withinReach

Helping children with upper limb differences live life without limits

Summer 2020 | Issue 144

LOCKDOWN?

YOU WILL BE AMAZED AT WHAT OUR FAMILIES HAVE BEEN UP TO!

Reach

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

withinReach

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Registered charity in England and Wales no. 1134544
Registered charity in Scotland no.SC049805

withinReach magazine is printed
by ABC Printing Services, 69 West St,
Tavistock PL19 8AJ

Comments, articles, requests, ideas:

We welcome comments, articles, requests or suggestions for future editions of **within**Reach.

Letters:

Any letters for publication should include the name and address of the sender, but these can be withheld from publication if requested.

The views expressed in this journal are not necessarily those of Reach and are not intended to reflect or constitute Reach policy, or in any way portray an official view.

Reach membership

Membership of Reach is open to parents of children with upper limb difference and other individuals of 18 years and over who are interested in furthering the work of the association. Junior membership is given to children who have an upper limb difference. The UK subscription is from £36 (£35 if paid by direct debit) and the Ireland subscription is €45.

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.

BE PREPARED BEFORE YOU GO TO YOUR CHILD'S ASSESSMENT

If you're preparing yourself and your child for a paediatric assessment for equipment or adaptations, the BHTA has created this handy guide for professionals, parents and carers of children with a limb difference to help them understand what an assessment is and what outcomes should be achieved.

For information, visit: http://bit.ly/2M6u7Hn

BHTA GET WISE

Preparing for paediatric equipment or adaptation assessments?

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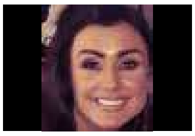

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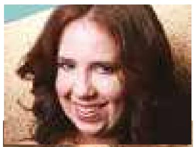

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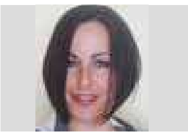

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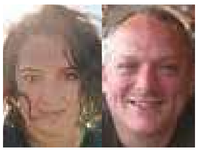

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THE LINK TO YOUR LOCAL COMMUNITY

HO will give you lots of support in this crucial Reach role. We can help with marketing and promotional material and all the items you need for fundraising events.
Call us on 0845 130 6225 or by mobile: 020 3478 0100.

WELCOME TO OUR SUMMER ISSUE

NATIONAL COORDINATOR

What a strange change of reality we have been living through over the last few months. Who would have thought, when the last **within**Reach was being produced, that by the time it was finished we would be in lock down?

I hope you have all been managing ok and have been able to keep your spirits up.

It has been a difficult time for the charity as we have been very concerned about the lack of opportunities for fundraising. Although all events have been postponed until next year or cancelled, there are still all the overheads and costs attached to running a charity that must be paid. We have investigated all our outgoing costs and cut them down where we can, without losing the vital services we offer our members. We were all furloughed from work which helped save some money.

The London Marathon organisers came up with the brilliant idea of the 2.6 challenge where everyone and anyone could do something to raise some money or donate to a charity of their choice. Our members pulled it out of the bag and between them raised over £18,000. This is an astonishing amount of money, and with the addition of some legacy donations it has saved us from a very frugal year.

Limb Loss Awareness month was a huge success too. We increased our Facebook followers by 152, and over 100 new members joined Reach charity. Thank you to everyone who shared our posts and helped boost awareness of Reach.

Our Branch Coordinators have been keeping in touch with their regional members via email and Facebook. If you have not heard from them, contact us to make sure we have your correct email address. (reach@reach.org.uk). Our members have been supporting each other through the closed Facebook group and the response to activity on our open page has been brilliant as we now have over 3,200 followers.

The LiMITTless project started in April and our members are now beginning to receive their Mitts, so keep a look out on our social media platforms for their stories.

We welcomed our new Trustee Sam Young, who is already making a fantastic impact helping us to organise RAW and the Annual Family Weekend (AFW) on-line. Information for the AFW will be shared with you shortly, but to reassure you we still have all our speakers and lots of activities lined up, all of which will be expertly virtually managed by Reach members James Jones & Alastair Greener.

We are down to two members in head office now so to make sure your query always gets answered please send any emails to reach@reach.org.uk. We hope our Branch activities will be able to start up again ready for the Xmas parties, we will keep you all updated.

Debs Bond
National Coordinator
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NEW EDITOR NEEDED!

withinReach is looking for a new editor to take over in the spring, as I am planning to retire in the new year. It has been a difficult decision to make as I love you all and have nothing but admiration for Reach. I have enjoyed producing the magazine and the winter 2020 issue will be my 22nd and my last. I will miss it enormously but I would like to spend more time with my grandchildren and my many interests - I won't bore you with them all here!

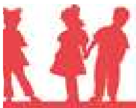
So what does the job entail: Well, I have done everything from coming up with ideas for articles, to commissioning them, interviewing people, writing articles and editing them, reporting on events like RAW and the Family Weekend, taking photographs and collecting pictures.

I have then assembled it all, edited the copy, formatted the photos, designed and laid out the pages and produced the magazine. It is quite a big job, certainly varied, and very rewarding to see through from start to finish.

My career began in newspapers. I was news editor of a big provincial paper before going freelance in 2001 and my skill set over my career has expanded. The job could certainly be divided between members of an editorial team and I am hoping that the talent and experience already there in Reach members could be tempted to take on at least some of the role. I know the next chapter for the magazine will be exciting! Time for new people and new ideas!

Jane Garrett

Reach Board



CHAIR'S REPORT

Well. Where to start? Four months ago, I'd expected my summer note to be all about the vast array of social and fundraising activities that Reach members were involved in across the UK and Ireland, and what an exciting time it was for the charity and blah blah blah happy stuff. But here we are, still in the No Man's Land of social distancing and possibly a more divided and dislocated society than ever, as we split into the ill/healthy/scared, working from home/working on the front line/out of work/doing the lot on top of supporting remote schooling with our domestic IT and broadband stretched to the max and beyond.

And yet, still Reach continues as a bright, shiny, orange beacon of hope. Despite all the obstacles, our fundraising has continued (albeit on a much reduced scale), we have embarked on new projects (anyone else's mind blown by the excitement of the LiMITTless project and all the updates from new users?) and branch and other activities have moved on-line.

Is it as good as being able to meet up in person? No, of course it isn't, and we all hope it will be possible to resume normal branch and other activities again. But it has been wonderful to see contact continuing, and our closed Facebook groups continuing to provide a source of information and support for members.

Huge thank you to the Head Office team and all the Branch Coordinators for the work they have done to keep Reach-life going during lockdown. And, from me, special thank you to all of the members of the Reach oRchestRa for taking the leap of faith to get on board with that new venture. Watch this space for news of 'oRchestRa Rides again' later this year - new members welcome!

The Trustee Board's focus over the past few months has mostly been on finance, data security and other governance systems. Money continues to be tight, and we need to make sure we can sustain the charity through the next couple of years so that it can continue its important work. Covid-19 has made us all think differently about how we organise ourselves and we are continuing to review the best way to manage the charity in this strange new world. Some of this is tedious but important nuts and bolts-type governance stuff, but we're also trying to think of exciting new ways of doing things.

We've seen a few changes of personnel over the past few months. Farewell to Abby Williams, who has left the Head Office team after seven years working for Reach; we wish her well. Welcome to all our new members and, especially, to new trustee, Sam Young. It is great to have a 'former Reach child' as part of the Board - really helps to ensure we are properly grounded in what the charity is all about: helping children with upper limb differences live lives without limits.

Clare Salters

WELCOME TO OUR NEW TRUSTEE, REACH MEMBER SAM YOUNG

Sam was born with VATER Syndrome and has been a member of Reach from a young age, regularly attending meet ups in London.

He graduated from the University of Bristol with a degree in Modern Languages (French & Italian) and he followed his early love for sport and began his career within the sports marketing industry.

Today Sam is Head of Marketing for LimeLight Sports Ltd, a sports marketing agency and rights holder working with clients such as Nike, The FA and The Royal Parks Foundation - based in central London.

Sam will serve as a co-opted trustee until the Annual General Meeting, when members will have the opportunity to endorse his appointment as an elected trustee. He brings a wealth of knowledge and expertise to the board as well having as a long term personal connection with the charity. Welcome to the team!

It was initially his parents who found Reach, taking comfort in the community and regularly attending meetings. It was from these early interactions with the charity that they gained confidence and belief in what life a young Sam might be able to go on to lead.

Sam will bring a wealth of marketing ideas to Reach that will help us raise our profile to potential new members and health care professionalise. It is great to have you on board, Sam!

THE POWER OF SOCIAL MEDIA

One of the success stories of Reach in recent years has been the use of social media, in particular Facebook and Instagram to link members safely in a closed online forum, and on public pages to raise awareness of the charity.

During Limb Loss Awareness Month great effort was made to expand the charity's public profile and it paid off.

The open Facebook page now has 3,222 people who follow Reach. Our Instagram page has over 600 followers. It's all about spreading the word about limb difference and helping new parents find us when they need us.

LOOK WHAT WE DID IN LOCKDOWN!

Covid-19 has a devastating effect on the UK's charities. Not only have Reach branch and youth activities been cancelled but opportunities for fundraising have been severely restricted. But out of this impending catastrophe came a brilliant idea.

THE 2.6 CHALLENGE

The 2.6 Challenge was launched on April 26th, the date when the 40th London Marathon was due to take place. People were asked to choose an activity based around 2.6 or 26 and fundraise for Reach. Well - you certainly ran with that!

SOFT TOY RAFFLE

Amy Roskilly-Green raised £300 with a soft toy raffle. She offered to make the bespoke toy from a Funky Friends Factory pattern. The toy could be made as a memory toy from old baby grows or t-shirts, or in patchwork from various material choices. The design options were plentiful! The soft toy could even have a limb-difference.

2.6K FAMILY GARDEN RUN

Ann Byers and her family decided to each complete a 2.6km run in the garden for Reach "because It's a wonderful charity that we'd be lost without." They raised £220.

"We had a few technical difficulties when recording our distance but as a family we raised £220 for our favourite charity Reach," said Ann.

REUBEN'S PAINTINGS

Alice Gair decided to paint 26 pictures using Reuben's little hand (which was quite challenging with a 10 month old!) and people who donated got sent a picture. They raised £551

TOTAL RAISED: £18,000 +

CARTWHEELS....

Chloe Giffard did 500 cartwheels in one day and raised over £1,000 for Reach. She was born with a rare form of ABS - the only case ever in the UK, so she has the limb, but no elbow joint. Nerves are damaged and she has no dexterity in her hand and she can't bend or straighten her elbow. What a fantastic cartwheel achievement!

....AND MORE CARTWHEELS!

National Co-ordinator Debs Bond did 26 cartwheels raising £526.

BIONIC FIZZY'S SUPER HERO LEFT-HANDED CHALLENGE

Fizzy Sharp was born with a limb difference on her left side.

"At an early age I was told that I was meant to be left-handed," she said. "I wore NHS cosmetic prosthetics until I was around 7 years old, but soon decided they weren't for me. I started working for Open Bionics in August last year and I received my Hero Arm just before Christmas.

"When I heard about the 2.6 challenge I was keen to take part, so I came up with the idea of 26 everyday tasks using my left hand with the Hero Arm as my dominant arm. Some of the tasks included:

"Riding my bike - Making breakfast, lunch and dinner - Folding the washing - Painting my nails - Gardening - Housework - Writing - Drawing.

"I came in a little late to the game and wasn't able to push my fundraising page too hard and ended up raising £80 for Reach."

> *I was never involved with Reach as a child, but looking at what you do, I wish I was. As a young child I felt very alone in my experience and I definitely think my parents could have done with the support too - keep up the amazing work."*

FAMILIES SET TARGETS OF 26 DIFFERENT ACTIVITIES

Chloe, Fern and Eilidh Matthews raised a total of £1,274.75 by completing 26 different activities on April 26. Bravo girls!

"Reach have been there supporting us and our family since our 20 week scan when we found out Chloe had a limb difference," said Catriona. "They've provided support, reassurance, information and hope. The charity has given our family the chance to meet others effected by limb difference and made a huge difference to Chloe's confidence and self belief.

Chloe says: "They've helped me learn that I can do lots of things with a little arm. At Reach I can meet lots of other people with little arms and have fun."

"It was busy, busy, busy in our house," said mum Catriona. "26 birds spotted, 26 somersaults, star jumps and trampoline jumps completed, five minutes of mindfulness done, 26 fancy dress outfits, reading 26 books, 26 cartwheels and hardest of all eating 26 sweets."

Reach Ambassador and Paralympian Claire Cashmore set a target of £260 and raised £777!

She was the inspiration for Ella Dickinson, Meghan Willis and Melissa Johns, supporting Ella on-line with the running and doing the 26 challenges virtually with Meghan.

My 26 challenge

. 26 alternated planks
. 26sec handstand
. Bake 2 cookies for 6 peopl
. Ab workout for 26 mins
. 2.6km run
. Eat 26 haribos
. Do 26 swimming strokes
n the trampoline (my pool hadn't come yet😢)
. 26 squats in a wetsuit/skin
. 26 mins of Pilates
0. 26 pushups
1. Wear 26 pairs of socks
2. Run around the garden 26 times
13. Cycle 2.6km
. Swim for 26 mins in a paddling pool
5. Do 26 chores
16. Message 26 British para swimmers
17. Put 26 plaits in my hair
18. Play a game for 26 mins
19. Tell 26 jokes
20. Take 26 selfies
21. Learn 26 new dance moves
22. Wash 26 things
23. Read for 26 minutes
24. Do 26 chores
25. Climb the stairs 26 times
26. Balance on each leg 2 minutes and 6 seconds

Meghan Willis tackled these 26 challenges "because Reach is awesome!

She raised £454.

RUNNING FOR REACH

Ella Dickinson ran 2.6km everday from the 26th April till the 26th May "because they have helped myself and my family since birth." She raised £805.

AEROPLANE RUNS

Blake Maslen completed 26 Aeroplane Runs of their alley "because we love our REACH family." Blake raised £310.

WALKING AND RUNNING

Ed Waldron drew our attention "to a wonderful little girl fundraising for Reach.

"My close friend's daughter Isabel Rawlings, aged 5, is walking/running 10 x 2.6 miles, he said.

"Isabel has talked to me about why I only have one hand and what it's like, and was told that I ran the London Marathon. So when the 2.6 challenge was in the media Isabel wanted to do something for the charity."

"I want to raise lots of pennies for Reach to help children who have upper limb deficiencies," she said. "It is something that means a lot to people I know.

"I am walking and running a minimum of 2.6 miles every day to reach 26 miles, which is the equivalent of the London Marathon. All of my walks are being saved on Strava. I am going to run the last 2.6 miles in my Little Red Riding Hood dressing up clothes with my daddy."

She raised £343. Thank you, Isabel!

THE 2.6 CHALLENGE

26 ONE-HANDED CHALLENGES

"I decided to do 26 one-handed challenges in pictures and video because the have supported my family brilliantly," said Molly Gaughan.

"14 years ago, my mum and dad went for my 20 week scan and discovered that I would be born with just one hand. This was a huge surprise to them and they sat shocked in a cafe near the hospital and worried about all the things I would need two hands to do and how difficult life might be for me-(silly now, right?) but back then they felt very sad. Luckily they found Reach, which put them in touch with other parents and helped them to stop worrying and enjoy watching me reach all the milestones be it slightly differently than Ted and other children do." Molly raised £838!

BADMINTON

Kate Hoare and her family - Andy, Jacob, Emily and Marnie -took on a badminton challenge. They had to hit the shuttlecock 26 times over the net without letting it hit the ground! They raised £150.

WALKING & CYCLING

Laura Hanley walked and cycled 26 times around her local park and woods. She raised £110 and another £110 via a birthday fundraiser.

Trustee Julie Detheridge walked 2.6 miles to her parents' house, and raised £85 selling homemade cakes with her mum.

James and Alexis Tibble walked 2.6 miles to feed 26 ducks - and then walked all the way back again. They raised £30.

BURPEES

Rilee Parker aged 7, completed 26 Burpees and raised £419.

GRACIE'S WORDS OF ADVICE

Gracie has turned 18, graduated from The BRIT School and is on the brink of a career in the theatre, something she always felt destined to do but isn't the natural choice for someone with a limb difference. Here are her words of advice she wished she had been told when she was younger.

Prosthetics - to wear, or not to wear

I wish someone had told me that although the advice was to wear a prosthetic, I didn't have to if it wasn't working for me.

I began wearing my first prosthetic at three months old and wore it every day for 11 years. In my head it was a piece of clothing that I put on every morning along with my school jumper and just like the jumper, it was sweaty and uncomfortable. I used to remove it as soon as I got to school – eventually I was told to stop bringing it in because everyone wanted to play with it during lesson time!- Looking back now, I wore it because it was very important for my parents but kids are openminded.

Be the teacher when people have questions

Sometimes when I'm in public, I notice children stare at my limb difference and whisper to their parents "what's wrong with her hand mummy?" to which the parent replies "it's rude to stare". But I would want to tell those parents to encourage their children to ask me that question so I can explain to them in a way that they'll understand. I didn't find out until I was 11 that the person who had the most expertise in my limb difference was me. Children look to adults for answers. which is why when children had questions for me, they would often go to a teacher. What I eventually learnt to do was teach them myself because no one knows you better than you.

Adapt and overcome

I spent (and often continue to spend) far too much time getting frustrated over struggles where I found my limb difference was preventing me from achieving something. It is important that young people can think outside the box and tackle problems in a different way from their two-handed friends.

There is nothing I can't do, but I have to acknowledge that tying my hair took some time to perfect and I wasn't always able to lace up my shoes. I think it's also important for parents of young people with limb differences to not force their children into the 'two-handed' world. Giving children the space to try things out and problem-solve without judgement is essential to the growth of a young person.

Let them treat you differently

Positive discrimination is something that someone with a limb difference may experience in their lifetime. As long as it is not negative discrimination, I think it is key for young people growing up with a limb difference to accept help where it is offered and not be afraid to ask for help if you need it. I definitely think there is a stigma around asking for help (even from friends and family), but you'll be surprised that lots of people are much kinder than you'd expect.

Don't swim in a circle because others think you can't swim in a straight line

This point is based on a conversation I had with a teacher when I was younger. When a class swimming trip was announced, my teacher assumed that I wouldn't want to go because my limb difference might mean that I wouldn't be able to swim.

I kindly told her that I was an excellent swimmer and that she needn't worry. In people's ignorance, it is common that they may immediately assume that you won't be able to achieve certain things or may struggle in some areas. It is important that a person with a limb difference doesn't play into this because there is nothing that a young person with a limb difference can't achieve once they've persevered and practiced. Sometimes you just must remind others of this.

THE AMAZING REACH oRchestRa

One of the biggest team efforts for the 2.6 Challenge was the inaugural performance of the virtual Reach oRchestRa. Their recording of *Reach for the Stars* has had nearly 1500 views and raised £1,855, which just shows the power of music!

The oRchestRa was the idea of music teacher and Reach chair, Clare Salters, who had wanted to showcase the wonderful range of musical talent within the Reach community.

Rhian Hughes (tenor horn) was the oRchestRa's star recruiter, signing up grandad Jim on bass, dad Dave on guitar & ukulele and mum Emma on recorder (for the first time since primary school!).

The other Reach children were Andrew Traynor (drums, with dad Carl on bass), Anna Welch (trumpet), Arthur Bramley (tambourine, with mum Stefanie on clarinet), Ewan Gwilliam (violin, with dad Lee on guitar), Grace Baker (euphonium, joined by brother Jonathan on oboe), Harry Arnold-Pepper (guitar), Henry Luke (recorder), Jake Carswell (guitar, with brother Stan on bass), Maria Grecu (recorder, with brother Andrei on violin) and Sam Carter (trumpet).

They were joined by some extremely musical Reach adults: Beth Stephens (piano, with boyfriend Cam on guitar and dad Tony on cornet), Dave Muncey (trumpet major at Guildhall School of Music), Joe Oxenbury (cornet, plus mum Emma on flute), Lynne Bishop (cello), Steph West (professional harpist) and Suzanne Parker (tenor horn, with daughter Grace on cornet). Trustees Clare (recorder) and Ruth Lester (violin) completed the ensemble.

The musicians were united by a love for music, but also a love for Reach. Guitarist Harry summed it up perfectly: "Reach means a lot to me because it gives me a sense of belonging. I'm really excited to be part of the Reach virtual orchestra and I hope that by coming together we can show people that, whilst having one hand may mean we play our instruments a bit differently, we can create something special and inspiring that people will enjoy."

THE ANNUAL FAMILY WEEKEND - BUT NOT AS YOU KNOW IT!

Saturday 24th october

There is a fantastic line-up of speakers this year who will be doing live online question and answer sessions after their talks, so the event will be as interactive as possible.

The technology will be managed by our brilliant Reach tecky, James Jones and the compere will be our loyal supporter Alastair Greener- THANK YOU BOTH!

Paratriathlon Olympic silver medallist, and winner of TV's Celebrity SAS: Who dares wins 2020, Lauren Steadman will be doing a pre-recorded interview with a live Q&A session.

Mountain-climbing action man Miles Harrison will be talking about life as a bilateral amputee from birth. We featured him in the spring issue of **within-**Reach. He is an inspiration!

A big welcome back to Jennie Sands, Reach member and now a fully fledged teacher. She will tell it like it is!

Max Swinhoe, a freelance copywriter, will be talking about her amazing travels around the world and new adventures and challenges, including a van conversion with her husband.

And watch out for Award winning music producer and DJ: Total Recall, Darren Marsh

Very exciting news! Briony Williams, who was crowned 'Star Baker' in the Great British Christmas Bake Off 2019 following her Great British Bake Off success will be running a special Reach cookery competition with a workshop a week before the Family Weekend, demonstrating a recipe for people to follow.

Members can send in photos of their attempts and Briony will judge them.

Meanwhile keep an eye out at www.reach.org.uk for news about more exciting interactive workshops!

THE SHOW WILL GO ON!

IF AMBITIONS ARE THWARTED BY COST - APPLY FOR A REACH BURSARY

We love helping our members to fly! Reach Bursaries are available to help support a Reach child to fulfil their potential through sport, music, mobility or adventure.

Typically they are awarded to help pay for expensive items like car adaptations, to enable them to learn to drive. Bursaries have also been given to help pay for sports training including paraclimbing and snow-boarding, musical instruments and more.

Young musician Sam Carter had demonstrated his enthusiasm for learning the trumpet and he needed a better brass instrument to enable him to progress up the grades. The panel were so impressed by him that they took the unusual step of awarding the full amount requested of £575 - a unanimous decision! So keep practising Sam, we want you to play well!

Would your child benefit from that bit extra? Apply now. Our Bursary Panel is keen to help out. If you need help applying just contact head office.

Sam said: "Thank you very much for funding the money for my brand new trumpet. I have played the trumpet since Year 4 and I have enjoyed playing it ever since. I started off with a plastic trumpet that was meant for beginners and gradually made my way to a brass trumpet that I have had for four years that was good but wasn't good enough to play my grade 2 music.

"So I asked mum for the funds for it and you guys managed to help so much by paying for it. I really can't thank you enough for doing this for me. It is like my birthday all over again. I promise you guys that this trumpet will help me go far and if I ever win an award with it, I would say that you guys were the ones that helped me so thank you so much. I really appreciate it."

Sam Carter

HOW TO NAVIGATE THE DISABILITY LIVING ALLOWANCE MINEFIELD

So you are contemplating applying for DLA - Disability Living Allowance. That is quite a big decision. Former Reach Trustee and active disability rights campaigner **Frank Letch** has a wealth of experience in handling DLA applications. Here is some of his advice.

The weekly benefit is definitely worth having from a financial perspective, but many parents do not claim on behalf of their child because there is a clear dilemma. If you claim, your child Is necessarily drawn into the system, and you are highlighting the fact that you consider that your child has a disability.

You might feel that you will be putting your child through a process that will accentuate psychological and social problems that did not previously exist. This will be particularly relevant if you have to go before a tribunal. I would advise parents to look at all the issues, be prepared to be turned down and be ready for a long campaign.

Disability Living Allowance is a social security benefit for people who need help with personal care or who have problems of mobility. It is not means-tested or taxable and the care component is granted at three rates, low, medium and high. The mobiity just low and high.

You can apply for DLA from your child’s birth until they are 16. Over 16 yr olds need to make a fresh application for personal independence payment - PIP.

For DLA, ask your local Social Security Office for booklet DS706 Disability Living Allowance for Children,call the Government free Helpline for families of children with disabilities on 0800 808 3555, or go to https://www.gov.uk/help-for-disabled-child

Decision made: you are going for it. Take a deep breath.

The application pack is long and daunting. Fill it in carefully giving as much information as possible. Do not underestimate the things your child cannot do unaided and think about what help they need.

To qualify for DLA your child must need care, supervision or watching over by another person because of their disability. Your child's needs must be substantially in excess of the normal requirements of a child of similar age or it must receive substantial care, attention and supervision that a child of the same age would not.

The wording is important. **Supervision** means a passive state, being there ready to intervene. **Attention** is active intervention and rates highly in care needs. **Attention** is the active help that your child needs because of their disability to do such everyday things as eating/drinking, toileting, dressing, undressing, washing and help with medication or putting on a prosthesis or help with physiotherapy.

TOP TIPS:

- Make sure that you specify that your child is disabled.
- Fill in the application as carefully as possible.
- Include supporting evidence from doctors, schools etc. This carries a lot of clout!
- Compare your child very carefully with their two handed peers so that you can accurately describe where your child needs extra help.
- Don't exaggerate. If the claim goes to tribunal you will be caught out so at all times tell the truth.
- Seek advice from Citizens Advice or from Reach via Frank Letch.
- Dont give up!

Send the completed form to your regional Disability Benefits Centre where your claim will be assessed by an Adjudication Officer who is not a doctor. To help them reach their decision the AO uses a guide called the Disability Handbook but the officer may call on your GP or another doctor for a report.

The Decision

After a few weeks you will receive the AO's decision which will give you the rate awarded, length of the award or a rejection.

If you are unhappy you have three months to ask for a review from the Disability Centre that first handled your initial claim.

This review will be carried out by another Adjudication Officer and will not necessarily come to the same decision. If you are still unhappy you can appeal a second time within three months. This time the appeal will go to a Disability Appeal Tribunal which is an independent body.

The Benefits Agency will have a representative there. You will be required to attend and **Frank strongly advises that you seek the help of a trained adviser to attend with you.** They will be better able to put your initial objections to the previous decision and their very presence may give you confidence. You can ask to see your case papers and if your claim has reached the tribunal stage you should definitely do so, as they may well help you to direct your line of appeal to the tribunal.

If the tribunal rejects your claim you do have recourse to a further appeal to a commissioner but you can only appeal on a point of law so the independent tribunal is really the end of the road. However but you can submit a fresh claim later if you think your child’s circumstances have changed.

Frank Letch has campaigned for a fair deal on behalf of people with disabilities for decades. His major complaint with DLA has always been about chronic inconsistency in the granting of the allowance.

Before applying, gather together as many experts as possible to support your claim. Contact the nearest Citizens Advice, ask your limb fitting centre to put you in touch with the unit’s disability welfare officer. Seek out your local Welfare Rights Adviser. Get a copy of the Disability Rights Handbook and the Guide to Disability Living Allowance. If in doubt, contact Reach or Frank Letch direct at frankletch@aol.com.

Reach member Hannah Palin has just gone through the process and highly recommends the charity Contact, who were really helpful when she was applying for her son. They are at https://contact.org.uk/

Contact is a trading name of Contact a Family. The Charity is registered in England and Wales (284912) and Scotland (SC039169)

HOW TO HELP CHILDREN TRANSITION TO, AND BETWEEN, SCHOOLS

Starting school or changing to a new school is a rite of passage for all children - perhaps even more daunting for the worried parents. Will their children be popular and make friends? Will they cope? Will they keep up academically? Will they be picked for the sports teams? Those anxieties are justifiably magnified for Reach parents worried about reactions to their child's limb difference. The Reach Facebook groups regularly feature posts from parents desperate to protect their children from bullying, ostracism and unkind behaviour.

The good thing is that there are lots of positive actions parents can take to help going to school go smoothly. And now is a good time to be making preparations for that relaxed, stress-free transition.

A quick run through Facebook posts recently threw up a mum whose 10 year old was nervous about changing schools and meeting new people because of his little hand and a dad wanting to know how other families had helped make starting school a positive experience for a four year old.

These are very real concerns, and they elicited real and practical responses based on personal experience. Here are just a few:

"Our teacher read My Story to the class and then amazingly, our little girl took a Q&A! She had said she didn't want to talk about it so we were a little shocked. We found that after that, no-one has mentioned it again and that kids are really matter of fact about it anyway."

"We were worried about our daughter starting too. We did lots of socialisation in advance, mixing with kids she didn't know (playgroups and whatnot) - this gives you an environment where you can observe other kids' reactions to it, and how she deals with the questions. She's always been matter of fact about it (as we have).

"We were really careful not to tell her that anyone might say anything mean about it, the uppermost thing in our mind is she knows that it's not a big deal, and of course everyone is different. We thought that as soon as we say someone else might think it's a big deal, then she might wonder.

"But she has been better than fine, she's made 3-4 really firm (new) friends. Obviously we had a word with the teacher who was watching out for any difficult situations. She told us that she did overhear a little boy asking about it once, but she dealt with it in a matter of fact way. "

"When our little girl started school, they did a whole school assembly about difference, and a very brief explanation in the reception class - and that did the job! We found that at age 4 children just accept difference quite easily...I kept checking with the teacher about how she was getting on, but after about a week she said the questions had stopped completely as they'd found out what they needed to know!

"It does seem a bit more of a challenge with new children joining the class when they are older. She is ten now and has only had mean/ignorant comments from the children who have moved to the school more recently and haven't grown up with her and her arm. But it happens so rarely and other children are quick to step in."

"At preschool we made a book about her, with pictures of her doing everyday things - riding a scooter, baking cakes, beading necklaces etc. I was also able to incorporate photos of her with her '10 fingered' friends doing the same as her but also pictures with her friends who have the same hand as our daughter. They used it as a tool for the children who didn't quite grasp the importance of "everyone is different and that's ok.

"I also armed them (the preschoool and then school) with all our story books that we had bought about all sorts of differences to read with our daughter.

"My youngest who is in his final year at primary has coped amazingly. We didnt make a big issue about it. He has always been happy with the "I was born with it" line and he is usually the first to introduce his hand to others. At that age the children don't really focus on differences. They may ask questions but they accept the answers and move on. I liaised with the school so that if there were any issues no matter how minor to speak to me but generally we didnt make an issue."

"My daughter made her special book with me and she showed it to her new teachers with pride and even 2/3 years down the line she stills loves looking at it now. Every child is different and every scenario is different. Which is why this group is helpful because you can ask for people's experiences and you can pick and choose what you think is right for your child."

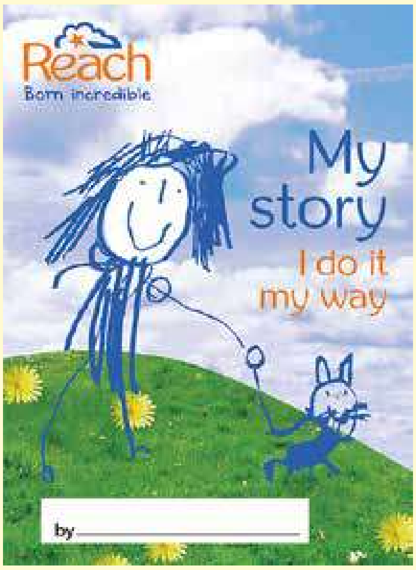
"I took in the book ***Different is awesome*** and the teacher read it with the class during circle time. Our son is in year 1 now and hasn't had any issues at all."

There are some clear messages here. Most children will accept a different limb if the child is matter of fact about it and the school addresses difference as a topic.

And there are lots of books and educational material available for parents to share with the school including, importantly, ***My Story.***

MY STORY

My Story is a valuable tool to help your child, your family, friends and school accept difference and present it in a positive way.



Share it with teachers to help them understand your child's attitude to life and overcoming challenges.

My Story is part of the Reach Welcome Pack sent out to all new members but extra copies can always be obtained from Head Office if you email Reach or make a request via Facebook.

withinReach asked Melissa Beesley, South Wales co-ordinator, teacher and Reach mum to draw on her years of experience and come up with some advice for parents, and she widened the scope by asking her branch members to contribute their advice and ideas as well.

You cannot do better than learn from the experience of parents who have been through the process. Here are their thoughts - all good, sound, practical ideas to choose from.

- If the school does not request a meeting with you to discuss your child, book one. Take the time to talk through issues, both physical and emotional. They have probably only considered practical issues. Make them aware of any emotional support that your child may need too.

- You could create a one page profile to explain/describe your child. Likes/dislikes. What they night need help with/ what they don't need help with. General information about them. You could use the Reach ***All About Me*** booklet in the same way and ask for it to be shared with all staff.

- Some parents have found it useful to allow their child to use circle time to introduce themselves and have an opportunity to speak about their limb difference. Some prefer for the teacher to hold a well timed 'differences' session (this sort of stuff really should be happening in schools anyway).

- Lots of parents worry about learning to count. Suggestions here would be for a variety of teaching methods to be used eg number lines, counting objects, Numacon etc. These resources should be available for all children rather than just a special set for your Reach child.

- Pick uniform that is easy to get on/off. Practise opening water bottle/lunchbox at home. But also remember that most 4/5 year olds are not independent with this yet.

- Take some books to the school that feature limb different children/characters (and other differences too) e.g Chops. Different is Awesome, Finding Nemo, Uniquely Me, Little Miss Jessica Goes To School etc.

- Discuss openly with the teacher your child's limb difference. There is a strong possibility that they will have never met a child like yours before and they may not know how to discuss it with you. Tell them the words/language that your child uses to describe their limb difference. Maybe also tell them the words you do not use to describe the limb difference. Tell them to be confident to approach you to ask any questions.

- Request that someone just 'keeps an eye' on your child for the first couple of days, both in class and on the playground. This will be to help your child to fend off the many questions and to help other children move the conversation along. Questions are ok, but there are only so many a child should have to deal with on any given day.

- Point the teacher in the direction of the Reach website.

Melissa says: "Just a few thoughts. I hope they are useful. It is by no means an exhaustive list but I think the consensus is... teachers will consider the practical stuff, but are likely to be a bit unaware of the more emotional stuff.

"Most of us felt that our children really didn't need help with day to day tasks, but did need a sensible/sensitive teacher to oversee the more emotional side of things e.g. first time on the playground with older pupils and just a dinner lady, at lunch. And they need help with the words used to describe difference etc.

BOOKS MAKE A HUGE DIFFERENCE

Parents frequently ask if there are books available that help to prepare children (and school teachers) to accept a limb difference. The answer is a loud, clear, YES!

VISIT THE REACH WEBSITE

https://reach.org.uk/starting-school/
This gives a parent's and a teacher's perspective.

And read our booklet -

WELCOME TO THE REACH FAMILY

MEET THESE FUTURE FRIENDS WHO WILL HELP EACH OTHER TO GROW INTO CONFIDENT AND ACTIVE YOUNG ADULTS....

Anthony Joshua aka AJ

Anthony Joshua, known as AJ, is Amanda Wilkins's grandson, one of three grandchildren for whom she and husband Michael are kinship carers.

"I had Reece (16) for 8 yrs before meeting Michael four and a half years ago," she said. "Ella-Rose (6) came to us in 2017 and AJ has been with us since November 2019, a week before his 1st birthday.

"The birth parents of AJ were aware of his lower left arm not being formed at the 20 week scan. We know AJ had weakness on his left side and he had physio to strengthen his neck muscles when he was very young. He amazes us everyday with his determined attitude.

"I came across Reach after doing a search on Google for support groups for children with missing limbs. Before this lockdown we attended a baby group in the local children's centre which gave me the opportunity to meet other adults with babies/toddlers. This is all well and good but it will be good to meet other families with children with missing limbs.

> ***From joining the organisation I have felt so much better and the lovely welcome on the Facebook page is much appreciated.***

Chester John Webb

"Chester is 19 months old and we spent the first 4.5 months of his life in hospital with various acute medical needs," said dad Jamie Webb. His limb difference, although a complete surprise and not diagnosed ante-natally, has been the least of our issues at the start of his little life.

However he is developing amazingly well and continues to amaze us everyday with how he just adapts to his left arm limb difference. He's incredibly smiley and developing quite the cheeky personality already!

Joel Scollen

> ***We're so happy to have found Reach and know that it will come to be a source of great support over the years as he grows up.***

See what new member **Noah Steele**, aged 7, got up to, on page 23

Bertie Trebes-Bass

Harry Scott

Lucas Speed aged 6

Cayden Masterson

Sophia Hallinan

....LIKE OUR NEW ADULT MEMBERS WHO HAVE JOINED REACH

Laura Johnson

Laura Johnson has Symbrachydactyly which affects her right hand."I recently became a member of Reach because I would like to continue helping other children and adults by providing support and advice, and I would also love to be involved in future events and meet more people like me!" she said.

"As a child with a limb difference, I always noticed the 'looks' and comments from other children and adults and this made me feel extremely uncomfortable and it made me feel like I was different in a negative way," she said.

"These messages were often internalised, and impacted on how I viewed myself. From this, I often isolated myself and I developed anxiety; subsequently, I struggled to engage in school and I struggled to create and maintain relationships with other children. I always kept my hand hidden up my sleeve as this always gave me a sense of invisibility.

"This sense was also backed up by the media with pictures of "perfect" girls; and it's certainly hard to feel pretty when the media dictates what "pretty" is. Following school, I didn't have any qualifications and I bounced from course to course in college because I didn't feel I was good at anything. However, at 19, I met my partner, and I became pregnant with my first child, Oliver.

"When Oliver was 11 months old, I pushed myself to go back to college and then university where I gained a BSc first class honours degree in mental health nursing and I now work for both the NHS and the independent sector as a qualified mental health nurse and I have two beautiful children, Oliver and Harley. Whilst I was at college and university, I also volunteered for a local charity to help victims of crime and I specialised within children and young people who had been bullied and/or harassed.

"I am also a member of numerous limb difference groups across Facebook and I have the title 'visual storyteller' meaning that I share content that gains a lot of engagement from readers. I contribute as a member by sharing my story and supporting parents of children with upper limb differences by answering questions, providing advice and guidance, and by giving them hope and reassurances with positive words of wisdom as growing up with a limb difference provides a unique perspective on how to adapt successfully through the many challenges of childhood.

"I also have a social media account on Instagram (@misslaurajanexx) where I share my story, promote diversity and inclusion and I support people with limb differences and mental health problems by providing an open door and letting everyone know that I am available to talk if anyone needs to at any time.

"In addition to this, I was signed to Zebedee Management model agency two years ago and through this I advocate for body confidence and self-love by participating in events, such as: walking on catwalks in London, Manchester Fashion Week and local fashion shows to promote diversity to inspire others to embrace their uniquely perfect differences and to promote diversity in the media.

Chris Perrior

Chris Perrior, 38, was featured in **within**Reach 23 years ago when he was on his way to becoming a professional footballer. Sadly that dream ended with a cruciate ligament injury when he was 16.

"I self-assessed myself with Amniotic Band Syndrome because when I was born my parents weren't really given any guidance or a definite explanation," said Chris. "They were just given a Reach pamphlet and a contact number for the founder, Sue Stokes.

"I'm now married to a wonderful wife, Alison, and we have two children, Ella aged 13 and Felicity, 9. I'm Managing Director of TEK Contracts Ltd, a manufacturing and shopfitting company based in the West Midlands. We are currently in our 17th year of trading and still going strong even through covid-19. I have an Instagram page: chrisperrior. I initially made this page up to promote my personal journey back to fitness and show my adaptions of equipment use in the gym.

I have been a Reach member before, having featured in an earlier 1997 edition when I was on my way to becoming a football player. But injury scuppered my chances of fulfilling that opportunity. I did attend a Paralympic trial when I was 26 years old - I remember visiting the trial with my wife and we remember how taken aback I was by the talent in the room. I quickly realised that maybe I'd left too big of a gap. Some of the people in those trials were phenomenal. So we were happy to just take in the experience and wish them all the best.

"I thought my parents were still members, but I think they must have stopped as I was growing older. I was looking through the website and noticed I could sign up and become a member yearly, so that is what I did. It was great seeing so many young talented people just getting on with whatever it is they wanted to achieve. The information in the magazines, on Facebook, the websites, is brilliant. The availability of information has come a long way since the pamphlet we used to get sent through. It was great looking through all this information with my wife and my kids. It was brilliant.

"It has been on the back of my mind for some time, but I would like to somehow get involved in Reach - help support, or play a part at away days and other events."

Thank you, Laura and Chris. We look forward to seeing more of you! Adult Reach members are really important as they make such excellent role models for younger members and give enormous reassurance and comfort to parents.

THE liMITTless PROJECT

THE GOAL: PROSTHETICS FOR EVERY CHILD IN THE UK

"During Limb Loss Awareness Month, in partnership with Reach and LimbBo, we launched project Li**MITT**less - a pilot project that aims to make a prosthetic accessible to every child in the UK who needs one - and soon, every adult too!" writes Nate Macabuag, founder of Mitt Wearables.

"In January I had talked to Debs and Kate and said we had money to cover Mitts for some children as we had received money from charitable donors. They would get a dedicated Mitt made and tools they could swap and upgrade for a year. We would just post them!

"In April alone, we were able to provide remote fittings for 31 users with limb difference, despite the lockdown - accepting limb measurements online, manufacturing each sleeve bespoke to the wearer and shipping them out by post.

"This meant that we reached our 100th person fitted with a Mitt within eight months. Our aim is to do 2,000 children in the UK at a cost of less than £1,000 a year. We did two arms and four or five tools per Reach child at a budget of £800 per child. We want to make it free for people at the point of service.

"We provide a surrounding service which is important. We support people with a bespoke service and people are much more comfortable with that. We respond to their feedback. We discovered kids love a pure white Mitt sleeve that we provide with washable marker pens. They can decorate the sleeve and it will wash off and they can draw something else. We are hoping to run a design competition for them.

"We are learning that a full prosthetic is not a necessity and we focus on making things that are really useful and enjoyable to use. We are also making a new sleeve for newborns, just for them to get used the putting things on their little arm."

What next?

"Moving forward, we plan to accelerate access to a couple of products and projects:

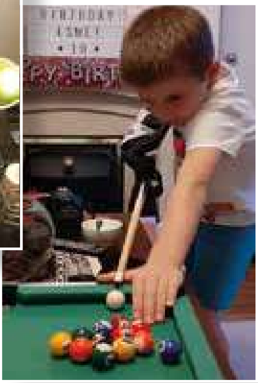
"Helping more young people: We are expanding project Li**MITT**less. If you know a young person who would benefit from having a Mitt, to help them carry out activities while at home, please get in touch! Or if you would be interested in supporting the project by funding a family, please reach out to us - your help is needed now more than ever.

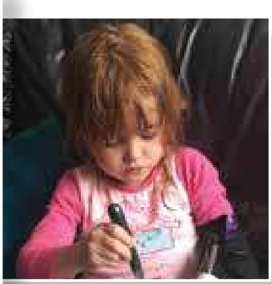
"Helping adults: We‘ll be launching our adult-optimised range of Mitts in the coming months and have applied for UKRI funding to support this. If you know someone who might be interested in one, please send them our way! Or if you are an Occupational Therapist or Clinician, please get in touch as we’d love your input to help us assess and perfect the product. Contact Nate@wearMitt.com or go to https://reach.org.uk/free-mitts-reach-members/"

It's such an exciting moment when the Mitt arrives! Cleo Bird's face says it all.

And when Grace Baker received her white Mitt, in no time at all she had decorated it with blue and purple stars matching her Reach sweatshirt.

Two more happy Mitters:
Ava Stuart and
Zak Atherton-Howlett.





liMiTTless APPEAL

PROVIDING PROSTHETIC ARMS FOR UK CHILDREN

The Douglas Bader Foundation which provides Reach youngsters with fabulous flying and adventure opportunities, has launched an appeal to raise money for the li**MITT**less project. To donate, go to: https://douglasbaderfoundation.enthuse.com/cf/limittless-project.

NEW FUNDRAISING PLATFORM

Wonderful.com have closed their fundraising platform. They were the favoured platform for Reach as 100% of donations came directly to the charity, whereas Just Giving and Virgin Money Giving both take a % plus an initial set up fee.

We have now signed up with a new fundraising platform called Givey who will also give 100% of donations inc gift aid directly to Reach, so if you are thinking of opening a page in the future please consider using them. The link to our Reach page on their site, www.givey.com, is Reach Charity - Fundraising Page.

INCREDIBLE DELIVERY PARENT PACK

Reach trustee Alice Gair, mum to Reuben, is an occupational Therapist. She spotted that there was great potential to make our Welcome Packs much more positive, helpful and useful and has set about giving them a fabulous makeover. Thank you, Alice!

"The Incredible Delivery Packs are a new initiative being trialled for new members of children up to the age of 2 years old in an effort to support and bring comfort to families of new and very young children with upper limb differences as we welcome them into our Reach family at what is often a very raw, emotional beginning on their journey together.

"Reuben's hand difference was not picked up antenatally and, after what had already been a complicated pregnancy, we were thrown into a whole rollercoaster of emotions when he arrived and we had the shock of his hand not being fully formed. I felt very isolated in the first few months and found we had pretty much no signposting to support, like Reach, from professionals.

"This had a major impact on how I felt about Reuben's hand difference and my own mental health. I experienced a whole range feelings from extreme sadness to anger and resentment, as well as having difficulty just enjoying my baby and doing things like baby groups and spending time with friends with other babies of similar ages. Finding out so many other Reach parents had a similar experience I felt I needed to do something with Reach to help to take away some of that pain but also to acknowledge it. I had spent hours designing his nursery and, as a huge Lion King fan, had had a Hakuna Matata ' no worries' sign made! The irony! With the order came a little wooden token with the words 'Be Brave' engraved and I had kept this. I kept looking at it and decided to put it next to his first baby picture on his window sill as a reminder. It's still there. Reuben might be able to use that token to help him accept his limb difference. I thought this could be a way of giving more specific support to our Reach baby parents.

"So we decided to include traditional baby items including a Reach logo baby vest and handmade baby hat with our usual Reach new member's information, decorative quote prints from members and a specially created booklet that welcomes parents at the start of their journey. We hope it will help better signpost parents to support and meet some of those early mental health needs by encouraging reflection and mindfulness and a sense of peer support from our members. And, of course, we are including a Be Brave token in the packs too.

"Searching for support on my own social media which resulted in 75 baby vests being donated and printed, nearly 200 baby hats being made and a huge supply of tissue paper in the Reach colours being donated. We asked Reach members for words of inspiration to be made into decorative prints and for help with the development of the packs and the booklet.

"We had a great response. Illustration and design work is being done by Matt Jenkins (author of Chops) and Jennifer Jamieson (the mammoth project #100daysoflockdownlife to fundraise for Reach). Amy Roskilly and some of our Reach young people, adults and parents contributed content.

"We hope that the booklets for the packs will be finalised around Autumn by which time they can start going out to new members. As the packs are a trial we will be seeking feedback and if successful we hope to secure funding to develop age appropriate packs for older children too.

"They are intended to fit in with a wider aspiration of the charity to evaluate parents' and carers' perceptions of support and awareness of Reach and how we may be able to work collaboratively with local communities and health providers to improve families access to our charity and the much needed support when having a child with an upper limb difference."

Alice Gair

RUTH LESTER IS OHMI TRUSTEE

Reach trustee Ruth Lester OBE FRCS has joined the OHMI Trust's board of trustees.

"My father (a headmaster) taught me to read music using the recorder as soon as I could read English!" she said.

"Music always featured during my childhood, learning piano, cello and singing. As a mother of three children, encouraging them to learn a musical instrument was paramount. Together with my third child, we went through Suzuki violin training.

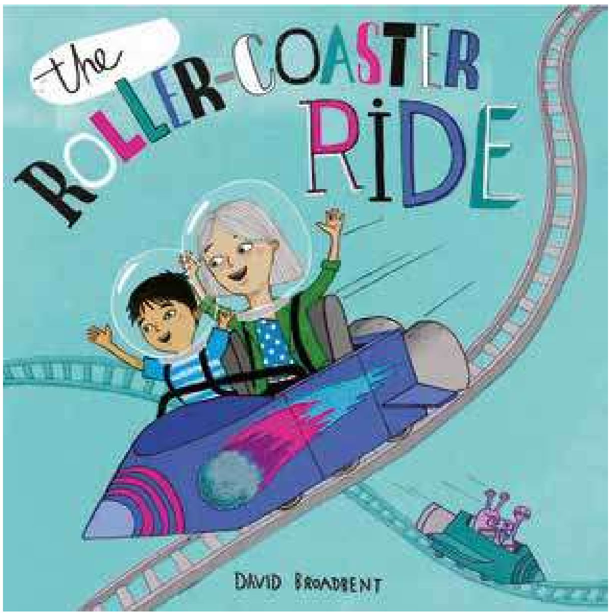
"Learning the violin, much later in life, I was astounded that I could still make progress! During retirement I have enjoyed playing in an orchestra of doctors and some smaller ensembles as well as continuing and upgrading my piano playing.

"A few years ago, I was introduced to OHMI and in particular, their Music-Makers programme. For over 25 years, I have had the privilege of working as a consultant surgeon specialising in children with upper limb differences and was, therefore, able to interpret some of their difficulties when learning musical instruments.

"I was all the more delighted to be invited to join the OHMI trustees at an exciting time in their development, where many opportunities to support the removal of barriers to music making for the physically disabled are being explored – where else could I bring together the two main passions of my life?"

RAISING AWARENESS WITH BOOKS

AND THE DIFFICULTIES FACING AUTHORS IN GETTING IT RIGHT



Books are great for introducing children to new things so they become familiar and part of their everyday life. And it is important that they depict a wide range of people. Reach members have been involved recently in helping the authors and publishers of three up-coming children's books featuring characters with an upper limb difference.

Publisher Child's Play (International) Ltd hired inclusivity consultant Beth Cox to help make David Broadbent's book ***The Roller-coaster Ride*** accurately reflect a limb difference.

Floris Books in Edinburgh got in touch through the organisation Beth founded, Inclusive Minds, for help with Ross MacKenzie's book ***The Otherwhere Emporium*** and novelist Gigi Griffis contacted Reach for help with her novel.

Beth explained: "I was chatting to a friend whose mum is a Reach trustee and when I was consulted over the Roller-coaster book I suggested including an upper limb difference."

Publisher Neil Burden said; "Up until this point, none of our books had represented someone with an upper limb difference, and this seemed like a good opportunity to do so. Once the decision had been made, we contacted Reach for support. Debs at Reach shared the enquiry with their members, and we were overwhelmed by the feedback we received about what people would like to see, whether they would like to see the child using a prosthetic or not, as well as lots of other suggestions.

"In previous books we’ve featured background characters with foreshortened limbs , but we were keen to show someone with a shorter limb and a hand in this book, as the feedback we received indicated that this wasn’t something that had been done before. We decided to depict someone with a radial difference as this was mentioned by a lot of Reach members, and we also decided to show the child with fewer digits on their arm with the difference.

"There were different opinions about prosthetics, but in this instance we decided to go with the majority and not include one and depict the character using his arm and hand as it is. We had some great feedback from members about how to show the character being active, and included a particular suggestion about him hooking his arm over the roundabout.

"When we’d made these decisions, Reach put us in touch with some of their members who could support us further and answer any questions. We liaised with Max, Hilary and Gita who provided feedback and suggestions for how Vincent could more actively use his arm. They also used various props to replicate scenes from the book in order to provide photographic references for the illustrator. We are incredibly grateful for their support, time and enthusiasm."

This book was for young children. If it had been pitched at an older audience, however, it could have sparked controversy. Teenage Reach members have often met with discrimination at adventure and theme parks based on their limb difference and been refused entry to rides. But this is not widely known.

Including limb difference in literature is to be welcomed but it is a bit of a minefield, as Reach member Megan Walker found out when she was asked to act as an inclusivity consultant for an American novelist who had given her main character's best friend an upper limb difference.

Gigi Griffis very sensibly contacted Reach asking for help with sensitivity. "I'm a novelist working on a young adult historical adventure story and the protagonist's best friend has a congenital limb difference (born without her left arm)," she said.

"I'm looking for someone to do a sensitivity consultation with me as I get into the novel. What I'd like to do is talk that person through my novel's storyline to make sure there are no red flags in authenticity or sensitivity and perhaps ask some questions related to the story and character."

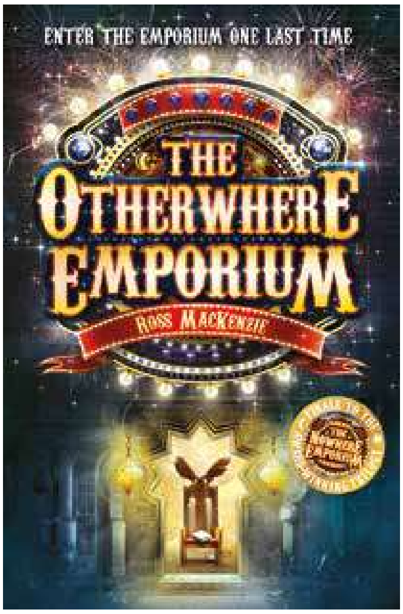
This was a wise approach, but afterwards Meghan said: "If I’m completely honest I’m still not 100% sure how I feel about the book that I helped with, as in the end, it turned out not to be a congenital limb difference." Without giving away the ending we can just say it was a bit more science fiction.

"I was pleased with the way she had introduced the character and tried hard to not let the difference define the character, and I do very much think the author's heart was in the right place. But without first hand knowledge of someone with a difference it’s very difficult.

"Some of the issues she raised were very good and well thought out but some things didn't ring true. Your limb difference is not the first thing your friends notice about you. They stop noticing it. My mother forgets about it.

"She handled things well but was very ignorant, talking about it as a defect. The language you use is important. That was very negative. I feel all over the place with her. It is very difficult for an author without any understanding of difference to get it right."

The author, Gigi Griffis was very pleased to have Meghan's help and thanked her for her encouragement. The novel is due out in the spring.



Ross MacKenzie's novel for 9-12 year-olds ***The Nowhere Emporium*** won the Blue Peter Book Award and the Scottish Children's Book Award.

For the third and final book in ***The Nowhere Emporium*** trilogy, ***The Otherwhere Emporium***, Ross was keen to write his new lead character Mirren with an arm difference. Both Ross and Edinburgh-based publisher Floris Books, knew how important it would be to portray Mirren and her experiences authentically. That's where members of Reach generously helped out.

"The wonderful organisation Inclusive Minds, who encourage inclusion and diversity in children's books, connected us with your charity, and four members of Reach – Cathryn and Grace Baker, Anna Hanger and Maria Hutson – very kindly read the book during lockdown. They advised us on many aspects, such as whether to use the term 'stump' or 'little arm', descriptions of how Mirren swims and plays video games, and on lots of subtle feelings and nuances that are beyond our lived experiences," said editorial director Sally Polson.

"We hope that, with the invaluable support of Reach, children with limb differences will see a strong, inspiring and authentically portrayed hero leading Ross's thrilling story. We also hope that you'll join Mirren on her incredible adventure in the magical Emporium."

SURPRISE STAR OF GARDENERS' WORLD

Sue Kent, who has helped advise on exercise and posture for Reach members at the Family Weekend and is a professional sports masseuse, revealed another claim to fame recently.

During lock down, *Gardeners' World* gave viewers the chance to send films of their own gardens to the programme and Sue submitted her Welsh garden, explaining how she manages it with a bilateral arm difference caused by the Thalidomide drug.

She was an absolute natural in front of the camera. Sue is a fantastic role model - positive and enthusiastic - for people with an upper limb difference and her garden looked fabulous!

We are all hoping she gets invited back on TV!

THE LONELINESS OF GROWING UP WITHOUT THE REACH COMMUNITY

"Last summer I met someone who had never met anyone with the same disability as his until he met me," writes Emily Tisshaw. "Lennon had exactly the same arm as me. It seemed so alien to me that anyone would have grown up not knowing there are people who look the same as you. A world without Reach with all the support they offer. I was intrigued. We met at a party in my flat. A friend said he had someone he wanted me to meet. As soon as I saw Lennon I shouted "snap!" This is something I do whenever I see someone with the same arm as me and I didn't think about it.

"When I met Lennon again, he told me that was the first ever time he had met someone with the same disability as him. I was shocked! He was 19 years old so had lived his whole childhood and adolescence without meeting another person like him. I felt bad that he had bumped into drunk me and not someone more worthy of a first one-arm encounter! We have met several times since, and he is now a friend. So I asked about our first meeting:

"It was a bit surreal I guess. I always hear from people that they know someone who's cousin's daughter has one arm but I have never actually met someone the same as me so I was really happy to see for myself. The second time we met you said a lot of things that I totally agreed with but 'normal' people never understood. There was one time as I was leaving you said "I get it, you know" it was just a really cool thing for you to say because even though people try to sympathise with me it's not the same as someone actually understanding on a personal level.

" You made a huge impact on me purely for being the first person I've met with one arm and you are just so cool about it. The best way to describe how I felt would probably be like a weight lifted that I didn't know I had. It's just a relief knowing there's at least one person I can talk to openly about my arm who 100% gets where I'm coming from."

It was a relief knowing I had made a positive impact. I introduced him to Reach and asked him what it was really like growing up not knowing anyone."

"For the most part it was alright. When I was young I didn't really think about it. It was when I started high school that I really started to struggle and the older I got, the more I would be aware that I'd never met anyone the same. A lot of the time whenever something happened involving my arm like in school tasks or kids making comments, I felt I had to just deal with it myself as I felt like I couldn't really talk to anyone because I knew they wouldn't get it.

"When other kids got teased about something they always seemed to have at least one other person who was similar but it was just me getting teased for my arm. I always worried about what future I would have as an adult too. Obviously it's something we have to go about differently but I never had anyone to help "show me the ropes". I had my family but they were just as in the dark as I was about things like what I needed to do about driving etc. This made me feel alone, the feeling of loneliness was probably the worst bit."

"Despite Reach, at times I have felt lonely too. I reassured Lennon that he was never actually alone. At school I was known as "the girl with one arm". Even with Reach, these comments can make us feel like we are the odd one but it is a great and familiar feeling to be part of something like Reach. Welcome to the community, Lennon!

POLLICISATION - A SURGEON'S VIEW

Many of you have heard about, been offered, or have experience of the operation of 'pollicisation'.This article by Reach Trustee Ruth Lester aims to tell you about why pollicisation is considered the most rewarding and satisfying operations a children's hand surgeon carries out!

She explains the function of the thumb in humans, how it developed anthropologically and what to expect during and after surgery.

Definition: Pollicisation is a surgical technique which creates a thumb from an existing finger.

What is a thumb? The thumb is the first digit of the hand. It is different from the other fingers because:

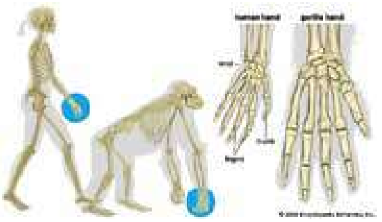
1: It is opposable to the other fingers

2: It has 2 phalanges rather than 3

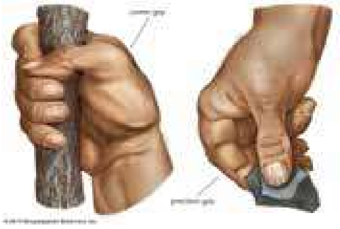
3: It is bigger in the distal phalanx than the proximal phalanx

4: It is very mobile at the base which enables a rotation movement and opposability

Some other primates have thumbs, but many are non-opposable. All great apes and Old World Monkeys have opposable thumbs as do gibbons/lesser apes but these thumbs are longer. Chimpanzees have elongated fingers to help with climbing, while the thumb has remained short.



The thumb represents 40% of the function of the hand, and because of its position and opposability, it provides the stability for a power grip and a precision grip.



Children and adults with no thumb tend to use the index finger and middle finger in the same way as a thumb and index – but can only achieve a side to side pinch and it looks awkward!

Why are some children born with Small or absent thumbs?

This situation can either occur alone or in association with other differences of the hand and arm eg: radial hemimelia (radial longitudinal growth disturbance, radial club hand).

One in 100,000 live births shows thumb hypoplasia (small thumb). In more than 50% of the cases both hands are affected.

As I've explained in a previous article, the development of the upper limb in utero is complex, occurs very early after conception and is complete by 7-8 weeks after conception. Small or absent thumbs occur when the patterning of the developing limb does not proceed as expected due to a wrong message in the system at a very early stage in the development of the upper limb – i.e. before the mother knows she is pregnant.

The operation of pollicisation aims to improve the function and the cosmetic appearance of a child's hand by:

1: Reducing the length of the index finger

2: Turning the index finger through 120-160 degrees

3: Adjusting the little muscles inside the hand which move the thumb

4: Creating a joint at the base of the thumb which can move in all directions except backwards.

The ideal age for this operation is around 12-18 months but the operation can be carried out when the child is older – however, the older the child, the longer it takes for the rehabilitation process.

The operation can take between 2 and 4 hours and the baby/child will probably stay in hospital overnight. A bulky dressing is applied, and some sort of protective sling/baby harness is used to keep the child comfortable. The first dressing is usually carried out at 2 weeks and sometimes sedation is used for this procedure.

Most babies and young children will begin to use their new thumb immediately as the operation purely enhances the existing function of the index finger.

Parental concerns:

Where there is no thumb or a very small floppy thumb which is not being used, a surgeon may advise the operation of pollicisation.

1: It may seem counter-intuitive to reduce the number of fingers in order to create a thumb, but this procedure enhances the existing function and creates a more pleasing appearance. From our experience, the gain in function and cosmesis is more than the loss of a finger.

2: The reduction in the number of fingers is not so noticeable with more normal functional use of the thumb.

3: The presence of a small floppy thumb which has to be removed during this operation can cause significant concern by parents, but if the child is not using this digit, they are unlikely to ever gain sufficient use to make it worthwhile keeping it – it just looks different and also can get in the way!

Example of appearance of absent thumb +/- small accessory digit/thumb and hand after Pollicisation

VOLUNTEERS NEEDED FOR PROSTHETIC CONTROL RESEARCH

Recruitment has begun for Upper-Limb amputees to take part in a paid study on improving control and affordability of electric prostheses. The activities will last for approximately 45mins and will involve participants making hand gestures whilst wearing an Electromyography sensor.

The location for the study is flexible but it would primarily take place in the Bristol area, with travel expenses covered. Participants will also receive an incentive for giving their time. If you are interested in taking part, please contact ennsugbe@yahoo.com.

The initial research was conducted by the lead researcher at Bristol University, and is currently being done on an independent basis alongside three amputee charities-including Reach. Dr Ejay Nsugbe is a Control Engineer and the lead researcher on this project, he is a 3x Chartered Professional(CEng,CMath and CSci) and is a member of the International Society of Prosthesis and Orthotics(ISPO) and British Association of Prosthesis and Orthotics(BAPO)

THIS WAS THE FACE OF REACH - (AND EVERYONE ELSE) IN THE BIZARRE WORLD OF LOCK DOWN

South Wales had a virtual meet up in May. Members logged in on Zoom accounts, all sat at home and had a family quiz.

Questions ranged from Beatrix Potter to Thomas the Tank. New facts were discussed, such as how many times the average person breaks wind per day, to where the Statue of Liberty is! We also discovered who had the most toilet paper in their house!

Congratulations on the night went to team Moyes and team Matthews on their joint win. And a big ‘thank you’ to quiz masters Suzanne Elizabeth, Amy Roskilly-Green and Sian Mitchell.

Oh, and a big apology from branch coordinator Melissa, for encouraging children to run around the house finding objects in the hope of winning points. Lockdown did not stop South Wales from catching up and having a giggle.

Melissa Beesley

TYNCAE CAMPING WEEKEND REINVENTED IN A VIRTUAL WORLD

For the first time in its 23 year history, the Davies family had to cancel their legendary Reach camping weekend, an event that is always a magical highlight of the calendar.

But they weren't prepared to abandon it altogether. Always full of invention and ideas, they came up with a virtual alternative. Hurrah for the Davies!

Emma Hendry writes: "Reach Tyncae has and will always be a huge part of my life. At the age of nine, back in 2010, my family and I first made the trip to mid-Wales, where we found an amazing group of people from the Reach community. I cannot thank the Davies family enough.

"They continuously, without fail, provide the campers with fun activities and entertainment. The children are never left bored, with workshops usually led by the brilliant boys and their friends. As well as the planned events there is ample time for the kids to play and make new friends and for the adults to share stories and socialise. At every Spring Bank Holiday - it’s an event to remember.

"Sadly, due to the pandemic, this year had to be slightly different… With the world at a standstill many events had been postponed or cancelled, but thankfully Reach’s Tyncae weekend went ahead; well virtually...

"The weekend started off with a welcoming video edited by Josh Broughton-Herrick showing many of the Reach families virtually passing a sleeping bag across the country to Tyncae. Workshop instructions, comments and photos were shared using the ‘Reach Tyncae Camping’ Facebook page. It was wonderful to see old faces and many new ones.

"Just like old times there was still lots of activities to do. These included a step by step tutorial on how to make gorgeous fancy bookmarks by the amazing Michael and Jo and a box-making workshop with Rob and Dawn. This brought back a personal special memory of the bird box they helped me make years ago, at my very first camp. It is still in my garden today!

Emma and her Dad

Frankie Hughes

"I also enjoyed William and Elinor’s four fun science experiments and Jay and Katy’s Mickey and Minnie Mouse drawings. A big thank you to everyone.

"My dad and I followed Steve and Lindsey’s chocolate brownie recipe which went down a storm with the rest of the family. We enjoyed eating them together whilst completing the family quiz, created by Roger, Steven and Lindsey, that evening. The Sunday evening quiz was always Mum and Dad’s favourite part of the family weekend, and despite it not being quite the same as in the sunny hills of Wales, it did bring back some incredible memories.

"Here's hoping life returns to normal next year!"

100 DAYS OF LOCKDOWN LIFE

Jen Jamieson, aka Jen Davies, is the branch co-ordinator for the 3 Counties. She is also the talented graphic artist who created our stunning front cover. Thank you Jen! This is her story.

"I am a mum of two and a graphic designer/ illustrator, living in Buckinghamshire. Reach is really special to me as my youngest, Beau, was born with an upper limb difference. I really love the community Reach has cultivated and already find it an incredible resource and support for our family. I am really honoured to be the branch co-ordinator for Beds, Herts and Bucks.

"I found the start of lockdown quite a difficult time, as many freelance creatives did. But I decided to use the time to work on a personal project illustrating people's lives during lockdown. I found the project a really great way to still feel connected to people, and the response was really positive.

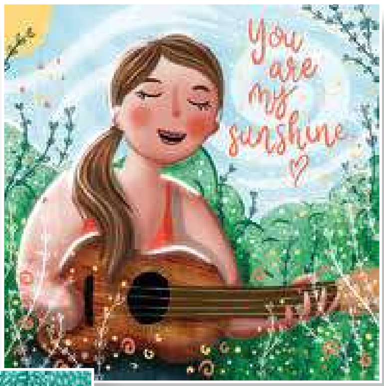
"I portrayed how families were coping with parents working and homeschooling, how businesses were adapting to lockdown life, I reached out to key workers on the front line, and Captain Tom and Joe Wicks even made an appearance! I tried to keep it fresh and served as a visual commentary to what was happening in the world around us, whilst we watched on from our little bubbles.

"It was becoming clear that many charities were going to lose out on a lot of money from cancelled fundraising events, and as people started to ask if they could pay for the portraits, I thought it would be nice to suggest they donated to Reach.

"I got in touch with members and started incorporating Reach portraits in the series. It became a great way for me to help raise Reach's profile, normalise limb difference and show the wonderfully diverse personalities within the Reach community.

"It was really great to draw people during their own fundraising events and help them to raise money. I made so many friends during the process and it felt great giving people such a special keepsake to remember this time.

"You can see the series on Instagram using #100daysoflockdownlife or by visiting @ jen_jamieson.



"I finished the project on day 100 with a portrait of my little boy Beau, who really is such an inspiration to us and why we keep doing what we do."

Jen Jamieson (Davies)

GUESS WHO ARE OUR COVER STARS

① Abdul & Aayan Mohammed ② Reuben & Alice Gair
③ Tracey Smith & Jason Smith ④ Jacob Gunn
⑤ Matthew Phillips ⑥ Melissa Stonard ⑦ Daniel Tennant
⑧ Summer Paxton ⑨ Amelia Emmet ⑩ Chloe Matthews
⑪ Layla Church ⑫ Landina Seignon-King
⑬ Cheryl Danson & Elwood ⑭ Ruth & Leah Hompstead
⑮ Blake Holborn ⑯ Sahib Singh & Rupinder Kaur

A FUTURE PROSTHETIST IN THE MAKING?

New Reach member Noah Steele, age 7, has won top prize in Brian Cox's Science Summer School Competition.

As part of the first Northern Ireland Summer School – which takes place in November – the Mid and East Antrim Borough Council had challenged local school children to 'Activate Your Curiosity' by designing an innovative idea that could improve lives.

Noah, a pupil at Harryville Primary School in Ballymena, scooped the Overall Winning Design in the competition.He designed a superhero prosthetic arm and a prototype is going to be made by local manufacturing firm, the PAC Group, which will be on display at a gala hosted by Prof Brian Cox in Ballymena November (Covid-19 permitting).He has also been invited to join the London version of the gala which will be held via zoom due to the virus. What a fantastic opportunity!

Noah's innovative concept is of an arm equipped with a range of interchangeable attachments, just like the Avengers' Ant Man, and would be the 'world's first mind controlled robot arm'. He was born with part of his right arm missing and said he wanted to create 'something special' for children and adults like him.

In his submission, he wrote: "There are lots of other children like me and I have even met some. I know there are also adults like me and adults who have lost their arms in accidents or in wars. I want to make something special for all of us. Everyone will be able to have their own arm."

Noah's idea will be displayed alongside the other creations in the Gallery of First Attempts at The Braid Museum in Ballymena, when the Activate Your Curiosity - Making Sense of Science event gets underway later this year.

Mayor of Mid and East Antrim, Cllr Peter Johnston, said: "Well done to Noah Steele on his amazing, award-winning idea! I was so impressed by his design, and by his consideration for helping others who face similar difficulties. He should be very proud of himself! Innovation and creativity are essential to the pursuit of science and the associated subjects."

Rachel Doherty, Head of Marketing for PAC Group, added: "Science, Technology, Engineering, and Mathematics (STEM) skills are vitally important for the Future of Work and the future of the Northern Ireland economy. We are keen to support initiatives that promote careers using these skillsets to young people, who are the innovators, engineers, and problem-solvers of tomorrow. If the quality and creativity shown by Noah and his fellow competition entrants are anything to go by, our future STEM capabilities are in good hands."

HELP IMPROVE MIDWIVES' TRAINING

Orla Duncan is a Psychosocial Nurse Practitioner with the plastic surgery and congenital hand difference teams at the Sick Children's Hospital in Edinburgh. She specialises in the long term psychosocial outcomes for children with visible differences and is a familiar face at the Reach Family Weekend.

"I have worked for many years with children with appearance differences and have witnessed the impact that the use of positive language can have on a child who has an upper limb difference, and their family. We are always looking to improve services for children with an upper limb difference and parents' first contact with a health care professional may be one of the most important.

"Most new parents have told me of their excellent experiences surrounding the birth of their precious baby with an upper limb difference. Some parents have however let me know that their midwife was unsure of what to say, or said something that parents have found unhelpful. I am hoping to explore this with a view to reflecting with and possibly provide training for midwives regarding supporting parents of infants with appearance differences.

"It would be helpful in the first instance to get a sense of how parents feel about their postnatal experience. If anyone would be willing to share their experiences, I would be grateful if you would send a short paragraph describing your experience to Reach head office.

THANK YOU ALL !

Head Office received an amazing gift recently - a cheque for £52,357:60. The only clue was a note to say it was paid on behalf of the late Mary Hill.

Our most senior member, Janet Douglas, added £64 to her membership sub, rounding it up to £100 - really kind.

The Club Weekenders donated £50 raised through their quiz night, back when quiz nights were allowed!

Regular supporter Geraldine Griffiths, Freya's grandmother, has sent in another cheque for £40 raised with a collection box in Newport.

Ballymena Congregational Church, which is attended by Noah Steele and his parents Julie and Michael, donated £600.00 from their collection on Christmas Day.

The Dere Street Barristers Charitable Trust donated £1,333 in March and have given us another cheque for £2,420. Thank you for your generosity and support,.

Doncaster Methodist Church donated £2000.

Loyal supporter the Elizabeth & Prince Zaiger Charitable Trust donated £4000.

The Warwick Masonic Charity donated £500.

Newbury Model railway donated £50

Helping children with upper limb differences live life without limits

Jasper Barnes. Summer solstice in Somerset

If you have pictures celebrating your child's Reach difference, we would love to see them. Send them to kateh@reach.org.uk

Charity Nos: England & Wales 1134544 and Scotland SCO49805.