



HCCN the Charity – Annual Report 2017

Registered Charity No. 1163051
HMRC registration reference EW23930

HCCN the Charity – Trustees Report 2017

1. Introduction and executive summary

HCCN the Charity operates as a fully constituted membership charity registered with the Charities commission. This past year has been one of consolidation. HCCN comprises the Hunts Community Cancer Nursing team working in partnership with HCCN the Charity.

Our lead nurse Gini Melesi who founded the charity - along with Trustee Susan Moore – moved onto a new role as Quality Improvement Manager with the East of England Clinical Network. Karen Moseley was promoted to lead the community cancer nurses and bring her team back up to full strength.

We have reached financial stability to fund our current objectives, with a healthy balance sheet and strong reserves. Our operating budget is in the region of £35,000 per annum, funded mainly through donations from a wide range of people and fund raising activities.

Having built up the Trustee team to five people, all unpaid volunteers, with a good skills mix sadly two people have decided to move on to different challenges. Therefore we need to recruit new people.

The charity delivers a clear programme of activities focused on health, emotional wellbeing and education, that deliver evidence based impact.

The benefits of the Community Cancer Service have been recognised nationally and the Clinical Commissioning Group (CCG) has re-commissioned the service. They are looking at how lessons learned can be spread across the Cambridgeshire and Peterborough CCG. The charity is aiming to be in a position to support this further expansion of the service once the CCG has secured the necessary funding.

During the year there have been no risks to the charity. The Trustees consider risk management to be a key part of their role and monitor potential risk through their Risk Management Policy at Trustees meetings.

The charity has reviewed its financial controls and has in place healthy reserves as agreed by members at the AGM. Funding for the charity is being closely managed in order to establish a regular income flow which will enable some of the funds held in reserve to be released. We have no reserved funding.

2. Objectives

HCCN is a local charity run by volunteers supporting the Hunts Community Cancer Nursing Service based out of Hinchingbrooke Hospital. Working together our aim is to help people who are recovering from or living with cancer in the Hunts area to take back control of their lives and play an active part in managing their health.

Our goal is to encourage a more objective view of cancer and to help people understand the trajectory of cancer is ever changing. Increasingly cancer can be lived with in the same way as other long-term conditions such as heart disease, diabetes and asthma, particularly when individuals are actively involved in managing their health.

- There are 2 million people in England with a diagnosis of cancer. This number is likely to grow by more than 3% per year, reflecting the increasing incidence of cancer and better survival rates.
- By 2030 there are likely to be around 4 million cancer survivors in UK.
- Evidence shows that the current model of cancer follow-up is not meeting people's needs and will not cope if the number of people living with cancer increases at the expected rate.

While the NHS funds the nursing service through CCG funding, every other aspect of the support we offer to patients is provided through HCCN the Charity free of charge.

We supplement the NHS with several wellbeing services. We support the nurses to deliver a home-based nursing service plus educational conferences where we share current research on diet, exercise and emotional well-being - demonstrating how changed habits can improve health. We then support people as they adopt those new habits by offering opportunities which bring people together. This results in a reduced use of hospital-based services.

Through our *Get Active* programme, we support people to remain active during and after cancer treatment. Current research points to the importance of people with a cancer diagnosis returning to exercise whilst still undergoing treatment and then to maintain the exercise habit as they live with or recover from cancer.

3. 2017 Achievements

3.1 Educational Conferences

We held two bi-annual successful patient conferences offering 80 free places and bringing together a variety of speakers including:

- Dr Paul Edwards – sequencing the DNA of cancers
- Lisa Hughes – genetic testing
- Dr Alex Martin – what's new in cancer treatment
- Professor Robert Thomas – lifestyle after cancer
- Suzanne Miller – oncology clinical trials
- Christina Jassi – emotional impact of having cancer

Following feedback from delegates, we believe we have achieved the best local venue in The Jockey Club at Huntingdon Racecourse. We have invested in improved audio and visual facilities and these technologies have greatly improved the experience. A raffle during April's conference raised £ and we started awarding medals gained by people involved in the Buddy Band Scheme (part of *Get Active*).

3.2 Nurse learning and development

The charity funds the nursing team through additional specialist training in all aspects of cancer care. Courses recently attended include:

- the National Acute Oncology conference
- Nurse Non-Medical Prescribing
- Pancreatic Cancer UK study day
- Addressing Sexuality and Cancer
- a conference on Cancer Nursing Practice
- Foundations of Cancer Practice with the Royal Marsden
- Level 3 counselling skills exam towards a Diploma in Counselling

Additionally, our Trustees and some of the nurses attended an End of Life Coaching workshop, enabling us to build a shared picture of how to deal with conversations around death and loss.

3.3 Exercise

The charity funds and delivers a wide range of courses and activities that help people as they seek to take back control of their lives and reduce the impact of their cancer. Everything we do is underpinned by a strong evidence base and a desire to support people back to independence whether recovering from or living with cancer. All new initiatives have clear aims and objectives, and are piloted and evaluated before being offered to large numbers of people.

Our core offering of simple *exercise circuit* classes continue to grow from strength to strength. Getting a person newly diagnosed with cancer, or who are in treatment and are often physically and emotionally at their lowest ebb to reengage in being active, is a huge challenge and this is one of the most significant contributions our volunteers make through emotional encouragement, motivation and mentoring. The clinical evidence for being active before, during and after treatment is clear, compelling and well accepted, but is not implemented by the NHS as part of the care pathway or mandated by NICE. Circuits now form a key element in our *Get Active* programme, running three times per week within Hinchingsbrooke Hospital.

We run regular seated *Yoga* on Friday mornings at the Holiday Inn, Brampton to a full house and a delighted clientele. Our yoga teacher has become an essential part of conference by offering the last session before we close. This helps people return to the here and now and to prepare to go back to their lives and last time encouraged new people to join the class. Another class is set to run in Ramsay. Concurrent with the Friday yoga sessions is the opportunity to 'Drop In' for a coffee and chat with a nurse or another patient who understands what people are going through.

We piloted a *Relaxalot* course at the Old Bridge Hotel in Huntingdon - a six-week programme to equip people with another way to manage their emotional response to cancer. Subject to evaluation, we will look to offer this again.

We tried to bring *dancing* to our range of activities to encourage a fun and different form of exercise. We were well supported by the Generations Dance Academy in Huntingdon, but after offering two sessions a week at different times, this was not what people wanted and we decided to remove dancing from our programme.

Something else we tried was *meditation* – which we believe is a valuable tool to help individuals manage themselves through difficult times. To date we have not been able to run mixed classes. We run a 6 week trial to establish what we might want from a mixed meditation class but have yet to identify an appropriate solution.

Efforts to grow and consolidate our *Get Active* programme resulted in several achievements. It is aimed not only at helping people return to activity but also to stay with it forever. We therefore try to tailor a package to match the individual. People must be referred to this programme by their nurse.

3.4 Emotional Wellbeing

The *Colour Analysis Course* runs during the summer months when the light is better. The impact this event has on people who need a confidence boost makes it very worthwhile. Feeling good about yourself is much more than simply wearing the right colours but your outward appearance is often a reflection of how you feel inside and knowing you look good is a positive boost.

3.5 Nutrition

At our last conference, we supplied some samples of Turmericicious drinks and asked those who tried it for their comments. If we get a good response, we will investigate how we could supply the product through a 'retail arm', along with possibly supplying Pomi-T. Patients would then buy through us instead of sourcing their own products. Polyphenol-rich foods, such as pomegranate, green tea, turmeric and broccoli, have demonstrated anti-cancer effects in laboratory studies. In humans, observational studies have linked their intake with a lower risk of chronic disease, including cancer. Concentrating these foods into a capsule is a convenient way to boost an individual's polyphenol intake.

We continue to value our partnership with Professor Robert Thomas, Consultant Oncologist at Bedford and Addenbrooke's Cambridge University NHS Trusts, and author of the book "Lifestyle and Cancer". This book remains a valuable source of reliable information to ensure people can make the right lifestyle choices after cancer. A popular speaker at our conferences, and prolific researcher, we aim to share more on our website *Health Matters*.

Reliable research and advice on self help with diet and nutrition when living with cancer remain areas where we wish more was available.

3.6 Media coverage

We seized opportunities to feature on Local Radio programmes to help local people understand who we are, what we stand for, how we fit with the nursing service and how we

are funded. Our social media presence focused on using our FaceBook page to update our followers about our activities. We used print media to raise awareness of who we are and what we do – both the nursing team and the charity. Our website however needs refocusing on providing timely and relevant information.

4. **Impact and value**

As a case study of the impact the charity has achieved, we launched a new health initiative supporting patients to remain active during and after cancer treatment. Current research points to the importance of people with a cancer diagnosis returning to exercise whilst still undergoing treatment and then to maintain the exercise habit as they live with or recover from cancer.

The scheme named *Get Active* features the *Activ8rlives BuddyBand2* – a wrist worn waterproof activity tracker, which monitors people’s activity and is uploaded to an Apple or Android App. In conjunction with the patient and qualified personal trainer, a personalised activity plan is drawn up and includes home-based exercises, structured exercise classes or going to the local gym. HCCN has linked with local Leisure Centres to provide access to classes, guided walks etc. We also continue to fund weekly yoga and circuit classes for all our cancer patients.

Within *Get Active* every referred person identifies what activity suits them best and is then supported to achieve their goals. This may well open other opportunities for activity that they might not normally consider, such as dancing.

The *Activ8rlives BuddyBand2* is supplied at a nominal fee of £30 for participants, along with comprehensive training and support. The *Activ8rlives* solution provides the means to monitor progress, targets and be linked into online help, messaging, adventures and rewards to ensure individuals gain the maximum benefits from the whole integrated programme of *Get Active*.

Physical activity is monitored through collecting data from the band and if any readings generated are not what would be expected, the Personal Trainer can get in touch to ensure the individual is okay and alert the nursing team if necessary. The scheme allows people to become independent and confident in their activity and fitness plans whilst undergoing treatment or beyond.

A pilot of the *Get Active* scheme, using the BuddyBand2, has recently been experienced by 15 cancer patients at cancer Phase 3, who considered it “excellent”. Consequently, we are now rolling it out to HCCN patients across the Huntingdonshire area. We work with two local businesses on this project:

Forefront Fitness who oversee the personal training element of the project. Marion Foreman, a nurse with many years in cancer and palliative care, has been instrumental in getting the project up and running. She and her husband Steve, are both passionate about

fitness and have a desire to want to help others to get fit and healthy. Marion became a Personal Trainer several years ago and after Steve was diagnosed with a melanoma, Marion trained in Cancer Rehabilitation. They used Steve's critical illness cover following his diagnosis to set up 2 gyms. Marion says, "We read about HCCN in the newspaper and all the good work that they do – we really wanted to help. This system opens up a way of helping and monitoring many people on their own cancer journey."

Aseptika Ltd (part of the Spirit Family of Companies) are a local award winning healthcare technology company, who develop integrated health and wellness solutions for individuals or groups of patients with long-term health conditions. This empowers them to self-care and self-monitor their health parameters and to share this data with their healthcare providers if they so wish. Kevin Auton Ph.D, Managing Director, has worked with HCCN, the patients and his team to capture additional parameters, other than activity, that cancer nurses feel will be beneficial for patients to record. This process could lead to patient-generated data being integrated into their patient records (at the individual's sole discretion as an opt-in). Kevin says, "Having met the HCCN team at the local Hunts 10K Fun Run earlier in the year, we talked through how we could work with them on improving services locally. I'm thrilled we are involved in a project where we can work with a group of individuals that embrace self-monitoring and feel empowered to take ownership and responsibility for their recovery and wellness going forward or detecting declining health early."

As we continue to partner with Aseptika we have approached the Eastern Academic Health Science Network (EAHSN) for additional funding. Firstly, they have approved our business case and funding of £20,550 to support the development of the cancer rehabilitation classes, through the automation of data and expansion of the programme for up to 250 participants.

Once on the road to recovery, we need to graduate these participants to a programme of activity and peer-group support which has a lighter touch (and is much less expensive to provide). We want to progress our recovering participants to a lower-cost Phase 4 class in a non-medical setting to encourage independence and build self-confidence in their own ability to stay well. A classic process of rehabilitation and self-dependence as the crisis has passed, but a slow one which requires support, empathy and encouragement. Together with Aseptika and Huntingdon District Council (HDC) we are approaching EAHSN to establish a programme of rehabilitation classes at the Phase 4 stage for participants recovering from serious medical conditions who have been referred by the NHS to stepped-down Sports-led classes conducted by a Phase 4 trainer employed by HDC.

We look forward to the outcome of our bid and the opportunity to take *Get Active* to the next level.

5. Fundraising

We can only deliver what we do if we can raise funds. This is not easy as there are so many people fishing in the same pool for funding and this year has seen the NHS withdraw funding from some very important groups in our area. Local individuals continue their generosity in donating to us from dances, cake sales, sponsored events, and sadly funerals. In addition, we run a '100 Club' and maintain a Just Giving site. Donations currently provide the largest proportion of our income.

As a local charity operating only across Huntingdonshire that can also limit our ability to fundraise. Fundraising activities include:

- a raffle at conference
- an annual virtual balloon race
- a cake sale and raffle at the Huntingdon Riverside Gala
- a tombola at Houghton Feast Week
- we have plans for a pay to enter run/walk starting and ending with a picnic at Houghton Mill

Our nurse administrator (and her family) has constructed a 'human fruit machine' which has proved to be great fun and a real draw at public events. Children especially enjoy taking a turn. We are looking at what other traditional fun fair games we could introduce to raise funds.

Approaches to local businesses such as Mick George and Waitrose have resulted in significant raffle prizes.

However our unpredictable income flows require attention. A fundraising sub-committee has been established and a policy around grant applications is also being developed.

6. **Volunteers**

HCCN is run entirely by volunteers and always welcomes help as additional hands-on support at the many events. We raise funds through a wide range of people and activities, from individual donations, sponsored events, corporate gifting, 'in memoriam' donations and legacies.

We are growing our team of regular volunteers. In support of this we have introduced a robust set of people policies and processes through which we recruit, develop and manage volunteers. We have a fledgling management team in place to drive our various operational activities, such as course management and fund raising, providing the Trustees with more time to focus on strategic planning.

7. **Ambition and medium term strategies**

Above all we seek to assure our continued close partnership with the Hunts Community Cancer Nursing Service – Karen and her team. For instance, we have been asked to fund the purchase and maintenance of both basic and specialist nurse equipment – and are happy to

do so. Understanding how we can best work with the nursing team takes time but is looking very positive.

In response to the future challenges of this partnership, the Charity aims to focus efforts on:

- Growing the management structure
- Creating sustainable fundraising processes
- Developing the programme of activities and conferences in response to research
- Continuing to partner with Aseptika to grow our *Get Active* programme

Participation in HCCN funded activities 2017

PROGRAMME	NUMBER OF ATTENDEES
Conference – November 2016 & April 2017	150
Get Active – launched September 2016	60
Yoga and Drop In	20 people per week / 46 weeks
Relaxalot (pilot)	6
Meditation (pilot)	6
Colour Analysis	24
Counselling	29