



Annual Review

April – April

2017 — 2018





Executive Summary

Our third year of establishment has been another great year and at the same time a challenging one.

Our trustee Arran Bailey stepped down from the charity after two years. This vacancy was filled by Adam Cavelle, a property developer from Nottingham who has been keen to make a positive change to the community and felt The Harley Jae Trust was a great opportunity to do that.

This year has been another successful one for the charity and this is down to the overwhelming support from members of the public and business supporters. Once again, we have managed to operate and provide financial support to children and families in need without any additional funding streams. For the third year in a row, all of the support we have been able to provide has been achieved through private fundraising events held by the charity or our supporters in the community. This I feel, is a remarkable achievement.

We remain committed to our goal of providing support to children and families who are unfortunate enough to be experiencing a life limiting condition as well as to the hospital staff based at Nottingham's PCCU.

We would like to thank all of our amazing followers for their unbelievable support over the past year. Their generosity, enthusiasm and willingness to help us has been overwhelming and it is because of them that we now go into our third year with a strong foundation and the enthusiasm to continue to provide support the children that need it.

To all of our supporters, donors, sponsors and partners; we thank you all for your ongoing generosity and we look forward to another successful year together.

Joseph Rafter
Chairman



Our Aims

The Harley Jae Trust has an ultimate purpose of supporting the advancement of health, the saving of lives and improving care for children with life limiting conditions as well as their families.

This is achieved by aiding the relief of disease or human suffering, as well as the promotion of health in children under the age of 18 who have a life limiting or life changing condition whether permanent or temporary by providing aid and support to children under the age of 18 of whom are in the care of Nottinghamshire NHS Trust whether permanent or temporary.

The Harley Jae Trust is for the public benefit, to contribute to the relief of children in Nottinghamshire, up to the age of 18 who are in need through the suffering of ill health by reason of a life limiting or life changing condition.

We aim to achieve the following outcomes:

- To provide equipment that aids or relieves the symptoms of children that suffer with ill health due to a life limiting or life changing condition.
- To provide equipment and support to medical units that enables them to provide high quality care for children with life limiting and life changing conditions.
- To raise awareness of life limiting conditions that affect children through promoting community involvement in fundraising initiatives.



Our Mission

Our mission is to improve the quality of lives of children who suffer from ill health due to life limiting conditions by providing either health related equipment or other items that improve the livelihood or emotional wellbeing of the child.

Our core values are:

- To improve the morale and emotional wellbeing of children with life limiting conditions and their families.
- To improve the quality of lives of children with life limiting and life changing conditions
- To provide aid and relief to children with life limiting and life changing conditions
- To raise awareness of life limiting and life changing conditions that affect children

How we achieve our outcomes:

- The Harley Jae Trust aims to achieve the specified outcomes through the following:
- Raise public awareness of life limiting and life changing conditions that affect children.
- Form relationships with paediatric medical units, in particular but not exclusive by High Dependency Units and Paediatric Intensive Care Units, Community Nursing Teams, Children's Charities and Children's Hospice's.

- By identifying which medical units require additional resources to enable them to deliver high quality of care to children with life limiting and life changing conditions.
- Providing resources in the form of, but not exclusively by medical equipment and other items that enhance the health and emotional wellbeing of children with life limiting and life changing conditions.
- Identify families who require additional support with caring for their child and meeting their needs which have resulted as part of their life limiting condition and working directly with them.

These will be achieved by means of:

- Raising awareness through, in particular but not exclusive by social media and social networking and website
- In particular but not exclusively by Individual, Private and Corporate sponsorship and fundraising
- Supporting and forming fund raising events
- Forming relationships

Our Achievements

Artist Ed Waite becomes an official partner of The Harley Jae Trust

“The Harley Jae Trust is the lasting memory of a little boys magical but short life. When I discovered the work they do to support children with life-limiting conditions and the endless time they spend fund raising with different projects I was very happy to get involved and will continue to donate my artworks to raise money for such an inspiring charity.”

Ed Waite

See more at <https://bit.ly/2RvlpPr>

April 2017



The charity has started to increase its presence within the wider community resulting in more fundraising events being held for our charity. Throughout the reporting year more and more people within the community chose The Harley Jae Trust for their chosen charity!



Another family supported by the Harley Jae Trust enjoying their first holiday away.

May 2017



Charity trustee's and friends take on the the worlds biggest obstacle course at 20 miles long with 200 obstacles!

June 2017



Nuffield Health Club in Nottingham choose the Harley Jae Trust as their chosen charity and hold their annual ladies night fundraiser.



Enterprise Car Rentals donate £1500 to the charity!

July 2017



10-year-old Ruby Moreton saves up 2 years worth of reward tokens at her school to win a bike and donates it to The Harley Jae Trust. She even made the local press! Incredible stuff!

August 2017



Burton Joyce Football Club become official partners to The Harley Jae Trust.

September 2017



Family Fun Day

The Harley Jae Trust hold a family fun day for all the parents and children who are associated with the Paediatric Critical Care Unit. Both families and nurses attended the event where there was catering, fairground rides, face painting and garden games. The charity put the event on for the families so that they could network with each other and share their experiences.

Golf Day

We hold our first charity Gof Day raising £1100 in partnership with Springwater Golf Club.



Equinox 24

26 runners come together to take part in a 24-hour running event at Belvoir Castle; Equinox24. Those runners raised £10,000 and donated the money to Nottingham Hospital Charity's Big Appeal an hour after crossing over the finish line!

Resuscitation Dolls

Thanks to donations from fundraisers, Nottingham-based charity, The Harley Jae Trust, has been able to donate two resuscitation dolls, at a cost of £9990.75, to the Long-Term Ventilation team at Nottingham's Children's Hospital to train staff and parents.

The charity, which supports children with life-limiting conditions and their families was set up by, Chairman, Joe Rafter and his family whose son had a rare neurological condition before sadly passing away in 2013. Since then, they have already worked with the hospital as part of their BIG Appeal to renovate ward rooms and other fundraising events to fund equipment.

Before receiving the new dolls, the hospital had been using regular resuscitation dolls which couldn't be manipulated in a way that allows parents of children and hospital staff to practice the range of skills that include tracheostomy suctioning and care, gastrostomy feeding, catheterisation and others.

The new dolls can also be used to simulate different emergency situations such as a chest infection or difficulty breathing which can all be controlled from a sim pad. The pad can also show simulated vital signs and control scenarios. Breathing is another simulated feature to the extent that sounds can be heard from the chest and mouth.

The Long-Term Ventilation Team at the hospital will use the dolls to train parents and carers before children are discharged from the hospital. This is in hope that parents will be able to effectively deal with emergencies themselves, preventing crucial time being lost seeking medical attention.

Joe Rafter, Chairman of the Harley Jae Trust commented: "We hope the resuscitation dolls can be used as an effective addition to the Long-Term Ventilation Team at the hospital. It's great to see the resources be put in to train staff and parents on how to resuscitate and care for the most vulnerable children.

"We could not have raised enough money for these dolls if it wasn't for all of our dedicated supporters who donate to us every month and help us during our fundraising events. Without the public, the trust would not have been able to donate the money towards the hospital for the dolls."

November 2017



Award

The Harley Jae Trust win an NUH Community champion Award for all the support we have given to the PCCU. We couldn't be prouder!



Present Dash

Our annual present dash saw families and children delivering over £2000 worth of gifts for the children on the PCCU

January 2018

We receive another thank you letter for all the support we have provided to the hospital



December 2017



Christmas Decorations on the PCCU

The charity trustees visited the Paediatric Critical Care Ward for the third year in a row bringing Christmas trees and decorations for the families and children who would be staying there over the festive period!



Christmas Eve

The Charity's Trustee's visit the children and families on the PCCU and deliver food hampers for the parents who will be spending Christmas eve with their children on the hospital ward.

Impact & Value

The Harley Jae trust has continued to find opportunities to help support children and families who experience long term stays in hospital. Families who have long term stays on the paediatric critical care unit spend their time caring for their children who have severe health difficulties. This can be emotionally and physically draining for them especially when, in most cases, they do not know when they will be able to return home. Some children are born in hospital and do not leave before their first birthday.

Any additional help we can provide families during these times can have a huge impact. Just knowing that someone is thinking of them can often put a smile on their faces. This year we have provided the support in the following ways:

Parents Accommodation at Nottingham's Children's Hospital

During the reporting year, we donated £10,000 towards the Nottingham hospital's Charity Big Appeal. £10,000 of this money will go directly to fund the refurbishment of a parent's accommodation room. These rooms are essential to have so that parents have a safe and comfortable place to stay whilst their child is in hospital. Without these rooms, parents would have to travel to and from the hospital, leaving their child or they would have to opt to sit by their child's bed all night. When children are in hospital long term, neither of these options are feasible.

Paediatric Critical Care Unit

- Three bugaboo donkey pushchairs: These pushchairs allow parents to take their children out of the hospital even if it is just for a few hours to get them away from their bed. What is special about these pushchairs is that they have special compartments that enable the children's mobile ventilators and saturation monitors to be transported with the child. Without this equipment some children would not be able to leave the hospital ward.
- Other sensory equipment: Other equipment purchased included cushioned mats for children to spend time somewhere else other than their beds, wall stickers, curtains for the ward and small sensory hand toys.

Resuscitation Dolls

The charity spent £9990.75 on purchasing new state of the art resuscitation dolls. The new dolls can be used to simulate different emergency situations such as a chest infection or difficulty breathing which can all be controlled from a sim pad. The pad can also show simulated vital signs and control scenarios. Breathing is another simulated feature to the extent that sounds can be heard from the chest and mouth.

The Long-Term Ventilation Team at the hospital will use the dolls to train parents and carers before children are discharged from the hospital. This is in hope that parents will be able to effectively deal with emergencies themselves, preventing crucial time being lost seeking medical attention.

Christmas

Every Christmas the Harley Jae Trust make a series of visits to the Paediatric Critical Care Unit. In 2016, the charity spent £3,180.40 over the Christmas period on the following:

- Gifts: Through out 'Harley Jae Present Dash' event, over 30 children from the public signed up to take part in the event. They walked two miles carrying bags of presents to the Queens Medical Hospital where the trustees were waiting for them to collect and take to the children on the PCCU. The gifts were a mixture of small sensory toys, clothes, games, books for the children and bigger pieces of equipment for the ward.
- Ward Decoration: The board of trustees along with a few volunteers attended the PCCU with boxes of Christmas decorations and Christmas trees to help give the ward a Christmas feel. This is important for the children, families and staff on the ward to help keep up morale and bring some Christmas spirit to everyone.
- Food Hampers: On Christmas eve, the trustees attended the ward with 15 luxury food hampers for the parents. Caring for your children in hospital when their health is in a critical condition is extremely difficult at any time of the year. On Christmas eve, it may be even harder. Providing the parents with a food hamper will not take their problems away however it will show them that we are thinking about them and that we care. It also provides them with some really nice food!



Operating Costs

This year's operating cost has increased from the previous accounting year however, they still remain significantly low. Our overall operating cost was £9,737.00 for the year which remained in line with the previous year. The charity is still being supported by external partners which office space, stationary, finance management and accounting and website management.

Our marketing budget also remained in line with the previous year with total spending at £4,028.00. This money was primarily spent on social media advertising and management as well as marketing materials and fundraising resources.

We raised a total of £49,718 (gross) through external donations and charity events with general overheads, marketing and fundraising costs equating to £20,430 giving a net of £29,288.



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