

Hunts Community Cancer Network

HCCN Charity Annual Report 2019

Registered Charity No. 1163051
HMRC registration reference EW23930

HCCN Charity Trustees Report for the year ending 30 April 2019

1. Introduction, purpose and executive summary

The Hunts Community Cancer Network (HCCN) comprises of the NHS funded Community Cancer Nursing team working in partnership with its charity to provide community-based care for people across Huntingdonshire living with or recovering from cancer. HCCN the charity operates as a fully constituted membership charity, registered with the Charities Commission, number 1163051.

Our purpose is to preserve and protect the health of patients with a diagnosis of cancer who are supported by the Community Cancer Network in Huntingdonshire by providing and assisting in the provision of facilities, support services and equipment not normally provided by the statutory authorities. Also, to advance the education of the public in healthcare related to cancer by the provision of lectures, for and by the publication of newsletters devoted to cancer healthcare.

HCCN's four trustees are:

Jan Davis, Chair (reappointed)

Susan Moore, secretary (reappointed)

Karen Mosely, head nurse (appointed seeking reappointment at the AGM)

Amanda Orchard (reappointed)

All trustees give of their time freely and no remuneration or expenses were paid in the year in relation to the work of the charity. They have a good mix of skills and are well supported by a growing team of enthusiastic volunteers. Their 'gift of time' makes a significant contribution to the impact that the charity achieves - delivering a clear programme of activities focused on health, emotional wellbeing and education, that delivers evidence-based impact. We take seriously our commitments to our people and their care, and reserve to the trustees responsibility for establishing and implementing procedures in this area.

The trustees are responsible for setting the strategy for achieving the objectives they have set. At the monthly trustees' meetings, they agree the broad strategy and areas of activity for the charity, including consideration of risk; policies, procedures and performance; safeguarding; training; diversity; financial decisions and reserves management. In the context of the charity's 5-year strategy, this report includes an explanation of the target level of reserves, the reserves held, and the charity's plans to increase its reserves.

This past year has been one of continued growth and a strategic focus on the longer term. The charity has reached financial stability to fund its current objectives, with a healthy balance sheet and strong reserves.

Karen Moseley continues to develop the capabilities of her team of NHS funded community cancer nurses. The nursing service has nine team members, receiving record numbers of referrals for the whole spectrum of cancer types requiring nursing input and psychological support. The nursing service can be accessed by anyone over the age of 18 across Huntingdonshire affected by any cancer, either directly or indirectly, and works across 23 GP surgeries. The benefits of the Community Cancer Service model have been recognised nationally. The Clinical Commissioning Group (CCG) has funded the establishment of a nursing team at Peterborough Hospital, with Karen and her team providing their induction.

2. Objectives

HCCN is a local charity run by volunteers supporting the Hunts Community Cancer Nursing team based out of Hinchingsbrooke Hospital. We work together with the nurses, who provide a home-based service that aims to help people who are recovering from, or living with, cancer across Huntingdonshire to take back their lives and play an active part in managing their health. This results in a reduced use of hospital-based services. The charity funds specialist nurse training and equipment, as well as evidence-based supportive activities such as health and wellbeing services, rehabilitation classes and nutritional advice.

While the NHS funds the nursing service through CCG funding [Clinical Commissioning Groups which replaced Primary Care Trusts], every other aspect of the support we offer to people is provided through the HCCN charity, free of charge. Everyone involved in running the charity volunteers their time freely. To continue this work we need funds constantly available to assist people - and ensure that people who are in need, receive the vital help and support they deserve.

- In the East of England, in a population of 6 million, there are about 180,000 people living with cancer.
- By 2020, almost one in two people (47%) will get cancer at some point in their lives.
- On a positive note, people now live nearly 10 times longer after their cancer diagnosis compared to 40 years ago.

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.

Yet the NHS is overwhelmed: current models of provision cannot support the demand on cancer services. Patients experience significant delays to appointments; they are more want say in their treatment; they want treatment closer to home, and to continue to work. We are committed to providing evidenced based information to help people move from being victims of cancer to accepting their diagnosis and understanding how they can help themselves. Increasingly, the partnership approach adopted by HCCN is seen as pioneering.

3. 2018/9 Achievements

The Trustees have developed a 5-year strategic direction for the charity, based on our unique proposition, namely:

- Enabling people diagnosed with cancer to live well and feel in control
- Powered by a unique clinical nursing team partnered with its charity that provides the things the NHS cannot
- Ensuring patients receive an holistic care package to treat the effects of cancer
- Treating the whole person
- Designing and delivering interventions proven through research to make a difference

We have successfully approached and appointed two key Patrons as goodwill ambassadors and influencers: **Dr Cheryl Palmer**, Consultant Oncologist, Lead Cancer Clinician for Hinchingsbrooke and Clinical Lead for the Woodlands Centre; and **Professor Robert Thomas** is a Consultant Oncologist at the Primrose Oncology Unit, Bedford and Addenbrooke's Hospitals.

3.1. Educational Conferences

We held two bi-annual patient conferences offering 80 free places and bringing together a variety of speakers. Conference management is in the safe hands of Gill Monsell.

In November 2018 we included talks from Professor Thomas on nutrition, Dr Oana Linder - University of Leeds - talking about what we all call "chemo brain" and local consultant Sally Harding about palliative care and how it links to the work of our nurses.

In May 2019, we heard from Dr Hannah Thompson - Chief Operating Officer, Cambridge Cancer Genomics on "The Future of Cancer treatment"; Tony Elliot from the Carers Trust on the work of the Carers Trust; and Dr Sam Smith - Academic Fellow at Yorkshire Cancer Research, University of Leeds, "Fact versus Fiction - public awareness of risk factors for cancer".

Participants value the venue we continue to use at Huntingdon Racecourse with the support of The Jockey Club. Our investment in improved audio and visual facilities with PRISM Events has greatly improved the experience. The regular conference raffle raises around £250.

3.2. Nurse learning and development

It has been another year of change for the nursing team. Amy left for pastures new to the Royal Marsden in London and we recruited Mel Scholes who was a breast care nurse at Hinchingsbrooke. Mel has settled into the team very well and looks after the patients in the St Neot's area. Harriet will be going on maternity leave in August and we are currently recruiting for this post.

Maureen and Cheryl have both applied for the Nurse Associate course. It is a two-year course: if successful at securing a place and completing their studies, they will return to the team in their new roles. A Nursing Associate is a new member of the nursing team in England – the role is designed to help bridge the gap between health and care assistants, and registered nurses. Nursing Associate is a stand-alone role that also provides a progression route into graduate level nursing. The role will contribute to the core work of nursing, freeing up registered nurses to focus on more complex clinical care.

Also the nursing team have been heavily involved with the configuration of PCCN - the new nursing service in Peterborough to mirror the service we offer in Huntingdonshire. We have worked very closely with the team and they have all spent a few weeks with the team to see what we do. Some of you may have met them with your regular nurse. We will continue to work closely with the team.

The HCCN nursing team continued their additional professional training with the support of the charity:

- Karen and Harriet successfully completed a one day ‘speciality’ acupuncture course with the British Medical Acupuncture Society in Birmingham. This focused more on symptom control for oncology patients and they learned some new techniques. The course enabled them to realise how successfully they have established the current acupuncture clinic for our patients.
- Sandra passed her Non-Medical Prescribing course and she is now an efficient prescriber which is having a huge benefit to our patients.
- Amanda continues at college with her counselling training and in September will have a Diploma in Counselling, allowing her to practice professionally.
- The whole team has had presentation skills training.
- Andrea Cliff is embarking on a lymphoedema course later on this year.

The ongoing support from the charity not only enhances the nurses training and development but also enables the nursing team to expand the events/activities they can directly offer patients. This is forever growing and we listen to what patients want or where we see the need and feed this back to the charity so they can continue to expand what is on offer.

3.3. Programmes

The charity funds and delivers a wide range of activities that help people as they seek to regain control of their lives and reduce the impact (physically and emotionally) of their cancer. Everything we do is underpinned by a proven 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, are piloted and evaluated before being offered.

3.3.1. Exercise

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. However, getting a person newly diagnosed with cancer, or who is in treatment and may be physically and emotionally at their lowest ebb, to re-engage in being active is a huge challenge. This is one of the most significant contributions our volunteers make through emotional encouragement, motivation and mentoring. All our offerings are free to cancer patients and their partners.

Circuits is a gym based 1-hour fun circuit training class where people of all ages and capabilities spend 1 minute at each station to do what they can achieve. It is not competitive - rather it is a very supportive atmosphere. Our ex-nurse Personal Trainer reminds everyone to stay within their capabilities. Working in partnership with Huntingdon Leisure Centre we now also offer paying classes for recovering cancer patients.

We offer three regular seated *Yoga* classes – seated, seated/standing and standing. These free classes can be used sequentially to rebuild strength or accessed according to capability.

Two *Tai Chi* classes are available - a seated class followed by a paying standing class. People can choose to stay in the seated class. Those taking part describe feeling a great sense of peace and deep relaxation after each class. Over time balance improves for those in the standing class.

In May 2018 we launched our new *Saturday Strollers* - monthly guided walks lasting a maximum of 45 mins with seats and short cuts for anyone feeling weary. The walk ends at a café. These are designed as family and social outings which will appeal to those put off by the other forms of exercise.

We continue to offer activity trackers at a reduced rate of £30 to people who want to actively monitor their exercise.

3.3.2. Emotional Wellbeing

We know that the emotional impact of cancer can be long lasting. People sometimes get stuck emotionally and find that they can't move forward in the way they would like to after receiving a diagnosis of cancer.

Our *Holistic Centre* at Ellington is run by Annie Thantrey and her volunteer team, providing a drop-in for people who want somewhere safe to talk with skilled people and for people who want to look before they try. Described by many participants as a place where they feel welcome from the moment they open the door, Ellington provides a wide range of classes and activities including arts and crafts; reflexology, hand massage and facials; guided

relaxation, Tai Chi, yoga and line dancing. There is always a warm welcome, a drink and piece of cake for anyone who wants to take part.

Following a successful pilot last year, our *Patient to Person* programme has been building momentum. Designed specifically for people who are ready to move on but find themselves emotionally stuck, who don't need counselling and don't have deep seated psychological issues, the programme designed by Colin Russell is delivered by highly trained and skilled facilitators who are able to work with a number of issues. Funded in part by a grant from the Ridgeon Family Charity Fund secured through the Cambridgeshire Community Foundation.

In April 2019 we launched a new *Sleep Course* to offer skills and emotional awareness for those struggling to sleep at night. The programme - designed and delivered by Sallie Crawley - moves from developing an understanding of sleep, preparing the bedroom for sleep, and ends at the recognition that how we address what happens during the day can affect sleep.

Another new venture for 2019 has been our *Men's Group*. Looking at the research into how cancer affects men made us realise that we do not do enough to support this significant group. Although everything offered by HCCN is available to anyone affected by cancer, it hasn't been sufficient to attract many men. Our new men's support group provides men with a sociable place to connect with other men coping with cancer or supporting someone with cancer or bereaved through cancer. Managed by Andrea Lines and supported by a committee of users, the men attending are helping to create an environment welcoming to all men. Darts, carpet bowls, snooker, table tennis, and a drop in to chat are offered as standard, with monthly information or fun sessions proposed by the group, such as a photography course, a bbq, a patch of ground to work. Funded in part by a grant from the Whales Foundation.

For those requesting in-depth *counselling*, we have maintained the level of one to one referral to a team of qualified counsellors for adults, couples and children.

The *Colour Analysis Course* continues to be run by Annie Thantrey, as 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.

3.4. Raising our profile

An important part of running the charity is going out into the community to talk about the nursing service and charity. We do that so that people know what help we can offer them and to hopefully be in their minds when thinking of a charity to support. We have focused on raising our profile in the Hunts area, to make sure that everyone who could benefit from the nursing teams support know we exist, and that we can encourage more people to support us financially.

- Our use of social media – Facebook, Twitter, Instagram - has increased, with the nursing team regularly updating to make our page more useful and informative.

- We have featured articles for local free magazines and give talks to local groups.
- We have one logo that both the nursing service and charity use. We have HCCN pins of the same design, in silver, which are a good way of advertising our services.
- We have agreed a call-off contract for HCCN logo'd sports/activity clothing, purchased at cost price by supporters and fund raisers.
- We have reprinted our Nurse introduction leaflet with a new group photograph, and provided a new poster to all the GP surgeries that the team covers.
- We created a single page glossy sheet for putting up in shops and a more impactful 'thank you' poster for businesses who have our collection pots
- Our booklet of services can be found in the Woodlands Centre.
- We are creating a new patient welcome handbook and timetable capturing the full range of services and activities available to them.

4. Volunteers

HCCN is run entirely by volunteers and always welcomes help as additional hands-on support at the many events. We are gradually growing our team of regular volunteers and received support from new volunteers both to help us fundraise and to become part of the charity management team. We have developed a volunteering strategy and have volunteer management processes in place.

5. Finances

Our annual operating budget is in the region of £65,000 per annum, funded mainly through donations from a wide range of people, grants and fundraising, hence our income remains largely out of our control. A detailed finance report can be found at Appendix 1. A copy of our audited accounts is appended at Appendix 2.

An analysis of our expenditure highlights the significant cost of suitable places (room hire) for our wide range of activities - we are committed to minimising this or preferably using our own accommodation. If we could use this same money to create our own permanent space then the return on the payment would be greater as it would allow us to increase our equipment holding (storage) enabling us to cater for more people, as well as having a permanent display area of useful information such as key health messages.

Our experience of operating our new Holistic Centre at Ellington (launched September 2018) has demonstrated:

- our ability to successfully launch and manage a day of varied safe and impactful activities that are valued by our users
- our ability to attract a range of willing volunteers and activity providers
- our ability to manage to a tight budget

We have investigated similar dedicated buildings (the Robert Horrell Centre at Peterborough Hospital and the Carers Trust in St Ives) and have a clear vision of the space that we want to

create for HCCN in Huntingdonshire. Our immediate goal now is to explore options for renting/acquiring our own premises together with a fundraising plan.

6. Impact and value

While the NHS funds the HCCN nursing service, every other aspect of the support offered to people is provided through the charity, free of charge. Everyone involved in running the charity volunteers their time freely.

Patients say: “The complete care ethos provided by HCCN makes the cancer treatment journey much easier to cope with. The personal visits from the support nurses, the yoga and the exercise classes, the acupuncture sessions, the conference days.” Jim Smith – January 2019

As a local charity for local people, we seek to create effective partnerships with local organisations. By working together, we add value to the services provided and increase the learning. For example, EAHSN wrote up a case study of one of our patients (Colin) and filmed a video to create a model for others to follow.

“HCCN operate the Get Active programme, and I joined their circuit training. There is growing recognition in the medical profession that cancer patients keep healthy for longer if they stay active. When you are told that you have a life-threatening condition, it damages both your confidence and self-esteem. HCCN and the Active+ programme brought back my confidence, helped by the comradeship of a great bunch of mutually supportive people that fully understand what it’s like to have experienced cancer. I now also attend a gym, primarily to do cardio-vascular exercise, and I live a normal healthy socially active life. The involvement with HCCN has given us back our lives, and with all the walking, my dogs must be the fittest in Cambridgeshire!”

Getting control of his life back has been extremely important to Colin: “I want to be at the centre of my treatment, not just reacting to medical guidance. Using the Activ8rlives App I can track my weight, which is really important for cancer patients, and I can also monitor my steps, sleep patterns and general wellbeing. This information can also be transmitted to the clinicians who can view my progress - if they see for instance that your steps are significantly lower than usual or your sleep patterns are poor, then it’s worth checking if something’s wrong. My great hope is that the whole process could be rolled out more widely throughout the UK. It’s given me the knowledge and support structure to control my own situation and reduced the frequency with which I need to contact my medical support.”

The financial impact of what we achieve is not easily measured. However, we know that these people are at high risk of requiring earlier use of adult social care services, and through increasing activation and self-care, we can delay the need for this intervention by up to 4 years.

7. Ambition and long-term strategies

Above all we seek to assure our continued close partnership with the Hunts Community Cancer Nursing Service – Karen and her team – to understand how we can best work with the team to ensure the best possible care and activity for their patients. The emotional impact caused by a diagnosis of cancer is devastating. We firmly believe that being part a community of people sharing a common experience can help people return to or build a ‘normal’ life.

Our vision is to normalise the experience of cancer by providing a place where people can go, as and when they need to, to access therapy, learning and social interaction. In line with our philosophy of providing a local service for local people, our goal is to create a smaller, non-clinical supportive environment where learning, information, rehabilitation, and survivorship can all take place, that is by having our own accommodation, creating a ‘one-stop-shop’ where service users, their families and individuals can access the services and information they need.

We have consequently set aside £50,000 of our reserves to provide seed corn funding of the project. We also hold reserves of £70,000 to cover one year’s expenditure.

In response to the future challenges, the charity aims to focus efforts on:

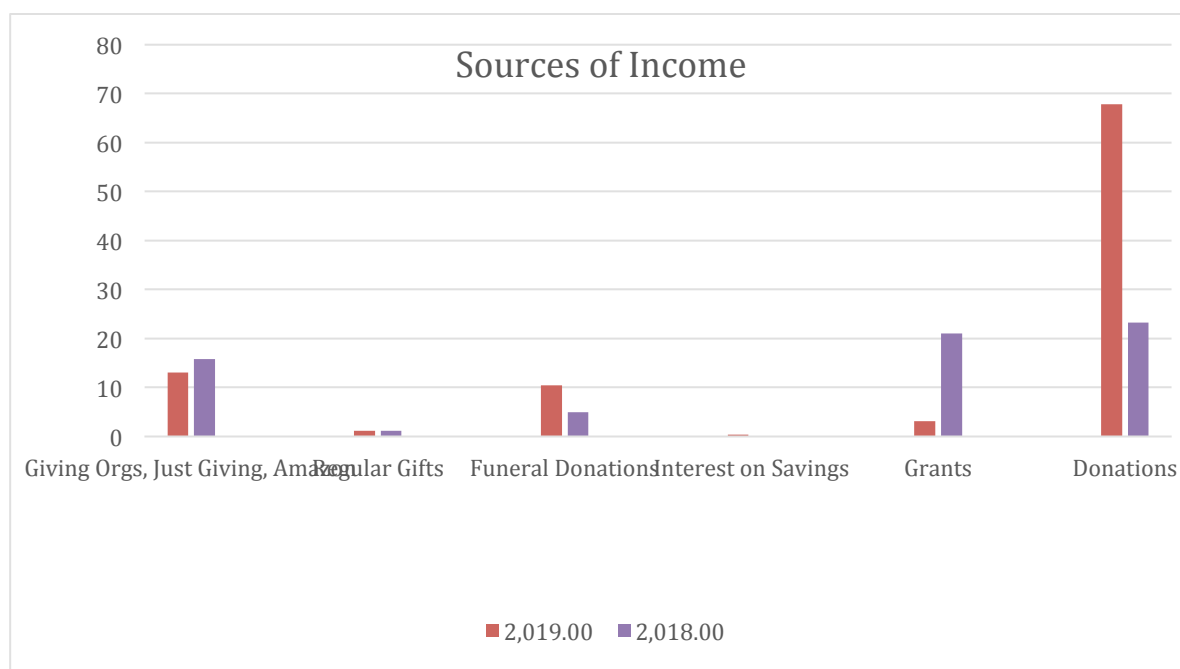
- Raising our profile across Huntingdonshire eg educating a wider audience,
- Creating sustainable fundraising processes eg securing a major donor(s)
- Developing our programme of activities, services and conferences in response to research eg practical nutrition and cooking advice
- Growing our family of volunteers
- Researching and costing our own accommodation/premises
- Using all available technologies to make our support available to all users.

Finance Report

Our financial performance improved notably during 2019. Income increased by 45% - from £66k in 2018 to £97k in 2019. Outgoings increased by only 15% which has allowed new projects to be introduced.

The graphs below analyse that income and expenditure.

Income



Giving Organisations

HCCN has focused on increasing the income generated through schemes such as Give as you Live and Amazon Prime. Online shoppers can deliver a sizable increase in revenues to the charity at no cost to themselves and over a whole range of goods and services. We are seeing a trend away from Justgiving to Facebook giving. This is also very beneficial for us as Paypal, who administer Facebook giving, do not levy any charges on the receiving charity. We could achieve greater revenues if more people were happy to leave their details as this allows Gift Aid collection enhancing the donation by a further 25%.

Regular Gifts and Legacies

We have a group of three people who make a monthly payment to HCCN. Gift Aid is collected on these contributions. This is another area we would like to grow as predictability of income allows for better planning.

Funeral Donations

These have doubled over the last year.

Interest on Savings

This is not a considerable sum but as HCCN seeks to fund raise to establish an HCCN property we expect to this area to grow in importance for at least a short period of time

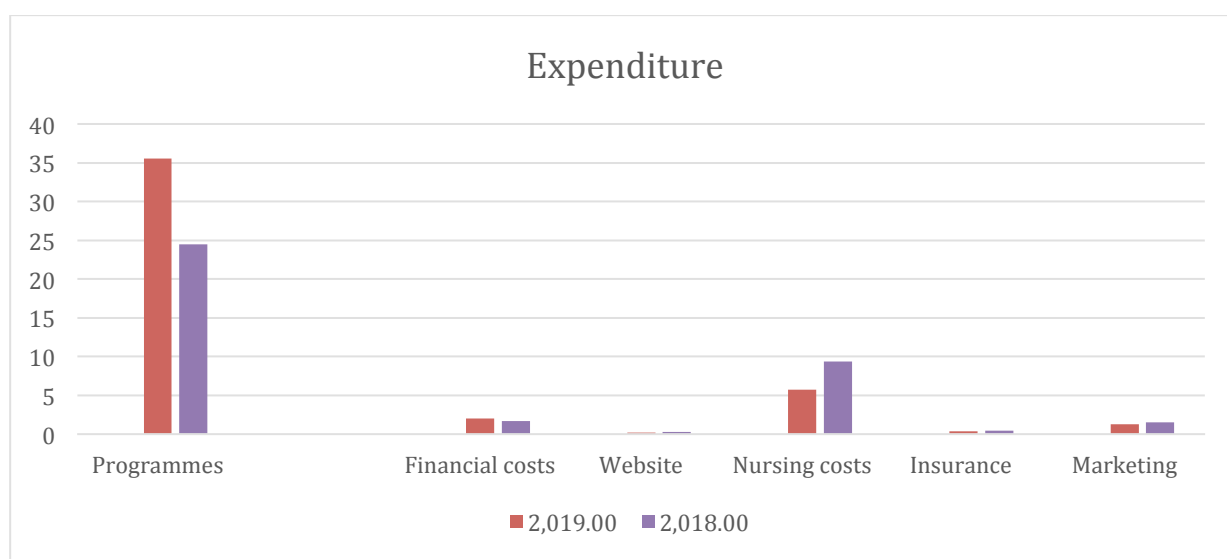
Grants

The figure for 2018 was a one-off payment from EAHSN to improve the Buddy Band software; consequently, it was used by our partners Activ8rlives. The trustee team has become more skilled in winning grant bids during 2018/19 and although only £3k has gone through our books this is because the waiting period can be up to one year for grants to be evaluated and paid. This will remain a major focus for us.

Donations

There has been a 300% increase in this area. Donations include organisational giving such Brampton Golf Course £14k; our own activities £14k; and the considerable support we have had from friends and supporters of HCCN collecting from friends in lieu of birthday gifts, undertaken runs, etc. Such generosity has contributed to the increase in income during the last year.

Expenditure



Programmes

Our programme and planned activity expenditure has risen by 15%. This is offset by a 40% reduction in nurse training costs. This has allowed new programmes to be offered, resulting in increased usage last year of 20%. This again underlines the importance of pulling all activity to a single site to allow people to access multiple activities in one visit. The Holistic Centre at Ellington demonstrates this: average weekly usage is one person to a minimum of three activities. Introducing this across all activities will allow us to offer better care options while delivering economies of scale. Our volunteer team - contributing time and effort for free - have greatly assisted us to keep our costs down.

Financial Costs

The costs for our book keeper and auditor have remained largely unchanged even though volumes have increased.

Website

Increasingly expertise is being developed inhouse thus allowing development of the website without incurring increased costs.

Nursing Costs

These have gone down this year simply because the training undertaken by the nursing team has been less expensive. However the budget for 2019/20 will remain unchanged.

Insurance

Public Liability Insurance remains at the same level as in previous years.

Marketing

External printing and ink have been the main costs here allowing the nursing team and charity to use colour in its publications expected as standard by users.

Reserves Policy

The trustees have agreed to hold reserves (unrestricted funds) to cover one years running costs of the charity £60k.

It is also building reserves in order to fund the rental of a specific HCCN building which will enable the charity to deliver more of its services to its populations more easily. It will seek to build these reserves to £200k in order to look for external support to ensure long term viability of this plan. Reserves are held in interest bearing accounts

The charity holds no designated reserves.

Summary

Hunts Community Cancer Network has shown a 46% increase in income over expenditure this year. However, in line with most charities, fundraising and reputation management require constant attention if the charity is to continue to grow its share of the local charitable giving market.

HCCN is increasing its offering to users while managing to control expenditure.