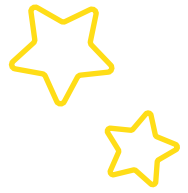


Lifelites



Highlites

The latest news from the charity donating technology for children using hospice services.



What's inside

Magical technology

Hospice Heroes

Read Ruby's story



Welcome to our 2020 Highlites newsletter

With your help, Lifelites is able to donate assistive technology for over 10,000 life-limited and disabled children using children's hospice services across the British Isles. In this newsletter we are seeking to share our success with you so you can see for yourself the life-changing impact of our work...

You can read about Ruby and her mum's story of how Eyegaze has transformed the life of a girl with Rett syndrome. You will also see a story about one of our hospice heroes – these are the experts who apply our technology to make a difference to the lives of the young people they care for.

If you'd like to get in touch with us about anything in this newsletter or if you would like to support our work, please contact us using any of the details on the bottom of this page.

Thank you.



Simone Enefer-Doy
Chief executive



What is Lifelites?

Lifelites donates and maintains specialist technology packages for the 10,000 life-limited and disabled children and young people using every one of the 60 children's hospice service across the British Isles. They can use our life-changing technology to play, be creative, control something for themselves and communicate, for as long as it is possible. Most importantly, it doesn't cost the hospices a penny for all our equipment and services.

www.lifelites.org 0207 440 4200 info@lifelites.org

[@LifelitesOrg](https://www.facebook.com/LifelitesOrg) [@Lifelites](https://www.instagram.com/Lifelites) [@Lifelitesorg](https://www.linkedin.com/company/Lifelitesorg)

Registered charity number: 1165791

News and updates

Celebrating 200 magical donations

The year 2019 was an extra special one for Lifelites as we celebrated our 20th year and the delivery of our 200th special technology package.

The recipients of the 200th donation were the children at Ellenor Hospice Service in Kent, who received one of the biggest packages we have ever donated, packed full of the latest assistive technology.

Simone Enefer Doy, Lifelites chief executive, said: "The technology we donate now is unrecognisable from our very first donation back in 1999. Back then the desktop PCs we donated were state of the art, but now we donate life-changing technology like Eyegaze. I could never have imagined we'd be where we are today."



Overseas support for Lifelites

Long-time supporters of Lifelites, the Freemasons of Jersey, have launched a further campaign to cover the costs of our new life-changing technology and related services for children using the Island's care services.

The technology they want to fund will be delivered to Oakwell and the new and developing Jersey Children's Hospice at Home service, giving the life-limited and disabled children opportunities they never thought possible to escape the confines of their conditions.

Provincial Grand Master of Jersey Freemasons Kenneth Rondel said: "Lifelites opened doors to Jersey children when they provided their amazing technology four years ago, but this new and highly advanced equipment will be of enormous benefit to our youngsters and be a whole new experience for them."



We are delighted to be working with Lifelites to provide Jersey children with much needed equipment that will give them and their families wonderful new experiences that weren't previously possible or available in our island.





Ruby's story



Mum Laura told us Ruby is just like any other mischievous and cheeky nine year old. She LOVES Strictly Come Dancing, theatre and music. Hot chocolate always gets them a beaming smile... but for Ruby it has to be fed through a tube into her stomach.

That is because Ruby has Rett syndrome. This means she has seizures and breathing issues. She cannot speak and uses her eyes to communicate. She has splints on her hands and painful muscle shortening in her feet, as well as scoliosis - curvature of the spine. Cognitively, Ruby understands everything, but her body makes it very hard for her to respond as she would like to.

Thanks to Little Havens children's hospice service, Ruby and her family have enjoyed special support for years. This help has been invaluable in times of crisis - they've been flooded twice - but has also given John and Laura the rare

chance to be mum and dad, instead of just carers.

Among the other things Ruby loves, is the Beamz from Lifelites. She really enjoys using her hands to create music. She was quite taken when she first saw the Lifelites Mobile Magic Carpet, enjoying watching other children playing on it, as well as joining in herself.

Laura takes up the story:

"The reason I know the Lifelites technology can be life-changing for children using hospices is because we used to use low tech solutions to communicating through eye movement. Then we saw how important Eyegaze might be and self-funded our own unit for Ruby. She has been using it since she was two years old and is a whizz at playing games. She is now using the same Grid 3 app that Lifelites provides, as her main communication tool.

"Eyegaze has really opened up the world for Ruby. People often dismiss children in wheelchairs who are non-verbal, assuming they don't understand anything. But with Eyegaze, Ruby has the opportunity to show people she understands and that she is listening. She will even tell me: 'Stop interrupting. I haven't finished talking!'

"Possibly her favourite thing to do with Eyegaze is to be cheeky. She likes to record phrases and then select

'speak'. It will then repeat back everything at high speed. Ruby thinks that's the funniest thing in the world, especially as she knows it drives me mad!"

"Girls with Rett syndrome are very clever, so we are trying to get the school on board with using it in the classroom. We feel we have reached a point where communication and education need to be more of a focus. We know Ruby's personality will mean that we have to make it fun else she will just refuse to play ball!"

"Eyegaze gives Ruby a voice; she can make herself heard. I know it will also be the key to keeping her safe and being able to tell me far more than eye pointing could ever do.

"I remember when I was first told Ruby had Rett syndrome and all the horrific things that it encompasses. Very shortly afterwards, we took delivery of the Eyegaze and then I watched my daughter use a computer and take control. I could see she understood instructions and was just completely there. Eyegaze enabled us to see the possibilities for her for the first time ever....and it continues to do so."

If you'd like to help Lifelites fund more technology like Eyegaze, please visit our website to find out how you could support us: www.lifelites.org



The impact you make



"The Lifelites technology empowers our children to make decisions and take control. It gives them back a sense of identity and independence which was taken away by their illness."

Robin House



"Giving children the ability to make and record their own music using the Lifelites technology gives them a sense of achievement, an opportunity to express themselves and develop their creative identity. They can maintain their interests and keep their sense of self which is so crucial."

Rachel House



"Lifelites technology is invaluable in helping provide the children in our hospice the opportunity to do so many things that they never thought possible because of their illness or disability, such as paint a picture, create music, play a game or communicate with their family."

Christopher's



"The Lifelites iPads are often used by our children and young people with autism as they are quick, easy and portable. Children can use these in an instant if they are struggling with their emotions or coping with a difficult situation where they need to wind down."

Haven House

★ Spotlight on our magical technology – iPads

Thanks to Lifelites, the humble iPad is turned into a very special piece of equipment perfect for children with disabilities. They are small, lightweight, portable and engaging. Lifelites also packs them full of specialist apps suitable for all abilities.

What are they?

A portable tablet computer that children with disabilities can enjoy using in a wide variety of ways. We donate them with a drop proof case which is easy to hold and makes them virtually indestructible!

How are they used?

Our iPads are packed full of specialist art, music, sensory and communication apps. They are incredibly versatile and loved by children of all ages and abilities. The bright colours and sounds are very engaging and mean that they can even be used by children with visual and hearing impairments.

How much do they cost?

Our iPad package includes the iPad itself, the case, the apps, a charging station and some special mice, which give the user an extra level of control. We also provide a flexible mount to attach the iPad to a wheelchair and a waterproof



Bluetooth speaker. The total cost of all this is £692.

What do the families say?

Heavenly had a stroke during an operation to remove a brain tumour when she was just six years old. Now, at the age of 14, she uses the iPad for everything. Her mum Kelly said:



The iPad has made such a difference to Heavenly's life. I could go on forever about how important this tech is to her; the whole family can use it to communicate and play with her



To help Lifelites donate more magical equipment like this, please visit our website and see how you can support us: www.lifelites.org/get-involved

★ ★ Our hospice heroes

The success of our work relies on the hospice staff themselves. It's so important that we are able to tap into their expertise to make the most of our special technology for the children they work with. Luckily we meet so many hospice workers who are passionate about the Lifelites technology. Here, one of our hospice heroes, Kirree Norton, talks about why Lifelites' contribution is such a vital aspect of the care they provide at the hospice:

Kirree has worked as a nursery nurse at Rebecca House children's hospice since 2007 and has a background in Special Needs education. She said that when she first heard about Lifelites, she was initially dubious because she thought it seemed too good to be true! She said: "We thought there

must be a catch, but there wasn't and I'm so glad that we are now utilising the magical technology from Lifelites."

Kirree is passionate about using Lifelites technology, and has seen first-hand the impact it has with the children that she cares for. Kirree said: "The Lifelites technology not only enables lots of fun, but is also a gateway to communication. It gives those with physical disabilities a voice and the ability to control things with increased independence."

When speaking about the specific items of technology we donate, Kirree singled out the Mobile Magic Carpet as one of her favourite pieces: "It's a brilliant resource which we use for so many different activities. It's great for incorporating into physio sessions, to encourage rolling, crawling and reaching.



The older children love it for playing games and creating their own ones. It's just so versatile."

Thank you Kirree, and all the other wonderful hospice staff who champion the use of our technology.

To find out more about our work for children using hospice services, please visit our website: www.lifelites.org





There is a Lifelites project near you



In addition to donating continuous services for life-limited and disabled children using children's hospice services, this map indicates where we would like to deliver a whole new technology package in 2020.

Can you help us raise the funds to support our work for children from your area? Please give us a call on **0207 440 4200** or email info@lifelites.org

2020 projects

1. Bluebell Wood, West Yorkshire
2. Charlton Farm, Somerset
3. Chestnut Tree House, West Sussex
4. Claire House, Wirral
5. Demelza SEL, London
6. Isle of Wight Hospice at Home, Isle of Wight
7. Jessie May, Somerset
8. Martin House, West Yorkshire
9. Northern Ireland Children's Hospice, County Antrim
10. St Oswald's, Northumberland
11. The J's, Essex
12. The Shakespeare Hospice, Transition Service



As well as the hospices on the map above, we provide regular training and ongoing technical support at every children's hospice across the country, so all our projects are always in need of funding. If you think you can help us, please call us on **0207 440 4200** or email info@lifelites.org.



Who's your friend? Campaign



We know that building and maintaining strong relationships can be the key to getting lasting support for life-limited and disabled children in hospices. Can you help us expand our network?

We're a very small team at Lifelites, and it can take a lot of work for us to identify new supporters and build a relationship with them. However, as the old saying goes: "It's not what you know, it's who you know". Lifelites' latest campaign aims to expand our network and make connections which can help us continue to give children with limited lives, unlimited possibilities.

Could you connect us with someone who might be interested in supporting our work? Perhaps you know someone who is part of a sports club or community



organisation, a friend who is an enthusiastic fundraiser, or someone at work who we could build a fundraising partnership with? If you could introduce us, we'll do the rest.

Just think, if every one of our supporters encouraged one friend to help us in some way, that could potentially double our fundraising reach. Might

you have a friend you could put us in contact with who you think could help? The impact this could have on the children we support would be invaluable.

Find out more by emailing info@lifelites.org or calling **0207 440 4200**.



Our fundraising stars

Our fundraisers are our stars; we simply wouldn't be able to do what we do without them. Here's what some of them got up to in 2019:

£3,000



Paul Brown
Paul raised an incredible £3,000 when he took part in the 25km Thames Bridges Trek.

£890



Samuel Davies
Samuel climbed mountains for Lifelites in the Baran Trail Race in Poland, raising £890.

£3,281



Future Games of London
A team of superstar runners from our corporate partners Future Games of London raised a phenomenal £3,281 when they took part in the London Landmarks Half Marathon.

£39,900



Rick Wakeman
Musical legend Rick Wakeman held his third Christmas appeal for us in 2018, this time raising £39,900 from Freemasons across London.

Sustainable funding

We'd like to say a huge thank you to donors who choose to support Lifelites on an ongoing basis. We depend on support like this to move our work forward and make a bigger impact for life-limited and disabled children. We're very grateful for the on-going support of these trusts, companies and their staff: The Edward Gostling Foundation, The British Medical Journal, The Crerar Trust, GamesAid and the Worshipful Company of Information Technologists.

Fundraising focus on...

The Mark Benevolent Fund

In 2019 Lifelites received a staggering donation of £141,423 from the Mark Benevolent Fund, which will change the lives thousands of the life-limited and disabled children we support.

The Mark Benevolent Fund is the official charity of The Grand Lodge of Mark Master Masons, a registered charity that began in 1868 as an efficient way to donate money to the charities of the Mark Master Masons. Their charity manager Darren Coleman-Heald told us why they selected Lifelites to benefit from their fund:

"We are delighted to have joined forces with Lifelites in this all-important project that reaches deep in to the heart of your community giving enjoyment and stimulation

to life-limited and disabled children. Our 36,000 members will be pleased to know that their donations are being used wisely by helping those in need across the UK."

Among other things, this vital funding will support one of our newest projects; the Lifelites Tech Trunk. The Tech Trunk is a solution created by Lifelites for children's Hospice at Home services that deliver palliative and respite care out in the community. The portable trunks enable hospice staff to take Lifelites' technology with them wherever they visit

the children, giving them the opportunity to have access to our life-changing technology in their own homes or in hospital.

We depend on donors like the Mark Benevolent Fund to help us continue our support for children for whom every second counts.

If you know any other organisation like the Mark Benevolent Fund which might be able to help us, please get in touch with Samuel Davies by emailing sdavies@lifelites.org or calling **0207 440 4200**.



Please support Lifelites with a donation



"Jess was introduced to the Eyegaze about three years ago and she can now tell us what she wants, what she likes, when she's in pain and what she wants to do. It's made a huge difference to her quality of life."

Liz, Jess's mum

Yes, I would like to help children like Jess with a gift of: £ _____

I enclose a cheque postal order CAF voucher **Please do not send cash**

Please complete all relevant sections and return your completed form with your donation to:
Lifelites, 26 Great Queen Street, London WC2B 5BL

My personal details

First name _____ Surname _____

Address _____

_____ Postcode _____

Phone number _____ Email _____

We would like to send you occasional updates about the children you are helping to support as well as activities and events you may be interested in.

Phone Yes No **Email** Yes No **Text message** Yes No **Post** Yes No

Use Gift Aid to boost your donation by 25p for every £1.

I want to Gift Aid my donations to Lifelites (Charity no. 1165791), including donations that I make in the future and have made in the past four years.

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations, it is my responsibility to pay any difference. I will notify Lifelites if I wish to cancel this declaration, change my name or home address, or no longer pay sufficient tax on my income and/or capital gains.

Signature _____ Date _____