Helping children with upper limb differences live life without limits

Living life without arms

Toes on my adult hand

Amazing Achievements

Fantastic

Fundraising

The Official Magazine of the Association for Children with Upper Limb Deficiency

ELSIE

withinReach



Please send photographs and stories for withinReach to Jane Garrett, addressed to:

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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.

Advertising:

Within Reach has a print run of 1,600 and is distributed to members, subscribers, health services and specialists. If you need to reach this key audience, we would be delighted to consider including your advertisement. Contact Jane Garrett on 01483 203237

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 deficiency 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 deficiency. The UK subscription is from £36. (£35 if paid by direct debit) You will receive three issues of the magazine a year by post or email if you live overseas.

Reach Insurance

This covers any member aged between 2 and 85 years of age resident in the UK with a congenital deficiency 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.

SHARED EXPERIENCES

This book, published by Reach, is extremely useful for families who have discovered they have, or are about to have, a Reach baby.

Shared Experiences is a collection of accounts by Reach families of their own real life experiences of having a child with an upper limb deficiency. Their stories are shocking, saddening, funny, inspiring and captivating. All in all, a brilliant realisation of life with an upper limb deficiency.

Contact Jo Dixon at HO to order your copy.





BRANCH (O-ORDINATORS - THE LINK TO YOUR LOCAL REACH (OMMUNITY

This is such an important role, bringing local families together for support and shared fun and we now have vacancies in CSSCX, SOUTH AND WEST YORKSHIRE AND THE WEST COUNTRY.

Please give it a go. It doesn't have to be a headache! And you don't need to do it alone! Volunteer with a friend. You will receive lots of support from HO. Give Jo or Abby a call to discuss it on 0845 130 6225 or from a mobile: 020 3478 0100



NATIONAL COORDINATOR

I am delighted that we are fully booked for our newest event - the Family Activity Weekend in the Lake District in July, copying the Scottish family weekend which is so popular.

It promises to be an actionpacked weekend and we are encouraging all the family members to take part in the fun! There are plan to roll out the idea to two or more venues across the UK and Ireland in 2018 so keep an eye on your



emails and the website for where, when and how to book.

We have had lots of lovely feedback from health professionals and Reach families praising the new look and ever-changing website. Content is growing and if anyone would like to help us with the writing of a specific section please do - we also need bright and clear photos so that the site stays exciting and can be refreshed regularly.

RAW is booking well with just a few places for your 10-18yr olds - please contact us in the office.

As we approach the summer, things to look out for are;

Family Weekend 20-22nd October 2017 in Bristol - booking will open very shortly and we have a great line up of speakers for you again this year!

Bader Braves Flying Days - the dates are in an advertisement, they are fabulous day experiences well worth the trip.

Looking forward to September, on the 23rd is the North West Ball. Volunteer Jane Crook has the planning of this great fundraising ball well underway. See the back page!



NAIDEX is Europe's biggest and most far-reaching trade, professional and consumer show dedicated to the care, rehabilitation and lifestyle of people with a disability or impairment.

Setting no limit on potential, the event is the only place that gathers innovation, information, cutting edge supplies, and the most inspirational speakers from around the world to one venue, over three unforgettable days.

Reach works closely throughout the year with other voluntary organisations that have similar aims, and led by Douglas Bader Foundation (DBF), we jointly set up shop for three days at Naidex to promote our opportunities. We met lots of lovely people and strengthened our partnerships with DBF, Limbpower, OHMI, Steps, Sailability and Arctic1 during the event. It was a great opportunity to network and develop ideas and plans for joint working.



Jo Dixon

CHILDREN'S ACTIVITY PROSTHETICS FUND

This is a great opportunity for Reach members needing adaptions or prosthetics. Limb centres around the UK are now able to apply for funding of children's sports and activity limbs.

Up until now there has been no dedicated funding for children's sports and activity prosthetics, meaning that young Reach members may have been limited in the sports they could participate in.

The funding was launched in 2016 and includes a \pounds 750k provision for new sports prosthetics for children on the NHS. Limb centres can now apply for the funding, and clinicians will work with patients who are eligible for the funding.

Whether it is being able to play outdoors on the monkey bars or scooter, take part in competitive sport or just to blend in with friends at school, for many children this will open up a lot of new and exciting opportunities.

What is available?

There are off-the-shelf, as well as bespoke options for upper limb prosthetics, suitable for activities such as cycling, gymnastics, racquet and bat sports. It's worth making contact and asking questions.

Applying for funding

NHS Limb centres in England may request funds for an individual's prosthetic that they have prescribed, up to the value of £5000 for each limb (including all the associated costs of the new limb, such as a new socket). Limb Power will be overseeing the distribution of the paediatric limb fund and will be contacting all limb centres shortly to advise on the eligibility criteria and correct procedure for application of funds.

Be quick - this fund has a limited life span

To give you an idea of what you can apply for, look at Sydney's gymnastics arm on page 23 and Claire Cashmore's cycling arm on page 7.

£750,000 of this fund has been allocated to provide children up to the age of 18 with prosthetic limbs and components and £750,000 has been allocated to a research collaboration into identifying what children and their families want from their prosthetic service and how this can be delivered. NHS Limb Centres across the country have been prescribing activity limbs for children since October 2016, with over 50 children already in receipt of activity limbs.

LimbPower has been working closely with the Department of Health in administrating the fund and to facilitate the application and invoicing procedure to make it as easy and quick as possible for all Limb Centres. To find out more about The Children's Activity Prosthetic Fund contact Carly Bauert **carly@limbpower.com**



CHAIRMAN'S REPORT

Reach Board



Welcome to my first report since becoming Chair in October 2016. I would like to start by thanking our previous Chair, Gary Phillips, for his leadership and commitment to Reach over the last few years. During his tenure, the organisation undertook a number of important tasks that have strenghened the organisation and solidified its future.



These tasks have included significant but often unseen progress in improving the effectiveness of the board,

stabilising our financial position and undertaking reviews of our policies and procedures. In addition to these 'behind the scene' achievements we have seen a succesful re-brand and website launch to reflect the positivity and energy Reach stands for and to better serve our members.

As a result of Gary and the board's hard work I am in the fortunate position of inheriting a strong and stable organisation supported by the tireless efforts of our office team, Jo and Abby.

Whilst I shall continue to push for strong internal management of Reach, we enter a new period where our board will focus more than ever on improving the services to our members and offering more opportunites for families and children to connect.

This journey has already begun by expanding the fantastic work of our Scotland branches in recent years organising and hosting family weekends. These weekends offer an opportunity for families and children to get together and spend the weekend undertaking various activities, sharing experiences and most importantly, having fun!

This year our North West co-ordinators are hosting their first activity weekend in July which is looking to be a roaring success as it is already fully booked. It will be our intention in the future to replicate these weekends throughout our network of branches, so co-ordinators - if this is something you would be interested in being a part of, please get in touch with Jo and Abby to discuss the details.

Watch this space as we announce more projects in the coming months.

Finally, as I write this note, there are exactly four weeks until the London Marathon. As in recent years, we will have a number of runners on the course this year, including myself. I would like to say a big thank you not only to our runners, but to anybody who takes the time to raise funds for our community.

No matter how big or small the challenge, our fundraisers rise to it by setting goals and putting in a huge effort to succeed, often with the support of family and friends. This 'can do' attitude is typical of everybody I meet at Reach, especially the children, and the more Reach can support our community in achieving these goals, the better.

Lee Gwilliam

EDITORIAL DEADLINE Material for inclusion in the SUMMER issue must be sent to the editor by 31st July 2017

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REACH FOR THE SKIES

Our Reach symbol of the star shining in the cloud works well for our collaboration with the Douglas Bader Foundation.

Group Captain Sir Douglas Bader was commissioned as an officer in the RAF in 1930 but after only 18 months, he crashed his aeroplane and became a double amputee caused by "my own fault" in the aeroplane accident in 1931. He was discharged from the RAF but after the outbreak of the Second World War, he re-joined as a disabled pilot.

Douglas was a member of 222 Squadron and was promoted to lead 242 Squadron. His skill as an aviator and contribution as an outstanding leader and fighter ace during WW2, along with his continuous attempts to escape prisoner of war camp after he was shot down, were immortalised in the book and film 'Reach for the Sky'.

The Douglas Bader Foundation was formed following his death in 1982. The original Board of Trustees consisted of those who had flown with him side-by-side, had become friends in POW camps, had known him and worked with him post-war in his civilian life, and who were family. Douglas was honoured in 1976 with a Knighthood for his contribution and work on behalf of the disabled. The mission of the foundation is to continue Douglas' work in conjunction with and on behalf of individuals with a disability.

'A disabled person who fights back is not disabled.... but inspired.'

NEED TO KNOW







TOE TO HAND - THE FINISHED PICTURE

The most challenging decision often facing the parents of young Reach children is whether to go ahead with a toe to hand transplant. Will it improve their grip? Will it give them a hand that looks better? Will it cause unnecessary damage to perfect feet? What will it look like when my child grows up?

Eden Drury's mother Karen had the same concerns and decided to go ahead. Eden had the operation as a toddler and she is now a wonderful, glamorous young woman. She has bravely agreed to share images of her 'grown-up' hand and feet to help parents struggling with their decision. Thank you Eden.



Karen said: "Michael and I decided to go ahead with the operation due to the fact that Eden had only a thumb and a partial palm, and was unable to "grip" anything or use her hand to great effect. So in 2003 when she was

2¹/₂ yrs old she went in to St James Hospital in Leeds for Prof Simon Kay to work his magic.

"Although the op didn't give her the full pincer grip we were hoping for it has allowed her to use her hand more effectively and it has enabled her to carry and hold things more easily and steadily, if you understand that. Eden has a part time job in a Chinese restaurant/takeaway serving customers in restaurant with food and drinks and she does her job with ease! She is also doing a media hair and beauty course at college. She felt awkward at first when blow drying clients hair but she has found her own way of doing it."

"Eden said she can't remember what it was like not to have fingers, or tingers (toes and fingers combined) as she calls them but looking at her hand she can imagine if we'd left it she wouldn't find it as easy to do normal everyday things. Plus being a girl I think it has helped cosmetically having more on her hand. As for her feet, as you can see from the photos, no one ever notices the fact that she has only four toes and they look just like everyone else's feet.

"I really hope this helps other families going through the decision process and we are willing to talk to them if they wish."

ONE HANDED INSTRUMENTS - POTENTIAL FOR REACH BURSARIES

Peter Worrell in Norfolk makes and repairs wind instruments for one handed musicians. He was originally commissioned by Dolmetsch Recorders to create a design for a simple mechanism and keywork for a one handed instrument. He continues to make the mechanism and keys for the current one-handed recorder makers, Aafab, who are based in the Netherlands.

In 2014, his work won an award in the Playable Category of the OHMI competition and in January 2016 he met one-handed musicians at OHMI's reception in the House of Lords. This inspired him to design a one handed clarinet.

These beautiful instruments, designed for left or right handed players and hand crafted from African Blackwood with silver plated keywork, are suitable for anyone from beginners through to professionals. Peter has opened up new possibilities for our potential musicians, and Reach Bursaries are available to help with the cost.



Contact HO for details about how to apply for a Reach Bursary and visit www. peterworrell.co.uk for information about the instruments available.





SENSITIVE SYNTHETIC SKIN

A new sensitive synthetic skin for prosthetics that draws energy from solar power has been developed by engineers at Glasgow University.

Researchers had already created an 'electronic skin' for prosthetic hands made with new super-material graphene but they needed a power source to operate its sensors. The latest breakthrough has integrated photo-voltaic cells into the skin.

Dr Ravinder Dahiya, from the University of Glasgow School of Engineering, said: "The real challenge was 'how can we put skin on top of photo-voltaic and yet allow light to pass through the skin?' That's what we have done."

The skin uses graphene, which is about a million times thinner than paper and is currently the world's strongest material.Dr Dahiya said: "Human skin is an incredibly complex system capable of detecting pressure, temperature and texture through an array of neural sensors which carry signals from the skin to the brain."

Dr Dahiya said: "When the skin is placed on a prosthetic hand



and the amputee then touches an object they are able to feel the contact pressure as well as temperature."

The team's paper, Energy Autonomous Flexible and Transparent Tactile Skin, is published in Advanced Functional Materials.

HEALTH CARE RESEARCH

Charlotte Fielder from Reach has been working with the amazing Dr Judith johnson on a UK wide study collating experiences of parents about the time when their child's limb difference was first identified.

"So first of all, big thanks to those of you who kindly participated," she said. "We now have nearly enough participants. When I say nearly... the nearly part is because we have an under representation of parents from ethnic minority groups. which is a shame because our wish is that the survey is as diverse as possible.

"So if this is you, and you have a child under five, please will you consider taking part. The interview itself will be less than an hour and we will be most grateful. Many thanks." @UoLimprovingHealthcare

OPEN BIONICS

Early adopters! We have some exciting trials coming up with the NHS in the UK for children with our bionic hands. If you'd like to be the first to know when the next UK trial

starts (this year) and how you can get involved please subscribe to our newsletter. We'll be emailing you all some exciting news and more info on our first bionic hand release very soon! https://www. openbionics.com/



LOOK AT (LAIRE'S FUNKY NEW BIKE ARM!

"Thought some of you might be interested in my new bike arm!" writes Reach Paralympian Claire Cashmore.

"My stump slips into it and is suctioned in, but can quite easily get out if I need to. The red fingers loop over the handle bar and are like that so I can change position easily enough. The wrist is fixed in that position but you can change the position of the wrist and then screw it up again.

"My brakes and gears are all on my right hand side."



Why did the Paralympic swimmer need a bike arm? Because she has just joined the British Paratriathlon squad, adding running and cycling to her sporting repertoire.

As Claire was a relatively inexperienced prosthetic user, Alasdair Donaldson (Paralympic Talent & Development Manager at British Triathlon) arranged for her to have a free assessment at Pace Rehabilitation with prosthetist Paul Richardson, to investigate prosthetic solutions to assist her cycling.

Pace provides prosthetic support to several other Paralympic GB members including Lauren Steadman, and Claire was assessed, and a cast of her limb taken, all on the same day. With approval to proceed from British Triathlon, two weeks later, Claire had her first fitting of the device which provides a secure handlebar attachment when cycling. The following week, Claire took the trial unit home and is currently putting the prosthesis through its paces.

For more details about Pace's free assessments, please contact info@pacerehab.com, or telephone 0845 450 7357 or visit www.pacerehab.coms

PUT OLD STAMPS TO GOOD USE

Reach raises funds from used stamps and recently we have been gifted a large stamp collection. Thank you!

There are two ways to send us your stamps. Smaller quantities can be sent directly to Reach member, David Haughton at Derwen, West Lane, Keeston, Haverfordwest, Pembrokeshire SA62 6EH.

For large amounts, drop us an email at reach@reach.org. uk and we can pop a prepaid envelope in the post to you or arrange for a courier to collect a box.







66 I've had so many people judge me at first glance over the years but there haven't been many people just to sit down and get to know me.

I'm quite sure if everyone just flipping took the time to know me I'd be a very happy bunny rabbit indeed.

FACING THE WORLD WITHOUT ARMS

When Erin Power was born without arms, mum Nikky's maternal instinct kicked in instantly- she had two strong arms herself, so she decided she could do everything for her daughter.

Now however, she is encouraging Erin to become as independent as possible. Two factors in particular influenced this change of attitude: Erin's own personality and membership of Reach.

Everyone remarks on the special spark and drive common to so many Reach children and Erin is one bright cookie. For her, life is an adventure.

And Reach provide role models and support. Frank Letch in particular was an absolute inspiration to both Nikky and Erin, showing them how to overcome challenges and demonstrating just how much Erin could be capable of achieving.



This is Erin's story:

8

"Hello, my name is Erin. I am 12 years old and I live in Ireland with my mam, stepdad, and my younger brother and younger sister. I am missing both arms, my left arm above the elbow and my complete right arm to to the shoulder.

"I've been on this planet for 12 years and still have no clue what to do sometimes when I'm faced with a challenge, so I hope that this article helps someone as much as other articles have helped me.

"I personally like to think I am happy, bubbly and independent, but my mam still helps me with everyday things. I am able to do a few things myself like writing, eating and brushing my teeth. I sometimes think to myself about things I could do to help with some of these tasks, for example I have taught myself everything I know when it comes to video games admittedly that's not a whole bunch.

"But I hope one day in the future I will know enough to fulfil my childhood dream of becoming a famous gaming youtuber (or a Time Lord, you know, whatever comes first!). In all honesty it's pretty hilarious to see people's reactions when I tell them I

played Undertale with my feet. Oh good old times!

"I started secondary school last September and I love all of my school subjects. My personal favourite being English. I have been told by many teachers that my handwriting is better than most people in my year.

"I've become used to other people asking questions and making comments over the years and was slightly concerned about the new school, but I knew that there was nothing I couldn't handle.

"I was quite right and now I have so many friends and I really enjoy every school day (except Mondays, nobody likes Mondays.)

"I've had so many people judge at first glance over the years but there haven't been many people just to sit down and get to know me. I'm quite sure if everyone just flipping took the time to know me I'd be a very happy bunny rabbit indeed.

"I do hope this article helps some people in their day to day life and that one day I could be one of those people you'd see on the telly with their own chat show!"



This is Nikky's story:

I was 32 years old when I fell pregnant for the first time and from the moment I saw that blue line on the pregnancy test I was over the moon. Erin was born three days after my 32nd birthday. I didn't know until the moment she was born that she had no arms because it was not detected on any of my scans so it was a complete shock to me and her dad. Looking back though, I'm glad I didn't know because I would have been stressed and worried about her birth instead of looking forward to seeing my baby girl and busying myself with preparations for her arrival.

I decided that night she was born that she didn't need arms as I had two good arms and could anything and everything she needed, so after a good cry and a little sleep I put my energy into telling family and friends about her condition.

So I told them we have a beautiful little girl with the face of an angel but God forgot to give her arms. I tried to support them and my partner by staying positive as I settled into motherhood.

When we were out, I never tried to cover her up or hide the fact that she had no arms and people would stare sometimes too blatantly. I would feel like asking them if they would like to take a picture of my child so it would last longer

Erin was perfect in my eyes and I hoped that was how everyone else saw her. When we were out I never tried to cover her up or hide the fact that she had no arms and people would stare sometimes too blatantly. I would feel like asking them if they would like to take a picture of my child so it would last longer, but I never did, not wanting to draw attention. So I just ignored them and carried on my day doting on my little girl.

We joined Reach when Erin was six months old and I still remember the people I met at our first AGM in the Red Cow Hotel in Dublin. I was blown away when we met Frank Letch. There is nothing he cannot do and he has achieved so many great things in his life it took most of the worries I had about Erin's future away. We also met new friends and we still meet up with them at the AGMs 12 years on.

When Erin was 16 months old, a baby brother arrived. When I had discovered I was pregnant I was terrified that what happened to Erin through Amniotic Band Syndrome would happen to him.

So at the first scan we made the sonographer show us everything on the screen and we saw hands and feet and we did the same when her baby sister was born 14 months after that.

By the time Erin started school, she was a confident, sassy little girl with a baby brother and sister. She was dying to get out of the house to start her big adventure and she quickly made friends, some of whom she still has today in secondary school. She is now a cheeky, confident 12 year old, popular with the kids in her class and has no problem making new friends as she just walks up to other kids and introduces herself with not a care in the world.

She says she sometimes forgets she has no arms and does not see herself as any different from the other kids. I have never wrapped her up in cotton wool or treated her any different from the other kids. She goes on all the school trips and outings, the only difference is her assistant Lisa goes everywhere with her. Lisa has been with her since she was four when she started school and knows when she is needed and when to step back and give her space to enjoy being a 12 yr old.

While being a very determined and independent young lady there are still some things she cannot do, like open certain doors or sort her own locker at school, but she is learning new ways to get around obstacles every day.

Her hopes and mine for the future are for her to be more independent, not needing help with dressing and toileting. Technology is changing and improving all the time. But for now she is enjoying life and always looking forward with a great sense of humour and not taking herself or life too seriously, as I am enjoying life taking care of my beautiful, wonderful, happy little girl.

This is Frank's story:

When I made my appearance on 7th June 1944 I was a traumatic shock to the delivery team who whisked me away and only brought me back to my mother after they had thought of a way to tell her that her newborn baby had no arms. Such an occurrence today is very rare because we have prenatal scans and much more intensive prenatal care. (Though this was also the case with Nikki and Erin)

Unlike the inclusive schools today, I was sent to a "special school" which was anything but special. Today's bilateral amputees will normally attend their local school where they will grow up with their peers. They might need support which can be supplied by a skilled teaching assistant.

At home I used my feet a great deal for writing, feeding myself, brushing the family dog and helping my godmother prepare Sunday lunch. When I was five I was given a prosthesis, a

The challenge of using your feet comes when you have to do so in public. It is very easy to feel self-conscious so parents need to give their child the confidence to do in public what they do at home.

solution with which I persisted half-heartedly until the age of 19 when I decided that I would live using my feet, my little arm and what ever devices I could use to perform the daily living tasks.

Because I use my feet a lot and in an unusual way I make sure my tummy muscles are strong (100 sit ups every morning) and bending exercises to keep me supple enough to shave, brush my hair and teeth. Daily living does the rest!

I am always willing to pass on tips.



FIRM FOUNDATIONS



Sue Kent was born in 1962 with arms 8" long, one of over 500 children affected by the drug Thalidomide which was featured recently in Call the Midwife.

She learned to drive an adapted car, went to college, married, had two children and is now a grandmother. Sue runs her own business providing both sport and relaxation massage, which owes its success to her techniques using her feet.

Sue will be speaking and demonstrating at the Family Weekend in Bristol but here she gives some extremely helpful advice on health and development for families with children affected by bilateral deficiency.

"Thalidomide was a national tragedy and social services were overwhelmed," she said. "In 1962, led by my father, parents joined together to form the Thalidomide Society which is still going strong today.

"My mother was keen to do her best for me, and initially she did too much for me and I didn't develop as well as some other children did. When this was pointed out she quickly backed off and

allowed me to find my own way of doing things.

"I have 8" arms, three fingers on one hand and four fingers on the other. When I was born and through my younger years I didn't want to use my feet because I wanted to be

just like everybody else. I would use my teeth, my head, my arms but rarely my feet. This all changed when using my head to open the window I ended up in a neck collar with severe pain for many months.

"As parents of young children with similar disabilities there are some great foundations you can put in place to make sure your child has a body fit for the physical demands that are necessary to live independent pain-free life. I am one of the healthiest people with Thalidomide, although that does not mean much.

"One of the reasons I am as fit as I am, is thanks to my mum. At the age of five I was put into ballet classes. It was not the ballet but the pre dance stretches that gave me the ability to



reach my head with my toes and so to be able to wash and brush my hair and take my clothes on and off. The ballet itself gave me the balance to stand on one leg in a balanced position. It set me on a life of stretching.

"When I got to 14 I realised I wasn't going to be a ballet dancer and I moved to martial arts, which have similar warmup routines. Since the age of 27 I have done yoga every week.

LESSONS I HAVE LEARNED

Give your child gym, ballet and martial arts classes. If they want to do more cardiovascular sports that's great, but they must do the maintenance of body stretching and body balance.

Teach your child to swim. Swimming is one of the safest exercises and helps strengthen the heart and the legs and back without excessive wear and tear on the hips and knee joints. It also makes you feel graceful in the water as arms move freely and different muscles are activated.

Install good sleep patterns, as people with physical disabilities use up far more energy doing everyday things and need sleep to recover, restore and build muscle

If your child has aches and pains, think about giving or getting them a massage, perhaps getting them a private physiotherapist, don't rush towards medication or x-rays or surgery which have side-effects.

If your child is going to use their feet to do things, which in my mind should be encouraged, such as basic things like cooking and getting dressed, try and arrange things so they don't spend a lot of their time with their foot over a 90° angle to their hip.

For instance sitting on the floor cutting bread or chopping vegetables with your feet is not good, because your feet are at the same level as your hips. Sitting on the chair with your feet working at floor level is ideal. There will be a lot of times when they may have to put their foot up as high as they can get it, over 90°, but when you can, make sure this doesn't happen too much, as it's very inadvisable to do so for long periods. The hip was not designed to be stressed like this constantly. (Most people with thalidomide who have done this have had operations before the age of 55). Knees and hips are important, make sure they know this!

Try not to talk about your child's disability constantly in front of them, don't make it a thing. Most of the time they feel normal, so you pointing the difference out all the time is not helpful.Try not to make your child "special" as it sets up problems between siblings that can last a life time.

Hide your own fears. Make adjustments to your house, e.g. Bring plates down to the bottom of kitchen cupboards so the child can be involved in kitchen life, unloading the dishwasher, laying the table. You may do it quicker but they need to learn to do it themselves and feel needed and helpful.

Do talk about how they might work around a possible problem in the near future, eg going on a school trip and needing help with something. For girls how they will manage puberty: buy various products and try things out. For boys, try braces. More help on this is available.

Stand up for your child's right to be involved in any activity they want to do. It is also wise to give siblings time on their own to do things that interest them without having to hold back to accommodate the abilities of the disabled child. This may not be politically correct but it is important for family relationships.

If your child comes up against nastiness or discrimination, never show that it upsets you, they get their strength from your cool approach. Always remind them it is the small minds and ignorance of others, nothing to do with them.





Do any family sporting events available, so your child can be part of a team, as often they are left out at school. Maybe look at this Superhero event. I did a similar event two years ago and it was one of the best experience I have had.

Superhero in August 19th at Dorney Lake offers three uniquely designed triathlons - swim, bike and push/run that let you do as little or as much as you like. Team with disabled and non-disabled family members and friends. For details go to **www.superheroseries.co.uk**.

NB Nowadays there is a lot of emphasis on disability and Paralympic sport. Please think carefully before making sport too serious. There are lots of hidden downsides in aiming to be a Paralympian.

Join my worldwide Facebook gadgets group and ask any "how to " question you like: Gadgets to make life easier, disabling disability https://www.facebook.com/ groups/83214963722/

USEFUL INFORMATION

At the Thalidomide Trust (different to the society) we have looked into preparing helpful documents and videos for health care professionals to understand our needs.

There are links to two areas on this page that may be of use. A short video of how to take blood from someone with bilateral damage and the Upper Limb Statement, a document put together by those of us with upper limb disability, showing how the simplest of tasks can affect us behind the brave face. It is sobering reading and can help with understanding the issues and with PIP assessments, please don't get depressed by it! It is many people's experience, not just one!

http://www.thalidomidetrust.org/health-and-wellbeing/ health/health-resources/

My life has been nothing liked my mother feared. It has been a great ride so far. I put my health first where possible as I need all parts of my body and mind to work well, to keep my independence.

Despite no arms, Frank Letch has also led an interesting and fulfilling life. "I married, we had five lovely children and I now have five grandchildren. I had a satisfying career as a languages teacher. Since retirement I have worked for the Tribunal Service (Disability Living Allowance and Employment tribunals), for several local charities and of course for Reach. I am a town councillor and have been mayor of Crediton for the past nine years. In



the past nine years. In 2015 I was made an MBE for services to people with disabilities and the community. Being a bilateral upper limb amputee has not stopped me enjoying my life. I suppose you might say that my life is not normal, but who wants to be normal? Not me!

Frank Letch MBE



YES, YOU CAN BE A DOCTOR

Thanks to Reach and the support of our wonderful role model Dr Tim Smith, Consultant in Emergency Medicine at Leighton Hospital, a student with a little arm has been encouraged to pursue a career in medicine.

Georgia Gray, 23, was applying for Graduate Entry Medicine courses and she approached Reach for support with her applications. We put her in touch with Tim, who has a similar upper limb deficiency and he arranged for Georgia to spend a day shadowing him at work over Christmas.

He was able to give her valuable advice on medical school interviews and talked about how his disability hasn't stopped him from succeeding in the field. He also gave Georgia the opportunity to practice skills such as suturing, taking blood and resuscitation simulation.

Tim said: "We went through some of the practical skills that universities have flagged up as potential issues and it's given Georgia the confidence to know that they can be done. It's sometimes just a case of finding different ways of doing things.

"There are other doctors who are working and practising who have a range of disabilities, including upper limb deficiencies, and so it's definitely possible for those with a disability to pursue a career in medicine."

Georgia, who has now moved from New Zealand to England and been accepted on to a course, explained that the experience had been very encouraging.

She said: "It was a real stroke of luck finding out about Tim and it's been really cool to be here and to see the different ways he does all of the practical skills. I hadn't really considered A&E before, but now I've seen that it's not an issue."

Tim added: "We've all got different attributes, different skills and different abilities and that applies whether you've got a disability or not.

"The beauty of medicine is that it's so varied that you can find an area that suits you. You can do whatever you want as long as you've got the aptitude.

"There are challenges along the way, but all medical students and doctors have their challenges. The important thing is not to single yourself as having challenges

because of a disability."

11

A CARL STORE STORE

HURRAH FOR OUR FUNDRAISERS!



Reach members come up with some imaginative ways to raise money for the charity. Danny and Francesca Byers sold their artwork and raised £50.

SPORTY FUNDRAISING

Michelle Evans ran the Cardiff half marathon last year and raised a total of £1.708.75.

Alan Norris from Stamford raised £1,708.50 competing in the Rome 2 Home event.

Inspired by Amy Roskilly-Green and her Reach daughter Hero, Kim Calland from Llangarron ran the Vitality 10k Run last vear and raised a total of £845.43.

Kirsty Scott from Ayr completed the 5k Loch Ken swim and raised £250.

Josie Hewison and Jed Bewick took part in Total Warrior and raised £1,500.

Reach parents Helen and Jon Linscer, and Natalie Lee, took on the crazy challenge of walking the 100k of the Thames Path non stop from Putney Bridge to Henley raising money for Reach. "When Josie was born, Reach gave us valuable support and advice," said Helen. "They continue to offer much needed support for Josie as she grows into a strong-minded, independent and confident young lady full of potential." Their fundraising totalled £2,727.11.

Reach member Jasmine's intrepid dad Syd Valentine braved 45 obstacles including water when he took part in the Warrior Adrenaline 10k Obstacle Course Race. He raised a total of £99.25.

Claire Cashmore did a sponsored swim for Katrina Hill in West Midlands and donated the money to Reach - a total of £1,000.

Owen Burdett, from Congleton, whose son Lochlan is a Reach child, ran not one but two half marathons in aid of Reach last year and raised £78.75.

Mags Boland ran the Great Scottish 10k Run and raised a total of £537.41.

WELL DONE!



12





When we found out about my son's limb difference at our 12 week scan we weren't devastated or unhappy," said Lindsay Wright. "It wasn't bad news for

us and we certainly disagreed with the sonographer when she declared she had seen something 'wrong' with the baby (nothing wrong with him at all).

"A huge part of that reaction was because I had grown up with my mum as a childminder and one of the children she looked after for a few years had an upper limb difference, so I'd seen first hand the vastness of ability and how this wouldn't limit our child.

"Once we discovered Reach we wanted to find a way to help others discover and learn more about limb differences so then if they ever received that news themselves, that they too would have some knowledge about limb difference.

"After discovering a craft that I absolutely LOVE doing, I decided at the start of the year to take the plunge and launch my own small business making custom-designed cushion covers which are hand drawn and painted, from meaningful buildings and family photos to designs with typography.

" I discuss each client's needs with them to design and produce an extremely special cushion cover to display proudly in their home.

"Where does Reach come into this? 10% of the profit from each cushion cover sold goes to Reach, and I regularly talk about the charity through Facebook and Instagram where I currently sell the cushion covers. Each cushion cover is posted with a Reach leaflet inside spreading awareness far and wide. I'm really excited to see where this takes me, at the moment I'm fitting it in around a job, running a youth group and looking after the children, so life is busy, but it's great and it's wonderful knowing that more and more people will discover Reach."

Lindsay' markets her cushions via: Instagram: @handmadejustwright and Facebook: Handmadejustwright. They cost £25 for a cushion cover and £30 for one with a pom pom trim.

EVERY LITTLE HELPS

Sian Brooks was delighted when she saw that her local pub near Sampford Peverell had agreed to put a Reach collection box in a prominent place on the bar.

The new branding looks great!



THE STARS OF REACH Reach

THANK YOU ALL

Simon and Laura Fowler raised £146.50 with a Christmas concert at One Aldwych Hotel in Covent Garden.

Michael Simpson-Jones from Chesham donated £20, as a thank you for Eileen's knitted gift for baby Thomas.

North Cornwall Motor Racing Club raised £2,028 after Reach members Joseph Piper and his mum Joanne Wilton nominated Reach as a great charity to support.

Gerard Crofton-Martin from Sheffield donated £50 as he wanted to support a charity that helped people with an upper limb deficiency after his wife broke her hand and he realised how difficult life could be.

Elizabeth Gill from Fortrose donated £30 after bumping into the Reach Family Weekend while staying in Glasgow last October. "We had not heard of this charity until we were on a weekend away at the Marriott in Glasgow and spoke to a couple of ladies and children attending the Family 'Weekend there," she said. "We decided to make it part of our annual donation in lieu of cards."

Caroline Newell from Billingshurst donated £10 in lieu of Christmas cards as her niece is a Reach member.

Reach member Michael Matthews from Chepstow also donated $\pounds 40$ in lieu of cards.

The Whitbread League Golf Society in Kent raised £400.

Debojit Mujherjee from Bromley, donated £229 in lieu of presents for her Reach niece's father, Paul Green.

Pamela Harris from Newton Abbot donated £50 in lieu of a Christmas present for their son Toby, at his request.

Pervin Todiwala from Mr Todiwala's Kitchen Restaurant in London donated $\pounds 20$.

Rosanna Armitage from Cirencester donated £170. She won heads or tails at her office party and Steppes Travel has offered to match the donation. Rosanna supports Reach as her niece is a member.

Jack Gullen from Clackmannan donated £50 as he believes Reach is "a fantastic charity with a great sense of community."

Richard, Owain Beesley's granddad donated £100.

Marina Turner from Glasgow donated £200, the result of fundraising by Partick Housing Association staff.

Emma Lasikiewicz from Nottingham donated £50 inspired by a colleague.

Sonia Underhill, whose granddaughter Connie is a Reach member, has regularly sold chutney, jam and marmalade at Bitterne Bowling Club where she was secretary, with the proceeds split between the charity and the club. She made £450 for Reach in 2015.

Last year, the Bowling Club closed at the end of the season as the land was acquired for redevelopment, so all of the

proceeds of her conserving went to Reach – a magnificent \pounds 1,200. This year, though, the beneficiary of Sonia's cooking will be the local cancer wards that have been very important to the family.

Jennie Sands' grandmother Jean Churchill died recently and the family donated £250 in lieu of flowers at the funeral. Mrs P Stagg donated £20.

Donations in memory of Chris Penny's grandfather Gordon Collis totalled £1,000.15.

Wonderful family friends Sara and David Dunne have donated £20 to Reach. They have donated every Christmas since Lewis Humphreys was born over 13 years ago.

Earls Barton Folk Dance Club in Northampton had a charity donation box at Christmas in lieu of cards and raised £75.

Billy Terrell's grandparents Mary and John Hanson donated $\pounds 100$.

A golf day at Rye Golf Club with Summer, Julie, Phil and Sophie Paxton raised a fantastic £2,875 excluding gift aid!

Desmond Latimer, a former colleague of Charlotte Fielder from her Customs Office days, has donated £10.

Dennis Marshall, whose family has close ties with Stephanie and Daniel Tennent, asked for donations to Reach in lieu of presents for his 70th birthday, raising £400.

Mayfield Evening WI and Rosemary and John Finlay in Mayfield collected \pounds 121.48 in aid of Reach.

The National Oceanography Centre in Liverpool donated £100. The charity was nominated by Mary Linnane, whose granddaughter is Baylee Abbott.

Staff and directors of Northern Hi Tec Ltd in Lancaster raised £250 for Reach as one of their members has a Reach child.

Ottery St Mary Girl Guiding District raised £90 at their carol service.

Staff at the Customer Business Centre within Rolls-Royce Civil Aerospace in Derby held a raffle, cake sales and produce sale and split the proceeds between four charities. Reach received £250.

St Andrews Toddler Group in Clevedon held a bonfire/firework party and donated the proceeds of £40 to Reach as one of the regular members of the group is a Reach child.

 $\pounds 110$ was donated in memory of Amber Thacker's late grand-mother Susan Whitbread.

Staff at Tulip Ltd in Bodmin raised money with a quiz.

Colleagues at the Handelsbanken Birmingham Temple Row raised £85.50

Werrington Primary School, Peterborough, held a Christmas Fair and the reception class children made chocolate reindeer food to sell. They also held collections at their nativity play performances, raising a grand total of £142.

THANK YOU!

WELCOME TO OUR NEW MEMBERS







"Our daughter, Ciara was born on 05/10/16 with Synbrachydactly. It was picked up at birth rather than on any scans.

We attended our first consultation at Great Ormond Street with Gill Smith a few weeks ago and she recommended that I look up "Reach". I wish someone had

suggested I contact you sooner as the facebook page and support line is really good. I feel like I'm now much better equipped to tackle

the "why?" question from both her and her peers when she gets older and don't feel it's going to hold her back in any way! Looking forward to meeting other Reach children and parents in due course.



Vivienne Martin

Ciara Martin









PROSTHETICS FOR BABIES

Sol Ryan had his lower arm amputated at 10 days old because of a blood clot. And when his father Ben learned there were no functional prosthetics for young babies he decided to invint one himself.

Rolled-up pieces of foam taped to Sol's elbow resulted in him banging his toys with his hand - and his foam arm. It was the first time he had tried to use the left arm. It was the breakthrough moment for Ben. From there, developing a better prosthetic arm for young Sol became an obsession.

After experimenting on the kitchen table with bits of copper pipe and plumbing fittings, Ben walked into a newly opened innovation laboratory at Bangor University and asked them for help. Using 3D printing technology, Ben and the university staff turned his idea into reality. Today, Sol has a new prototype arm and hand that can grip with a moveable thumb, that can be built within a few days.

Ben has given up his day job to concentrate full-time on prosthetics, setting up a new company called Ambionics which has already won big name backing. Along with Bangor University's Pontio centre, Ambionics is also being supported by the Life Sciences Hub Wales and its entrepreneurship programme.



So far, the whole project has been funded by family and friends, but it is now the focus of a crowd funding campaign aimed at raising at least £150,000 to satisfy medical authorities his arm prosthetics are safe to use, finalise patents, and to develop the design.

NEW BRANDED HELP FOR YOUR EVENT

Contact Head Office for fundraising equipment. We have everything from Reach branded clothing for sporting events, such as running vests, hoodies, water bottles and stewarding kits, to marketing and publicity tools, printer cartridge recycling envelopes, foreign currency collection boxes and 'donations in memory' collection envelopes.

We also collect used stamps.

The new range of branded clothing in blue and orange



bears the stars motif and a range of positive messages on the back. So get in touch with Jo or Abby at reach@reach.org.uk.

CALLING ALL YOU RUNNERS!

Reach has places available for runners in the Westminster 10K on 9th July 2017. The minimum fundraise necessary is £250, so if you are interested please register with HO.



FLYING, GO-KARTING & SAILING DAYS 2017

Providing youngsters from 6-18, with limb loss or other physical disabilities, the opportunity of experiencing flying, go-karting and sailing activities around Great Britain.

Please see below for details of an event near you and dates

Fri 7th Apr	Go-Kart Day Stockwell, London SW8 2PD
Mon 10th Apr	Sailing Surrey Docks, London SE16 7SX
Sat 13th May	Moray Flying Club Kinloss Barracks, Forres, Morayshire IV36 3HU
Sat 20th May	Isle of Wight Airport Scotchells Brook Lane, Sandown, IoW PO36 0JP
Fri 2nd June	Hull Aero Club Beverley Airfield, Linley Hill, Leven, East Yorkshire HU17 5LT
Sat 10th June	Pembrokeshire Flying Club Haverfordwest Airport, Fishguard Road, Haverfordwest SA62 4BN
Sat 17th June	Shropshire Aero Club Sleap Aerodrome, Harmer Hill, Shropshire SY4 3HE
Sat 1st July	Ulster Flying Club Portaferry Road, Newtownards, Co Down BT23 8SG
Sun 9th July	West London Aero Club White Waltham Aerodrome, Maidenhead, Berkshire SL6 3NJ
Sat 15th July	Sherburn Aero Club New Lennerton Lane, Sherburn in Elmet, Leeds, North Yorkshire LS25 6JE
Sat 22nd July	Manchester City Airport & Heliport Liverpool Road, Eccles, Manchester M30 7SA
Sat 16th Sept	Cornwall Flying Club Bodmin Airfield, Cardinham, Bodmin, Cornwall PL30 4BU

For further information and to register go to: www.douglasbaderfoundation.com





SINGLE-HANDED MAN POWER

TONY ON 'FITTING IN'

Living in a world where people are driven by a culture to 'Fit In' can be particularly challenging for Reach members, both on a physical and an emotional level (well, it was for me any way). It can also be a blessing in disguise. If you're anything like me, the challenges you face growing up will shape you to become a more creative, resilient and confident person... if you mix this with a 'can do' attitude then you're set up to have a successful life, whatever you choose to do.

If you're able to learn from others' (I mean my) mistakes along the way, then that will just serve to helping get you there faster, which is nice.

Okay, so everyday tasks, like eating with a knife and fork, are either a limitation for you or they can be an opportunity to be creative. For me, it was initially a challenge to hold a knife so I used to use my hand as a 'clamp' to cut everything up (I love food so this could get pretty messy at times... especially with anything with a sauce!) so eventually I asked my Dad if we could create a special knife.

This led to us trying all sorts until we landed on a perfect knife... made by making a mold of my hand and using the same material used to make gum shields and then fusing a knife blade on to it. It was a bit tricky to do but eventually we made one that fitted like a glove... I've had the latest one for around 16 years!

16 RAU 30th July -6th August

IS YOUR CHILD AGED 10-18? Have you booked a place on the Reach Activity Week? It's utterly brilliant and they will LOVE it!

This year it is at Carlton Lodge, Thirsk, and the activities are fabulous. From archery and abseiling to kayaking and climbing, raft building and zip wire.

Be inspired - look at the website: carltonlodge.org.uk.

Our Reach children absolutely blossom at RAW. They learn from their peers and from young Reach adult, trained, mentors. They grow in confidence, discover new opportunities, make new friends, share stories, hopes and fears and have a blast in a safe, supportive and understanding environment. The feedback we get back afterwards is always amazing.

Places are heavily subsidised by Reach to enable all our children to take advantage of this fabulous experience. So if you have not booked a place yet, contact HO immediately for a booking form as there are just a few places still available.

DON'T LET YOUR (HILD MISS OUT!

On a slightly deeper level, trying to fit in with peers can feel like an absolute train wreck at times. For me, this is all to do with how happy you are within yourself, knowing your own identity and accepting who you are as a person.

Growing up you don't really know who you are yet or what you will become and this can lead to a lack of self-confidence and low-esteem. Questions like, "Will they like me if they find out about my hand?" can slowly creep up on you and one bad experience can lead to years of hiding an amazing part of your personality and who you are.

Okay, so what is the answer I hear you cry? I'm not a psychologist but these are a few tricks that worked for me (if only I'd known sooner). When you start to compare yourself to others, stop. Don't do it. It will only make you unhappy. Spend your time focusing on what drives you, what makes you tick, what makes you happy. And do more of these things.

Have a 'Can Do' attitude and 'Own' who you are as a person. Be the best you can be in order to maximise your potential and don't pretend to be someone you're not.

Your confidence will soon increase and you'll be a better person for it. People will see your confidence and happiness and you will thrive as a result whatever environment you're in.





CAMP TYNCAE CELEBRATES 20 GLORIOUS YEARS MAY 26-29th

Book quickly for the 20th Reach Family Camping Weekend with the Davies in Mid Wales. The family hosts this event FREE and it is a highspot on the Reach calendar.

Tyncae is a fantastic location, completely safe for children to have fun and make new friends. On Saturday morning we have workshops in the marquee, followed by a buffet lunch. In the afternoon are fun and games in the Leisure Centre and swimming in the local pool followed by a BBQ. Sunday we arrange a trip out with a picnic lunch. Soup and jacket potatoes are on the menu before the annual family quiz begins. A big fun event where new friends are made for life!

Bring suitable warm and colder weather clothing along with wellies and swimwear. Come on get your tent out, pack the car and head for the hills. It may be possible to accommodate one or two small caravans but we must know well in advance.

> If you have any questions please give Dawn or Rob a call on 01974 298904 or email to:belle1234@lineone.net LAST DATE FOR BOOKING – SATURDAY 13TH MAY

The name of the state of the st



GIRL POWER



EMILY ON 'HOW TO'

...tie laces

I used to tie my laces using the 'two bunny ears' method as I found it easier to hold the two 'bunny ears' in place with my stump. Alternative: Velcro!

...do buttons up

Put the button under thumb, index and middle finger on either side of the hole, and wiggle the button through the hole. Alternative: poppers!

....fasten zips

For zippers on jackets, I use my stump to steady the side with the zip-part on it, and then connect both sides of the zip at the bottom with both my stump and my hand and use my hand to pull the zip up. Alternative: Pullovers!

...do your school tie

I never had a tie as part of my school uniform but I did get my dad to teach me how to fasten a tie for my grandad's funeral. Admittedly, I got him to do it then slid it off over my head still done up the day before so it was ready to just slip on and tighten the next morning. I suggest asking a parent to teach you this one!







I used to be on the netball, rounders and rugby team at school so rest asurred, you will be able to catch a ball - there's always a way!

...thread needles

Using a table or hard surface, place the needle on the edge of the table so that the eye is away from the edge – I use my stump to keep the needle

in place. Then I use my fingers to thread the cotton through the eye.

...use scissors

Using the edge of a table again, I would place the paper/initial cutting area over the edge of the table and start cutting from there. Because I have no means of grip on my stump, I use a flat surface and my stump to hold things in place in situations where one would usually grip.

THREADING A NEEDLE THE EMILY WAY





23 YEARS ON, BETH IS ONE ADVENTUROUS ADULT

"I am regularly told how she really has turned out to become a lovely young woman, admired and respected by everyone. Which of course pleases me no end as a parent, proud to be her dad.

"Beth's progress from childhood through adolescence into adulthood, accompanied by her horses, has been well documented in articles in Within Reach. Time for an update - Beth at 23 yrs old.

"Beth graduated from Bangor University in 2015, with a good degree in Psychology. She spent the next year working as a full-time care -worker, visiting and attending to the needs of people with a whole range of disabilities and life-limiting medical conditions. Then in September 2016 she began a two-year postgraduate course in Occupational Therapy at Cardiff University, achieving high grades. My daughter Bethany Ehlen-Batt was born missing her left hand nearly 23 years ago," writes Terry Batt. "Since then a lot has changed in our lives, but - this is primarily for new parents who have recently joined Reach - Beth's left-hand absence has rarely - if ever - been an issue. Beth has managed outstandingly well in all she's done in life."



"The main big change has been Beth leaving home, at 18, growing up fast, growing in confidence and independence. She lived at first in a small cottage on Anglesey while still a student at Bangor, mainly to be closer to the horses she rides. She rides all the time. Hacks for miles out in the local countryside, and on beach-rides, joining in drag-hunts, galloping with high-adrenalin excitement cross-country, teaching others to ride, owning her own horses, looking after other riders' horses, competing in equestrian events, entering dressage competitions, winning many rosettes. She now lives in Cardiff - with a horse of course - which she rides on a hillside in Caerphilly.

"Beth drives manual cars with no adjustments needed, and is licensed to pull trailers (horse-trailers, of course). She has travelled abroad including France and Italy, and has a boyfriend, Alex. They enjoy walking and climbing in the mountains. So, those of you who are 'new' Reach parents, surprises await you. Time passes quickly. No need to worry at all. All will be well."

DRIVING TIPS



Learning to drive with an upper limb deficiency is a minefield. But there is help out there!

Our brilliant Learning to Drive video, which can be downloaded from the Reach website, has been given a big thumbs up by viewers. Our closed facebook page also offers sensible peer group advice and here Ryan Jackson shares his learning curve when he found adaptations more hindrance than help.

Reach strongly advises everybody to go first to a Driving Assessment Centre and a full list of these can be found on our website.



I have no right arm below the elbow, but full use of my left hand/arm. When I was 17 and wanted to start driving, I contacted the DVLA about what I should be doing. They informed me I must speak with a driving assessment centre. The assessment centre advised me to get a 'lollipop' steering aid. After $\pounds1,400$ for the adaptation, $\pounds100$ to fit, and a few more lessons, I passed my driving test in an automatic car!

Three years down the line and not having very much luck with my adaptation (which seemed to eat batteries), I contacted the DVLA to have the driving licence restrictions removed. After several calls back and forth, they told me to go back to the assessment centre and have another assessment as to whether I still required the adaptation.

I had another assessment, and both the centre and I agreed that I no longer required the adaptation, and had full control over the car with just my one arm. I went back to the DVLA with the centre's report, and they subsequently decided they did not agree with the report (never once having seen me themselves).

The DVLA then informed me that I must retake my practical test without any of the adaptations. Once booked, I again took my test and passed. Having no adaptations means I can drive any automatic car, including family cars, and hire cars, allowing me greater freedom than I had before.

Also be careful with insurance companies. If you are going to tell them about your disability, make sure you go through the complete process first, including getting a quote, then inform them about your disability, as at this point, they cannot increase the price without discriminating.

Ryan Jackson

"The Reach Learning to Drive video was such a great informative video," said Jeanette Martin. "We had gone down the route of trying to get a driving instructors advice but were getting nowhere so I thought I would look on your website having been members of Reach for 21 years.

"The advice to see a driving assessment centre was great and that is what we have done with Katy. She feels so much better for getting professional help all thanks to your video advice."

Having no adaptations means I can drive any automatic car Ryan's tip: "If you ever want to hire cars or change cars and you have taken your test with adaptions on, you will need them in every car you drive.

"I retook my test with no adaptions and am now fine to drive any cars as long as they are auto."

Lisa's warning: "A Ferrero Standard (cheap) steering ball just makes one handed steering easier- it does not

allow you to remotely use any indicators, horn etc. So if you're using that, you need to prove that you can reach and use all the legally required buttons and switches."

TWO DIARY DATES FOR LIMBPOWER JUNIOR GAMES

LimbPower is hosting TWO Junior Games this summer: the first at Small Heath Wellbeing Centre Birmingham on 24th June 2017 and then at Stoke Mandeville Stadium, Aylesbury on 30th September 2017.

Entry and Payment forms are available on the LimbPower website. Please return to LimbPower by 31st May 2017 for the June event and 8th September for the later event. Entry costs \pounds 10.

The Junior Games are open to young people aged 5-18 with a physical impairment. The games provide your child with the opportunity to receive coaching in a number of sports. These include Wheelchair Basketball, Track and Field Athletics, Cycling, Sitting Volleyball, Tennis, Badminton, Football and Archery. There will also be a climbing wall at this year's event. *This programme is subject to change.

Siblings of participants are welcome and where possible will be included in the activities. Please complete a registration form for each sibling who is attending.

PARACLIMBING EVENT

As a follow up to the recent successful Paraclimbing Coaching sessions held at White Spider in Surbiton, Be Climbing is hosting a second Paraclimbing Coaching event. This time it will take place on outdoor rocks in West Sussex. The date: Saturday, June 17th from 1-5pm.

> If you would like a place, email Be Climbing at: belinda@beclimbing.co.uk

NEWS



REMAP - MADE TO MEASURE!



Remap is a national charity that brings together two sets of people: volunteers who are skilled at making things, and those with a disability that could be helped by having the right piece of specialist equipment. The result each year is over 3,000 pieces of custom-made equipment which help transform the lives of disabled people and their carers.

Thankfully, there is a lot of equipment on the market to help disabled people, but

often a "made to measure" solution is required. This is where Remap's army of ingenious inventors comes in. They design and make equipment and gadgets for young or old alike and these are then provided free of charge. The aim is always to help people achieve independence and quality of life, filling the gap where no suitable equipment is available commercially.

Cameron wants to follow in the footsteps of cricketing hero Jimmy Anderson and play for England. When batting, he wears a prosthesis that was custom-made for him by Remap Bristol.

When Isabella's friends started to ride bikes, she could only look on longingly until Remap came along in the shape of Alan Jeffs, a volunteer with Remap Cambridge. Alan adapted a bicycle for Isabella (pictured above) so that she could effectively hold the handlebar and steer it. Now she goes out with her friends on bike-riding expeditions in the local parks and is thrilled with her new-found power.

Do you know someone who could be helped by Remap? For more details visit the website www.remap.org.uk or ring us on 01732 760209.

David Martin, Network Development Manager, Remap www.remap.org.uk

ROAMIN' BUILDERS

The Roaming Builders raised a magnificent £1,650 from a madcap challenge involving an old car and a 4,500 mile mara-



thon to Rome and back. Graeme Wilson Joiners and Murdoch Smith Construction signed up to the Rust 2 Rome £500 Banger Rally to raise money for two charities close to their hearts. Graeme lost his lower arm in an accident many years ago but still works as a joiner and beats Derek McIntyre at golf. Derek's sister in law lost her battle with MS at the age of 34. So they decided to raise money for Reach and the Multiple Sclerosis (MS) Society.



FUNDRAISING EVENT WAS A MASSIVE SUCCESS!

"If we can do it anyone can!" said Sharon Stuart after raising a fantastic £3,317.50.

"We joined Reach in 2015 after finding out at 16 weeks pregnant that Ava was missing part of her left lower forearm and left hand. Reach has been a great support to us as a family.

"It was the Chairman's report in the Spring 2016 edition of Within Reach highlighting concerns about the long-term finances and the future of Reach that prompted us to think about raising money for the charity. It is very important to us that Reach continues to be available to offer support to children and their families.

"We decided to hold a fundraising evening, we set a date and it snowballed from there.

"We were very fortunate to have a venue and buffet donated to us so all we had to sort out was the entertainment and how we were going to raise lots of money. We approached many organisations for raffle/auction prizes by letter, email and face to face. Family and friends also helped us with donations of prizes.

"The night was amazing. Family and friends joined us for a night of drinking, dancing and fundraising. We held a raffle and an auction. Our aim was to raise ± 1000 . We are pleased to announce that our total raised from the night and from donations from friends and family who were unable to attend the event is ± 3317.50 .

"It did take a lot of planning but it has been well worth it. We would like to say a massive **THANK YoU** to:

"Staff at the London Post Office Club, Jeff Loftus and the CWU, Tesco's (North Greenford), Sainsbury's (South Ruislip), Cineworld, The Entertainer (Uxbridge), Kempton Park Racecourse, American Golf, P Roders Restaurant Ltd (Ruislip), Sandown Park Racecourse, Nando's (Uxbridge), Miller and Carter (Ruislip), Newbury Racecourse, Paultons Park, Homebase (South Ruislip), Halfords (South Ruislip), Chiltern Railways, Boots (Westway Cross), Wimbledon Greyhound Stadium, Acton Vale Club, Post Office (North Greenford), Marks and Spencer's (Ruislip), WH Smith (Westway Cross), The Bike Shop (Greenford), Mediterranean Shipping Company, Hobbycraft (Greenford), Harbour food and wine Ltd (Greenford), Birring Fruit and Veg (Greenford), and not forgetting family and friends who

have helped us throughout.

Sharon Stuart

BRANCH NEWS





KENT branch co-ordinator **Martine McMahon** was bowled over by the success of her Christmas fundraiser in December.

"We had estimated 15 children would attend from Kent and East Sussex and we were astounded when 30 children and their families came to our party at the Discovery School, Kings Hill.

"The local communities very kindly donated the school venue, a fabulous Hartbeeps disco with Jamie, Charlotte's beautiful face painting, Dianne's scrummy food, Helen's wonderful Christmas presents, Theresa's funky balloons, and Sue and Sara's fab party prizes. Thank you to Devon, Lisa and her Mum for the amazing cakes and Sue and Tony Lyons for their hard work and support.

We also had a visit from Santa and the Christmas party would not have run so smoothly without the kindness of our family, friends, work colleagues and local communities.

We raised £1,500 through our amazing tombola, the auction of a French holiday home, individual and company donations (including Forever Living Products, Kings Hill Properties, Ward – Kings Hill and Sue Ryder - Kings Hill) and donations from the Whitbread League Golf Society.

We have had so many offers of help and support we have been able to start organising our summer Paralympic event on the afternoon of 10 June for Reach children and their families! (See back page) If you feel you may like to help us in any way for our next event please do let Martine Mccahon know (07854 019823 or martinemccahon@yahoo.co.uk)

SOUTH WALES WENT WILD!

South Wales held a super crazy biggest Christmas get together ever with bouncy castle, ball pit, arts and crafts, wii games and face painting/tattoos. And of course a fab buffet lunch and some prezzies sent over from the North Pole.

Melissa Beesley



WEST MIDLANDS

A message to members who are not yet in the West Midlands facebook group: Looking forward to our meet up in May at the Ackers for a dry skiing session. Five Reach families have already confirmed! If you need any more information, please get in touch!

> Tracey Smith midlands@reach.org.uk

NORTH WEST CHARITY BALL

The Ball is on September 23rd at The Last Drop Village, Bolton. Tickets are £45.00 each or £400 for a table of 10. Please contact janecrook7@gmail.com or reach@reach. org.uk. Rooms are £90 for a double with breakfast. There is a spa for guests and if you book in advance, Ruby Red Lips will do your make-up!

The event starts at 6.45pm with an arrival drink, followed by a three course meal, games, auction and dancing to Motown Hits. (See back page)

Auction items please! We need things like signed football shirts that could be framed or balls. If any businesses could help with sponsorship that would be a great help.

SOUTH LONDON SOFTPLAY

South London branch organised a softplay session in March and eight families met up and had a great time, raising £42.50 for branch funds!



SCOTTISH BRANCH GOES ON SAFARI

Following on from the Christmas party we have booked a date at Blair Drummond Safari Park for our next meet up.

This will be Saturday 10th June! Look out for the finer details of everything on the Scottish branch facebook page but we have already booked a marquee for us all to meet up and have lunch together.

BRANCH NEWS



SCOTLAND ENJOYED SNOW

The Scottish Branch organised an outing to Snowzone in Braehead, where the children could go sledging and have snowboarding lessons.

There was a small soft play available for the under 3's or anyone over 3 who didn't want to sledge and a room was booked for some party food and games.



YORKSHIRE WENT CLIMBING



Yorkshire Branch had a great day at Rokt Climbing Centre in Brighouse in February. The kids really enjoyed the experience and really got into climbing. It was great to see such enthusiasm. Afterwards we

went over to Millers for lunch where we all chatted and got to know some of our newer members. A big welcome to Jacob and his little brother Sebastian.

Sally Lambert

NORTH WEST FAMILY WEEKEND

The inaugural North West Family Weekend at Patterdale Hall, Genridding, Penrith is a sell out! We are delighted with the response. The dates are July 14th-16th 2017 at Patterdale Hall, close to the shore of Ullswater at Glenridding.

The weekend promises to be fantastic, families will be looked after from Friday night (arrive after dinner) to Sunday lunchtime (lunch included), all activities and meals are provided.

The weekend is about relaxed, fun, family time with Reach friends and some physical challenge thrown in (which are all optional). It is a great way to make new friends, meet up with old ones and take part in some fun activities. This type of Reach weekend has been a huge success for many years in Scotland. Families sleep in private bunk/dorm rooms with some shared bathroom facilities. We have sampled the food and it is good!

Reach are subsidising this event to keep the costs as low as possible, and Reach members are fundraising all year to help. So please crack on with the fundraising and make sure you don't miss a place on the next Reach activity weekend.



LONDON SCHOOL ASSEMBLY

Benny Romberg and his mum, Nicola, South London Branch Co-ordinator, did an assembly about Reach at his school in Subiton. The children were amazed to hear all the things that Benny has done through Reach and how at RAW he learned to kayak, surf and rock climb.

Benny talked about his success in swimming and skiing where he regularly beats able bodied competitors who are older than him! He won a gold medal in the backstroke last year at the London Youth Games.

The school said celebrating difference was a great way to start the day and they were incredibly proud of Benny and his positive attitude. The school had a sponsored odd socks day and cake sale in aid of Reach and raised over £800.

Nicola is happy to share the PowerPoint presentation if anybody would like to do a similar thing at their school?

KENT SPRING MEET-UP



Kent and Sussex members met up at a soft play area with high ropes for the older kids. Several brave ones successfully navigated the high ropes and the drop slide. We were also proud of our brave mums, dads and a nan as the younger ones explored the bigger kids' soft play area and disappeared for a while! Even our youngest went on the big slide! It was lovely to see new families as well as our regulars!



North West Christmas Party at Preston Mobility Centre

SPORTING HEROES



JUDO GOLD



Amelia Hannaford competed in a judo championship and won not only Gold in her age / weight / ability category, but also the overall Style Award for Girls.

TOP CHEER LEADERS



Anna Dixon's school won a cheerleading contest, beating seven other schools.

BEST PLAYER

Very proud. Becca Scott won best U11 Netball player at school. Not best onehanded player,









Elsie Hughes (see cover shot) is only six years old but she is already getting used to standing on the podium!

Reach children have an extra spark and Elsie's mum Emma agrees. "They are all so super strong willed," she said.

"I love Reach as they show us all that ANY ONE CAN DO ANYTHING. Elsie and I always say "Never say never!"



SWIMMING

And to prove the point, Grace Baker, competing in her first swimming gala at Loddon White Dolphins, won the Michael Hogarth Trophy for Tenacity, swimming a whole length on her back. Well done!

GYMNASTICS PROSTHETIC

Sydney Hewitt tries out her new gymnastics adaptation cartwheeling! Hooray! It works!





HIGH ACHIEVERS





A FAB LAB HAND

Andrew Traynor has been working with Beamont Collegiate Academy to create a 3d printed hand for him in their free to the public Fab Lab in Warrington.

The school has a STEM (Science Technology Engineering Maths) focus and students helped create the prosthetic using a 3D printer.

The Fab Lab engineers are happy to help other families in need of 3d printed hands or even to use their workshops for diy projects. Fablab@warrington.ac.uk

EVERY ONE MADE IT TO THE PODIUM



All 4 Reach members who took part in the National Paraclimbing Series Round 4 won podium places in the competition.

Isabella Walsh and Matthew Phillips took Gold, Lily Brown Silver and Anouche Husain Bronze. Lily Brown (14) deserves a special mention. She attended the Family Weekend climbing session in Glasgow where Matthew spotted her potential and after chatting to her parents Lily entered the competition. With no formal training she gave a tremendous performance coming 2nd in her first competition.

She has a bright future ahead of her if she wishes to take up climbing and already she is looking towards the next Paraclimbing Series.



WATERSPORTS June 24th INCLUSION GAMES /25th

The Watersport Inclusion Games 2017, a celebration of sailing, rowing and canoeing for people with disabilities or from disadvantaged areas, will be held at the Royal St George Yacht Club at Dun Laoghaire, Ireland on June 24-25.

The event is a partnership between the Irish Sailing Association, Dun Laoghaire Sailability, Canoeing Ireland, Dun Laoghaire Sea Scouts, and Dun Laoghaire Rathdown County Council. The Games are aimed primarily at secondary school students along with their families and friends, but are open to all ages to participate. Equipment will be provided. For booking and training check the webpage: www.sailing.ie/watersportsinclusiongames.

The programme: June 24, 10am-4pm Introduction, demos, practice sessions, 5pm Barbecue and music. June 25 10am-4pm, Practice Sessions, Games, Competitions 4pm Award ceremony and Barbecue.



MACEY'S GOT TALENT

"Macey Scott is loving playing the cello. She's been playing for well over a year now.

"She had top marks in her music test at school and the head teacher contacted me to see if there was anything we could do to allow Macey to play the cello.

"They didn't want her missing out. We contacted her prothesistist Vincent, who was excited to make her adaption.

"She plays at school, at the local church, with the "cello army" (which is a group of celloists from around South Ayrshire of all ages and levels of skill) and most recently in the town hall as part of South Ayrshire music festival. She was selected as one of the two lead basses (when with the cello army) and got to play centre stage, at the very front. I was so proud. Gave her a huge ego boost." **Kirsty Scott**

GUTHRIE THE ALL-ROUND SPORTING ACHIEVER



Short arm never an issue for Guthrie!!! Just back from representing the British School Manila in the Under 13 FOBISIA Games in Bangkok. Turned 12 three days before and was youngest boy in team.

Gold for football, Silver in 800m, Silver in Medlay Relay (breaststroke leg), Bronze for Basketball. Missed medals in triple jump and breaststroke but overall had a cracking 3 days!

