



OG Cancer NI

Stomach and Oesophageal Cancer Support



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IN THIS ISSUE

AWARENESS CAMPAIGN UPDATE

VOLUNTEERING MEANS TO ME

CNS UPDATE

OG CANCER SUPPORT GROUP

MAKE THE CALL

BIG IMMUNOTHERAPY UPDATE

CANCER REGISTRY DONATION

AUTUMN NEWSLETTER

SEPTEMBER 2020



CHAIRPERSON'S REMARKS AUTUMN 2020

Who would have thought that using Zoom would be the new normal for keeping in touch! It is such a pity that we cannot meet up as usual, to connect with the OG team, patients and carers and to chat over soup and sandwiches at the end of the Wellbeing Meeting. The second best option is a virtual meeting. I hope you can join us on Zoom for our meeting on Saturday, 3rd October 2020. Shauneen, who has put this newsletter together, has included easy to follow instructions for Zoom. If you have any difficulty with this then please ask a friend, a relation or a neighbour to help you. We have some interesting speakers lined up who will give you helpful, reliable advice and information.

Karen Kelly - Assistant Service Manager for Cancer Health and Wellbeing

Claire Murphy - McMillan Move More Coordinator

Michelle Casement - Make the Call

There will also be time for questions and answers.

During the last few months the Trustees and Committee of OG Cancer NI have been very busy. Lorraine, Frances and Leanne have been contacting the District Councils, Health and Wellbeing Organisations and Rural Support groups across the country to promote our message "Catch it Early". This has been in conjunction with the successful Awareness Campaign led by Andy Rice Creative.

Like other organisations in the charity sector, OG Cancer NI has been unable to undertake its normal fundraising activities this year due to the ongoing Covid19 situation and we extend our thanks to those who have fundraised or made donations in recent months. Perhaps some of you can think of an innovative fundraising project which is compatible with social distancing and other current constraints. If you can think of such a project we would be delighted to hear from you!

The link to our Facebook Donate page is: <http://www.facebook.com/fund/OGCancerNI> If you click on the link then you can create your own fundraising page. The Just Giving link is <https://www.justgiving.com/ogcancer.ni>

Thank you to everyone who has helped to put this newsletter together. I must mention Shauneen and her husband Diarmaid who have put up with my emails, telephone calls and generally being a nuisance. In these changing times we are all learning how to live our daily lives differently. I wish you all well and please take extra good care.

With warmest wishes,
Helen

DID YOU SEE OUR AWARENESS CAMPAIGN?

We've just finished our 2020 'CATCH it EARLY' awareness campaign. Targeting those in the medical sectors, such as pharmacy, GP's, nurses etc, those in the rural communities and people from a farming background. Launching in July and running to Mid-September we had information across the internet on Facebook, Instagram & Google. This was complimented with a Radio campaign. Did you hear our see our ads? We would love to know your thoughts and ideas for future campaigns.

CNS UPDATE

Karen, Louise & Maureen

Karen, Louise and Maureen are all back to normal working after a brief visit to the COVID wards. We continue to help and support our patients and families through diagnosis and treatment plans. Surgery is back up and running in the City site and we have recently moved to Ward 7 South.

There has been a bit of a change to where patients are being seen and treated from the Oncology team, all assessments are now being carried out in the Bridgewater Suite and all chemotherapy administration is being given in Ward 3A Cancer Centre. We continue to refer patients out for counselling and family support to the different agencies, such as Cancer Focus and Macmillian, a lot of these are done by telephone or Zoom calls.

We are aware that this is a very difficult and uncertain time for patients and families, and are keen to let patients know that we are still here for advice and reassurance.

We hope that you are all keeping safe and well.

KLM xxx



VOLUNTEER FOR OG

Lorraine Pinkerton - Volunteer Coordinator



This year has been different for us all. As a volunteer with OGCancerNI, I would normally be involved in manning the Information Desk at the Belfast City Hospital, helping at our Health and Wellbeing Meetings and attending various events to help raise awareness of oesophageal and stomach cancer. So COVID19 has curtailed these activities, but we have been determined not to let it stop us raising awareness which is more important than ever. Along with some other volunteers I have been involved in contacting district councils to gather information on local community groups, in particular those for rural and older populations. We have had an article by our Chairperson, Helen Setterfield published in some local news sheets along with our 'Catch it Early' campaign information. The links we have made will be invaluable in the future when once again there are events that we can attend to continue our worthwhile work. If anyone knows of any community groups in their area that we could provide with information please do let us know.

THE CYTOSPONGE – EXCITING NEWS.

The cytosponge is a tablet on a string.

The patient swallows the tablet, the nurse/doctor holds the end of the string.

The casing of the tablet dissolves in the stomach.

The pill expands into a small sponge.

The string is quickly pulled out by the nurse/doctor

As it is pulled up the sponge picks up cells in the oesophagus, which can be analysed.

The test detects Barrett's Oesophagus and potentially early stage cancer.

The test can be performed in the doctor's surgery.

The research into this test was led by Professor Rebecca Fitzgerald at the University of Cambridge.

The results of the Best3 trial were published recently.

Results of the test were very positive:

- 95% test success rate
- detection of Barrett's increased ten times

This test may be used instead of an endoscope.

Let's hope the test will be rolled out in NI at the earliest possible time.



VOLUNTEERING - WHAT VOLUNTEERING MEANS TO ME

Frances Hill - Volunteer



For me, someone who has suffered from oesophageal cancer, volunteering is about giving back and reaching out.

Those who have suffered from either oesophageal or stomach cancer know that returning to health and normal life would not have been possible without considerable specialist medical care and, for the fortunate, the invaluable support of family and friends. In my view, the best way to repay those involved in one's recovery, is to offer care and support to others who fall victim to these cancers and who may feel anxious, stressed and, possibly, alone. Few wish to burden family and friends with their concerns and may find it easier to discuss their situation with a stranger, such as an informed volunteer.

Most people who have been a cancer patient are very keen to ensure that others do not fall victim to these illnesses and understand the need to raise community awareness of cancers, and their symptoms, which may not be widely known, yet be on the increase - as is the case with oesophageal and stomach cancers. We volunteers can assist with this by, for example, setting up awareness stands at supermarkets and other venues, distributing informative literature to interested members of the public and assisting at awareness-raising events, such as charity walks and cycles. Many of those who have been recently diagnosed with cancer, are receiving treatment, or are in the post-treatment phase appear to derive great benefit from meeting and talking to others, who have either shared similar experiences, or who have insights deriving from close association with cancer sufferers. Again, most OGCancerNI volunteers fall into these categories and can provide this kind of information and support by participating in various events, such as the bi-annual wellbeing meetings organised by the Charity, by helping with its information stand at the Belfast City Hospital on the relevant clinic days and by participating in events organised for patients, past and present. In addition to giving back and reaching out, another very rewarding and humbling aspect of volunteering with OGCancerNI, is being able to associate with a wide range of people whom one might not have met otherwise. So many of these are good-humoured, interesting and inspiring, despite the tribulations they may have had to endure or are enduring, and it is a privilege to be in their company.

OG CANCER NI GROUP

As someone who worked in the health service for over three decades, Noeleen said she never knew anyone who survived Oesophageal Cancer. Her consultant put her in touch with a group of other people who had.

The OG Cancer NI group, which is Belfast based but has members from all over Northern Ireland and meet twice a year. The patient and carer led group offers support and advice to people who have OG Cancer.

Noeleen said the group has finally allowed her to meet others who have beaten the cancer.

"The support group provides help and information. It also allows us to find out more about the research being conducted into OG Cancer. Getting diagnosed with cancer has an impact on your mental health. As the years go by and you meet others in similar situations, you accept it a bit more."



27 YEARS SINCE SURGERY



Billy Montgomery's wife Diane was diagnosed with Oesophageal cancer 27 years ago.

Julie Hanna was the Sister in the Recovery ward in RVH at that time. When Diane was discharged she was given 2 small leaflets and received very little help for 6 years.

Fortunately Roy McMullan, along with Julie, started a support group for patients under the auspices of the OPA. Julie and Billy became Committee Members at that time. The organization has now reformed as a local NI based charity and both Billy and Julie remain as committee members.

Billy and Diane do a lot of walking, especially on the North Coast. Diane still remembers her joy of first meeting and talking to others who had also had the same surgery. Current patients still find meeting other OG patients a very positive experience.

PROMISING PROGRESS FOR IMMUNOTHERAPY IN GASTRIC AND OESOPHAGEAL CANCERS

Our immune system works to protect the body against infection, illness and disease and it can also protect us from the development of cancer. However, a cancer might develop when the immune system recognises cancer cells but it is not strong enough to kill them. A new form of treatment called immunotherapy can release the power of the immune system allowing it to destroy the cancer cells.

Results for a series of clinical trials were presented at European Society of Medical Oncology (ESMO) this month and they have shown that immunotherapy is beneficial for patients with gastric and oesophageal cancers. Chemotherapy treatments for oesophageal and stomach cancers, prior to their removal by surgery or for cancers which have spread have not changed for several years. The results of these clinical trials represent promising progress.

In patients whose cancer has spread at the time of diagnosis the addition of either of the immunotherapy drugs ivolumab or pembrolizumab to standard chemotherapy were shown to control the cancer for longer and lengthen life. Both of these drugs had limited side effects and results for their effect on quality of life are awaited. For patients who have received surgery to remove their tumour a course of the drug nivolumab immediately after the operation was shown to help to prevent the tumour returning.

Further information is needed to understand how best to use these drugs and which patients will benefit from them and both will need to be approved for use by the relevant government authorities before they become available. However, these first results are promising and represent positive progress in the treatment of oesophageal and gastric cancer.

OG CANCER NI GIFT £10,000 TO NI CANCER REGISTRY

The NICR will undertake an audit of oesophageal and gastric cancers diagnosed between 2017 and 2018. The last audit of the OG cancer patient's journey in N. Ireland was almost 15 years ago in 2005.

This audit will allow for direct comparison of performance in the care of patients with peer nations in England and Wales. It will provide the evidence base required to help service providers to improve services in Northern Ireland. This in turn will drive improved quality of care for OG cancer patients, with the aim to improve care and overall patient survival.



The second benefit is the ability to answer research questions and a lot of these are around access to care. Some cancer registries have reported that the distance someone lives from a Cancer Centre can influence whether they end up getting treatment. The Dutch cancer registry reported this year that females were less likely to be offered surgery for oesophageal cancer (they weren't really sure why. There is also data indicating that patients under 50 present with disease at a later stage and this could be due to delayed diagnosis or delayed referrals for treatment.

All of these issues could help in planning future services and making sure everyone is treated fairly.

MAKE THE CALL

To make sure you're getting all the benefits, services and supports you're entitled to, make the call on freephone 0800 232 1271. Most benefit services are still available as normal, however they may be experiencing higher levels of calls than normal.



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DURING THIS TIME CONTACT US ON

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