

# MISSION, VISION AND VALUES 2019-2022



## Our founder Melanie Kennedy



Our organisation was founded by Melanie Kennedy a cancer patient who identified the issues faced by cancer patients in our region through her own cancer journey.

Our founder Melanie was given a stage 4

breast cancer diagnosis in 2013 and was told her prognosis was 5 years at best to live. Determined to be around to raise her children she embarked on making survival her job and becoming informed as much as possible about the options available for patients with an incurable cancer. She forged links with cancer charities, worldwide, U.K and regional support groups and worked with health NGO's to understand the potential treatments that should be available to patients, their side effects and how to ease them.

Melanie has been through surgery, almost permanent chemotherapy and biological therapy during all this time and researched and tried and tested proven complementary therapies that made her quality of life better and negated the side effects of long-term treatment.

It soon became clear to Melanie however that because of her location, Northern Ireland, she was denied access to the latest drugs and treatments because of the local government policy and this meant that not only would this result in her own life and the lives of all cancer patients in Northern Ireland being cut short it also prevented access to clinical trials and put Northern Ireland decades behind the rest of the UK and the world in terms of appropriate treatment and life expectancy.

Melanie started a high-profile campaign to change the government policy on this and gained cross party support and a promise of a review from the local health minister but unfortunately the government in

Northern Ireland collapsed shortly after. Determined to still affect change she sought charity status for N.I.C.A.M. wanting to provide therapies to improve the quality of life for incurable cancer patients here, no other organisation offered these patients anywhere to turn.

Our founder has a very high profile and cancer patients turn to our organisation as they have seen Melanie fight for their interests as well as going through exactly what they are facing. One of other trustees is a former cancer patient and because our founder is still in the system she keeps abreast of the ever-changing needs and challenges patients here face. They feel they can come to her / us because we understand, we have been there.

Very Happily we received charity status in June 2018 and in September 2018 the Northern Ireland department of health changed their policy and we now have equality with the rest of the UK with the commissioning of drugs and they have agreed to create Northern Irelands first ever cancer strategy.

Since forming the charity and providing services to help with the side effects of long-term cancer treatment the number of patients who have approached us, has shocked us. Our services are needed, and we add services because we consult closely with patients to identify what they really need in the rapidly changing landscape that is cancer survival.

People are now living longer and with our help living better and we want to continue this keeping ourselves focused on the patient and retaining that relationship of trust we have with them as every patient knows we are there for them. Our first funds in fact came from money our founder raised for a treatment she was denied and when she was awarded this drug on the NHS through our lobbying she used the funds to set up N.I.C.A.M, so patients know we have their best interests at heart. It's the reason we exist.

#### What Is NICAM?

We exist to support cancer patients who have been turned down for treatments in Northern Ireland to extend and improve their quality of life and or improve their chances of survival. We provide support people of all ages, backgrounds and gender.

N.I.C.A.M. was founded in March 2016, initially as a campaign for equal access to treatments for cancer patients in Northern Ireland that were unavailable here but available in other parts of the U.K. Since then equal access and advocating for the rights and interests of cancer has remained one of our core aims but we now also provide services and assistance to patients with an incurable diagnosis and anyone who has been denied access to a treatment by individual funding request. Cancer patients are vital members of our society and we want to see them receive the respect and help they deserve by breaking down the stigma around cancer and promoting the rights of cancer patients.

Our founder Melanie Kennedy has been living with Stage 4 incurable breast cancer for more than six years and in that time fought for equal access to treatments and has worked with many other agencies to bring about change, especially for cancer patients in Northern Ireland who are currently subject to a postcode lottery.

We provide advice, support and financial assistance to those who cannot currently access treatments in Northern Ireland. Providing support and financial assistance to patients to relieve the side effects of treatments. Providing support and financial assistance to patients under financial strain because of treatment and supporting patient's family, friends and carers.



#### Mission Statement

"NICAM is a charity that advocates, supports and champions local people living with incurable cancer."

#### Vision statement

This vision statement is designed to motivate and enable individuals and volunteers to see how their effort contributes to our overall inspirational charitable purpose.

"To be living in a world where incurable cancer becomes a liveable condition and not a death sentence."



**Values Statement** 

# "NICAM will treat people with honesty, dignity and compassion while challenging inequalities in healthcare."

Our Values are defined as a set of behaviours that we all uphold whilst delivering on NICAM activities:

**Honesty** is demonstrated by what we say and by what we do. We will be honest in all that we do whether by action, deed or communicants.

**Dignity** is recognition of the equal dignity of all persons. We will always treat everyone regardless of circumstances with dignity.

**Compassion** – we will be sympathetic and show concern for the sufferings of people with an incurable cancer diagnosis and their families

**Challenging** – We will be the champion, and advocate for people who request our help. We will challenge on their behalf.

#### **Beneficiaries**

- People living with incurable cancer
- Carers
- Public
- People with physical disabilities

#### **Public benefits**

The Benefits will be for those cancer patients who have been turned down for treatments in Northern Ireland to extend and improve their quality of life and or improve their chances of survival and are for the charitable purposes of advancement of health and savings lives

The direct benefits include:

- 1) Improving the health, well-being and quality of life of beneficiaries by providing a range of therapies and treatments to treat, complement and support their holistic health.
- 2) By providing information, advice, guidance, moral and practical support for sufferers of cancer and their families, friends and carers, this will help them come to terms with their diagnosis, manage their symptoms, improve their health, well-being and quality of life.
- 3) By bringing together people with cancer, their families, friends and carers as well as those with an interest in the disease, this will provide encouragement, help and support for beneficiaries.

4) By providing financial advice and assistance this will benefit patients by relieving financial strain caused by treatments. Especially at key times such as Christmas. This will help extend or improve their quality of life.

#### How our benefits can be demonstrated

- 1) Provision of therapies and treatments to treat, complement and support holistic health Patients are currently and will have sessions of therapies such as Lymph drainage reflexology, Hyperbaric Oxygen Therapy and Cancer appropriate spa treatments paid for directly by N.I.C.A.M. We would aim to expand these services as this will improve their health and well-being and ease the side effects of treatment. Patients currently and will receive direct financial reimbursement for travel costs incurred in travelling for treatments not available in Northern Ireland, easing financial strain and making a previously unaffordable treatment option available and therefore prolonging and or saving lives.
- 2) Patients currently and will receive financial assistance in obtaining and paying for treatments that are currently not provided by the N.H.S. in Northern Ireland, prolonging and or saving their lives. Patients will receive use of our social media and media links to crowd fund for life extending and or lifesaving treatments not currently available in Northern Ireland. Relieving stress and resulting in them obtaining treatments that will extend or save their lives.
- 3) Providing information, guidance and support for patients and their families. N.I.C.A.M. have two medical trustees and one cancer patient trustee, we also have a medical advisor and part of what we do is keep up to date with the latest research and treatments for cancer so we can pass this information on to cancer patients who have reached the end of the treatment options currently available on the N.H.S. in Northern Ireland can make an informed choice about next steps. This will result in the prolonging and or saving of lives and easing the stress and burden on the patient, their family, friends and carers.
- 4) Bringing together cancer patients, their families and friends and everyone working to further the cause of cancer patients in Northern Ireland. We currently use our large social media platform to promote the services of all Northern Ireland based cancer charities to make patients aware of all the services out there and to promote fundraising for these services. We also use this platform to bring patients and patient's families together to support each other and to alleviate isolation for patients. Currently patients or their loved ones can contact us at any time or contact us to be signposted to other services. This is to make life easier for the patient and all who care for them as they are not burdened with researching, we do that for them.
- 5) Providing financial advice and support N.I.C.A.M. currently give direct grants to incurable cancer patients at key times such as Christmas and we would hope to expand this. We also signpost patients to benefits and financial advice provided by other bodies. We also have a database of other charities that provide holidays and services for cancer patients. This is to improve quality of life for cancer patients and their families.

### Approach – how we propose to engage our stakeholders and the beneficiaries

- By providing advice, support and financial assistance to those who cannot currently access treatments in Northern Ireland.
- By providing support and financial assistance to patients to relieve the side effects of treatments.

- By providing support and financial assistance to patients under financial strain because of treatment.
- By supporting patients' family, friends and carers

#### **Business Goals**

- 1. Campaigning for access to the best available treatments.
- 2. Provide therapeutic services to improve quality of life.
- 3. Highlighting the unmet needs of local people living with incurable cancer to secure financial and political support.
- 4. Grow the capacity and resources of NICAM to best serve our beneficiaries.

#### **Next Steps**

- ✓ Increase the number of Trustees of the Charity to meet any skills gaps identified by a Board Skills Audit
- ✓ Stakeholder mapping leading to understanding priorities for NICAM over the next three years.
- ✓ This will be further expanded in the Strategic plan 2019-2022 to be completed.
- ✓ An income generation and fundraising strategy to fund priorities as set out in the strategic plan 2019-2022.

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