Annual review 2016

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Lifelites is a fundraising charity which enriches the lives of children and young people with life-limiting and life-threatening conditions. We do this in children's hospices and similar environments by providing the latest assistive and inclusive technologies relevant to their needs and abilities. We also support the service providers with equipment maintenance and staff training, all free of charge.

Our mission
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Welcome from our Chairman and Chief Executive

Samuel’s story

#MagicalTechnology Children’s hospice staff conference 2016

#TeamLifelites

Fundraise for us

Putting Lifelites on the map

Thomas and Connor’s story

In the limelight

Getting the most out of our equipment

What’s next...

Lifelites and Transition

What’s next...

Hospice@Home

They ask we deliver

Our finances

VIPs

www.lifelites.org 0207 440 4200

info@lifelites.org @LifelitesOrg Lifelitesorg

Registered charity number: 1165791

Showcasing our technology at The Gadget Show Live, being featured on Sky News Swipe, launching our new fundraising video with Dame Esther Rantzen and being selected as a Digital Leaders 100 finalist, all served to raise awareness of our charity. We have also seen an increase in fundraising success thanks to more charitable trusts, individuals, community groups and companies lending their support for our work. This means that we can do more of what we are good at – harnessing the power of technology to enhance the lives of the children and young people.

We never forget that none of this would be possible without our generous supporters. If you are one of them, a big thank you on behalf of everyone at Lifelites. Please read on to learn more about the impact of Lifelites, magical technology.

Mike Woodcock, Chairman
Simone Enefer-Day, Chief Executive
Seven year old Samuel has cerebral palsy and is a regular visitor to Acorns for the Three Counties in Worcester.

Samuel’s mum Stephanie says he loves the magical technology Lifelites has provided: “Technology is really important for Samuel. Because he’s so clever it’s a way for him to express himself. Looking at him you might think he doesn’t understand a lot of things, but he’s incredibly alert. He likes to make decisions and be independent and the Lifelites equipment helps him do this.”

Rachael Lenzi is a Health Care Assistant at Acorns who often works with Samuel. She says:

“Samuel benefits greatly from Lifelites technology. He is very alert and aware and wants people to interact and communicate with him. He likes to show people how the equipment empowers him and widens the scope of what he can do and you can see he feels a sense of achievement.”

With his limited mobility, Samuel likes to use the Eyegaze – an eye tracking device that enables him to control a cursor on the screen just by moving his eyes – because he doesn’t need his hands to control it.

“At the moment it is just games but he will be able to use it a lot more for communication. We know he’s got plenty in his head so this is a way to try and get it out.

“As much as it makes me sad that he can’t talk, it makes me proud and happy that he can use the equipment and achieve something. It also means that Samuel is able to interact with his friends independently which is important for him and us.

“Do I dream that he will be able to talk tomorrow? Of course I do and I still hope – but it will always be difficult for him, so I know this technology is the future for Samuel.”

Samuel’s mum
We use the Facetime video call app on the iPads to call home and allow the child to speak to their parents from the hospice.

The benefits provided by the technology are so wide ranging. It provides fun and enjoyment, enables children to make choices and empowers them to do things that they would otherwise struggle to do.

We have a child who has a tracheostomy. The Proloquo2Go app on the specialist iPad enables him to type and communicate to tell staff what he wants. Although he can’t speak, it’s his words. It gives him a voice.

We use the Facetime video call app on the iPads to call home and allow the child to speak to their parents from the hospices.
There are lots of different fundraising events available for you to take part in throughout the year. From half marathons, to cycle rides to obstacle courses, there is always something for everyone.

- Holding a golf day
- Opening your garden
- Making Lifelites your company’s chosen charity
- Running your own fundraising event
- Getting the girls together and holding a Ladies that Lunch
- Or – to all you Freemasons out there – why not host a Brethren that Breakfast?

I had never done any running before so signing up to run 10K was a bit daunting but I felt really inspired and motivated to have a go by the amazing work that Lifelites does in enhancing and improving the lives of children with life limiting conditions in children’s hospices. I was so impressed with the Lifelites team providing lots of help and encouragement and by the generosity of my lovely friends and family who sponsored me for this great cause.

Superhero Run, fundraising participant

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PUTTING LIFELITES on the map

We work with every baby and children’s hospice service across the British Isles so wherever you are there is a Lifelites project for children from your area.

We don’t just fundraise and give the hospice the equipment and then walk away – our packages include installation, training care staff how to use it and unlimited technical support, all free of charge. Every four years we aim to go back to the hospice and give them a brand new package of the latest technology. Please see the opposite page for our schedule.

2015

Acorns for the Three Counties, Worcestershire
Brian House, Blackpool
Christopher’s (CHASE), Surrey
Douglas House, Oxford
EACH Ipswich, Suffolk
Ellenor, Kent
Forget Me Not, West Yorkshire
Haven House, Essex
Julia’s House, Dorset
Little Havens, Essex
Little Harbour, Cornwall
Oakwell House, Jersey
Richard House, London
Ty Gobaith, Gwynedd

2016

Alexander Devine, Berkshire
Bluebell Wood, South Yorkshire
Chariton Farm, North Somerset
Chestnut Tree House, West Sussex
Claire House, The Wirral
Demelza, South East London
Donna Louise Trust, Stoke-on-Trent
Hospice@Home, Isle of Wight
Martin House, West Yorkshire
NICH Horizon House, Belfast
NICH Horizon West, County Fermanagh
St Oswald’s, Newcastle
Zoe’s Place, Coventry
Zoe’s Place, Liverpool
Zoe’s Place, Middlesbrough

2017

Acorns in Birmingham, South West Birmingham
Acorns for the Black Country, West Midlands
Demelza House, Kent
EACH, Quenham, Norfolk
Helen House, Oxford
Julia’s House, Wiltshire
Lauralynn House, Dublin
Little Bridge House, Devon
Naomi House & Jacksplace, Hampshire
Rebecca House, Isle of Man
Shooting Star (CHASE), Middlesex
Ty Hafan, Cardiff
Four Transition projects
Four Hospice@Home projects

2018

Butterwick House, County Durham
Derian House, Lancashire
EACH Milton, Cambridgeshire
Francis House, Manchester
Hope House, Shropshire
Jigsaw Children’s Hospice, Cumbria
Keech Hospice Care, Bedfordshire
Noah’s Ark Children’s Hospice, London
Rachel House (CHAS), Kirkos
Rainbows, Leicestershire
Robin House (CHAS), West Dunbartonshire
St Andews, Lincolnshire
The Children’s Trust, Surrey
Brothers Thomas and Connor, aged 9 and 6, were born with life limiting complex congenital heart disease. Each has only half a heart. This means they have a reduced exercise tolerance and are unable to take part in competitive sports which other children their age would take for granted. Lifelites donated many magical items to Ellenor children’s hospice care in Kent, including the Mobile Magic Carpet, a system that projects interactive images and games that children with little or no mobility can play, simply by moving over the picture.

Sharon, Thomas and Connor’s mum, told us: “When Lifelites came with the Magic Carpet the boys were chuffed to bits to be able to play a ‘real’ football match. The carpet is a real leveller, allowing those with limited physical ability to compete and win against anyone and like most little boys it doesn’t get much better than scoring a goal past Dad!”

The boys have a number of other medical conditions, both physical and mental. Thomas has recently been diagnosed with autism and suffers from anxiety. He struggles in busy environments and finds it difficult to interact with other children and unfamiliar adults.

Katie Mealy, support worker at Ellenor said: “The Lifelites donations have made a positive impact on our children, boosting not just educational outcomes but overall confidence. The Magic Carpet gave Thomas the confidence to play a football game with a child he did not know. When Thomas’s mum noticed the interaction between the two she was thrilled – it was something she rarely gets to see. Thomas is now sharing his knowledge of the equipment to help others use it.”

In the latest Lifelites donation to Ellenor were also six of our special iPad packages. Their portability means the staff can use them with the children and young people in their own homes too.

Sharon says: “The iPads are great for Connor who has sensory processing disorder meaning writing and typing are difficult for him which, in turn, makes him very frustrated. The iPads are easy to use and entertaining which keeps Connor focused on tasks for longer periods and the voice activated technology really helps him overcome this barrier.”

We are so grateful to Lifelites and the generosity of those who helped raise the money for all the equipment that the boys love so much.
We were delighted to win the 2015 Nominet Trust 100 award – an annual celebration of the most inspiring uses of technology for good from around the world.

Lifelites staff training is an essential part of our donation. It is imperative that care staff understand the use and applications of the Lifelites specialist technologies to transform how they care for the children they work with.

Thanks to support from Khoo Teck Puat UK Foundation we have been able to develop more intensive training sessions on specialist equipment and specific themes pertinent to children in hospices:

- Introduction to Eyegaze
- Getting the most from your Lifelites iPads
- Making magical memories
- Making music
- Art and drawing activities
- Using switches and switch games
- Training at the hospices is great fun as the teams get together and feed off each other’s ideas about just what the children might be able to achieve with the help of our equipment.

"It's just so exciting especially for some of our non-verbal children. With the Eyegaze and Symwriter, you’re actually speaking with your eyes. It’s so clever!"

"The iPads are going to be great to use in specialised play sessions in the community."

As part of our donation to our hospice partners, our Technical Support Team is there to assist hospice staff with their Lifelites equipment either on the phone or onsite at hospices around the country.

We pay for this service on an ongoing basis to ensure that the Lifelites equipment continues to enhance short lives. So while we look after the equipment, hospice staff can get on with caring for the children for whom every second counts.

"The iPads are going to be great to use in specialised play sessions in the community."
Fantastic advances in medicine and quality of care provision mean more and more children with life-limiting conditions are living into young adulthood. The transition from children’s to adult services can be a scary and confusing time with lots to organise from social care to healthcare, education, housing and employment.

Children’s hospices across the country are putting in place projects to support the young people and their families through this important process and Lifelites has been looking at what value we could add through our expertise and specialist technologies.

In addition to meetings with Transition leaders at hospices, our research to date included a special Lifelites conference attended by Transition co-ordinators and other care staff from children’s hospices. We needed to understand what models of Transition projects are being implemented in children’s hospices, what challenges they face and what remit Lifelites might develop to support them.

From this research and discussions, Lifelites is now developing a programme to support staff and Transition groups to include:

- **Training for Transition staff on accessible technologies to show parents what would be useful for their son or daughter**
- **A Transition resource section on our website**
- **Incorporating Transition project requirements into our hospice application process**
- **Transforming our annual hospice conference into a combined ‘New hospice package and Transition projects conference’ – aiming for the first one in May 2017**
- **Further research and partnership work with regional Transition groups and enabling technology specialists**

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Breaking Down Barriers with Portable Technology

Hospice@Home services are being developed reaching beyond hospice walls to give children’s hospices the opportunity to provide more care for more children in their own homes. As our magical technology gets more portable, so Lifelites can assist with the projects by giving care staff tools they can use with the children wherever they are: around the hospice and gardens or at home or even in hospital.

The portability of the equipment means that where there isn’t a local hospice or if a family find it difficult to travel long distances to a hospice, care staff and community teams can reach more children by taking the special Lifelites technology to them.

We’ve already trialled portable technologies like our special iPad packages, Eyegaze and BEAMZ with several hospice community services including CHAS, Demelza, Alexander Devine, Noah’s Ark, Ellenor and on the Isle of Wight and have some very encouraging feedback.

Noah’s Ark Children’s Hospice explained how they had found the specialist iPad packages invaluable to support physiotherapy.

“When I visit homes, I hold the iPad at one end of the sofa and the child has to crawl towards it to touch the screen to get a reaction. Then I move it to the other side so they have to crawl over to the other side – it means they are getting their physio without even realising.”
We are achieving our goals thanks to the passion and dedication of Very Important People who are supporting Lifelites in so many different ways. They have all helped to bring smiles and laughter to children in hospices. Thank you all. Here are a few special mentions:

PATRONS
Peter Bowles: The Rt Hon the Earl Cadogan DL; Anita Dobson; The Baroness Finlay of Llandaff; Lady Pamela Kalms MBE; Joe Pasquale; Dame Esther Rantzen CBE; Rick Wakeman; The Rt Hon Lord Young of Graffham DL.

Britain’s Got Talent finalist and Golden Buzzer winner, 14 year old Jasmine Elcock, joined Lifelites this year as our youngest ever Patron. Jasmine plans to help us raise awareness and funds for the work we do for children in hospices.

PARTNERS
Capco; Children with Cancer; GamesAid, Khoo Tech Puat UK Foundation; Metropolitan GL Lodge of the Haberdashers’ Company; Provincial Grand Lodge of Essex 8Ald; Provincial Grand Lodge of Hampshire & Isle of Wight; Provincial Grand Lodge of Northamptonshire; Provincial Grand Lodge of West Kent; Revere Charitable Trust; Royal Masonic Trust for Boys and Girls; West Riding Masonic Charities; Worshipful Company of Information Technologists.

IN KIND SUPPORTERS
The Masonic Charitable Foundation continues to provide Lifelites with a very generous donation of offices and accountancy services at no cost. We are grateful for this as it helps us to keep overheads to a minimum, allowing us to invest more of the donations we receive in technology and services for the children we support.

OUR VOLUNTEERS
Trustees old and new and all our volunteers who support us by: taking part in sponsored events; running their own fundraising activities; assisting with technical support at hospices; training hospice staff on equipment; and speaking on behalf of the charity to raise awareness and funds for our work.
If you would like to make a REGULAR DONATION please contact us on 0207 440 4200 or visit www.lifelites.org/donate

Please make cheques payable to Lifelites. Please complete all relevant sections and return your completed form to: Lifelites, 26 Great Queen Street, London WC2B 5BL

DONATION AND GIFT AID DECLARATION

I enclose a cheque for a SINGLE DONATION of: £

First name: 
Surname:
Address: 
Email: 
Phone: 
Postcode: 

Permission to contact: Yes ☐ No ☐

☐ I am a UK taxpayer and wish to Gift Aid my donation.

Please treat all qualifying gifts of money made to Lifelites (charity no.1165791) today, in the past four years and the future as Gift Aid donations until I notify you otherwise. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax each tax year that is at least equal to the amount of tax that all charities and amateur sports clubs that I donate to will reclaim on my gifts for that year. I understand that other taxes such as VAT and Council Tax do not qualify and the charity will reclaim 25p of tax on every £1 that I have given. I will notify you should I choose to cancel this declaration change my name or home address, or if I no longer pay sufficient tax on my income and/or capital gains.

Signature: 
Date: 

Lifelites Ref (Office use only)