

focus on



Cancer
Focus
NORTHERN IRELAND

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CHIEF EXECUTIVE'S FOREWORD



Hello everyone! I hope everything has been going well for you since our last newsletter. Work is as busy as ever as we keep our minds focused on all things cancer related.

You may have been following our Equal Access to cancer drugs campaign, which we are pushing ahead with and we're hoping for more news in the coming months. You can read our update on page 6. As well as continuing to provide our wide range of care and cancer prevention services, we've also been attending a number of conferences to keep up to speed on recent developments. Our Head of Cancer Prevention Gerry McElwee was a guest speaker at the All Ireland Cancer Consortium at QUB University in May, with delegates coming from Europe and the US to share ideas on research, prevention and care.

And in November, we're hosting the European Cancer Leagues' (ECL) annual conference in Belfast. As a member of the ECL board, I believe it's essential to liaise with other countries developing innovative services and cutting-edge research.

Our Keeping Well service is also growing, bringing our health checks and messages into local communities. If you'd like our mobile health units to visit your workplace or organisation please email keepingwell@cancerfocusni.org or call 028 9066 3281.

We've been highly commended in the University of Ulster Placement Employer of the Year Awards. Each year we employ five or six students and give them valuable experience that will help them make a fantastic start to their new careers after graduation. I'd like to thank them for their valuable contribution.

I'd also like to thank all our fundraisers who work so hard to help us fund our good work.

Wishing you all the very best,

Roisin Foster
CHIEF EXECUTIVE



Why more care is needed for cancer patients

Research by the NI Cancer Registry at QUB, and funded by Cancer Focus NI, has highlighted the need for more support for local cancer patients.

The report, *Dying with Cancer – Perspectives of Bereaved Relatives and Friends*, has identified key factors influencing what enables cancer patients to die at home.

It says these factors need to be addressed urgently as the number of cancer cases in NI is set to rise by 66% over the next 20 years.

Information from 467 relatives/carers of cancer patients revealed that while almost three quarters of patients (74.7%) said they wanted to die at home, only over a third (38.2%) actually did. Another 41.1% died in hospital, 12.0% in a hospice and 8.8% in a care home.

The report calls for:

- more training in good communication about end of life care
- a key health care worker linking with the patient and family
- more studies on how to support carers in the home

You can see the full report on www.qub.ac.uk/nicr

Find comfort writing about your cancer journey

Louise Gough was first diagnosed with bowel cancer in 2012. Her cancer has come back for a third time and she's pinning her hopes on her very last cycle of chemotherapy - but keeps on smiling.

The young Belfast mum is tremendously supported by her friends and family, particularly husband Mark and their two boys, Darren (13) and Tony (9). But she also has important extra support from Cancer Focus NI. She says our counselling service is a real 'safety net', and our writing service is a valuable emotional outlet.

"Mark was devastated when I was diagnosed but it just didn't register with me," she recalls. "The surgeon was very frank and didn't sugar coat anything. He started to talk about life expectancy, but I stopped him in his tracks. I didn't want to hear that – I said if there was anything they could do to help me, just do it."

Louise had an operation to remove the tumour in her bowel and then 12 cycles of chemotherapy over six months, which shrank the tumours in her liver.

Two years ago, she had surgery on her liver. "I was very up-beat, I'm a strong, cup-half-full sort of person. As long as the doctors were saying there was a chance, I was determined to plough on.

"Then, I had another operation on my gall bladder and spleen, which was touch and go. I hit a brick wall - I just couldn't get back on my feet as quickly as before."

Everything was okay for a while, but then scans showed spots on her lungs and stomach. She has started chemo again – but this will be her last round. "It needs to work this time," she admits, "It's a real reality check."

"As soon as I have thoughts like I might not be around to see Darren go to university, or see another Mother's

Day, I quickly shove them out of my mind again. Tony only knows mummy's belly is sick, but the doctors are helping," she says.

Louise felt she needed to speak to a counsellor, both for herself and because she didn't want to overburden her loved ones. "I needed answers to help my family. My body wasn't the one I used to know so well, I was so scared and in a dark place. I just wanted to scream 'help' for as long and as loud as I possibly could."

Our counsellor helps her understand that her thoughts are normal and to look at things in a different way. He gives her guidance and strength, and helps her let the old Louise go and accept the new Louise.

Louise also takes part in our Writing My Cancer Journey sessions, which helps you express what's in your heart and mind. She's made important new friends who're going through similar experiences.

"I found I could write things I didn't think I was capable of. It's helped rebuild my confidence and look at things in a new way. Other patients have told me that they look at cancer as a gift, that's changed their outlook on life, and this attitude has helped me deal with everything I've been going through.

"I have a genuine smile and am forever the optimist, but a realist too. As soon as a negative thought pops into my head, I get rid of it and enjoy what I have now."



Louise Gough

If you'd like to join our writing group, creative writing course, art therapy or art journaling, please call us on **028 9066 3281** or email **care@cancerfocusni.org**.



Louise's husband Mark and sons Darren and Tony

A brighter outlook ahead for workers

Health Minister Simon Hamilton (second right) has given the stamp of approval to our new sun safety policy pack, which aims to prevent skin cancer.



We've produced it along with the Public Health Agency (PHA) to help farmers, builders, grounds staff, postal workers and other outdoor workers be more aware of safety in the sun.

With the Minister are (l-r) Ian Young, Causeway Coast and Glens Council, Des Campbell, DARD, and Peter Reavey, Graham Construction.

All's well with Well Aware

Our Well Aware service – which aims to raise cancer awareness and improve the health of over 60s - has had a very successful first two years.

A new report shows that our staff visited 105 venues and 1,037 people have had health checks. Another 1,386 attended health promotion sessions.

Our service visits over 60s - a group with a higher risk of cancer – in supported living schemes, residential homes and community groups.

Well Aware is a partnership between us and Oaklee Trinity (soon to be renamed Choice Housing) and is funded by the Big Lottery Fund for five years. Over the next three years, we'll be focusing particularly on men, people with cognitive impairment and smokers working in sheltered accommodation. For more info email wellaware@cancerfocusni.org or call 028 9068 0743.



Men's Health Month

The theme for Men's Health Month in June is 'Creating Culture Change – it's time for a new script'. The aim is to create a change in our culture to support the health and wellbeing of men and boys.

Around 100 delegates attended our Men's Health Conference in Antrim in June, updating health workers and others with an interest in men's health and cancer issues.



Irish rugby legend Tony Ward spoke at the conference about prostate cancer

Our Man Van was also there to give delegates a health MOT. To book our van for your organisation, call 028 9066 3281 or email keepingwell@cancerfocusni.org.

Thank you Lidl

Genevieve the Goat, Roisin Foster, Cancer Focus NI, and Eabha McGovern (3) thank Aoife Clarke (right) for



more than a 'Lidl' helping hand over the company's eight year charity partnership. Lidl raised €360,000 for our services including Lidl Fit Factor for P4s and Genevieve the Goat sessions for nursery children which help lower their risk of cancer in later life.

For more email schools@cancerfocusni.org.

Here's why we're so Proud to be Quitters

Teenager Rachel Armstrong (right), from Belfast, is one of the ex-smokers who's 'Proud to be a Quitter' - the theme for this year's No Smoking Day in March.

Rachel (15) says: "The work that Cancer Focus NI does with schools is great and really gave me the confidence and final push I needed to give up. The charity opened my eyes to all the harmful chemicals that are in cigarettes and long and short-term effects, which really brought home what I was doing to myself."



Lilliput Laundry Service employees in Dunmurry who took part in the PHA Workplace 28-Day Challenge to quit.

More than one in five adults in NI smoke, doubling their risk of heart attack and stroke. Smoking also causes more than a quarter of all cancer deaths. In fact half of all smokers will die from smoking. The good news is that quitting is the single best thing you can do for your health.

We hold stop smoking clinics, funded by the Public Health Agency (PHA), for all age groups in many venues, including workplaces, GP surgeries and in community venues. To find the one nearest you or to order a free Quit Kit visit www.want2stop.info.



Go dotty on Dot Day

Calling all secondary schools - put a date in your diaries for a fun Dot Day!

This is a day when your pupils and staff wear a dot sticker as a reminder to be body aware, to remember loved ones and to raise funds to help our community work.

Your school could organise a Dot Day as part of Healthy Schools Week and hold staff health checks, cancer prevention sessions, stop smoking support or get involved in volunteering for our charity. We've lots more ideas! To see how two local schools organised their Dot Days, why not check out our website - www.cancerfocusni.org/fundraise/fundraising-at-school - and watch their video.

Email suzanneoloughlin@cancerfocusni.org or call **028 9068 0741**.



Christian Brothers, Omagh, had a rock concert



Loreto Grammar, Omagh, dressed up for a Pink Dot Day

Fireman Fintan

Fintan Loughran, from Cookstown, made an anti-smoking TV advert in our Smokebusters schools' competition and won an exciting day out as a firefighter.

Congratulations Fintan!



Bagging a bargain

Belfast's Victoria Square bagged over £25,000 for us during a hugely successful one year charity partnership! A massive thank you to all the volunteers, staff and customers who contributed to the many fundraising events throughout the year including wrapping Christmas gifts, spinathons, collections and raffles.

Our Lagan Dragons are making a splash

Our newest service – the Lagan Dragons – is afloat!

Deirdre Conlon, Cancer Focus NI Care Services Manager, says: "Dragon Boat racing for women who are affected by breast cancer is well-known around the world but our team is a first for Northern Ireland."

"Dragon Boat racing helps women get fitter after breast cancer treatment, makes them feel better emotionally and is a great way to make new friends. It's a fun way to get your life back on track."

She adds: "Already we have a regular turn out of around 20 women, mainly from the Greater Belfast area. Bryson Lagan Sports have also come on board to provide us with boats."

"We meet each Saturday morning, row for an hour and finish with a cup of tea. We'd be delighted to hear from anyone who's interested in joining."

To join email leonnemorrison@cancerfocusni.org or call us on **028 9066 3281**.



Equal Access to cancer drugs - update

As you may know, Cancer Focus NI launched its Equal Access campaign in June last year calling for local patients to have the same access to cancer drugs as patients in England. These are specialist drugs that are not readily available here but which could extend the lives of patients, improve their quality of life and ease symptoms.

Our campaign has been hugely successful so far and as well as bringing the issue to the attention of our MLAs and MPs, we collected a petition of 26,000 names which we presented at Stormont.

Last year, the former Health Minister commissioned an evaluation of the existing system for access to these drugs – the Individual Funding Request (IFR) – and five improvements have been recommended.

The IFR process is intended to provide access to unapproved specialist drugs for patients where there is an agreed clinical need, but it currently denies access to 95% of patients in the initial stages of their request. The new recommendations include plans to remove the 95% barrier, and a proposal to re-introduce prescription charges to pay for a new Specialist Medicines Fund.

The Department of Health invited the public to six consultation meetings in venues across NI to discuss the suggested improvements and their views on the best way

forward are currently being considered by the Department.

Our Chief Executive Roisin Foster says: "We see these new recommendations as a great step towards securing equal access for patients here."

"However, we regret that the issue of equal access to cancer drugs and the re-introduction of prescription charges have become linked. We believe there are a number of other ways to fund a Specialist Medicines Fund.

"These include using the rebate from the Pharmaceutical Price Regulation Scheme (PPRS) to give access to new drugs, which it was originally set up to do. £30m from the PPRS is expected to be returned to DHSSPS this year alone, while only £6m – 8m is needed to give Equal Access to cancer drugs here.

"Alternative funding methods include increased prescribing of cheaper generic drugs and a review of the items currently available on prescription.

"We'd like to thank you for your support to date and assure you that this campaign will continue until we achieve equal access."

For more information on this campaign visit www.cancerfocusni.org



Coming up roses

We're delighted that Dobbies Garden World in Lisburn is one of our newest corporate partners for 2015. Employees will spend the next year raising funds by holding sporting challenges, events and raffles.

For more details on charity partnerships or to help with collections or events, please contact Cancer Focus NI eointreanor@cancerfocusni.org.

Giants pull a fast one for ManVan



Cancer Prevention Officer Stephanie Allen gets a helping hand from Belfast Giants Adam Keefe (left) and Craig Peacock, who are calling you to take up our ManVan MegaPull challenge during Men's Health Month in June in five locations around NI. For more information email eointreanor@cancerfocusni.org

Volunteers Week

Volunteers Week (June 1-7) is a time to acknowledge what our wonderful volunteers have been doing for us over the last year.

We want everyone to know the fantastic contribution each volunteer brings to our work.

We'd like to say a massive thank you to everyone who's helped us – whether in administration, driving patients, beauty therapists, family support, shop assistants, champions, box collectors, walk leaders, fundraising or helping at outside events and more. You're our local heroes! For more details visit www.cancerfocusni.org or call us on **028 9066 3281**.



Equal Access supporter John McAllister, from Belfast, is pictured with his granddaughter Dala and son Daniel. John was diagnosed with malignant melanoma in 2011 and has benefited from life-prolonging drugs.



Wine Inns

Thanks to the staff and customers at Wine Inns for their fantastic fundraising efforts during the past year which netted an incredible £13,877 – thanks to everyone including Leonie Bond, Wine Inns Marketing Manager, and Chris Comiskey, Assistant Manager, Cutters Wharf, Belfast.

Payroll Giving - working for a good cause is easy

Payroll Giving is a flexible scheme which lets you, if you're a UK income taxpayer, to give regularly and on a tax free basis to Cancer Focus NI directly from your salary.

Payroll Giving donations are deducted before tax so if you decide to pledge £5 per month it will only cost you £4 (for standard rate taxpayers).



Amanda Corbett

Amanda Corbett, from Belfast, says: "I work for Boots who are part of the payroll giving scheme. I really wanted to support Cancer Focus NI and decided to join the scheme a few years ago because it was the most tax effective way to support them.

"Cancer Focus NI is close to my heart as they really helped my Mum's friend when she was diagnosed with cancer. I keep up-to-date with their work and feel proud that my monthly donations are helping them help so many other local people."
For more information about how to start donating like Amanda, please email olliegovett@cancerfocusni.org or call **028 9068 0740**

Choir hits a high note

A crowdfunding project – fundraising using Twitter and Facebook – has raised an amazing £10,000 for the Sing for Life choir. Another £5,000 has been raised so far at bucket collections, concerts and other fundraisers.

Sing for Life is for people affected by cancer and is a partnership between Cancer Focus NI and the Crescent Arts Centre. It was inspired by the Sing With Us choir, which was formed by the Welsh cancer charity, Tenovus.

The money raised in this appeal will be used to send Sing for Life members on a journey to Wales to perform with Sing With Us this autumn.

We're delighted with the result. Many thanks to everyone who helped make this possible.



Love a challenge?

Why not take up one of our challenge events – and raise much-needed cash to help run our services for cancer patients and their families? You could take on the iconic New York marathon on November 1 or join over 50,000 runners/walkers in Newcastle for the popular Great North Run half marathon on September 13. For more details about these and many other events email Emma at events@cancerfocusni.org or call **028 9068 0771**.

Urgent help needed

We're urgently looking for volunteers to help us bucket collect in Belfast at the Gran Fondo cycling event in the Titanic Quarter, on Saturday 20th June. Please email Morag at moragchambers@cancerfocusni.org asap. **We can't do it without you!**

Getting away this Summer?

Did you know you can raise money for us whilst you book your travel - **Just by shopping online** and without it costing you a penny extra.
www.payrollgiving.com/join/cancerfocusni



For information on our upcoming events log onto www.cancerfocusni.org

