spaghetti/pasta spoon to serve salad rather than having to hold two salad servers. It works a treat!

Partners of Reach Koalaa Supplier of affordable arm



66 These salt and pepper

arinders are much easier

than traditional wooden

twisting ones 🤊

Manufacturer of bionic arms for adults and children. www.openbionics.com





prosthetics (The Mitt) to adults and children direct, online and to NHS or private clinics

Find out about their #ProjectLimitless which aims to give every child who needs one access to a prosthetic arm at www.vourkoalaa.com/projectlimitless



What Reach Does



Find out more by visiting: www.reach.org.uk

RAW (Reach Activity Week)

For Reach Children aged 10 – 17 years, it's all about fun together and plenty of action; from climbing, abseiling, and canceing to problem solving, archery and coasteering.

'Incredible Delivery' Pack

An extra special care pack for new parents with information about what to expect, the support available to them, and how Reach can help along the way.

Annual Family Weekend

Our annual conference is all about sharing experiences, inspiring stories, invaluable resources, and reconnecting the Reach family.







We see the potential in all our children and celebrate their ability, never focusing on disability.

How to Fundraise for Reach...





Find a run. Register. Select Reach Charity. Start fundraising! www.runforcharity.com

Birthday Fundraisers



Birthday coming up? Start your fundraiser – 100% goes to Reach. ▶ www.reach.org.uk/celebrate-yourbirthday-with-reach-charity/

Reach charity are funded 100% by donations and membership subscription. Help us to continue supporting Reach families with more ideas and how to fundraise for Reach at: www.reach.org.uk/fundraising/



Helping children with upper limb differences live life without limits

Work for Good



Making it quick and easy for small businesses to donate to charity. www.workforgood.co.uk

easyfundraising



Fundraise while you shop on the UK's biggest charity shopping site. ▶ www.easyfundraising.org.uk

