



Our First Year

'The journey starts here'

Trustee's Annual Report

Executive Summary

The first year of our charities establishment has been a challenging yet exciting year. As the Founder and Chairman of the charity my main goal was to start our journey towards the vision and goals that I'd always hoped to achieve. The establishment of our trustee board was a success as we have five individuals that are committed and enthusiastic in helping the charity to achieve its vision and also bring their own ideas, values and goals to the table.

The trustee board includes 4 business owners and a finance administrator which was, and still is of great value. However, operating a charity was somewhat entering the unknown for all us so we needed to ensure that we were clear and ready to embark on this journey. After studying the trustee handbook and acquiring knowledge on financial management for non-profit organisations we were ready to go.

We established 3 clear objectives for the first year; raise £50,000, Establish a strong relationship with Nottingham's Children's Hospital and to increase our visibility and strengthen the brand. We essentially achieved all three of these objectives so it is safe to say we have had a successful year.

Establishment was the key for our first year. This included community engagement and evidence of an increasing following of supporters. We are now confident moving into the next year knowing that we have a good foundation of regular supporters and people in the communities of Nottinghamshire are aware of our charity and are starting to identify us as their chosen charity.

We remain committed to our goals of supporting children with life limiting conditions and their families as well as the hard working staff at the PCCU in Nottingham's Children's Hospital. The future looks bright for The Harley Jae Trust and we are very excited for the coming years to see our charity develop further and increase its reach towards children and families in need.

We would like to thank all of our sponsors, donors and supporters for helping us to support these children and families and we look forward to another successful year.

Joseph Rafter - Chairman

A handwritten signature in black ink, appearing to read 'Joseph Rafter', written in a cursive style.

Our Aims

The Harley Jae Trust has an ultimate of 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 particularly 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 particularly 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

Achievements and Performance

Charity Launch

The reporting year was the first year of establishment for The Harley Jae Trust and the trustee's main focus was to create a robust operations model as well as raise awareness through public engagement.

Establishing how we were going to meet our objectives whilst staying in line with our values was our first priority. Supporting children with life limiting conditions and their families could only be fully achieved through establishing positive relationships with professionals from other agencies in order to make links with health care providers as well as examine what support was already being delivered within our region.

Within the launch period, establishing the charity with our community was also a priority. The trustees focussed on creating a plan to raise awareness through community engagement, fundraising events, PR and social media.

Relationships

In the reporting year, the trustees forged a strong relationship with the Paediatric Critical Care Unit (PCCU) at Nottingham's Children's Hospital. The PCCU is a medical unit that is made up of a combination of the Paediatric Intensive Care Unit (PICU) and the High Dependency Unit (HDU). After several months of discussing ways in which the charity could help with members of medical staff as well as member's senior management it became evident that The Harley Jae Trust could play a significant role in supporting the PCCU and the families that were receiving treatment on the unit.

The doctors and nurses on the PCCU stated that the unit needed significant improvements as well as additional equipment and facilities. The Harley Jae Trust agreed to commit to an ongoing relationship where the medical staff could request items they felt were vital for the patients but could not be funded through any other stream.

We have also forged a strong relationship with the Long Term Ventilation (LTV) team at Nottingham's Children's Hospital. The LTV team work with families with children who have long term ventilation needs which, more often than not, is a consequence of having a life limiting condition. We have been working closely with the LTV team to identify the needs of the children who require long term stays on the PCCU and whether there are any additional needs of those families that the charity can support.

In addition to this, we have also built a strong relationship with Nottingham Hospital's Charity. This is to ensure that both charities are aware of the services each one is providing and that we all work together to ensure that our services do not overlap. The Nottingham Hospital's Charity also aid us in purchasing when we provide equipment to the PCCU as they have prior knowledge and the ability to get items purchased quicker and in line with the hospital procurement policies.

Fundraising

In the reporting year the charity organised fundraising events which were aimed to raise awareness as well as raise funds for the charity. The trustees also started a fundraising campaign through social media which encouraged the public to also choose The Harley Jae Trust as their chosen charity when engaging in fundraising activities. This campaign started to see results by the end of the reporting year and public engagement started to increase.

These events raised a total of £15,699.83 and resulted in several articles in newspaper publications.

We received a further £22,477.16 in donations which was a result of our charity ball, public engagement, promotion and social media campaigning. In the reporting year we raised a total of £38,176.99 with a further £14,600 of pledges and donations from our annual fundraiser in March of 2015 in which we did not receive until the following financial year.

Impact and Value

The majority of our first year involved most of our time being spent on building the charities reputation through community engagement and fundraising events and activities. The funds raised in the reporting year predominantly came in the last 2 quarters and therefore limiting time for us to donate appropriately. We donated £12,784 during the reporting year. This money achieved the following:

- **Purchase of 10 x saturation monitors** – Children with life limiting conditions often have long stays in hospital and are reliant on vital lifesaving equipment whilst they are in hospital. Using such equipment means that they are often bound to their beds as it can be unsafe for them leave as they are unable to take the equipment with them. Mobile equipment is vital for these children so that they can spend time with their families away from the hospital bed and sometimes even return home for day visits. We purchased 10 of these pieces of equipment for the PCCU so that they can provide them for families.

- **Purchase of 10 x suction machines** – Children with life limiting conditions often have problems with managing their airways and their levels of secretion. This can be life threatening for the child and also cause high levels of stress for the family as secretion levels can cause serious airway problems at any time. Mobile suction machines are vital for families to have so that they are always prepared to manage such situations. We purchased 10 of these pieces of equipment so that the PCCU can provide them to families that need them.
- **Seating** – Parents of children who are experiencing a long term stay in hospital often need a break and a few moments away from the hospital bed to help them deal with the highly stressful situation they are in. The PCCU has a private parents room where they can be alone during upsetting times, however the seating was not adequate for them. We purchased a sofa and an armchair for this room so that parents can be more comfortable during these times.
- **Gifts** – During the 2015 Christmas period, The Harley Jae Trust spent (£) on gifts for all of the children who were on the PCCU on Christmas eve. The charity also funded decorations for the ward in which volunteers from The Harley Jae Trust took to the ward and decorated. The gifts included sensory toys which were suitable for children with learning difficulties. In addition to this the volunteers provided fresh Italian food hampers to all of the parents who were on the ward with their children on Christmas Eve. The feedback from parents and staff was excellent with one parent quoting the following:

“We were on PICU this Christmas with our 8-week old baby boy. He was on life support with RSV and pneumonia. We received one of these hampers on Christmas Day and my husband and I was truly moved! It restored our faith in humanity! It has also inspired us to do something for PICU next Christmas, so we just wanted to thank you, your kindness really lifted us at a time when we were petrified of losing our boy.”

- **Annual Fundraiser** – In March 2015 we held our first annual fundraiser which was a charity ball held at Blotts Country Club in Nottingham. We attracted 19 businesses to come together along with a further 70 supporters with an overall

attendance of 260 people. The overwhelming support for our cause resulted in a total of £32,000 being raised with £18,400 being raised on the night through an auction items and other prizes. The night was an overall success and attracted celebrities and premier league football players. The money raised was used in the following financial reporting period.

Strategy for 2016/2017

The Harley Jae Trust will move into year two with a larger base of supporters, funders and partners. The immediate goal is to continue to demonstrate to the public that we are able to identify additional needs and deliver support to children with life limiting conditions. This will continue to be carried out in partnership with the PCCU and the LTV team at Nottingham's Children's Hospital.

Identified Needs

The biggest identified need is children with life limiting conditions who need to have prolonged admissions into hospital. Some children are born and do not leave the hospital until they are 18 months old. The reality is that they will continue to have admissions into hospital for the majority of their lives. This is because they need to receive medical treatment and then receive intense care. It's our goal to ease the experience of these long term stays as they are highly stressful for both the child and the family.

Operating Cost and Model

The charity is currently operating at a very low cost. The total overheads for the charity were £1499 for the whole year. This is remarkably low due to all activities being carried out by volunteers as well as other businesses supporting the running costs (i.e. IT, office space, stationary etc.). During year 2, the trustees will be working towards improving our operating systems whilst still maximising the given resources of our supporting businesses. The trustee's aim to establish the true cost of running the charity and ensure that the charity can support itself moving forward and not be completely reliant on other businesses.

This will be achieved by creating a new business plan and financial forecast moving forward that accounts for operating costs including:

- Marketing, Website & Branding
- Promotional Materials
- Office and Equipment (IT, software, stationary etc.)
- Travel Expenses
- Labour
- Fundraising Activities

Once this has been established the trustees then identify which of these resources can be provided or donated by supporters, therefore providing an accountable cost in which can be recorded as savings made.

The trustees have also agreed to recruit our first employee in 2016. This role will involve a 16 – hour per week agreement and role will focus on administration, promotion and fundraising responsibilities.

Marketing

Another objective for the forthcoming year is to recruit additional help with marketing and branding. In order to reach the audience needed to achieve our ongoing goals, the charity needs to increase marketing efforts and invest in a strategy that will expand our reach.

This will be done by recruiting a marketing and branding consultant who will take control of all of social media activity as well as identify opportunities and liaise with potential business partners. Expertise in social media management is vital for today's marketing climate and ensures that we can directly engage with all of our supporters. Direct engagement allows us to keep followers up to date with developments, inform them of the growing needs of the children and families we support and appeal to them for support with our activities.

Finances

Below is a basic finance breakdown of the year's income and expenditure.

INCOME		EXPENDITURE	
Donations Received	£5,477.16	Fundraising Activity	£7,425.40
Income from fundraising events	£32,699.83	Promotional Merchandise	£1,366.07
		Website/Marketing	£1,351
		Expenses & Overheads	£1,498.83
TOTAL INCOME	£38,176.99	TOTAL EXPENDITURE	£11,641.30
		DONATIONS MADE	£9,208
		BALANCE	£17,327.69

Of the £32, 699.83 that was raised in 2015/2016, £17,000 was raised in March 2015 as a result of ticket sales for our charity ball. This money was included in the following years donations.

