

Helping children with upper limb differences live life without limits

within Reach[★]

SUMMER 2022 | ISSUE 150



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Parent Corner - "DONLOOKATME!"



Gill the One Armed Sewist in Representation Matters



Parent Survey Results & Next Steps

Meet our Wonderful Branch Coordinators

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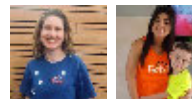
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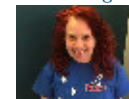
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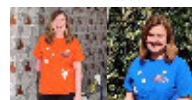
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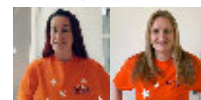
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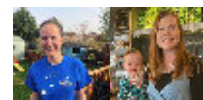
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Events 2022

Hello!

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



Reach Membership

Membership is open to parents of children with upper limb difference, and individuals of 18 years and over who are interested in furthering the work of the association. The UK and Ireland subscription is from £36 (£35 via direct debit) and the International subscription is £40.

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

- 1st to 31st - The Reach Charity Challenge
- 7th - South London - Summer Picnic, Horton Country Park
- 27th - Scotland - Branch Meet, Willowgate Activity Centre
- 29th - North West - Geronimo Festival

SEP

- 4th - 3 Counties - Branch Meet, The Rye, High Wycombe
- 4th - Northern England - Branch Meet, Lightwater Valley
- 10th - North West - Branch Meet, Anderton Centre

OCT

- 2nd - London Marathon
- 22nd & 23rd - Reach Annual Family Weekend, The Woodland Grange, West Midlands

DEC

- 10th - 3 Counties - Christmas Party, TBC
- 11th - West Midlands - Christmas Party, Hatchford Brook Golf Centre

For details contact reach@reach.org.uk or your local branch coordinator



STOP Reach emails going into your junk folder!

Please add reach@reach.org.uk to your contact list.



Stay up to date

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

Want to volunteer?

At the heart of Reach are our volunteers; organising branch meet ups, talks, activity weekends... If you'd like to get involved, please get in touch. Email reach@reach.org.uk

Give back to Reach



Introducing the new members of our Reach Team

Andrea



For the past four years I've been a Freelance Administrator, Project Manager and Researcher working for charities and local authorities. I've loved working at a music charity, initially as a volunteer, then administrator and now setting up a new creative programme for children and young people.

Aside from the practicalities of running a charity, my research about social enterprises and charities means I understand the challenges and opportunities the sector faces and I'm in awe of the amazing and often life-changing stories that I hear about. I bring with me experience of working with the NHS and local authorities from my time at the Department of Health and building teams and partnerships between people and organisations is always at the forefront of how I work.

I'm absolutely delighted to be invited to join the REACH family and look forward to meeting members, branch coordinators, and volunteers, supporting the Trustees and getting involved in the incredible work that Reach does.

Lisa



My Reach Journey began in 2005 when my son Jake was born. Jake was born with Ulnar Dysplasia which means that his right arm is shorter, and he is missing two fingers on his right hand. I found Reach through Google searches, and we joined right away. It was amazing to have found that we were not alone and that there was such wonderful support out there for us as a family. We had the chance to meet up with other families, which was invaluable, especially in the early days.

My personal journey with Reach includes crocheting Reach dolls and other toys to support families and fundraise for Reach. My son Jake has been a part of the award-winning Reach oRchestRa and through Reach, won a place in the National Open Youth Orchestra. He has also designed the Reach Christmas card and won the Sue Stokes Memorial Award which he is extremely proud of although he would never say (he is a teenager after all!)

I join the staff team on a part time basis bringing my own particular set of skills that include Digital Communications, Web Development, Data Management (across Retail, Charity and Local Authority sectors), and did I mention I am also a Crochet ninja?! I am really looking forward to supporting the trustees and the staff team in providing the best possible support we can for all the Reach families out there.

Lots going on... but lots more to do...

It's been lovely to see our closed Facebook group filling up with photos of branch meet ups, and young people heading off to RAW. Signs of normality after a very abnormal two years. Here's hoping the covid disruption is behind us forever and Reach can get on with bringing people together to support, inspire and live life without limits.

It's also lovely to see so much positive public representation of the limb-different community reflected in the pages of this edition of withinReach with a podcast all about people with limb differences, circus brilliance, Commonwealth Games baton carrying, the next great racing driver, and stardom on Sewing Bee and the BAFTAs!!!

But there is also so much more to do. We already know that the support we have been able to provide to children in Ireland has not matched what we have done for those in the UK, and we are taking steps to fix that. The research (page 26) that my fellow trustee, Ruth Lester, has been involved in with fellow healthcare professionals quantifies what we already knew intuitively: that support for new parents of babies with limb differences remains extremely patchy and a majority are still not getting sign-posted to help when they need it. And the thoughtful piece by Max on bilateral differences (pages 20-21) is an important reminder that, even within our own community, there is more we can and must do to support, include and advocate for children dealing with multi-limb differences.

All of those examples are things that the board and staff will need to work on in the weeks, months and years ahead, and our public advocacy work is something we want to develop.

Before closing - a few welcomes and thank yous.

A big welcome to our new staff Andrea and Lisa, and new trustee Nathan. It is great to have you all join the team - and especially good now to have two former Reach children on the board (also Sam, our vice chair, who joined in 2020). Big farewells and thank yous to outgoing staff Debs and Kate, and former trustee Jo (and belated thank you also to Alice, who stood down as a trustee before Christmas and I omitted to thank at the time - sorry Alice!).

A special thank you to former trustee Lee, for all his work over ten years as a trustee (including several years as chair of the board) and for his support for, and encouragement to, me during my time as chair - first as vice chair, then as co-treasurer and most recently as a member of the wide Reach community. Lee, you've been amazing - don't be a stranger!

Good luck to everyone in the Reach community who is starting a new school this August/September!



Clare

Clare Salters
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Reaches Board of Trustees

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Need some help?

Thinking about prosthetics, an adaptation for your child's bike or is there something your child is struggling with and you just can't find a solution? Reach is always happy to offer help and advice, and to point you in the right direction. Or why not speak to our partners who innovate and create to ensure everyone can live a life without limits.

ReVAMP
by LimPower



@rebecca@limbpower.com

Digital, 'Joe Wicks style' workout videos specifically designed to support amputees and people with limb differences

Team Unlimbited



https://www.teamunlimbited.org/

Empowering and inspiring people with limb difference through the design and build of innovative 3D printed arm devices.'

Remap



https://www.remap.org.uk/

Remap custom-makes equipment to help disabled people live more independent lives.

Changes within Reach...



Life has brought much change over the past few years, and now Reach is facing some changes within the Head Office as well as on the Board. To ensure the best team is in place for Reach going forward there is an interim team in place whilst things like skill-mix, numbers, functions and locations are considered.

In the meantime, in this summer issue we're celebrating Reach's people; with fond farewells to those who have left and warm welcomes to the new faces joining the Reach family, because Reach wouldn't be the same without its team and volunteers, and the community they help to build.

Read more on pages 8 – 9.

Great news! You're the stars of Reach's fundraising...

Your efforts for the 'Walk in My Shoes' Limb Loss Limb Difference Awareness Month 2022 challenge raised a whopping £23,500 for Reach, so may this fantastic fundraising inspire and motivate you all for your upcoming August R5ACH Charity Challenges 2022!

Whether you do 50 star jumps every day for 5 days or bake 50 cupcakes and hold a cake sale... If it's connected to 5 go for it! Need some more ideas? Visit Link <https://www.justgiving.com/campaign/R5ach22>



Do something awesome linked to the number 5

- * In 2021 Bertie was pushed 105 miles in his pushchair by Mummy & Daddy over the month of August.
 - * Nicole cycled 500km throughout August.
 - * Tatum did a family and friends 5K hike.
- Find out more on how to get involved by visiting: <https://reach.org.uk/5ach-charity-challenge22/>

Thank you!

We wanted to say a special thank you to all who have put Reach at the heart of their fundraising efforts in 2022 so far, your support has been absolutely fantastic and never goes unnoticed; from wedding gift donations and sponsored sporting events to special talks and even a black tie event... You, our Reach members are selflessly showing that your special events and occasions can be a wonderful platform for spreading awareness about upper limb difference and raising vital funds for your charity, Reach – so a big thank you and keep up the good work!

See the latest donations and fundraising for Reach on page 14 – 15.

There's an all new upper limb difference podcast!

John Brooker, adult Reach member and former parasailer with the British Sailing Team, has started an all new upper-limb-difference-focused podcast called 'Beyond Difference' – the first episode is now live, you can listen now.



Listen here >

<https://johnbrooker.com/pod/>

A podcast in partnership with Reach.

Goodbye to the legendary Tyncae Camp after 25 years!



"We have been Reach members since 1989 when our son Steven was 2 years old.

It all started in 1997 when Sue Stokes asked if anyone had any ideas for a Reach 'get together'. Rob said: "We hold an event for Mid Wales, Mini Club, so how about a camping and activity weekend?". In May 1998 10 families came to Tyncae.

A free camping weekend, it grew from 2 gazebos to a huge marquee; challenging and sporting activities, workshops, trips and meals for all Reach families.

We felt that Reach children would benefit from being with other children with upper limb differences. Reports from parents saying how much their child had gained from the weekend and the information shared with other families was proof enough and so it became an annual event that lasted 25 years.

Over the years we have seen children of all ages overcome their anxieties, share their experiences and become independent. This was always our aim."

- Rob and Dawn Davie



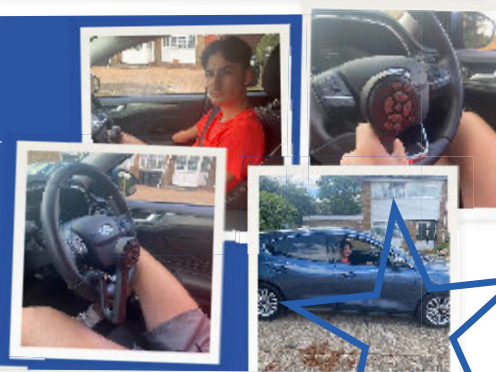
Bursary success

"Charlie's car has been fitted with a Lodgeson 13 way remote control switching system (R213). It took an hour to fit it by Ace Conversion Ltd (Ashford).

Charlie finds the adaption really helpful for driving, thank you Reach for help with this bursary for £1100 which helped us enormously and is much appreciated."

It has the following:

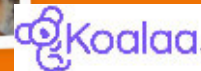
- Indicators
- Lights (dip/main flash)
- Horn
- Front wipers
- Front washers
- Rear wiper & wash
- Sidelights & headlights on/off
- Night time illumination
- Hazard



Koalaa X LEGO

"To celebrate uniqueness and empower users to personalise their prosthetics, the LEGO Group welcomed members of the Koalaa Community, including a number of REACH families, to exclusively try out a new product: LEGO® DOTS Stitch-on Patch.

At the event, the children were encouraged to use the newly launched LEGO® DOTS Stitch-on Patch to express their unique individuality. The children stitched the canvas design onto their Koalaa prosthetics, which, unlike traditional prosthetics, are made from fabric. This offered a new way to decorate, personalise and celebrate their prosthetic, with the children going on to create all kinds of designs."



Celebrating Reach's people!

We're celebrating Reach's people this summer by saying some big hellos and some fond farewells!

We're offering the warmest of welcomes to the new members of the Reach Team Andrea and Lisa, Trustee Nathan, and Branch Coordinators Jess, Hannah, Laura, Sarah and Navdeep. As well as celebrating some of the most recent branch meet ups organised by our Branch Coordinators, because after all, our volunteers really are the backbone and heart of Reach!!

Hello to our new Trustee!

"I recognise the positive influence of Reach - both personally and on others."

"As a child I was part of our local Essex branch and have fond memories of trips to Colchester Zoo, meeting other Reach children and their families. Having lost touch over the years, I'm delighted to be re-joining the Reach family as a Trustee. I'm looking forward to exploring exciting new fundraising opportunities which will enable us to increase the impact of our support to children and am especially passionate about the mental health and wellbeing of young people."



Nathan

Branch meet ups

West Midlands

Tracey and Jason organised a meet up for 18 families to go bell boating and dry skiing followed by a picnic.



North West

Jane and Cheryl organised a meet up at Wild Shore Delamere with the private use of the aqua park for an hour.

After 2 years of waiting the North West family weekend at Patterdale Hall finally happened too!

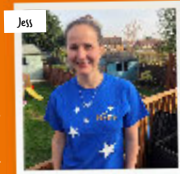
"It was fabulous to be all back together, a whole weekend of fun!" - Cheryl Danson



Welcome to our most recent Branch Coordinators!

South London

"I became a branch co-ordinator in late 2020 when the opportunity arose, as our lovely previous co-ordinators were moving on. How well I thought through that plan was I am not sure as I very quickly realised that not only had I never set up a branch event, I had never actually attended one! (Not for lack of wanting to go, we had been in lockdown since I joined!). Riley was only 1 at the time, and I wanted to seize the opportunity to connect with other Reach families, and also to help other families who like me had not been able to meet up due to Covid.



Jess

We implemented the buddy system, and Hannah and I work really hard to find members a buddy close in both location and the age of their Reach children- my record so far is a two-minute drive and a 5-week age difference! Our next event is a BBQ in the park where we have invited grandparents, aunts, uncles and cousins to join us too."



Jess's son

Hannah joined Jess in spring...

"I was delighted when Jess asked me to help the South London branch. I'm mum to Amelia who is almost a year and a half old. I'm hoping to set up an under 5's event to get the younger Reach members and their carers together.

My aim is to get to meet as many new members as I can, so that our gorgeous Reach children (and carers) can engage and socialise with others who have the same experiences as them, and to create a network/atmosphere to share advice and tips.

I've not been able to be as active as I would have liked with Amelia's appointments but I hope that I've made a difference and will continue to try and assist as much as I can!



Hannah

East Anglia

Welcome Navdeep!

"Hello Reach family! I'm Navdeep and I am delighted to be joining as joint Branch Coordinator for East Anglia alongside Jay. I decided to volunteer for this role so that I can give back to other families the support and reassurance that we have had since our Reach son, Arjan was born. I am a secondary English and Drama Teacher, and I am passionate about equality, diversity, and inclusion. I moved up to leafy Norwich from London with my husband Abbas, daughter Leila, who is 10 and our beautiful son Arjan who is now 5 years old. I hope to do more regular meet-ups for our branch in future and to strengthen the bond and support between families."



Navdeep

"I volunteer...so I can give back to other families the same support and reassurance that we have had since our Reach son, Arjan was born."

South West

Laura and Sarah became branch coordinators in the spring...

"We recently went to our local school to do a talk with the children about limb difference. It was a brilliant morning, we played games and read stories to the children and they asked



Laura

loads of really great questions about baby Finley's limb difference. It was also lovely to see the teachers getting involved as they also had their own questions.

We have made mention of this on our local community Facebook pages, so that if any other schools would wish for us to come and chat with them also then we can."



Sarah

Farewell & thank you!

"As you will most likely have heard Kate and I are moving on from Reach. I wanted to try to let you know how privileged I feel to have been part of the Reach family. Kate put the following words together and she managed to she captured mine and her feelings perfectly.

It is with a deep sadness and a heavy heart that we are leaving Reach. Reach is a truly wonderful charity. We have met amazing people and have been inspired by the strength, determination and resilience shown by individuals. It has been joyful to meet families, children, volunteers, practitioners, and the huge number of supporters of Reach, many who are the unsung heroes and the very backbone of the charity. The tireless support of branch coordinators, fundraisers, ambassadors, and partners, what an amazing community to be a part of. It has been a privilege to assist in the organisation of key events and branch meet ups in the Reach calendar, face-to-face and online. We are proud of the growth and reach of our social media platforms, regular posting has formed great partnerships, friendships and an online presence that is recognised in celebrating, raising awareness, educating, and uniting families across the world.

Reach is Community, and long may this continue, our biggest hope is that the members continue to remain at the very heart of the charity.

Thank you for allowing us both to be part of the Reach family."



Debs & Kate



Kate

"Reach has 25 wonderful, dedicated volunteer Branch Coordinators across the UK and Ireland! Our volunteers really are the backbone and heart of the charity, they are parents or family members of Reach children or Reach adults themselves, so have a real knowledge, empathy and understanding. The

meet ups and events they organise enable families in their area who are in a similar situation to get together, share experiences, concerns and successes. Parents, siblings and Reach children often make lifelong friendships. Reach is Community and thanks to our very committed and hardworking volunteers, families will never be alone."



Lee

"I joined the Reach board nearly 10 years ago following the birth of my son Ewan. I wanted to give something back after the support we received as a new parent of a child with a limb difference.

Throughout the past 10 years I have thoroughly loved being part of the Reach family. It hasn't always been easy, making and owning decisions never is, but the board and Head Office team have always had the best interests of Reach at heart, which has always given me confidence in our collective decision making. Seeing the positive impact some of those decisions have had has made it all worth it and I am proud to continue to be part of such a welcoming and caring community.

I may no longer be a trustee, but I have certainly not left Reach!"

"I wanted to give something back after the support we received as a new parent of a child with a limb difference."

Get the bike right!



Bryan McCullough



For Reach member Izi Chappell cycling was never a comfortable experience. Despite having an adaption to meet the needs of a shorter left arm, cycling gave her increasing discomfort, especially in her wrist and so her bike more often than not was cast aside.

In early 2022 however, Mum Diane took Izi to see Bryan McCullough at The Bike The Body, and here is when Izi's relationship with cycling changed. Finally, they found someone who understood not just bikes but the human body.

Bryan has made it his business to merge the two, understanding that "bicycles are, by their nature, symmetrical machines while we, as humans, are wildly unique and have an endless array of shapes, sizes, proportions, asymmetries and imbalances."

When chatting to Diane I could hear the joy in her voice as she shared a recent experience where her and Izi hopped on their bikes and made their way to a local pub for dinner before adventuring home in the dark – a memorable experience that was only made possible with the help of Bryan.

I spoke to Bryan about recognising problems with your bike, the importance of getting the fit right for young people and how he's working with Izi to find comfort and enjoyment in cycling.

Do you think people approach bikes with a 'one size fits all' mindset?

"By and large I think the bike industry at large tries to assist people in finding a bike that is in the right ballpark. Large companies need to be able to build and sell in volume to reach sensible economies of scale and this works pretty well for many. In most cases there is reasonable information available both online and in shops from staff to assist in bike sizing. However, this is only part of the picture. As an example, you may buy a suit which is the correct 'size' but it may not fit you well due to your proportions - let's say long arms and a short torso... The same can be said for bikes. This is where bike fitting can bridge the gap between a bike that is the right size and one that works in harmony with the individual riding it.

From the consumer standpoint there are also some preconceived ideas and misconceptions where one just 'expects' a bike saddle to be uncomfortable and therefore ignores the issue. This can extend even further to riders developing problems with nerve compression - most commonly in the hands but this can also occur in the nerves and blood vessels which supply the genitalia."

How do you at The Bike The Body combine physiotherapy and bike fitting?

"For me the most important outcome from a bike fit is to be able to create a synergy between the bike and the body. If the bike has to be adjusted too excessively to meet the needs of the body it is not likely to perform at its best in terms of handling or efficiency.

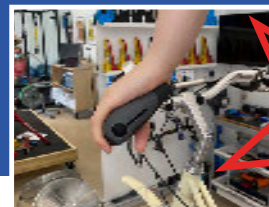
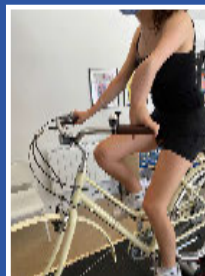
On the other hand, if the body has to work too hard to adapt to a position on the bike this is likely to lead to discomfort, pain or even injury and a general sense of poor connection and control of the bike which may also be a safety concern.

My experience as a physiotherapist helps me to better assess and understand the rider's individual strengths, weaknesses or indeed limitations which in turn allows me to factor that into the bike fitting process."

For Reach member Izi, you've helped her to enjoy cycling again, what did you do to help her?

"For Izi the key was first choosing a bike that she was excited to ride and matched her usage criteria in terms of terrain and distances etc. Once we knew what bike she was looking for we did some pre-screening work to allow us to choose the correct size bike.

Next up the key challenge was to allow us to first accommodate for her limb length difference in terms of reach to the bars and then the final part of the puzzle was to ensure we were able to construct a bespoke grip the conformed well with her hand so she could have a safe and secure grip and control the bike. I have to say, it would not have been possible without the assistance of my wizard mechanic, Tom, from Spindles Bikes in Whitley."



3 key things

to get right when it comes to the bike and the body?

- 1 - "If something hurts when you are riding don't ignore it - tell someone, perhaps your parents, or chat with your local bike shop."
- 2 - "Saddle height is the fundamental metric that will dictate most other elements of the bike fit so you want a position that allows good leg extension while maintaining a slight bend in the knee at the bottom of the pedal stroke. A nice way to get this into a good range is to sit level on the saddle, leaning against a wall (or having someone support you) and place your heel on the pedal (with the pedal in the lowest position), in this position you are aiming to have a straight knee. If it is bent, raise the saddle slightly, if you can't reach the pedal then lower it slightly until your heel rests on the pedal."
- 3 - "Build up your riding gradually. I see injuries in riders all too often who have been 'bitten by the bug' and are suddenly riding every day and for longer distances. Your body needs time to recover, especially when picking up a new activity."

What will you be assessing when you see Izi next?

"A bike fit should never be considered a 'one-off event' it is a process and as the rider changes and evolves so too must the fit. In the initial stages after any fitting session, I am always keen to get rider feedback about the pros and cons of any changes we have made so that if any further tweaks or refinements are needed, we can make them. In Izi's case the key will be to determine how her grip and control feels in 'real world' conditions both outdoor and longer duration. This may then give us some indications on any changes or if indeed any exercises may further help to improve any persistent challenges."

How important is it for Reach children and young people in particular, who have upper limb differences, to get the fit right now rather than later?

"It's really important. I think the first step is to try and improve awareness that bike fitting services with specialist skills actually exist. If people don't know there is help out there then they may give up riding which would be such a shame. I really appreciate the opportunity to be able to share this experience to increase awareness and hopefully be able to help more Reach children and young adults to enjoy riding their bikes."

How do you know if your bike is not right for you?

"Often problems can fall below the radar and are often only recognised retrospectively. A scenario where a parent wonders why their son or daughter stopped riding and finds out later that it was because their arm or shoulder was really sore but they didn't say it at the time. Pain that arises only when riding and subsides shortly thereafter is a pretty obvious initial sign. If addressed at this point it can stop the problem 'overflowing' into causing pain after riding or with other activities."

Are there common issues you see that could be helped by physio?

"Yes, in fact there are often cases where I see someone for a bike fit and their position and set up is actually quite good but they are still having pain and discomfort. This is where I need to put my physio hat on and dig deeper with physio assessment and screening to see if something off the bike is driving the issue on the bike. An example of this might be back stiffness from someone who has a desk or sedentary job and then rides a bike as their main hobby (again seated). Part of the solution here would be some mobility and strength exercises off the bike."



Welcome to Reach

Charlie



Kaia



Ella



Sophie



Oskar



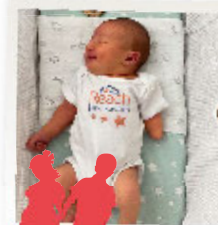
Ru



Thomas



Xander



Willow



Discover obstacle courses, walks, monthly step challenges and more, to help us support children and their families affected by upper limb difference.

We'll give you help and support right up to race day and if you pledge to raise at least £50 and you'll get a Reach t-shirt or running vest.

Find your race at: <https://runforcharity.com/charity/reach-charity-ltd>

Run for Reach

BADER'S BIG BAND



- BADER BRAVES
- BADER GRANTS
- TEAM BADER
- BADER INFORMATION

The UK's *ONLY* Big Band consisting of talented musicians with a broad range of disabilities. For more information contact: charley.bickers@douglasbaderfoundation.com

Massive Thanks

£500

Douglas Arter Foundation
Donation to our 'Walk in My Shoes' challenge.

£118

A collection in memory of Melvyn Hamilton; husband to former branch coordinator Jill Hamilton, Melvyn helped Jill, along with their sons, to organise Reach events.

Elizabeth and Prince Zaiger Trust

£4000

Mrs Joan Barrister
"In loving memory of a kind family friend, Jimmy Allen. Jimmy has known my daughter Susanna all of her life (she is now 25 years old) and always showed a caring interest into her difficulties along the way, and her abilities to overcome."

£10

£175

Russell Hinson
"I work for a betting company (Ladbrokes & Coral), we have a charity sweepstake each year for the Grand National and I proposed Reach as our charity - in honour of my little girl who had a limb difference. My colleagues were kind enough to donate a lot of their 'winnings' to boost our donation too."

£212

In memory of Megan Codd

Toni Walker
Donation after attending John & Ann's Strawberry Cream Tea charity event.

£100

Congratulations Emma & Stevie!

More than £850! Reach donations in lieu of wedding gifts "Like many others our daughter India's limb difference came as a surprise, however once we found Reach it really helped us. It's an amazing charity that works tirelessly to assist families like ourselves and so we asked guests at our wedding to donate a small amount as opposed to a wedding gift. We were overwhelmed with the generosity and really hope it goes a small way to help raise awareness and support! Keep up the amazing work!"

£850



Allison Campbell

"A small donation in honour of the beautiful India's Mummy & Daddy on their wedding day. Congratulations you pair of beauties! Such an amazing charity... best of luck with all your future fundraising! With lots of love, Alan, Allison & Cole xx

David Maclachlan

"A gift in honour of the wedding of Emma Downie and Steven Craig whose daughter India has Limb difference. They very unselfishly asked for donations to reach instead of gifts!"

Julianna
With Love from
The Mums xxx

Limb Loss awareness month 'Walk in My Shoes' Challenge total £23,500. Here are a few that were shared



Noah & Ryan

"The boys shared tasks, opening crisps, doing buttons up etc. "I am doing the walk in my shoes challenge for Reach because my best friend never lets anything get in his way!" - Ryan

£992

Country Kids Nursery

"The children have had lots of fun with pyjama day, messy activities, teddy bears picnic and lots more!"

£245

David Heaven

London 2 Brighton Ultra
"I should have learnt my lesson from the first time, but pain and toe nails are easily forgotten." David raised money for Reach and for his son Alex. "The most fearless little Heaven was born with dual upper limb differences affecting arms and hands."



£3234

Xavier Nero

Birthday fundraiser
Double the celebration, for Xavier's birthday and Limb Loss & Limb Difference Awareness Month

£280

Fundraisers

£1904

Jagdeep's Yorkshire 3 Peaks

A great charity that is close to our hearts, Reach helps to empower young people and families! My eldest daughter was born perfect; beautiful brown eyes, a gorgeous smile and bright and intelligent, she also has an upper limb deficiency. Reach have been great at helping us as a family get involved and meet other families.

Jen Davies & Sarah Boulton

Coffee morning
Branch coordinator Jen Davies for 3 Counties & mum to Beau helped Sarah run a coffee morning at Busy Bees nursery.



£200

Siobhan and her Team, Rocketsocks
Belfast City Marathon

"Our beautiful daughter Cara was born in February 2021. We discovered soon after her 20 week scan that she would be born without a right hand. We were so fortunate to find the amazing charity Reach, which was an invaluable source of reassurance and support."

£4053



Alberta & Sam McLean

Black Tie Charity Event
In honour of Reach and their son Albert, who was born with an upper limb difference.

£6500

£435

John & Ann Hall
Mercedes Club Event

John and Ann held the event at their house in Tiptree - "50 cars and 100 or so people turned up on a lovely sunny afternoon."

£1000

John and Ann Hall
Strawberry Cream Tea

Grandparent to Molly Palmy with Reach baby Beau did a Cream Tea and classic car rally.

£2000

Jane Crook

North West Branch Coordinator Jane Crook successfully secured funding from Arnold Clark for their branch.

£245

Mr Montrose at

Chapel End Primary School
Change collection

Hayley Wiles says a big "thank you Mr Montrose and all the children and parents" for collecting change over the past few terms for Reach.

£350

Kirsty Hillaby

A 'crafty' challenge!
"A friend suggested setting myself a challenge to achieve before I turned 50. I decided to see if I could make (crochet) 50 things before my 50th and raise some money for charity at the same time, so #50for50 was born!"



Tash Lillcrap

Raised money through Amazon Smile.

£19

£50

Marilyn Colquhoun

Book sale
Marilyn held a book sale after watching a Reach presentation to the Watch Ashore ladies.

£400

Gavin Richardson
Seminar

Member Mason attends Sensei Gav's Sho Go Ryu Karate classes which has been great for his confidence but he's faced some challenges along the way. Mum Louise Bennett told Gav all about Reach and so he chose to raise money for Reach at his upcoming seminar.

£321

Paul Ward

Cardiff Half Marathon

On March 27th Paul ran for Reach. "I have been running 10ks, some for Charity, but this is my first half marathon! Great

to be running in my home city of Cardiff and for such a great cause."

£43

Beth Stevens

Cafe sales

"Last week my class ran a 'French cafe' as part of their French learning and raised £43 for Reach!"

£385

Chris Penny

Ikley Half Marathon

"Looking forward to the next challenge and chance to keep raising awareness and money for the amazing charity Reach."

£593

Jennifer Jamieson

10K run in London

Reach Branch Coordinator for Bucks, Beds and Herts: "We found out about

Reach when we found out our son was going to be born with an upper limb difference. Since then, we've seen what an incredible and vital job Reach do for kids like Beau."

Have you heard of the National Open Youth Orchestra?

The National Open Youth Orchestra or NOYO is 'the world's first disabled-led national youth orchestra'. It was launched in 2018 seeking to 'give some of the UK's most talented young disabled musicians a progression route.'

NOYO supports 11-25 year-old disabled and non-disabled musicians in this pioneering ensemble that includes an array of instruments from 'acoustic to electronic instruments like the Clarion, which can be played with any movement of the body including the eyes.'

NOYO gives musicians a step to performing in high profile concerts, it develops musical skills, pushes them out of their comfort zone in the best way and encourages long-lasting friendships.

Jake

What instrument/s do you play?

Acoustic and Electric Guitar

How did you get involved with the National Open Youth Orchestra?

"My mum found out about the NOYO auditions through Reach. I watched the NOYO introduction video and decided to audition in September 2019 but then COVID happened which delayed my audition for 2 years."

How did your audition go? What did you have to do? Were you nervous?

"First, I sent a tape of me playing my guitar and then they invited me to audition in person. When I finally got to audition in person in October 2021, I played a song of my choice which was "Under the Bridge" by Red Hot Chili Peppers with Doug and Charlie who made me feel relaxed. The audition felt easy-going so I didn't feel too nervous at all."

Do you have lessons or tutoring at all as part of NOYO?

"Not as part of NOYO but I had private lessons."

I believe you played in the NOYO debut performance last month - how did it go and what's been your favourite NOYO experience so far?

"I've played in all four NOYO concerts; they went well, each one improved on the last and I was very proud of our performances. My favourite NOYO experience so far was hearing us play all together for the first time at the residential. It was a very powerful feeling being part of a large orchestra and felt quite emotional to hear the resulting collaboration."

Would you encourage other Reach musicians to audition for NOYO?

"Absolutely, go for it. You have nothing to lose. There are musicians of all sorts and abilities even auditioning is a great experience to have. Even if you don't get a place, the orchestra offers a trainee programme."

For you, what is the best part of being in NOYO?

"The best part of being in NOYO is getting to meet and collaborate with other disabled musicians and be part of a collective. It's such a great opportunity, I have made some great friends and had the chance to perform for large audiences in great venues."



Their residential, a favourite experience for Reach member Sam, saw musicians from all regions gather for a three day and night trip at the National Star College in Cheltenham 'to rehearse and socialise'.

NOYO's first commission, 'The Umbrella' by Liam Taylor-West, saw a British Composer Award in 2018, so the question is, will you be part of journey to the next award?

Auditions take place every spring so if you are a musician or you're a parent of a musician, get ready for spring 2023 auditions. Here is the official Applicant's Information pack.

<https://novo.org.uk/apply/>

<https://novo.org.uk/>

Two of our Reach members, Sam and Jake, have been members of NOYO this past year, and others are joining for the year ahead. I caught up with them to ask about their experiences so far and whether they would recommend NOYO to other Reach members.

Sam

What instrument do you play?

"The trumpet."

How did you get involved with the National Open Youth Orchestra Sam?

"I joined three years ago. I applied to be a part of the orchestra through Reach."

I believe you have to audition to join - how did yours go? Were you nervous?

"Yes, you do have to audition, my audition went well although I was extremely nervous!"

What's been your favourite NOYO experience so far?

"The residential was a key part of the orchestra's growth in music which is why it is my favourite."

Would you encourage other Reach members to join?

"Yes, as I thoroughly enjoy the experience, and the friendships I have made with those around me. I would like say that everyone is my friend in the orchestra."

What is the best part of being in NOYO?

"The music that you play and the times when the orchestra comes together to play a wonderful piece."

I loved the music and video for 'What Fear We Then?' Was it fun being involved and playing in it?

"The idea of all of us coming together to make a piece of music for a film was truly incredible and exciting. The orchestra is great and if you want to try and become a member just know that you will have everyone around to help."

Mum Simone says:

"We've seen Sam's confidence grow so much since he has been a part of NOYO."

A Podcast.

Inspiring people with limb differences.

Recently I've been recording a series of conversations with people who have thrived with limb differences. Here's a bit about me and why I started the podcast.

By John Brooker

I've been wanting to do a podcast for a while now as I know I would have found it useful when I was younger. The benefit of long conversations is we can get beyond the surface level, delving into topics more deeply.

The podcast covers many topics, ranging from the psychological side of limb difference to advice for succeeding in life (whether that be in health, happiness, or career).

We also answer some questions from Reach members so if you have a question you can email it to me at hello@johnbrooker.com

So, a bit about me. I grew up in Hampshire and from an early age I had a fascination with the world, especially anything to do with history or nature. I was also endlessly creative.

However, as I got older these hobbies took a back seat as they 'weren't cool'. I also started to become self-conscious about my arm. So in both ways, I'd lost myself by pretending to be someone else.

When I was about 14 my dad put me on a sailing course (against my wishes I might add!) I'd sailed when I was younger but wasn't a fan. I'd packed it in and went to play footy.



However, my life may have looked very different had my dad not booked me on the course.

After enjoying the course, I started racing a dinghy called a Laser 4.7. However, I struggled to keep up with my able-bodied peers.

After a year or so someone recommended I try Paralympic sailing. I jumped ship (literally) and started racing the 2.4mR - the class of boat used in the Paralympics.

Over several years I went from finishing regularly last to being selected for the British Sailing Team and competing in several World Championships. At the time of the Rio Games I was ranked higher than several sailors that went. Unfortunately, I wasn't selected to go as there's a limit of one boat per country and the top Brit was pretty good - having won gold in 2012!

That was to be an end to my sailing career as Rio was the last Paralympic Games for the sport of sailing. It was replaced as a Paralympic Sport for Tokyo.

At the time this was hard to stomach but it was a blessing in disguise. It allowed me to pursue other endeavours. I finished my degree (in Philosophy & History) and started my first business. The degree went well, the business not so much. But it taught me that if I wanted to work for myself, I'd need to be good at marketing which lead me to create a video creation and marketing agency. Its success has allowed me to pursue other endeavours such as a sailing YouTube channel and now a blog and podcast covering everything from limb difference to mindset.

As many of us do in our teenage years, I lost myself by pretending to be someone I wasn't. However, over time I learned to embrace both my body and my inner voice calling me to create. You will have a unique body and a unique calling. And you are the only person who can accept them.

It's topics like these that we discuss on the podcast so if you are interested you can check it out.



Listen here >

<https://johnbrooker.com/pod/>

A podcast in partnership with Reach.

Meet Ritchi Edwards

within Reach caught up with the delightful Ritchi Edwards; we chatted about all things acting, his enthusiasm to spread awareness for the charities close to his heart and a bit about what it was like for him growing up with a limb difference. Welcome back to the Reach family Ritchi!



Ritchi Edwards

Ritchi, you're a fantastic advocate and it's clear that you use your voice and platform as an actor to spread awareness of the causes close to you... Do you think that's an important part of your role in the public eye?

"Thank you so much that really means a lot. It was so lovely to get back in touch with Reach, a real blast from the past and so nice for me to be able to connect more now as an adult within the upper limb difference community. I think it's incredibly important [as a public figure] because when you have an audience, you're able to spread awareness for important things which they may not know about and you just don't know who you are going to Reach - excuse the pun [laughs].

I'm also an official voice & advocate for the Born Free Foundation who have held a very special place within my family since their beginning so now, to be an official voice and advocate for them means an incredible amount to me. I'll be running my third London Marathon for them this year, spreading awareness for two causes, as an animal lover and someone with an upper limb difference."

You've been acting for a long time, how did that journey begin for you?

"That makes me feel old! [Laughs] I started on stage with Theatretrain many years ago playing The Beatles manager Brian Epstein on the West End which was such a great experience. I can remember standing in the wing waiting to go on, there's a stagehand ready to open the curtain for you and a television showing the production playing out. Also, the nerves are playing out too but it's all good, you use those nerves to your advantage!

My Mum and Nan urged me to go to Theatretrain because they thought it would have a positive impact on my confidence and it did. I've always loved movies and have been so fascinated with filmmaking; the magic of it all, being transported into different worlds and meeting different characters - I've always wanted to be a part of that!"

“ I owe a lot to the arts for setting me free as a person and allowing me to be more confident with my upper limb difference. ”

Your industry is notoriously tough to get into, what challenges, have you had to overcome and what has been your proudest moment?

"Yeah, it is a very tough and crowded industry but I've always tried to keep the mindset that the biggest competition is only yourself and to be the best you can be. Mindset really pushes you forward and instead of putting you down it makes you want to thrive and do your best.

My proudest moment will always stay with me...Walking the red carpet with my grandad, Fuller, at the prestigious BAFTA & The Academy qualifying Raindance Film Festival, it's where Homeless Ashes had its World Premiere. Sharing that moment with those I'd become close with through the Homeless Ashes journey, this will always have a special place in my life and career."

How have you found navigating the industry as someone with a difference? Do you think it's improving?

"It's in such a better place than it was, although it's not at its full potential in terms of diversity, there's still work to be done. I understand as an actor with one hand, that in reality there may be characters I can't play but the word 'limit' is one I dislike so I also carry the mindset that, 'you may be looking for someone with two hands but let me show you what I can do with one before making your mind up'. I think mindset is always important, I'm very lucky to have my agents Donna & Ray at T-ypo Talent Agency who support my vision as an actor with an upper limb difference and support my dislike of the word 'disability' and the limitations the word holds."

How do you deal with questions about your limb difference?

"I've had a lot of questions over the years; I'm a lot more comfortable and confident answering them now than I was when I was younger. I would try to avoid it as much as possible but now I feel comfortable talking about Stumpy and offering an insight into living life with a limb difference."

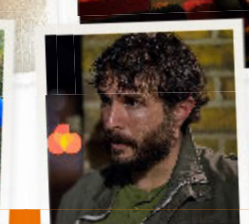
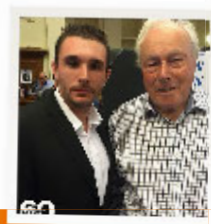
You were a member of Reach as a child, do you have any memories of events you attended that have stuck with you?

"I can always remember Santa with the presents while Wizard's 'I Wish It Could Be Christmas Everyday' was playing. I remember sitting around the table with my fellow Reach-ers eating our food but I was the one who stole all of the Wotsits off the table, so if any of my fellow Reach-ers from back then are reading this now, yeah... That was me! [Laughs]

Back then Reach was such a great community and reconnecting recently I can see it's still going strong which is so nice to see. My Nan and Grandad also helped with the raffle and prizes when I used to attend back in the 1990s."

Would you mind if I asked what it was like for you growing up with an upper limb difference?

"Of course, I was really shy when I was younger, I had challenges with name calling but now I pity those people because they were petty and uneducated. I used to hide 'Stumpy' under a hat or in my pocket or even under my sleeve. At times I was really self-conscious about it and people looking at me but now I look back and regret hiding Stumpy because this is who I am! At that age I didn't have experience and I was just a self-conscious boy but I'm so grateful that as life has gone on that my confidence has grown and I can hopefully inspire others in the upper limb difference community with my journey."



Quick Fire Round

Biggest pet peeve?

"My biggest pet peeve... I have quite a few [laughs] but, ignorant people and those who think they are a step above everyone else and look down on others, but my biggest has to be those who are unkind to animals!"

One weird fact or thing about you that people might not know?

"On my dad's side we're related to King Richard III; I think that's a cool little fact that people might like to know!"

A lot of Reach members talk about feeling the need to prove themselves to people as our ability is often underestimated, have you found that yourself?

"I have been in situations before where people have seen me as less capable. I think it's a natural instinct for someone to see us as less capable and feel the need to step in and help and in the past I've done things to try to prove myself because you want to show that you can do this or that."

“ We don't need validation from anyone but ourselves, we are our biggest critic... Not proving things to others but proving things to ourselves is the way forward! ”



Who would you love to act with if you could choose anyone?

"Cor, that's a hard one! ...I'd have to say Leonardo DiCaprio, Tom Cruise, Christian Bale, Daniel Craig, Gerard Butler, Patrick Wilson, Kate Beckinsale, Jennifer Lawrence... The list could go on! [laugh!]"

If you could only speak one phrase for the rest of your life, what would it be?

"Never give up on your dreams" - It's simple but powerful."



Bilateral Difference

We're not all the same

Editorial by Max Swinhoe



Reach works to create a community that brings comfort and support to its parents, children and adult members but it can't be everything to everyone. Sometimes acknowledging what we don't share can help us to remain inclusive and welcoming. We aren't all the same; even within Reach we are all unique and have different differences.

Representation means being able to 'see ourselves' reflected in the media, or on charity websites for example, but even inside the realm of disability we sometimes only see certain differences and one group still being underrepresented is the bilateral community.

We can start at 'home', as members of Reach we can spread awareness and educate ourselves and those outside of Reach about other differences, and even how unique each of us are within our charity.

Reach mum Stephanie recognised the importance of having Reach when they found out about their son Daniel's differences. However, as "invaluable" as Reach was and has been in their lives, they feel at times there is a "pre-conception that every child feels better just because they have Reach, when in reality that isn't always the case when they have differences on both arms."

For Daniel growing up, sometimes Reach wasn't enough for him. "He didn't feel 'the same' as everyone else at meet ups as there was no one else with bilateral differences." And if his parents referred to other Reach children, he would say: "But they have one hand!"

Despite this understandable frustration, meeting children who were "similar to him" did bring Daniel comfort and confidence; on the way to Annual Family Weekends he would tell his parents: "I can take my jacket off now, I'm at Reach!"

Stephanie and Daniel's story reinforces the importance of families finding Reach but also reminds us that Reach is a piece of a larger puzzle. In order to complete it, we need society to keep progressing and to ensure we're seeing representation of all differences inside and outside of our charity.

Despite being born with a limb difference, before I re-joined Reach I was ignorant about other differences and how different diagnoses or syndromes can affect day-to-day life.



Reach member Rhys, now aged 15, was born with bilateral differences affecting his arms and legs. For mum Sian the early days were tough.

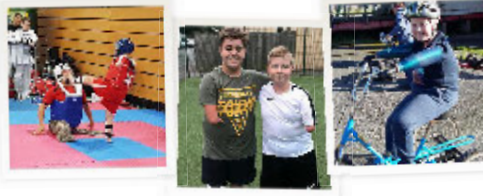
"We had no support but then a friend found Reach for us."

But Sian feels that people, inside and outside of Reach, should be more aware of how bilateral differences can affect other areas of everyday life.

"We were worried about things he wouldn't be able to do, such as write his name, feed himself or ride his bike. Rhys is able to do a lot but there are still quite a few things he is unable to do, such as dress himself fully and clean himself after the toilet."

Sian says

“66 having bilateral differences is much harder than people think. ”



"Missing one hand is hard but missing both, especially with feet affected, makes life very difficult. Rhys was born missing toes off both feet and the bottom parts of his legs are not developing the way they should, so Rhys is unable to use his feet to help him with day-to-day life. Speaking to a few mums of children with bilateral differences, and bowel and bladder problems are common as well."

An important reminder that for some Reach children self-care should be a consideration when organising events so that everyone can feel included and can participate, if they wish.

Like many teenage boys Rhys loves playing Xbox, seeing friends and watching rugby, "especially Wales". He's studying Business Studies, Drama and ICT but isn't sure yet where it'll take him career-wise.

"We still have a lot of challenging times ahead. Rhys is leaving school next year; as his mum, I've told him that he can do whatever he wants to do, but deep down I know it won't be that easy."



Within the Reach community peoples' assumptions about ability is often a challenge and Sian wants people not to judge Rhys before they know him.

"Don't judge a book by its cover. When Rhys changed schools several years ago, I called to speak to some and I could hear the worry in their voices, but when we took him in, the staff couldn't get over how much he could do after meeting him and watching him.

On paper, 'bilateral differences' sounds bad but get to know the person and you'll realise how special they are. Yes, Rhys needs a lot of help, but boy can he give someone on the Xbox a run for their money!"

Sian emphasises that when it comes to inclusion, at times difference should be "treated differently". For example, for Rhys to attend a day activity "he needs help with his toileting and personal care".

However, Sian also acknowledges that even within the bilateral community there's a huge range of differences and that "some bilateral children have smaller hands so some activities might suit them better than those missing both arms".

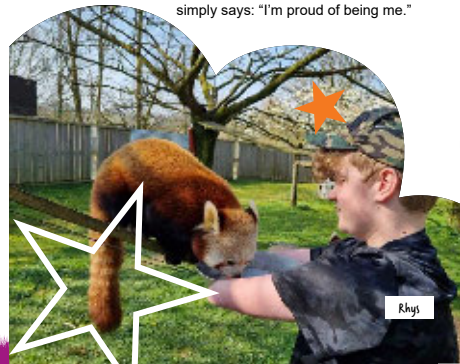
For Rhys, Reach has given him a lifelong friendship with Adam whom he met around 10 years ago, whilst Sian found "a friend for life in Adam's mum Juliette", sharing how important it is "having someone who understands".

"It makes life easier having a good friend with similar differences because he's going through everything that I am. We connected straight away and have been friends ever since. He's taught me a lot and he's still teaching me new things. When we visit it's like we've never been apart", says Rhys.

When it comes to people asking questions Rhys finds it easier the older he gets, telling those who ask that his arms were "bitten off by a shark!" But people still make assumptions.

"People automatically expect that I can't do anything for myself!"

Rhys says his biggest challenge has been accepting that he needs help but he's "always determined to do things by himself". When asked what he's most proud of, he simply says: "I'm proud of being me."



Reach parents Natalie and Callum found out about their daughter Kaia's bilateral differences at Natalie's 20 week scan.

"I know there's no right way to tell someone but it felt like the rug had been pulled out from under us... We were first told everything was fine but then came the 'but'.

[After the scan] We were urgently referred to a foetal consultant who confirmed the diagnosis of 'bilateral amputation of the foetal forearms.'"

Natalie and Callum found it hard at first, particularly noticing a lack of representation of bilateral differences.

“66 I'll be honest, we struggled quite a lot when we first found out about Kaia's limb differences. ”

It was quite hard to find stories or experiences of people with bilateral differences.

"Joining Reach was great for us in so many ways and we've received tonnes of support."

However, despite the comfort found in Reach Natalie and Callum have felt somewhat "isolated" due to the under-representation of bilateral differences.

"It's through Reach though that we've managed to establish contact with families of children with similar differences to Kaia; the branch coordinators have gone out of their way for us, which has been amazing."

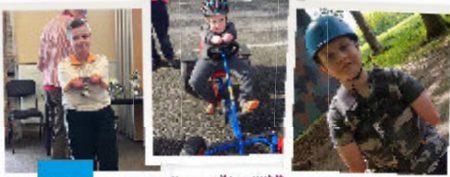
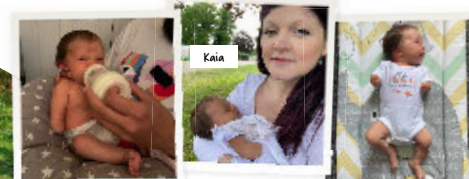
"The pdf leaflet on the Reach website about supporting children with multiple limb differences was also extremely helpful and mentions things we hadn't considered, like the fact that Kaia may get hotter than other babies as she has less surface area through which to release heat from her body..."

Natalie considers one of the biggest challenges ahead of them may be other peoples' perceptions.

"A lot of people aren't familiar with this kind of difference and assume that her life will be so limited as a result which is not the case. I also hate the fact that some people are already looking at her differently. This hasn't happened nearly as much as I thought it would, but just yesterday my partner caught someone staring at her like there was something really wrong. It makes you worry and want to protect her from people's limited understanding and prejudices. I just don't want her to have to deal with that but I know that she'll have to."

Reach has been a great support for Natalie and Callum but they want people to recognise it a platform for all upper limb differences.

"Reach is not just there for children with unilateral differences. We would love to see more illustrations featuring children with bilateral limb differences. And initiatives like 'how to do things with one hand' don't really apply to us, so including something additional in these discussions for children like Kaia would be good."



DONLOOKATME!!!

By Stuart Waterman



was the day when, faced with a little girl looking at him with curiosity, he shouted, "HEYYYY! DONLOOKATME!!!"

It really caught me off guard. It was like he felt the little girl had broken the rules of a game. I've never witnessed him expressing self-consciousness or displeasure at being looked at before.

It's happened again since. I don't know if Kit knows why people might be staring; he just doesn't like the fact that they are. Which is understandable.

We've tried to broach the subject of his arm with him, but without much success. As his parents we feel the instinct to try and 'get ahead' of any upset he might feel, to head it off at the pass.

But we won't always be by his side as he negotiates all life's challenges, and similarly we can't dictate his level of consciousness about his limb difference (or how he feels about it). At this point we can't even stop him shouting at other kids!

All we can do is be mindful about his development, try and figure out when he's ready for certain kinds of conversations and prepare accordingly.

Alongside this, of course, our own anxieties sometimes come to the surface. The other afternoon I was in a park with Kit, sharing a picnic with other kids from his nursery and their families. After a trip to the playground I looked around at all the other parents enjoying seemingly carefree conversation and frivolity in the sun.

I found myself feeling jealous, and somewhat resentful, that I was instead mentally processing the latest round of stares and comments. And then a spiral of self-reproach kicked in as I reminded myself, once again, that we can only control our own reactions to situations.

But I think it's OK to acknowledge that some days are harder than others as a Reach parent, and for every challenge there comes, from somewhere, a reward. When we got home after the picnic, Kit exclaimed: "I'm using the pedals, Daddy!"

He's had this little trike for ages, and always avoided using the pedals, instead moving it by running his feet along the ground. Not anymore!

For the first couple of years after your Reach child is born, your main interaction with their visible difference might be through the reactions of others. And so you visit Reach's helpful Facebook page, familiarise yourself with how others handle this kind of thing and formulate your own approach of how to respond to questions/comments/stares.

If you're anything like us you try to be patient and considerate, especially when the questions come from curious and well-meaning children. (But, also, sometimes you might just say your child's arm was eaten by a T-Rex. The open-mouthed silence you get as a response is totally worth it.)

And it goes along like that for a couple of years or so, to the point where you may forget that one day, you're also going to have to think practically about how your child responds, too. And that's where we find ourselves at the time of writing.

Kit, who is three, is a bit delayed in terms of cognition and speech, so his seeming lack of self-consciousness about his small arm hasn't been a huge surprise. What was a surprise





“ It really caught me off guard. ”







Every Hero Needs A Sidekick!

Meet the new companion for your Hero Arm.

Get ready to personalise your Hero Arms! With the Sidekick app, our heroes get greater control over their bionic arm settings with our brand new Bluetooth feature.

-  Adjust LED brightness, beeper volume, and vibration power
-  Check battery status
-  Train to use your Hero Arm
-  Drag and drop the order you want your grip modes to appear based on daily needs



-  Take part in interactive challenges
-  Test the strength of your muscle signals
-  Get real-time visualised Hero Arm usage data
-  Share stored data with clinicians or use it to track progress

Jacob Hyatt - Bionic Boy



Jacob Hyatt has been having fun with his Hero Arm since he got it in February. "My favourite thing about the Hero Arm is I can do cool tricks like the thumbs up, fist bump and other stuff like that. I like to ride my bike with it, and play lego with it and especially playing basketball with it. And now I can carry my bag to school!" Jacob's favourite feature of the app is practicing Freeze Mode so he can confidently keep a strong grip. Tell us what your favourite feature of the app is!

Jacob's mum, Bernice Hyatt, believes building confidence is the key for Jacob to live his best life.

"As a mother, I just wanted to make sure he has the best opportunities for his confidence and his mental well-being."

Just like Jacob, you can now unlock new cyborg powers with Sidekick for your Hero Arm. Find out how you can control, change, train, and track your bionic arm using your smartphone at openionics.com/every-hero-needs-a-sidekick

Do you qualify for free Hero Arm funding?

Thanks to generous collaborators, people experiencing financial hardship may be eligible for a free Hero Arm!

Download our latest brochure to find out about funding support available, the new Hero Arm Sidekick App and latest technical specifications of the Hero Arm.

Scan to download brochure:



Gill from the Great British Sewing Bee 2022

Did representing upper limb difference on the GBSB empower you and if so, how?

"Being a limb different contestant on a national TV show was incredibly empowering for me. It made me face one of my biggest fears – of being seen without my prosthetic. When I taught myself to sew, I didn't wear my arm. So, if I was going to take part in the show, I knew I had to do it without my prosthetic, because I didn't know how to sew with one.

I was terrified and at first it was excruciatingly embarrassing. But then I realised I was the one who felt the most uncomfortable about my arm, not other people. And actually, not wearing a prosthetic felt so much better for me – I wasn't hot and sweaty, I didn't have any chaffing and most importantly, for the first time in my life I felt like I wasn't pretending to be something I'm not, I wasn't trying to fit in and be a two-armed person. It literally set me free."

What does representation mean to you? Have your thoughts on representation changed since being on the show?

"Representation really matters to me. I haven't seen many people who look like me, in either the media or in real life. All my life I've struggled to feel like I fit in or belong. I always wanted to blend in and hide my arm, to avoid standing out because of my limb difference. I think seeing other people who look like me would have made a big difference to my confidence and helped me feel less ashamed of my body."

@theonearmedsewist



Mason Joined Team BRIT at Dunsfold

Mason experience representation in action when he was invited to spend a day with Channel 4's Packed Lunch crew and Team BRIT at Dunsfold. The all-disabled racing team welcomed Mason to explore their garage and experience their driving simulators, and best of all, drive around the top gear track!

I asked Mum Louise how Mason found the experience:

How did it feel to meet the racers of Team BRIT? I know being part of Reach makes me feel like I'm part of an awesome club, did Mason feel like that meeting the team?

"I think it made him feel like anything is possible, he saw that limb issues or other disabilities don't limit or restrict your abilities and dreams. Believe and achieve is their motto."

What was the best part about Mason's awesome day at the track?

"For Mason, the best part was doing some laps of the top gear track in the McLaren with driver Aaron."

So what will it be... Karate champion, racing driver or both?

"He definitely wants to be a race driver!"

And for you Louise, how has representation of upper limb difference impacted you and your family? Have you seen a difference in Mason's confidence?

"As a family we have always told Mason he is capable of anything and he believes that as much as we do and he is very confident on the whole but spending time with the team has brought to reality that no matter what "disability" you have, that your dreams can come true, it's definitely boosted his confidence."



Milton Lopes is a Multi-disciplinary Performer

He was born in Cape Verde islands and grew up in Portugal. He is currently based in London. He has been in several TV shows and films, worked as an aerial circus artist in various productions and he is a singer song writer who plays guitar and who is learning to play the drums.

What does representation mean to you?

"Representation means to show how diverse the world is and that a homogeneous society is an illusion. It also means to create role models for those who believe that they are "different", so they can achieve anything they want in life. I believe that only through examples can we advance in changing the narrative that disabled people are not able to contribute for development of society and have a happy and fulfilled life."

How does it feel to represent upper limb difference in your work/life?

"I feel a great responsibility, which I love. I'm always pushing myself,

not only to achieve my goals, but also because I know that a parent who is struggling to come to terms with their child's limb difference, can look at my videos on social media and be reassured that their kid will be OK.

Sometimes when I find myself wanting to give up, I think about all those people who have limb differences and are too afraid to follow their dreams because society told them over and over that they can't. So I pick myself up and carry on, hoping to encourage as many people as possible."

@1000tonlopes



Para Triathlete Tammy: Batonbearer for the Commonwealth Games

"My friend Melwyn Moore nominated me to be a Queen's Baton Bearer. It was a real surprise and an honour and I was totally blown away when I was actually chosen! Carrying the baton and meeting so many others with amazing stories was an absolute honour. I'm very proud to represent the NHS, myself as an individual, and as a mum and as an athlete with a limb difference. Despite any difference you acquire or are born with, you can succeed despite life's challenges - anything is possible if you want it enough."

Tammy swam with a swimming club until the age of 14 but left after being told she "Couldn't take it any further". Para sport hadn't "taken off" yet but Tammy continued swimming and "encouraged by dad" started running, joining two local running clubs. Despite a passion for fitness Tammy wouldn't compete again until the age of 30, after having three sons and running her own childminding business. She re-joined the swimming club as a "master swimmer" and got "classified as a para swimmer in the S8 category, subsequently qualifying for national and international events "often coming away with medals".

During her time as a childminder Tammy found a love of caring for children, leading to her diploma for Children's Nursing and then qualifying as a paediatric nurse in 2012, "one of the proudest moments" of her life, and then she "completed" her family with the arrival of her daughter.

Eight years ago, Tammy began competing in para triathlon but life and work was busy so she discontinued triathlon and "concentrated on swimming", her "first love". After the pandemic Tammy returned to cycling and swimming, leading her to enter and win a Sprint Para Triathlon series in 2021 in her category. Tammy continues to compete and is focused on the Master Nationals later this year, October 2022.



Parental Experience Survey

Debs with Consultant Plastic and hand Surgeon Dr Andrea Jester

Thank you all for your participation in the Parental Experience Survey on receiving the unexpected news of a congenital upper limb difference.

We had 261 responses from all over the UK and Ireland - a great response!

The headline results show that not many of you felt supported when you first saw or heard the surprising news that your child had a limb difference... Many of the midwives, sonographers, neonatal paediatricians etc. who first saw you were also not well equipped with the right information or the right degree of positivity.

So, we have work to do!

Firstly, the results of this survey were presented at an international conference of hand surgeons in early June in London. This was just the beginning!

Although similar surveys have been undertaken from around the world, this the first and largest UK wide survey identifying what is really going on with regard to parental experience at the time of the surprising news that a baby has an upper limb difference.

The presentation at an International Hand Surgery Conference has significantly helped to raise awareness amongst Hand Surgeons of the real issues which parents face before being seen by themselves as specialists and hopefully will stimulate more discussions locally in the UK regions and an improvement in the information and signposting which future parents will be given.

Parental experiences shared within the Reach community, and stimulus for this project:

“ We were told at the 20 week scan that our son's right forearm was missing. We never found out why. I'm really glad I've found Reach. I hope to make friends with people in the same situation as I've not really had chance to talk to anyone about his arm. ”

“ Our son's right hand hadn't fully developed. This wasn't picked up on any of the scans... We had been referred to a hand specialist and told they'd be in contact within 2-4 weeks. After 9 weeks of constant phone calls from me we eventually got an appointment. ”

The results will be fully published in a Hand Journal but also made available to midwives both by presentations at their professional meetings as well as being incorporated in their training - hopefully!

Our team were at the London meeting and made contact with several surgeons from the UK and were able to hand out information about Reach which hopefully will get to new parents.

Secondly, a draft booklet is being worked on which will give information for families and another similar one is being written for health care professionals.

We hope to get these booklets available nationally electronically and that all midwives will be able to get access and signpost new parents to this information as well as understand how amazing our Reach children are and what they can achieve.

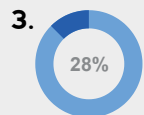
Headline results from the survey in figures:

1. Most parents received verbal information as opposed to written

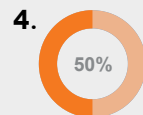
2. 75% of parents felt 'unsupported' following the news about their child. We do have more written details around how parents would like to be supported.

This includes:

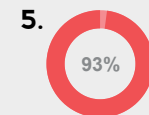
- a) Understanding the cause of the limb difference
- b) Being directed to a support organisation such as Reach
- c) Understanding about what the future may hold for their child both functionally and surgically and the wider life implications.



of responders thought they were given useful information at the time of the 'surprising' news.



had an appointment with a specialist by 3 months after birth.



of parents searched for information themselves.

Imagine if all Reach parents could feel supported and comforted by the health professionals they meet from the moment they find out about their child's limb difference.

Our aim is that all medical professionals, from midwife to sonographer, know more about rare visible differences such as limb difference. We hope to educate them how to support, and provide the help and confidence our Reach parents need at a vulnerable time.

“ We found out two weeks ago at our 20 week scan that our little boy's right hand and half his lower forearm has not developed... We're still in shock and trying to process this information... I've been told by Reach mums that it will be ok. It's so hard not to think of the negatives and I'm so grateful for Reach as we have not had any other help or support from the medical professionals. ”

Books

Books that discuss or illustrate differences are an effective tool to spread awareness, start conversations and break barriers, and a fantastic way to introduce difference to children, at home with siblings or friends; or at nursery, playgroup or school. Buy these titles through Amazon Smile, choose Reach as your charity and Reach will get a percentage of the purchase. It's that simple!



Hands (My Body, Your Body) by John Wood

<https://www.amazon.co.uk/Hands-My-Body-Your/dp/1786377438>



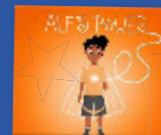
Splash by Claire Cashmore

<https://www.amazon.co.uk/Splash-inspiring-Paralympic-medallist-Cashmore/dp/075550285X/>



Chops by Matthew Jenkins

<https://www.amazon.co.uk/Chops-Mr-Matthew-Jenkins/dp/1986674061>



Alf's Power by Mina Minozzi

<https://www.amazon.co.uk/Alfs-Power-understand-self-awareness-Intelligence/dp/1838309209>



Roxy and Maliboo: It's okay to Be Different by Hillary Sussman

<https://www.amazon.co.uk/Roxy-Maliboo-Its-Okay-Different/dp/1649908861/>



Uniquely Me by Trace Wilson

<https://www.amazon.co.uk/Uniquely-Me-Trace-Wilson/dp/B08V0QJB13/>

The Roller Coaster Ride by David Broadbent

<https://www.amazon.co.uk/Roller-Coaster-Ride-Childrens-Library/dp/1786285606>

5 Fingers and 10 Toes by Dawn Civitello

<https://www.amazon.co.uk/Fingers-10-Toes-Dawn-Civitello/dp/1539712028>

The Otherwhere Emporium by Ross MacKenzie

<https://www.amazon.co.uk/Otherwhere-Emporium-Kelpies-Ross-MacKenzie/dp/1782506632>



Insignificant Events in the Life of a Cactus by Dusti Bowling

<https://www.amazon.co.uk/Insignificant-Events-Cactus-Dusti-Bowling/dp/1454923458>



What makes you super by Fernanda Neves

<https://www.amazon.co.uk/What-makes-you-Super-Amniotic/dp/6500422562/>



What Reach Does



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

RAW (Reach Activity Week) 'Incredible Delivery' Pack

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

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...

Run for Reach!



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

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

Birthday Fundraisers



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

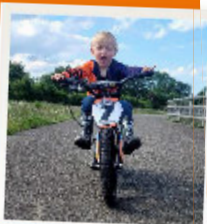
Reach charity are funded 100% by donations and membership subscription. Help us to continue supporting Reach families with more ideas and how to fundraise for Reach at:
👉 www.reach.org.uk/fundraising/

August is REACH CHARITY CHALLENGE

Do something awesome linked to the number 5

- ★ In 2021 Bertie was pushed 105 miles in his pushchair by Mummy & Daddy over the month of August.
- ★ Nicole cycled 500km throughout August.
- ★ Tatum did a family and friends 5K hike.

Find out more on how to get involved by visiting:
<https://reach.org.uk/r5ach-charity-challenge22/>



Helping children with upper limb differences live life without limits

