



WE ARE NOW
newlife
THE CHARITY FOR DISABLED CHILDREN
Registered Charity Number: 1130125 in England & Wales.
HELP US CHANGE
A CHILD'S LIFE

25 YEAR **IMPACT** REPORT

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Foreword

Working together to change lives

Clive Lewis Chairman of Newlife Trustees



When I found out that thousands of disabled and terminally ill children have to suffer because they can't get the equipment they need, frankly I didn't believe it. Now, having served for 25 years as a Newlife Trustee, I see that it is an everyday reality.

The system is 'broken', pieces of a jigsaw that simply don't work together to make child health, care and welfare a priority. In the UK we now have more disabled children than ever before, yet the funds needed to support them are shrinking. Reliance on charities, of which Newlife is now the largest in its field, is enormous.

Birth defects remain the biggest threat to child health in the developed world. Newlife is seen by researchers as a vital asset in the fight to improve child health, because we have invested in their goal to combat rare conditions.

Every day our nurses hear how tough life is for families who have to live with the broken pieces of the system. Newlife is there to help families, often when their need is greatest.

Newlife works every day to make sense of the broken pieces, trying to fit them back together – influencing policy, providing equipment and, quite literally, changing lives.

The Board of Trustees supports the tremendous work of our staff and volunteers to improve healthcare and highlight the issues

to decision makers. Much has been achieved, despite the fact that Newlife isn't well known. We don't spend money on billboard advertising and celebrity endorsements; instead, we use the funds we have to get the job done.

Thank you to everyone who has reached out and supported us. With your continued help we will go forward, driven by the words of a Paralympian supporter – 'Never mind what I can't do, give me the right equipment at the right time and I will show you what I can do'.

Together, let's give hope to every child challenged by disability and give every child who is terminally ill real quality in the life they have.

My hope is that, when you have viewed the work we do and the way in which we do it, you will see Newlife is a very different charity. I do hope you will feel able to join us.

Remember, we can only complete the jigsaw by working together to change lives, taking positive action today.



care services:

changing children's
lives



<< Every day in the UK ordinary children in ordinary families become disabled or are diagnosed as terminally ill. Every day Newlife is there to support them and their families. If it was your child you would want the very best for them. Newlife is the UK's largest charity provider of specialist equipment for disabled and terminally ill children. // Our helpline is staffed by a dedicated team of nurses who support and care for families. Our Grants service provides equipment that reduces pain, allows children to walk, talk, go to school and play with family and friends. // Newlife's unique Emergency Equipment Loan service ensures children who are terminally ill, life limited or are in danger through lack of appropriate support get the right piece of equipment at the right time, often within 72 hours of an application being made. Play Therapy Pods offer loans of sensory toys to aid development and interaction. Comfort Capsules help families of terminally ill children make precious memories. >>

“

This year, for the first time, when we went on holiday she was even able to get around the pathways on the caravan site.

”



Mum's dream comes true for Libbi-Faith

£16 MILLION

Newlife has spent over £16million helping close to 11,000 children through our Equipment Grant service.

Mum Eloise had one simple dream – that one day her daughter Libbi-Faith would be able to get out of her wheelchair and walk. Thanks to the equipment Newlife provided, her dream came true.

Fighting Spirit

Libbi-Faith, from the West Midlands, has Quadriplegic Cerebral Palsy, is fed through a tube in her stomach and needs oxygen when she is unwell. She can't operate her wheelchair herself, so constantly relied on other people.

Although mum Eloise says her pregnancy was 'textbook', a uterine rupture during labour meant Libbi-Faith was starved of oxygen for just over 20 minutes. Not expected to survive, she spent three weeks in a neonatal unit before being transferred to a children's hospice for end of life care. However, Libbi-Faith demonstrated her fighting spirit by improving to the point where she could go home, and, although there have been numerous hospital admissions since, at the age of six she continues to defy expectations.

Libbi-Faith refused walker by local authority

The family's local statutory service refused to give Libbi-Faith a specialist walking frame because she was unlikely to be able to develop her skills and go on to walk independently. This meant that she was constrained to a wheelchair that she couldn't

operate herself, so she had to rely on others to push her around. So the family turned to Newlife and we were able to provide the walker Libbi-Faith needed just a few weeks later.

Loves playing tricks on us!

Now Eloise's dream for her daughter has come true. "Within a few weeks of getting the equipment from Newlife, Libbi-Faith was able to access the whole of the downstairs of our house," she said. "She loves nothing more than to sneak up behind me, grab my tea towel and throw it on the floor or surprise her dad when he is doing the washing up.

"Libbi-Faith is doing so well. She loves being in the walker during evenings after school, at weekends and in the school holidays. It gives her so much more independence and is making a huge difference to her life."

Using the walker – which was provided through an Equipment Grant – has improved Libbi-Faith's muscle control to the point where she is now attempting to weight bear occasionally with support when transferring in and out of her wheelchair. It has

also sparked her interest in the world around her, particularly in their garden, which she now loves to explore and has even prompted her to say her first word – 'garden' – when she decided she wanted to go outside, much to her family's joy.

Eloise said: "I think she was bored in her wheelchair, and the walker is so easy to take out with us. This year, for the first time, when we went on holiday she was even able to get around the pathways on the caravan site. She also loves to dance at parties, especially to dance music, but the louder the better. It's about her engaging in normal family life. Libbi-Faith really enjoys using her walker and she always has a big smile on her face when she does."

“

Her occupational therapist has said how much her posture has improved. We think that's mostly down to the buggy.

”



Daisy is stronger and more able thanks to special buggy

Following an 11 hour operation, Daisy needed a special buggy to support her – Newlife stepped in to help.

One in a million

Little Daisy from Hampshire underwent intricate brain surgery lasting 11 hours in a bid to halt epileptic seizures and help develop her mobility and cognitive skills.

Mum Kate explains: “In babies and young children, the right hand side of the brain ‘talks’ to the left. But because her right side is bigger, the messages were misfiring and causing the epilepsy. It’s not genetic, and the chance of having this condition is one in a million.

“There were no issues during the pregnancy and we never for one moment thought there would be anything wrong because things like this happen to someone else, not you. Because Daisy’s condition is so rare it is still a bit of mystery.”

What this means for Daisy

Daisy has a diagnosis of Hemimegalencephaly, which resulted in epilepsy as well as developmental delay and left-sided body weakness. To help improve her core strength and prevent

deterioration of her spine she needs to be appropriately positioned at all times – and regular pushchairs just don’t offer the support she needs.

Newlife stepped in when local statutory services couldn’t help

Following surgery, Kate needed a specialist buggy to be able to get Daisy out and about in safety and comfort. However, nothing was available through local statutory services and Daisy’s occupational therapist was concerned that any delay could have a detrimental effect on her long-term health. So the family contacted Newlife – and we were able to offer them just what they needed when they needed it through our Equipment Grants Service.

Posture has improved, due to the buggy

Mum Kate said: “Daisy uses this buggy on a daily basis and it has been really important in helping her posture and strength. The surgery has been successful, so far, and she has come off

her epilepsy medication and her development has improved hugely – it’s like a fog has been lifted. However, because of her significant left-sided weakness she still needs the extra help.

“She absolutely loves being in the buggy – the additional padding and supports keep her in an upright position and means she can reach out for things. Her occupational therapist has said how much her posture has improved. We think that’s mostly down to the buggy.”

On getting the equipment, Kate stressed to us that Daisy’s core strength was vital because it was her ‘ultimate aim’ to see her daughter walk. Now her wish has come true – Daisy has recently started taking her first steps, with a little help from mum and dad. Kate said: “Developmentally, we are seeing more from Daisy than ever before.”

Dad Will added: “Daisy has made us realise what life is all about. You just appreciate everything she does, every tiny milestone – each one is so important. Since the surgery she is developing in the same way as any other child – just more slowly.”

1,500 GRANTS

Newlife has ‘fast tracked’ over 1,500 grant applications over the last seven years due to an urgent need for equipment.



Having Finley in the buggy means we have peace of mind when we are out and it has made life so much more enjoyable for the whole family.



Finley has taught us to enjoy each day

900 CHILDREN

Newlife's Emergency Equipment Loan services have helped over 900 children and their families since inception in 2011.

Finley's parents are determined to enjoy the time they've got together as a family. Thanks to his new special buggy, they can.

Finley's rare condition

Finley is a two-year-old from Hampshire. Just popping out near their home with Finley in a standard pushchair was difficult for parents Louisa and Michael. Finley has a rare degenerative neuro developmental condition called Aicardi-Goutières Syndrome which has caused brain damage; as a result his body and head are floppy – so if his head falls forward it can restrict his breathing.

Louisa says: "Finley has a short life expectancy; most likely under ten years, possibly under five. We don't know how long we have with him so we try to make sure he is comfortable and he has the best quality of life we can give him."

Restrictions on life

His old standard pushchair had limited carrying space which meant one parent had to manage the bulky medical equipment – oxygen cylinder, monitor, feed pump and suctioning machine – that Finley needs with him at all times, while the other pushed him around. This really restricted life for mum, dad and Finley's brother Thomas. Louisa said: "Thomas isn't your typical four-year-

old – he is a young carer. It is very hard, but Finley has taught us not to sweat the small things, but to enjoy each day."

Newlife stepped in as local wheelchair services couldn't help

Finley isn't even eligible for an assessment from local wheelchair services until he is three years old – so Newlife stepped in to fill the equipment gap. As his need was so urgent, Newlife ensured the family got the equipment within a few days of the application being made.

Finley can now get out and about in safety, thanks to the 'life changing' emergency loan of a special buggy which gives him all the support he needs to minimise pain, help him breathe properly and has extra space for all of his vital life sustaining equipment.

Not only does the buggy have additional supports to keep Finley's body upright and his head in position so his breathing isn't compromised, the seat can face towards Louisa and Michael so they can monitor his condition at all times.

'Equipment has changed our lives'

Now Finley and his family can pop out whenever they want, attend hospital and clinic appointments easily, take day trips and have even been on their first family holiday together – all of which helps them make precious memories.

"The equipment has made a huge difference. It has changed our lives. Having Finley in the buggy means we have peace of mind when we are out and it has made life so much more enjoyable for the whole family."

"Finley is definitely more comfortable in his buggy and because he is fully supported he is able to sit up and look around and be involved more. The first place we took Finley in the buggy was to Peppa Pig Land for Thomas's birthday," said Louisa. "I don't know where we would be without the buggy now."



The bed is brilliant – Paige loves sitting in it and having stories read to her. It helps keep her safe from further head injuries.



Special bed keeps Paige safe

Five-year-old Paige from Staffordshire desperately needed a special bed to keep her safe as one small bump could be fatal.

Paige's story

Paige has a rare genetic condition called Tuberous Sclerosis which causes tumours; this is combined with severe epilepsy and a brain aneurysm. Mum Rebecca said: "When Paige was born we noticed there were problems and she started having seizures in the first couple of days. She was in hospital until she was 12 weeks old when her condition was diagnosed; Paige has tuberous growths in her brain and her lungs, one in her eye and a small one in her heart. When she was 18 months old an MRI scan detected a brain aneurysm which was operated on; the result isn't permanent and she may have to be operated on again."

She added: "It is so rare for a young child to have a brain aneurysm that she has been the doctors' guinea pig' in terms of determining treatment and consultants from all over the country have been involved."

Up to 70 seizures in one day, but the family were left without a special bed

During the day Paige wears a protective helmet to help prevent potentially catastrophic head injuries, but it is uncomfortable for her to sleep in this.

Paige's seizures peaked at over 70 a day; several of these were at night-time – and when she hit her head against her bed she ended up with significant swellings. So her parents moved her into their bedroom to keep a constant watch over her. The family's support worker from the local hospice and Paige's occupational therapist both recommended a specialist safety bed, but there was no immediate funding available from local statutory services.

Safe at last

Newlife stepped in to provide the padded safety bed through an Emergency Equipment Loan. This, combined with a grant for a video monitor, means Paige has been able to return to her own bedroom and her parents have peace of mind.

Mum Rebecca said: "The bed is brilliant – Paige loves sitting in it and having stories read to her. It helps keep her safe from further head injuries and takes a lot of stress off us. She needs to wear her protective helmet during the day, but it is good for her to be able to take it off at night and let her head breathe.

"Having the video monitor has also helped – it has night vision so even if we hear her stir or wake up, we can see her clearly."

Dad Michael added: "We were petrified of waking up and finding something had happened to her. We try to do the best for Paige that we can and we are really proud of her – she is a little star."

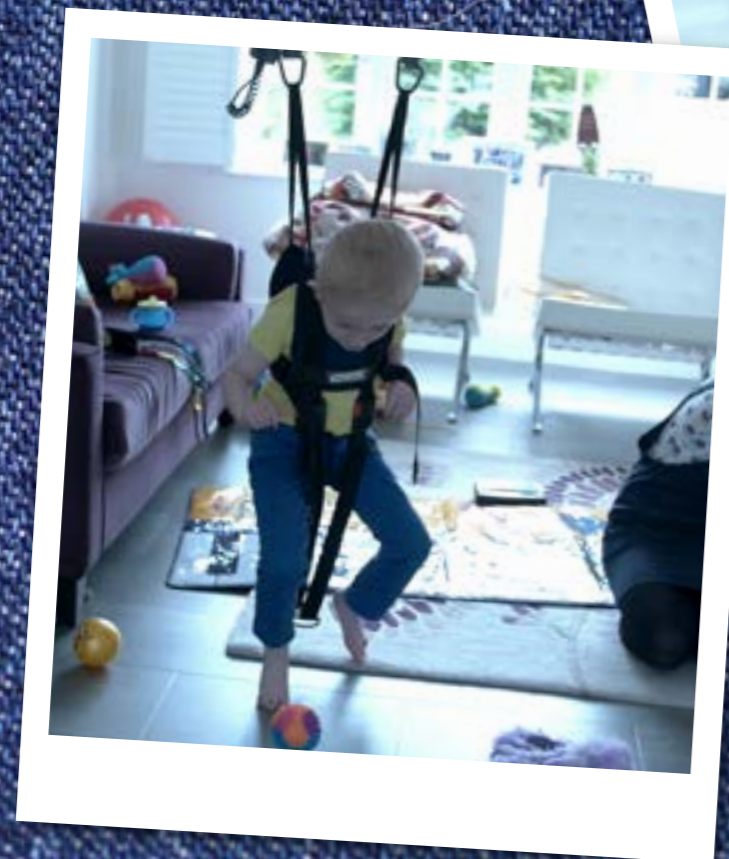
The loan bed ensures Paige is now safe and we are working with statutory services to secure long-term provision.

72 HOURS

Our Emergency Equipment Loans support children with unstable, life-threatening or life-limiting illness and help those who face injury due to the absence of appropriate equipment. We aim to deliver and install equipment support within 72 hours, anywhere in the UK.



He absolutely loves the toys, it's amazing how much he has interacted with us since he started playing with them.



Giant keyboard and other special toys help Henry learn to play

2,700 LOANS

Over 2,700 loans of Play Therapy Pods to children around the UK.

Five-year-old Henry from Surrey is learning to play with his family and develop new skills, with the help of specialist toys.

Henry's story

Henry was a longed-for baby – mum Caroline and her husband Gareth had undergone several attempts at IVF. Despite a smooth pregnancy, Henry was born with Cerebral Palsy, epilepsy, impaired vision and severe learning difficulties. "It was quite a shock," said Caroline.

He was found to have cysts on the brain and brain damage. Caroline added: "He has had a few brain surgeries; by the time he was five months old he had had seven operations so we were in and out of hospital. It has been tough, but Henry is our world."

Caroline and Gareth have adapted their lives around Henry and take each day as it comes. Caroline said: "Having a child with a disability changes your outlook on life. I don't care if he's not ever going to walk or talk, as long as he is happy."

It was like Christmas

Having received a Newlife special needs all-terrain buggy for Henry, so they could get out into the local countryside, Caroline

was interested in the easy-to-access Play Therapy Pod service. This aims to stimulate senses as well as helping children be comforted and distracted from pain through play.

Caroline said when the first Pod arrived 'it was like Christmas' and Henry's little face lit up.

Breaking barriers and relationships strengthened

The family have experimented with different types of toys to help Henry explore varied forms of play – interactive toys designed to help improve hand-eye co-ordination and auditory toys to encourage interaction with others through play and sound. As well as benefitting children's development, there is a vital emotional aspect to playing; it is in these moments that barriers are broken, bonds are forged and relationships are strengthened.

Caroline said: "Because specialist toys for children are so expensive, Play Therapy Pods are a great way for me to find out what Henry enjoys. It would be a shame to spend a big sum of money on one specialist item for him not to take to it."

Ladybird and giant keyboard are a massive hit!

She added: "He absolutely loves the toys, it's amazing how much he has interacted with us since he started playing with them. It enables us to play together as a family. His favourites have been a ladybird and a giant keyboard which he can use with his feet. It's wonderful to see that the toys have brought so much out of Henry; they have made a big difference."

Newlife has developed the service with the help of a dedicated play therapist and built on its early success to extend it to offer toys suitable from birth upwards, across a wide and complex range of needs. There are now around 400 pods in circulation.



We didn't know that anything like the Comfort Capsules existed, but it is an absolutely fantastic service.



Creating precious moments with Patrick

82 FAMILIES

Since March 2015, when the service was launched, Comfort Capsules have helped 82 families make precious memories together.

Watching your baby grow is a remarkable experience – but when the future is uncertain and you are taking each day as it comes, the experience becomes all the more precious.

Patrick's story

Eighteen-month-old Patrick from Nottinghamshire has a rare brain condition called Pontine Tegmental Cap Dysplasia, combined with global developmental delay, seizures and hearing loss. He only has one kidney, which doesn't work properly, and no nerves in his face which means he will often bite his lips without realising what he is doing.

Patrick's condition is so rare that it is uncertain what the future holds for him.

Mum Vicky said: "We were so excited when we found out I was pregnant, and with twins; but at the 20-week scan we found out there was something wrong with one of the babies. Twin one – Freddie – was OK – but then as they checked twin two – Patrick – they noticed he had cysts on his kidney and carried out further investigations to check his brain. The back of his brain had stopped growing, and as the weeks went by they found more things wrong."

Precious memories

After Patrick was born, he needed special care. Vicky and partner Dean were told about Newlife by the family's support worker. Newlife provided a special buggy to ensure Patrick is positioned correctly to help his breathing and digestion; it accommodates all of his life sustaining equipment. Newlife also provided a Comfort Capsule from our newest service.

Comfort Capsules have been put together with the help of an expert team. The carefully chosen items in each one aim to help families make the most of their precious time with their child, creating special memories they can treasure forever. Within the box there is a soft blanket, supportive V-pillow, hand print maker, camera and digital photo frame as well as a portable DVD player – giving families the opportunity to make and preserve memories.

Vicky said: "The digital camera has been brilliant for us – we are taking as many pictures as possible of Patrick and his twin Freddie, together with our other children. We also have quite a lot of hospital stays with Patrick so the DVD player has been really helpful at distracting him when we are there."

'A fantastic service'

"He loves the teddy bear – Patrick doesn't really like to be held but he does love contact; the weight of the bear on his tummy feels like he is being touched and helps distract him from discomfort. Patrick and Freddie have used the handprint maker together – we are trying to make as many memories of the two of them together as we possibly can for our family memory box."

Vicky, who wants to raise more awareness of Patrick's condition, said: "We didn't know that anything like the Comfort Capsules existed, but it is an absolutely fantastic service."



The nurse I spoke to was so understanding. Finding out about Newlife was a godsend.



Newlife Nurses are there for you

16,000 CALLS

The nurses have had over 16,000 calls to the helpline service in the last five years!

No parent or carer thinks their child will be disabled. One mum of a child with severe disabilities told us recently that finding out there was something seriously wrong with her unborn baby was like a “bomb going off in my life”. Families don’t have to go through this alone – Newlife’s nurses are there for you.

‘Finding out about Newlife was a godsend’

The charity’s dedicated nursing team is on hand to help guide families and carers through what can, at times, seem like a ‘maze’ of disability issues. Families are full of praise for the Newlife Nurse Helpline.

Mum Annmarie Briers from Cheshire said: “The nurse I spoke to was so understanding. Finding out about Newlife was a godsend.”

Being the parent of a vulnerable child is extremely challenging and our nurses are available to discuss anything and everything concerning disability. That might be to de-mystify technical medical jargon, help a family access a local key worker, discuss benefits to which they are entitled, provide information about relevant support organisations – or just be a ‘listening ear’.

Parents feel lost

Newlife Care Services Lead Nurse Karen Dobson said: “Sometimes parents can feel lost, with no-one to talk to. We take dozens of enquiries each week and no two families will have

the exact same needs. That’s why we concentrate on offering information and support tailored to each individual child. Families and carers can talk to us about anything regarding a child’s condition – and we appreciate that sometimes they just need that listening ear.”

She added: “One of our main aims is to keep families plugged in to local services wherever possible, and we often act as a liaison between the two. Also, where a child doesn’t have a formal diagnosis and doesn’t fall within the remit of a specific support group, parents can often feel isolated; we offer support and assistance and have connections with relevant professionals to get the information they need.”

The nurses also support families as they access the charity’s own range of free practical services. “The Newlife application process is designed to make getting the right equipment at the right time as hassle free as possible,” added Karen.

Leicestershire mum Rebecca Barbour said: “We had been going round in circles for a while, trying to get a safe sleeping space for our son, but we finally got somewhere when we approached

Newlife. The application process has been really straightforward and we have been pleasantly surprised by how quickly Newlife reacted.”

Nurses play a pivotal role in Newlife, trusted by families when they feel they have no-one else to turn to. Karen Dobson added: “We find ourselves working with families over many years as their children’s conditions change and they face different challenges and transitions. It is important to us to keep in contact and offer support when it is needed.”

Mum Ruth Rankin, from Wigan, said: “The nurses are angels – always happy to take a call and chat through any problems we have. In recent years they have helped our family by providing a specialist car seat and sleep system for our gorgeous daughter, as well as loans of toys through the Play Therapy Pod service.”

♥ THE BEST THING ABOUT MY EQUIPMENT IS 😊

SIMPLY PUT, EQUIPMENT CHANGES LIVES. DON'T JUST TAKE OUR WORD FOR IT. HERE ARE THE THOUGHTS OF SOME OF THE CHILDREN NEWLIFE HAS HELPED.

Aliyah Canning Williams, aged 12, from Conwy
 I regularly blog about living with disability and I have been telling everyone about the brilliant new bed, which enables me to sit up by myself. It means I have a bit of independence and don't have to call my mum to help me all the time.



Gracie Davis, aged six, from Newport
 I love my big girl chair, it's my favourite.



Stacie Stroud - aged 12 from Hampshire

The wheelchair is so comfortable, which is very important because I use it every day, everywhere I go. It's really cool and fun to drive.



Sam Ardley, aged 16, from Leicestershire

My arm supports mean I can do all sorts of things for myself now, like cleaning my teeth. The equipment also allows me to join in with class sports sessions at school, which I love.



Robert 'Bobby' Allen, aged five, from Worcestershire

My standing frame helps me keep up with my little brother and it makes me faster!



LUCK MARINARD-BELLINGER, Aged NINE, Buckinghamshire

I STRUGGLE WITH HEARING. BEFORE I HAD THE LISTENING DEVICE I STRUGGLED A LOT. I COULDN'T HEAR THE TEACHER, AND FELT LEFT OUT, AND NOT PART OF THE WORLD. NOW, WITH MY LISTENING DEVICE, I CAN HEAR THE TEACHER AND JOIN IN WITH MORE ACTIVITIES!



Katie Dawson, aged 13, from London

My radio aids help me every day. I find it easier to concentrate which means learning is easier and less confusing.

Saki Roussos, aged 16, from Yorkshire

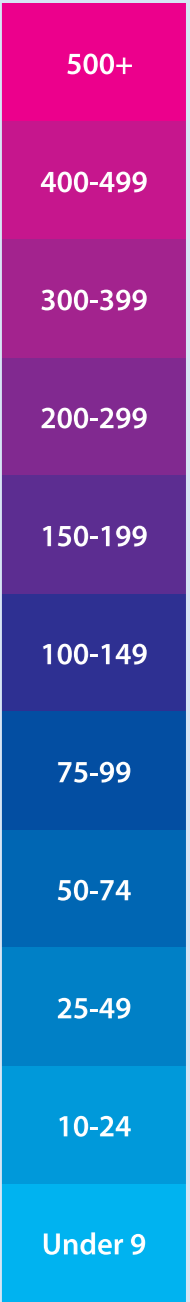
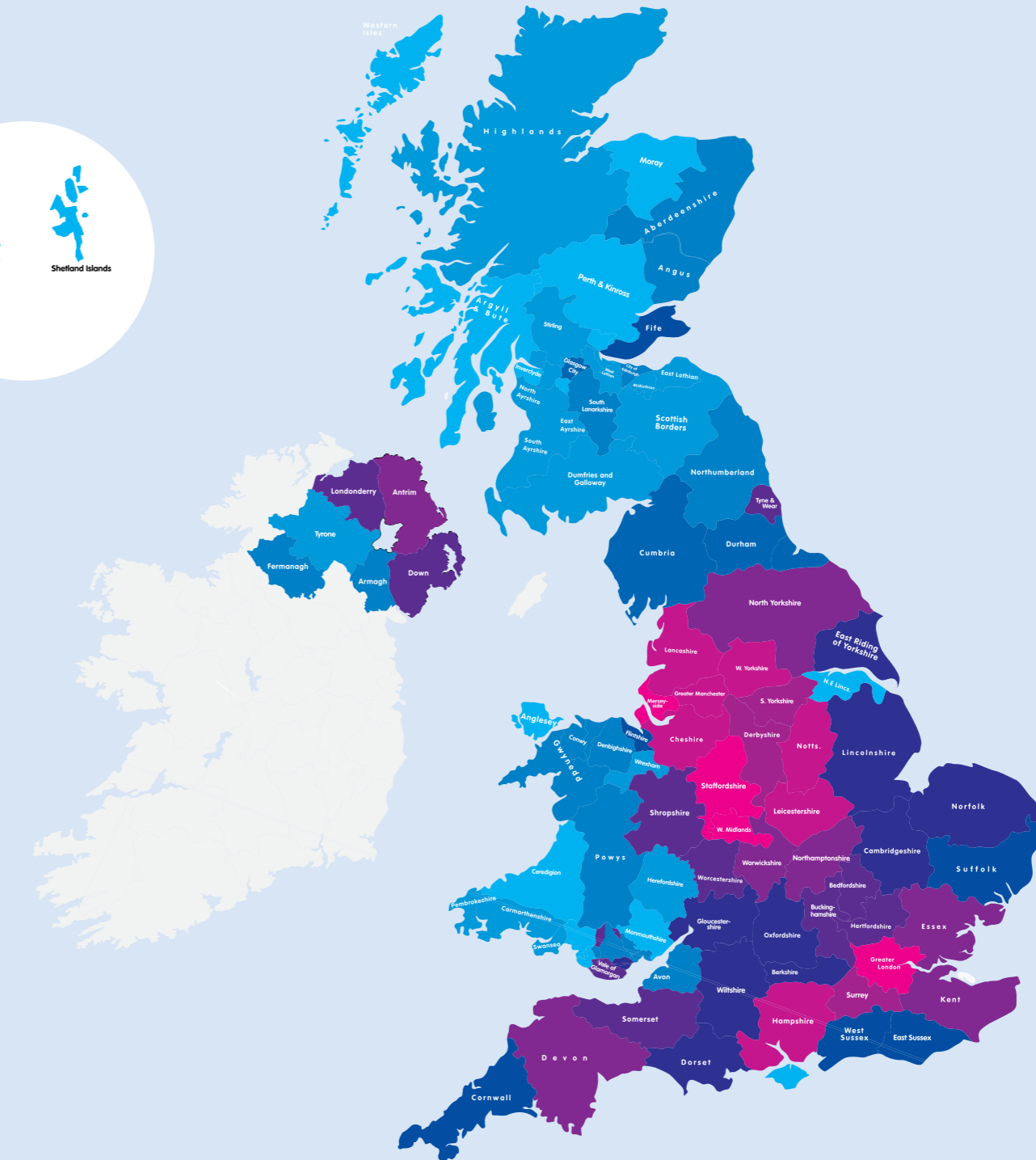
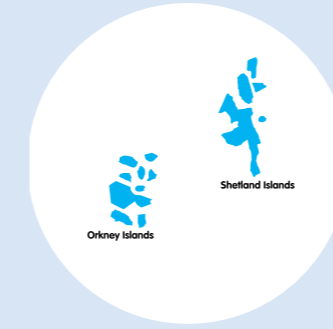
I think the scooter is fab and I can now go out with Tilly, my dog. It was really helpful on our recent trip away as it meant I could still get out and about and enjoy the holiday.



Changing Children's lives across the UK

Newlife has helped children in 101 of the 104 counties across the UK

County	Children Helped	County	Children Helped	County	Children Helped	County	Children Helped	County	Children Helped	County	Children Helped
Aberdeenshire	36	County Antrim	221	East Sussex	97	Kent	282	Northumberland	26	Suffolk	89
Angus	35	County Armagh	28	Eilean Siar	0	Lancashire	436	Nottinghamshire	402	Surrey	357
Argyll & Bute	7	County Derry	70	Essex	260	Leicestershire	422	Orkney Islands	2	Swansea	15
Bedfordshire	185	County Down	155	Falkirk	19	Lincolnshire	119	Oxfordshire	128	Torfaen	20
Berkshire	143	County Fermanagh	28	Fife	80	Merseyside	581	Pembrokeshire	15	Tyne & Wear	172
Blaenau Gwent	175	County Tyrone	44	Flintshire	71	Merthyr Tydfil	17	Perth & Kinross	8	Vale of Glamorgan	159
Bridgend	7	Cumbria	62	Glasgow City	66	Midlothian	10	Powys	36	Warwickshire	214
Buckinghamshire	179	Denbighshire	63	Gloucestershire	131	Monmouthshire	7	Renfrewshire	16	West Dunbartonshire	15
Caerphilly	39	Derbyshire	362	Greater London	856	Moray	4	Rhondda, Cynon, Taf	40	West Lothian	23
Cambridgeshire	121	Devon	299	Greater Manchester	420	Neath Port Talbot	7	Scottish Borders	18	West Midlands	1379
Cardiff	109	Dorset	119	Gwynedd	43	Newport	35	Shetland Islands	0	West Sussex	79
Carmarthenshire	12	Dumfries & Galloway	14	Hampshire	411	Norfolk	146	Shropshire	179	West Yorkshire	407
Ceredigion	5	Durham	72	Herefordshire	20	North & North East Lincolnshire2		Somerset	192	Wiltshire	101
Cheshire	412	East Ayrshire	16	Hertfordshire	163	Highlands	22	North Ayrshire	10	South Ayrshire	12
City of Edinburgh	39	East Dunbartonshire	18	Inverclyde	2	North Lanarkshire	12	North Lanarkshire	12	South Lanarkshire	36
Clackmannanshire	1	East Lothian	16	Inverclyde	2	North Yorkshire	275	Northamptonshire	203	Staffordshire	919
Conwy	31	East Renfrewshire	0	Isle of Anglesey	9	Northamptonshire	203	Staffordshire	919	Stirling	15
Cornwall	95	East Riding of Yorkshire	119	Isle of Wight	7						





campaigning



to give families a voice

<< Families of disabled and terminally ill children often feel abandoned and alone, which is why Newlife campaigns for change – both nationally and locally – to give them a voice. // At national level we’ve lobbied government, resulting in a law change that could benefit up to 70,000 wheelchair using children. We held a week-long exhibition at the House of Commons highlighting the barriers preventing some of the UK’s one million disabled children getting the equipment they urgently need. Newlife continues to work with Ministers, MPs, MEPs and members of the House of Lords in a bid to find solutions to the issues that disabled children and their families encounter every day. // We also work with local authorities to plug families back into statutory provision. This service has resulted in £1.8million of additional equipment being funded by local authorities, ensuring that families’ needs are taken into account when budgeting for the year ahead. In some areas we have worked with local services to change provision policies. >>

Newlife changed the law...

The law in question is the 'Use of Invalid Carriages' section of the Road Traffic Act 1988. Until March 9th 2015, children and adults with disabilities were not allowed to use wheelchairs over 150kgs in weight as they were classed as cars!

This restricted anyone who didn't hold a driving licence from having the most modern, hi-tech wheelchair. Children with the highest levels of need were refused life-changing wheelchairs due to an antiquated law.

As technology has advanced, so have wheelchairs and some now have a 'sit to stand' facility which not only has health benefits – to muscle tone, circulation, kidney and bladder function – but enable children and young people to socialise and be more independent. However, additional functions result in additional weight – and many of these wheelchairs are closer to 200kg.

We met with the Department for Transport every six months over five years. We knew the government was committed to helping us resolve the problem. We were asked to help rewrite the relevant part of the act and before long we received a call from the then Secretary of State for Transport Patrick McLoughlin giving us his support.

Soon after, we got the good news that our campaign had been successful. This means a potential 70,000 additional children and young people now qualify for a hi-tech wheelchair. On the day of the change, DfT Minister Baroness Kramer presented the first of Newlife's 150kg-plus wheelchairs.



for 70,000 disabled children like Callum

Teenage brothers Callum and Lewis from Hertfordshire both have the genetic disorder Duchenne Muscular Dystrophy. They were diagnosed within ten days of each other, 14 years ago.

There is a degenerative, life-limiting condition that affects their mobility and both boys have had to undergo invasive surgery to have metal rods implanted in their spines.

Callum was one of the first teenagers to receive a hi-tech wheelchair from Newlife as a result of the law change. He is now 18 and studying in Watford – something he would struggle to manage without this equipment.

Callum said: "I used to be able to walk around but my condition gets worse as I get older. The new wheelchair helps a lot because it means I can drive it around at college; using the lifts I can access every single building."

The wheelchair has also enabled him to do things like go to a gaming convention with his friends and join them for nights out. "They understand what is wrong with me and treat me like a normal person; I just want to do whatever anyone else does," he said.

Because the wheelchair allows Callum to change position and stretch out he is in less pain and so can use it all day.

His 15-year-old brother Lewis, however, who is currently waiting for similar equipment, has to go to bed as soon as he gets home from school because he is too tired and uncomfortable after being in an upright wheelchair for several hours.

Dad Andy said: "Callum's old wheelchair, which was privately funded, fulfilled his basic mobility needs but didn't have all the additional features needed to support him in everyday life. Our local wheelchair services didn't want to know – but then somebody told us about Newlife and, to be quite honest, the charity was fantastic; they picked up on Callum's needs."

So now it's Lewis's turn. He is in his final GCSE year at Hemel Hempstead School and Newlife is working with local statutory services to provide him with a similar hi-tech powered wheelchair so he, too, can make the most of life's opportunities.

650 MP's

Newlife has worked with 650 MP's to help change children's lives.

1,300 CHILDREN

Newlife has leveraged more than £1.8million of equipment working with local authorities to help 1,300 children.

Newlife at the House of Commons

“One of the most impressive exhibitions I’ve ever seen in Parliament”
Lord Rennard

The number of disabled children in the UK has increased by 30 per cent in the last ten years to around one million. The families of many of these children cannot get the essential equipment they desperately need from their local statutory services. At Newlife we believe in action and so in July (2016) we held a week long exhibition at the House of Commons. This gave us the unique opportunity to highlight to decision makers the challenges that families encounter, while also presenting innovative solutions.

Why call the exhibition ‘Breaking the Barriers’?

The exhibition showcased some of the fantastic pieces of equipment that are available. The right piece of equipment provided at the right time can give our children the opportunity to be the best they can right now and in the future, so they can fulfil their potential.

In short, equipment can be transformational. Yet Newlife routinely sees how barriers to equipment provision such as ‘no budgets available’ or ‘we don’t provide that equipment’ can

cause worsening health issues, unnecessary pain, significant risk through absence of equipment and social exclusion.

We also find that the criteria for provision is currently based on what a child can already do, rather than on what their potential might be given the chance to succeed. For example, a child featured at the exhibition was denied a walker by her local authority because she was deemed unlikely to ever be able to walk independently. Newlife provided the equipment and she has since learnt to walk around her home, playing tricks on her parents as she goes!

In addition, Newlife has been told there is as much as £90million of specialist equipment sitting, unused, in individual statutory services’ warehouses around the UK. Much of this is new or barely used and yet it may be earmarked for landfill to reduce storage costs. Breaking the barriers that lead to this waste is a crucial step forward and we have made decision makers aware of our national equipment recycling service that takes redundant items and refurbishes them for re-use. We have already helped more than 500 families in this way, with over £1 million of equipment that would otherwise have been scrapped.

What did Newlife achieve through the exhibition?

During the week over 50 MPs and members of the House of Lords came to speak to our team including the then Minister for Disabled People and the MP who chairs the All Party Parliamentary Group on Disability. This exhibition has proved vital in developing relationships with decision makers across the UK and has already led to children receiving equipment who would otherwise have been denied. Newlife is developing a strategy to build on these relationships to inform national policy development and secure a better deal for families.

Newlife is now calling on decision makers to:

- Recognise the true number of disabled children in the UK and budget accordingly.
- Put in place fast and responsive services for terminally ill children. Newlife delivers equipment, anywhere in the UK, within 72 hours for families who just can’t wait.
- Instruct local authorities to make redundant equipment available to charities for refurbishment and re-use.

BELOW
MP Chris Evans meets
Newlife’s longest
serving employee
Heather Campbell at
the event.



RIGHT
Newlife CEO and
Co-founder Sheila
Brown O.B.E with MP
for Cannock Chase and
Sponsor of the exhibition
Amanda Milling.



RIGHT
The team also got
to meet with Brian
May and money
saving expert Martin
Lewis who were very
interested in the work
of the charity and
posed to have a photo
with members of our
lucky team!



research

gives real
hope to families



<< Newlife’s investment in pioneering medical research provides real hope for the future. We have invested more than £16million in over 300 individual projects at more than 80 research institutions across the UK. Over 50 disease causing genes have now been identified and Newlife is funding projects into new treatment. Our innovative start-up grants provide funding of up to £15k to give researchers the opportunity to test out theories before applying for future grants. Newlife’s ten-year medical training programme helped over 60 students get an insight into the world of research. // The Newlife Birth Defects Research Centre was opened at the Institute of Child Health in London by HRH The Princess Royal in 2012. It is Europe’s biggest centre dedicated to research into birth defects, the number one threat to child health in the world today. // Finally, Newlife brought the brightest minds together at an international symposium to look at the potential to reverse the effects of intellectual disability. A subsequent £1m investment is looking to realise this lofty goal. Newlife remains committed to helping the children of the future today as we believe medical research holds the key that unlocks the door to reducing disability and improving child health. >>

Why my child?

We believe that medical research holds the key to answering this question. Through research we can provide real hope to families – by understanding why birth defects occur and ultimately finding treatments or new methods to prevent these devastating conditions from occurring.

Medical Research BREAKTHROUGH: MICROCEPHALY

Microcephaly is a birth defect which causes a child's head to be smaller than expected. This often results in intellectual disability that delays development. Newlife has funded research into the condition of Microcephaly with some exciting results.

What do we know about the causes of Microcephaly?

Until recently, very little. There are many causes of Microcephaly such as infections – recently a link has been established through the Zika virus – but the main cause, as with many conditions, is genetic. There are many thousands of different genes in the human body and it only takes one fault in one gene to result in a birth defect.

What research did Newlife fund?

The research we funded took place at Exeter University and was supervised by Professor Andrew Crosby. The aim of the project was to identify the causes of Microcephaly by looking for several of the genes that cause the condition.

What did the research team find?

Using a research technique called gene mapping that looks closely at a person's genetic make-up, the team were able to focus on genetic markers to narrow down the area of the chromosome where the faulty gene occurs. The team were able to identify one gene that is responsible for severe, complex Microcephaly and another which is responsible for the atrophying brain malformation Pontocerebellar Hypoplasia.

What does this mean for now and in the future?

We are now able to offer diagnostic tests for Microcephaly in the UK. The next stage is to advance our understanding of brain development and how it affects cell division. The hope is that through this understanding and the development of stem cell technology and other innovative approaches we will be able to provide treatments in the future. Newlife Medical Director and Trustee Professor Michael Patton summarised the potential when he said: "The research of today is the treatment of tomorrow".



Further research could mean that, in the future, children born with Microcephaly can be treated – or the condition can be prevented altogether. Right now, we remain committed to helping those with rare birth defects just like Hannah.

This is her story...

Eleven-year-old Hannah, from Staffordshire, has Microcephaly. More than anything else, she loves to dance – but as her muscles are weak Newlife has provided a special walker so she can join in classes for children with additional needs.

Mum Claire said: "The walker brings all the fun stuff and happiness to Hannah's life!"

The ability to stand up also has a lot of health benefits for Hannah's circulation, internal organs and her muscle tone.

Hannah is a happy and mischievous girl who communicates with laughs and smiles. Born with Microcephaly, when she was just four weeks old she suddenly stopped breathing. Claire said: "I put Hannah down in her crib one night and walked away, but I had a really strong urge to go back and check on her. When I did, she was the colour of blue jeans. I just picked her up and rang 999."

This was the first of Hannah's seizures – at one point she experienced up to 30 a day – which cause her to stop breathing. They are a result of Microcephaly. Claire said: "This has completely changed our way of life – you just have to accept it."

She added: "Hannah loves being on her feet, especially for dance classes, and without the walker she would be in her wheelchair all the time."

Claire is pleased to know that great strides are being made in the world of research specifically related to Microcephaly. She said: "It's comforting to know that Newlife is supporting families in so many different ways, including through research. There have already been significant breakthroughs which are the building blocks for the future."

£16 MILLION

Newlife has spent close to £16million on pioneering research project across the UK.



Let's get started...

83 INSTITUTIONS

Newlife has funded 305 research projects at 83 different institutions around the UK.

One of Newlife's greatest strengths is listening and responding to the needs of those we support. We were hearing from researchers, who were increasingly frustrated, that there was nowhere to go to get initial funding to test out their theories before embarking on full research projects. Newlife listened – and launched its innovative Start-up Grants Programme.

Grants of £15,000 for start-up projects promote collaboration and aim to find new discoveries which are often the first steps on the road to opening new areas of medical knowledge. In short, they give researchers the opportunity to test out new theories.

Start-up grant holder Siddharth Banka, senior clinical lecturer at the University of Manchester, said: "There are not many existing schemes in the UK that fund preliminary studies in the area of rare disabling diseases of children. I think that the Newlife start-up grants are absolutely vital in supporting new ideas that need to be tested."

The data certainly supports this. A recent Newlife survey asked our start-up grant holders a series of questions; their responses showed us that a combined £90,000 of investment from Newlife had enabled six researchers to gather enough results to secure £725,000 of additional funding to take their work on to the next level.

The grants also delivered some exciting results. The researchers told us that they had developed new understanding of the conditions they were investigating and the research had had a significant impact on their careers.

This was the case for Beth Holder, a research associate at Imperial College London, who examined communication between an expectant mother's immune cells and her baby. Her research discovered a previously unknown route by which the immune system can communicate with the placenta and "could have important implications for protection of the baby during maternal infection or inflammation".

She said: "This was my first independent funding and allowed me to pursue a new avenue of research. I developed collaborations with researchers at different institutes. This led to several outcomes including a first author publication and presentation at several international conferences. I also won the Bronze award at the SET for Britain, which is a competition where scientists present their research at the House of Commons".

Newlife remains committed to its start-up grant programme. We believe that medical research is key to unlocking the door to the greatest threat to child health – birth defects. Our initial funding gives researchers the chance to take the first steps on their road to discovery and provide hope for families of thousands of disabled children throughout the UK.

A focus on Noonan Syndrome

Every day in the UK around 42 children are born with a significant birth defect – that’s one in every 45 live births. Over the last 25 years significant strides have been made in diagnosis, understanding, prevention and even treatment of many rare syndromes. One such condition is Noonan Syndrome. This is linked to congenital heart defects and can cause serious health complications. However, advances in research have been made which will benefit children and families around the world.

Noonan Syndrome is a genetic disorder that causes a wide range of health problems including heart defects and is characterised by short stature and distinctive facial features. Prior to Newlife funding, very little was known about the condition, so we invested in a long-term study to find answers.

The Newlife study, in collaboration with experts in the US and Holland, identified the very first gene (PTPN11) acknowledged as a cause of Noonan Syndrome. We have also played a contributing role in identifying a further six genes known to be responsible for the condition. These causative genes are some

of the most important for cell growth and have even helped us to understand the genetic causes of cancer. As a result of these discoveries, diagnosis of Noonan Syndrome has significantly improved and tens of thousands of children around the world are now being tested for the condition.

Crucially, we have developed relationships with families of children who have Noonan Syndrome and provided the initial support for the patient group. The participation of the families has helped broaden our understanding of what it means to have the condition, moving through childhood and into adulthood and we have been able to develop a greater knowledge of the long-term effects of Noonan Syndrome.

In 25 years we have come a long way, but there is more to do. We want to understand how the genes involved can cause heart defects in children with Noonan Syndrome so we can learn to treat these complications and change lives for the better.



Investing in the future



“The BSc course is probably the single most useful thing I have done to advance my career”

Dr Wisam Alwan

It takes great minds to make breakthroughs in the world of genetics . . . to understand what causes a rare condition to occur, to use new and exciting technologies to test out theories and make discoveries that could change children’s lives now and in the future. Newlife believes it’s worth investing in students to give them a taste of the world of genetics and medical research. Newlife funded a ten-year BSc programme to do just this. We know that without such courses it becomes very difficult to attract a new generation of scientists who will make the next big breakthroughs.

Exposure to medical research during the formative stages of a doctor’s career has a lasting influence on their approach to medical practice. Working in partnership with St George’s Hospital, London, Newlife funded a clinical B.Sc. studentship programme that helped 60 doctors over ten years take a research-based course in the field of inherited disease and in particular its management and prevention. The project has combined clinical and laboratory work to give students an entry qualification into the world of genetics research. Six students (ten per cent) have been awarded prestigious MRC clinical fellowships.

Nicol West, consultant paediatrician at Swindon’s Great Western Hospital, said: “It gave me a grounding in genetic theory and practise which is very helpful in a career in paediatrics to keep up with the pace of change.” Nicol is currently involved in clinical research as a Principal Investigator in paediatric studies at her hospital.

Former student Yvette Adjei-Gyamfi has completed a paediatric fellowship at Great Ormond Street Hospital and now specialises in paediatric radiology. She said: “The training formed the fundamentals of my research knowledge, especially experience gained in laboratory techniques.”

Dr Una-Marie Sheerin is a specialist registrar in neurology at her London hospital. The BSc course sparked a real interest in genetics for her. “I have now completed a PhD in the genetics of Parkinson’s Disease which built on what I learned in my BSc in genetics.”

Opportunities generated by the course have helped shape the careers of many as they have gone on to work in areas of medicine such as trauma and orthopaedics, obstetrics and

gynaecology, urology and neurology – not only at leading hospitals in the UK but at institutions around the world.

Dr Chang Kotecha completed his BSc course and went back to his native country of Uganda and has now set up a chain of medical clinics there. He said: “The funding was very important; without it I would not have had a whole year in the laboratory.” Dr Kotecha is part of a team looking at genetic disorders and widening the access to medical care in Uganda.

64 STUDENTS

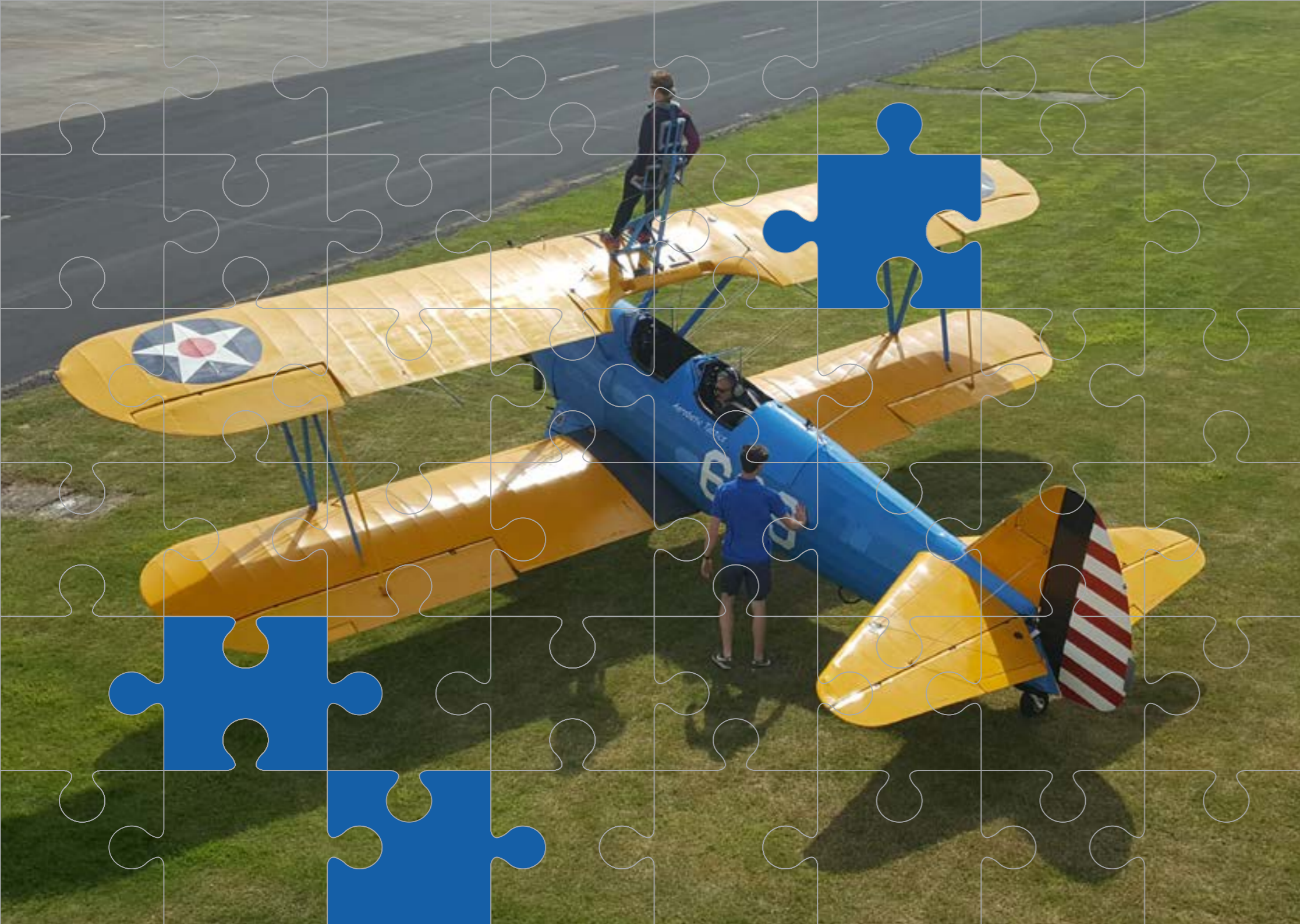
Newlife has supported 64 students (BSc and PhD), giving the next generation of researchers experience in genetics.

Newlife Research around the UK

Newlife has funded over 300 research projects at institutions around the UK.

Name of Institute	No. Grants	City	Name of Institute	No. Grants	City	Name of Institute	No. Grants	City
University of Aberdeen	5	Aberdeen	Blizard Institute	1	Greater London	Royal Liverpool Children's Hospital	1	Liverpool
University of Bath	2	Bath	Charing Cross Hospital	1	Greater London	Moorfields Eye Hospital NHS Foundation Trust	1	London
Birmingham Women's NHS Foundation Trust	6	Birmingham	Great Ormond Street Hospital, Institute of Child Health, University College London	75	Greater London	St Mary's Hospital, University of Manchester	15	Manchester
University of Birmingham	6	Birmingham	Hammersmith Hospital	1	Greater London	University of Manchester	13	Manchester
St Michael's Hospital University of Bristol	3	Bristol	Imperial College London	8	Greater London	Institute of Health, University of Newcastle	4	Newcastle upon Tyne
University of Bristol	1	Bristol	Imperial College of Medicine	2	Greater London	Newcastle Fertility Centre	1	Newcastle upon Tyne
University of Cambridge	8	Cambridge	Institute of Obstetrics and Gynaecology	1	Greater London	Northern Region Genetics Service, Newcastle	1	Newcastle upon Tyne
University of Cambridge Institute for Medical Research	3	Cambridge	Institute of Psychiatry, Psychology and Neuroscience Kings College London	1	Greater London	Royal Victoria Infirmary, Newcastle	1	Newcastle upon Tyne
Addenbrookes Hospital University of Cambridge	5	Cambridge	International Centre for Eye Health, London School of Hygiene & Tropical Medicine	1	Greater London	The Institute of Genetic Medicine, Newcastle University	1	Newcastle upon Tyne
University Hospital of Wales	1	Cardiff	Kings College London	1	Greater London	University of Newcastle	4	Newcastle upon Tyne
University of Cardiff	2	Cardiff	NOFAS-UK	1	Greater London	The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	1	Oswestry
Westlakes Research Institute	1	Cumbria	Queen Charlotte's & Chelsea Hospital	1	Greater London	Churchill Hospital	3	Oxford
MRC Human Biochemical Genetics Unit, University of Edinburgh	3	Edinburgh	Royal Brompton & Harefield NHS Trust	1	Greater London	John Radcliffe Hospital, Oxford University Hospital NHS Trust	6	Oxford
University of Edinburgh	7	Edinburgh	Royal Veterinary College	3	Greater London	St Catherines College Oxford	1	Oxford
Western General Hospital	2	Edinburgh	St George's Hospital Medical School	29	Greater London	University of Oxford	14	Oxford
Royal Devon and Exeter NHS Foundation Trust	3	Exeter	St Thomas' Hospital London	1	Greater London	Wessex Regional Genetics Laboratory	2	Salisbury
University of Exeter Medical School	4	Exeter	Wolfson Institute of Preventive Medicine	1	Greater London	Sheffield Children's Hospital	6	Sheffield
Royal Hospital for Sick Children	2	Glasgow	Guy's Hospital	2	Greater London	University of Sheffield	2	Sheffield
University of Glasgow	1	Glasgow	St James' Hospital University of Leeds	7	Leeds	The Princess Anne Hospital	6	Southampton
Northwick Park Hospital	2	Greater London	University of Leeds	2	Leeds	University of Southampton	4	Southampton
Barts & the London School of Medicine	2	Greater London	University of Leicester	4	Leicester	The Institute of Cancer Research	2	Sutton
Birkbeck University of London	1	Greater London	Institute of Child Health, Alder Hey Children's Hospital	2	Liverpool			





working together to change lives

<< Very much like a jigsaw puzzle, it is only when everything comes together that you can see the final result. At Newlife there are many dedicated people who work together to change the lives of disabled and terminally ill children. // Newlife has worked with organisations such as Central England Co-operative, Morgan Foundation and River Island, raising vital funds that help change young lives. // Newlife guarantees 100 per cent of all monies donated or raised is spent on the service or in the county of the donor's choice. // Jumping out of planes, holding bake sales, running through mud or across the Sahara desert, getting crafty or dressing up as a superhero... our supporters have found innovative ways to raise money for us. Volunteering for Newlife is a passion that many share. In fact, volunteers give over 2,000 hours of their valuable time every month to help make a difference. // Our successful recycling and retail business works with hundreds of store chains, supermarkets and designer labels to offer a unique environmentally-friendly service. Saleable items are de-labelled and sold in six stores across the Midlands and all profits go directly to the charity to help change young lives. >>

Putting the 'fun' in fundraising



£8 MILLION
 £8m raised through fundraising alone.

Last year the charity spent over £4.5million on its charitable aims. It's therefore vital that we continue to raise the funds needed to meet this growing need. At Newlife we encourage the 'fun' in fundraising and here are some great examples of different ways that people all around the UK have been helping to change lives.

News from Northamptonshire

People who are passionate about making a difference to the life of a child are vital to Newlife – and a dedicated team of volunteers from the village of Deanshanger have been showing just what a difference they can make.

Elly Hance along with friends, the congregation of Holy Trinity Church and members of the local community have raised an outstanding £7,853 in just two years, helping provide equipment for six children across the Northamptonshire and Buckinghamshire areas.

Fundraising activities have included a sponsored walk, car wash, sing-a-thon and craft making. Ten-year-old Kerenza Willis tackled a sponsored ten-mile walk along the Grand Union Canal and 12-year-old Laura Holland made flower hair clips, brooches, decorative soaps and tasty treats. She received a Blue Peter badge from the iconic children's TV show for her efforts for Newlife last year.

Brave or Bonkers in Barnsley

For some people fundraising is the perfect opportunity to release their inner daredevil and commit to doing something a little wild, wacky or just plain hair raising – all in a good cause.

Nick Moore, a 21-year-old assistant quantity surveyor with Taylor Wimpey Yorkshire which has adopted Newlife as its charity of the year, took part in a wing walk – with the plane reaching speeds of up to 130mph.

Thrill seeker Nick, from Barnsley, said the experience was 'absolutely fantastic' and he was really proud to have raised in excess of £1,000.

"Wing walking made me feel euphoric, it was like nothing I had ever done before. I am so proud that I have done this, but the most important thing is that children will benefit from it. Taylor Wimpey are passionate about supporting Newlife and we hope to raise £15,000."



Great goings on in Great Yarmouth

Car crazy duo David Bersconi and Ian Cade from Great Yarmouth took on a banger challenge through Europe which raised £1,027.

David and Ian drove from England to Italy in five days as part of the Motoscape Rally, travelling through France, Belgium, the Netherlands, Luxembourg, Germany and Austria, before finally reaching Venice 1,500 miles later.

David said: "We chose Newlife after reading about how the charity had helped a girl in Great Yarmouth who has Cerebral Palsy and needed specialist seating. My cousin has Cerebral Palsy and that, combined with the fact that I work with disabled people and know some of the issues they have to live with on a daily basis, led to us to Newlife."

Wacky in Wolverhampton!

Fundraising can be as individual as you would like it to be, so when 35-year-old Jonathan Green from Wolverhampton was in training to run the London Marathon, he decided to think of quirky fundraising add-ons – and came up with a uniquely cheeky plan.

Jonathan decided to sell permanent advertising space on one of his buttocks to the highest bidder who could choose whatever they wanted to have tattooed, so long as the inking fitted on one cheek. The winning bid belonged to friend and running buddy Dave Anson, who requested his name as the tattoo and paid £200 for the privilege. Once the deed was done, it brought Jonathan's fundraising total for Newlife to over £3,000.

Jonathan said: "Specialist disability equipment can often be key to disabled children living a decent life so the work that Newlife does is something I am very passionate about."



TED BAKER
LONDON

George.

MATALAN

Everybody wins

£40 MILLION

£40million passed to Newlife charity from Newlife's trading company to support its aims and services.

As the number of disabled children continues to grow, so does the need for funds. Newlife's solution to this is a recycling service that retailers and manufacturers can depend on and trust to protect their brand and good name while helping them to achieve their environmental objectives.

Underpinning everything that Newlife does is the work of our recycling and retail business. Simply put, we breathe 'Newlife' into redundant stock contributions from corporate donors, turning it into essential support for children with disabilities and terminal illness.

All donations – from the smallest earring to the largest piece of furniture – to Newlife's secure recycling service are a fundamental factor in the charity's ability to support families who often have nowhere else to turn.

This is a trusted solution for leading companies – including Marks and Spencer, Primark and River Island. We help businesses manage their environmental responsibilities, demonstrate corporate social responsibility, reduce storage costs and combat fraud. Newlife provides these companies with a sound and viable offer. We don't ask for charity; we know there needs to be a mutuality of support. This way everybody wins.

Great for the environment

Newlife's ethical recycling solution is great for the environment as it ensures that thousands of tonnes of end-of-line stock, customer returns and damaged goods do not end up on landfill sites; instead they are recycled or are de-labelled and then sold in one of our six Midlands stores.

Great for corporate donors

Newlife offers an invaluable service to donors whereby we highlight manufacturing faults, enabling them to improve their stock control. Newlife collects stock from anywhere in the UK and increasingly across Europe, free of charge and at the convenience of the donor. This ensures they no longer have to worry about rising storage costs for stock they no longer want.

Great for disabled children

All the profits help Newlife change the lives of disabled and terminally ill children. The nurse helpline offers information and support to families; vital equipment provided at the right time, either as a grant or a loan, reduces pain, prevents conditions

from worsening, promotes mobility and independence and keeps children safe. Pioneering medical research gives real hope to families that we can overcome the biggest threat to child health, birth defects. We are also able to give disabled children and their families a voice by raising awareness and campaigning on their behalf.

Primark views working with Newlife as an integral part of being a responsible retailer. For them it's not about ticking the box for corporate responsibility but about recycling responsibly, helping the environment and supporting Newlife to change lives.



THE WHITE COMPANY
LONDON

schuh



Corporates 'making a difference'

100% OF ALL FUNDS

100% - Newlife guarantees to any donor that 100% of all funds raised or donated will be restricted to the county or service of their choice.



Newlife has worked with leading organisations to change children's lives. Here are a couple of great examples.

Central England Co-operative

Central England Co-operative has been supporting Newlife and helping children with disabilities and terminal illness by raising an amazing £1.2million – and there are plans to add to this as it has recently extended its target to £1.5million.

In May 2012 Central England Co-operative colleagues chose Newlife as their employee-elected charity. Their tireless fundraising activities have so far helped over 530 children across their trading area receive the vital equipment they need. Going above and beyond, employees at Central England Co-operative stores have taken part in a wide variety of activities to raise money, ranging from fun days, wearing fancy dress and washing cars to sponsored walks, having their heads shaved and even throwing themselves out of planes for sponsored sky dives.

One of the fundraising activities in summer 2016 saw Central England Co-operative's Bakewell supermarket manager Wayne Ingham joined by colleagues, friends and family for a seven-mile sponsored walk in the Peak District which raised an impressive £450. The group enjoyed themselves so much they swiftly planned another sponsored walk to take place this autumn.

Central England Co-operative was recently voted the Leading Co-operative of the Year 2016 and Corporate Responsibility Manager Hannah Gallimore said she believed 'Central England Co-operative's partnership with Newlife played a big part in that achievement.

Hannah added: "Working with Newlife has provided a great opportunity for us to achieve a large scale fundraising goal on behalf of an incredibly worthwhile charity and the fundraising partnership with Newlife has gone from strength to strength thanks to the professionalism, dedication and support of their highly engaged team. We are looking forward to being able to help even more children as we fundraise to meet the new target of £1.5million."

The Morgan Foundation

The Morgan Foundation charity golf day and gala dinner in 2014 raised over £450,000, which was generously donated to Newlife to help make a real difference to children across The Morgan Foundation area of North Wales, Merseyside, West Cheshire and North Shropshire. They have followed this up with a further

donation of £100,000. So far more than 350 children have received equipment.

Christmas 2015 saw some very excited disabled children treated to an early Santa surprise at the luxury Carden Park Hotel in Cheshire at a party hosted by Morgan Foundation chairman Steve Morgan. The children and their families who attended the festive event had all received much needed equipment from Newlife funded by The Morgan Foundation, including specialist buggies and beds, standing and walking frames; all of which have one thing in common – making life better.

The Morgan Foundation founder and Chairman Steve Morgan, CBE, said: "Over the past two and a half years, The Morgan Foundation has given over £550,000 to Newlife. Every penny of this money has been spent on providing essential equipment to 357 disabled children in our region. I started The Morgan Foundation with the aim of 'making a difference' and I'm pleased to say our partnership with Newlife certainly has."



In Newlife we 'Trust'

£900k RAISED

Newlife has raised close to £900k through trust fundraising.

In 2006, Newlife began approaching trusts, foundations and other grant-making bodies for help in funding our on-going work– with fantastic results. To date, around 300 children have received equipment they urgently needed as a direct result of this support. Securing trust funding has also helped drive forward many of Newlife's services.

Trust funding of £400,000 has supported numerous equipment grants and donations of more than £475,000 have ensured equipment loans.

Funding from Trusts has also helped develop services. Play Therapy Pods of developmental toys can make a huge difference, by distracting a child from pain, helping them play with siblings or developing skills which can enable them to fully achieve their potential. Comfort Capsules have been sent to families where a child is terminally ill, providing the opportunity to help make memories to treasure.

Newlife's unique selling point is that we offer trusts the ability to restrict 100 per cent of their donation to the county or service where they wish to make a difference.

The Big Lottery Fund made a grant of £91,281 over two years for our 'Reaching Out project', which aims to inform and support families of disabled children who are living in hard to reach communities. This makes a real difference to their everyday lives. Outreach support workers liaised with local groups and communities throughout the West Midlands – particularly those

from Black, Asian and Minority Ethnic (BAME) backgrounds – to make more families aware of the specialist help available through Newlife's equipment services.

The Garfield Weston Foundation has been supporting Newlife since 2010, providing four grants totalling £65,000 towards the development of equipment loan services to provide vital items such as beds and buggies when they are needed most.

The Brian Kennedy Trust has funded Emergency Equipment Loans, Equipment Grants and Play Therapy Pods in Greater Manchester. The funding has helped change lives in a variety of ways, from keeping children safe through the night in a special bed to helping them develop their skills with the Play Therapy Pod toys.

Trust manager Linda Miles said: "The Brian Kennedy Trust is passionate about supporting children and young people who are affected by illness and disabilities. We are delighted to be able to support Newlife Foundation with the play pods, which we hope will bring some benefits to both the children and families who need them."

We would like to thank all the trusts which have supported Newlife over the years. Without their vital support we would not have been able to establish and maintain some of our invaluable services which are changing lives every day.



Volunteers are our lifeblood

500 HOURS
Newlife has 500 hours of volunteer activity every single week.

Volunteering for Newlife is a win, win opportunity. It gives people the chance to give something back and help change children's lives. But for many, volunteering also gives them a lot in return, whether it be new skills, new opportunities or the chance to meet new people.

Newlife has volunteering opportunities at its three retail stores in Cannock, as well as stores in Market Drayton and Uttoxeter, in Staffordshire, and Heanor in Derbyshire. Roles are flexible and volunteers can offer between two and six hours per session at times which suit them. Newlife welcomes you into a growing community, where lasting friendships have been forged.

Many of the activities that we ask volunteers to do are associated with our recycling centre. Tasks range from repairing jewellery to de-labelling clothing donated by our High Street retail donors. By volunteering, people can gain new skills, meet new people and help disabled and terminally ill children get the equipment support they urgently need.

Whether you're retired or have a few spare hours a week, volunteering is something we value at Newlife. It can provide the sense of knowing that what you are doing will change a child's life, that it is a meaningful act that will contribute to improving a child's future. Volunteering at Newlife is the perfect way for people who may be disadvantaged in the workplace through disability to gain valuable work experience and skills.

Josie Grimley, volunteer at Newlife for eight years said: "I like volunteering at Newlife because I know where the funds are going and you can see the children who have been helped. They offer different services depending on the child's situation which I think is really good. I have made many friends over the years and we all come together to do something for a good cause, plus it gets me out the house a few days a week."

Helen Collins, volunteer at Newlife for 18 months said: "I retired two years ago and found that I had a lot more time on my hands than expected. My friend told me about Newlife and said I should think about volunteering, so I filled out an application form and have been here ever since. I feel good doing something because even though I am retired I can still work and what better way than helping children in need of specialist equipment?"

Richard Fowler, volunteer at Newlife for seven years said: "I started off working in the warehouse where I would cut the tags off clothes and replace them with the Newlife labels – now I volunteer twice a week at the Opportunity Centre, where I work on shoes and ties. I like volunteering for Newlife as they raise money for children."

Volunteering for Newlife does not have to be within our stores. There are plenty of opportunities to get involved at home, in your workplace, in your community whether this be repairing jewellery, hosting a jewellery 'sparkle party' or helping at any of our national and local events.





Our Vision, Mission and Values

Our vision for the future

WHY?

Because if it were a child you love – you would want the best for them

VISION

That EVERY disabled or terminally ill child and their family, get:

- The equipment they depend on
- The quality of life they deserve
- The caring support they need and the chance to benefit from pioneering medical research.

MISSION

Together, we will make life better for disabled or terminally ill children and their families

OUR VALUES

- Always compassionate and deserving of trust – in all we do
- Making things happen – for those we serve
- Leading in our field – to make things better
- People at our heart – every day



Some of Newlife's staff who have worked for us for ten years or more.

Meet the Trustees



Sheila Brown, CEO

1	2	3
4	5	6

- 1 Bernard Lewis
- 2 Clive Lewis
- 3 Professor Ieuan Hughes
- 4 Leonard Lewis
- 5 Professor Michael Patton
- 6 Chris Caulfield



Clive Lewis

Clive is Chairman of the trustees at Newlife, Chairman of River Island Clothing Company Ltd and Joint Managing Director of Lewis Trust Group.

Qualified as a barrister in 1979 he has spent his entire career with Lewis Trust Group, parent company of River Island, mainly in real estate, finance and investments until 1994 when he joined River Island. He was CEO from late 1990s to 2007 and as of January 2008, Deputy Chairman, River Island Clothing Co and Joint Managing Director, Lewis Trust Group Ltd, responsible for retail and non-US real estate, private equity and fund investments.

Clive said: "The Board of Trustees is there to provide a framework for the charity's activity. Newlife has an outstanding team of staff and volunteers who are the real energy of the charity. One of the greatest strengths of the charity is that the team have come up with a succession of good ideas that rejuvenate all we do. For example, it was through one of our nurses that the idea for the equipment grants service began. This was put together at short notice and has gone from strength to strength."

Leonard Lewis

Joint founder of the Birth Defects Foundation (now Newlife Foundation).

Originator of the brand River Island and MD of River Island to June 1994. Board director of Lewis Family Holdings and trustee of the James Lewis Foundation.

Bernard Lewis

Chairman of River Island Clothing Company. Limited Director of Lewis Trust Group. Lifelong experience in retail and management.

Professor Michael A Patton

Professor Patton is both Trustee and Medical Director of Newlife. He is Consultant Clinical Geneticist and Emeritus Professor of Medical Genetics at St George's Hospital, London and Honorary Professor of Medical Genetics at University College London. Following a university education at Cambridge and Edinburgh he was appointed at St George's in 1986 to set up a Regional

Genetic Service with clinical and laboratory services for a population of three million in South West London, Surrey and West Sussex. He has also run the academic department and has a research interest in birth defects and gene identification in genetic isolates. Emeritus Professor Michael Patton has published over 170 research papers and contributed to the discovery of 15 disease genes. He is a founding member of the charity and also serves as Medical Director responsible for the selection and management of research grants.

Professor Patton said: "Thanks to 300 research projects that Newlife has funded we have discovered 50 genes right here in the UK as responsible for many birth defects. As a result we have a greater understanding of what causes these devastating conditions."

Chris Caulfield

Having obtained a first class honours degree from Cambridge University, Chris became a lawyer specialising in UK and International commercial and corporate disputes. Chris is currently a partner in Baker Botts Litigation Practice Group based in London. He joined the Newlife board in 2012.

Chris said: "The Trustees meet regularly to assist and provide guidance to the executive members of Newlife. Newlife itself is a fantastic model, using profits from its own trading subsidiary to help disabled and terminally ill children."

Professor Ieuan Hughes

Having graduated from the Welsh National School of Medicine in Cardiff, Professor Hughes has had a long and outstanding career in paediatrics and genetic research, with the aim of helping to improve child health.

Emeritus Professor Hughes, Department of Paediatrics at Cambridge University, was awarded the James Spence 2014 medal by the Royal College of Paediatrics and Child Health

for his outstanding contributions to the advancement or clarification of paediatric knowledge. He joined the Newlife board in 2012.

Professor Hughes said: "We are living in a world where statutory cuts are hitting hard. Newlife ensures that some of our most vulnerable and in need children won't go without the essential equipment they need by operating a variety of innovative equipment services which really do change lives."



“

If it was
your child,
what would
you want
for them?

”

Putting the pieces together to create a better future for our disabled children

In shaping future plans for Newlife we must think about what really matters and what will truly change the lives of children with disabilities and their families.

So we must ask one very simple question.

If it was your child, what would you want for them?

Every parent will answer the same – **‘The best!’**

The Newlife vision is to give children with disabilities the very best chance in life, through equipment and medical research and by campaigning so their needs are known and understood.

As children’s healthcare improves, we will see increasing numbers of children with long and short-term disabilities. As a nation we are unprepared for this. The number of disabled children in the UK has increased by 30 per cent in the last ten years as we now save more young lives than ever before. Too often we save them and then fail to deliver the subsequent support they need. As the UK’s largest non-statutory supplier of equipment to disabled children, we have to be ready for this challenge.

No family thinks disability will affect them, but it can. Ordinary mums and dads know this. In every town and city we have children with disabilities.

The amazing achievements of our Paralympians started with someone, somewhere helping them to succeed. If this is what we would want for our own child, we must commit the energy and resources to make it a reality. Failure will resign thousands of children to increased pain, worsening conditions, isolation and dependency. So it is not an option.

Newlife can only achieve this vision if we work together. Society, policy makers and government have to work together to make sure all disabled children get the right equipment at the right time and that the future of our country is one where disabled children can thrive and achieve.

So we need your help, and in return we will pursue some important values. We will work hard to be deserving of your trust. We will put people at the heart of all we do. We will look to lead the field in innovation for a brighter future and we will use our voice and skills to make things happen.

Anyone can break up a jigsaw. By working together we can create a new picture. Join Newlife and help us make a better future for children with disabilities and their families.

Mrs. Sheila Brown OBE
Chief Executive Officer

Thank you



Dylan Miles from Hampshire sadly passed away in 2014, aged 17. Dylan was given a specialist bed and wheelchair through Newlife's Emergency Equipment Loan service and a special seat through the Equipment Grant service.

Mum Dominique Morrison said: "There are not enough words to explain how grateful we are to Newlife – for taking away the stress of trying to provide the equipment our son needed and enabling us to make the most of the last 18 months of Dylan's life happy, knowing that he was able to make the most of every experience we shared in complete comfort. It was such a relief to work with an organisation that was happy to help Dylan get what he needed when he needed it – that was priceless."

Jonathon Inkin, aged 16 from Cornwall, received a hi-tech wheelchair.

Jonathon said: "I am so grateful to Newlife for providing me with my new wheelchair; it has given me my old life back. I can now go anywhere I wish almost pain free. It is amazing!"

Saul Shoebridge, aged three from Aberdeenshire, received a specialist bed.

Mum Sarah said: "He now has the freedom to have as much sensory input as he needs when he is in there, so he can throw himself about and still be unharmed. He now looks forward to going to bed which is amazing – and it will last him into adulthood! I'm not being overly dramatic – this has changed our lives."

Lewis Graham, aged 11 from Glasgow, received a SafeSpace bed.

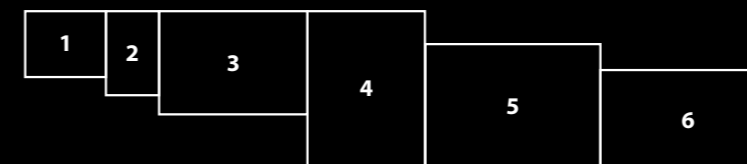
Dad Steven said: "We applied for the SafeSpace as we were trying to improve the quality of his life. We were at desperation stage before and knew we had to do something – it scares me to think we were considering a residential school for him – but the SafeSpace worked very quickly and as things stand now we are just looking at schools for complex needs."

Angel Riley, aged one from South Yorkshire, received the loan of a Play Therapy Pod.

Dad Andrew said: "We feel that the play pod has brought new things to Angel's life in different ways. If it wasn't for Newlife providing us and Angel with the Play Therapy Pod I don't think she would be as far in her development as she is now."

Joshua Humphreys, aged six from Cheshire, received a walker.

Mum Lisa said: "It has given him a massive new lease of life. Joshua is delighted with his new-found independence – and we have all cried over seeing him able to do so many more things thanks to the walking frame. For the first time in his life he has been able to walk to school carrying his own book bag, play bat and ball games with his friends and take a more active part in school PE lessons."



- 1 Dylan Miles
- 2 Saul Shoebridge
- 3 Lewis Graham
- 4 Joshua Humphreys
- 5 Angel Riley
- 6 Jonathon Inkin



Newlife Foundation for Disabled Children

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