

Progress

In this issue find out how you can help us Take It On during Pancreatic Cancer Awareness Month. Join hundreds of people across the country this November, helping to raise vital funds for research that will save lives.



3. Northern Ireland

Find out all about our Northern Ireland Community Coordinator, Andrea.



4. Patient support

Read more about the importance of addressing the psychological needs of patients.



6. PCAM: November

Pancreatic Cancer Awareness Month is almost here! Are you taking part?



9. Young fundraisers

Age is no barrier to fundraising for us. Find out about our youngest fundraisers.

Up and coming

September – November 2018

Living with Pancreatic Cancer Support Days

If you're living with pancreatic cancer, we'd love you to come to a support day near you. We have a number of free support days lined up around the UK and you're welcome to bring a family member or friend with you.

pancreaticcancer.org.uk/supportdays

March 2019

The Vitality Big Half

10th March

Join our team for the second year of this fantastic half marathon starting in Tower Bridge and finishing in Greenwich.

pancreaticcancer.org.uk/highalf

May 2019

Edinburgh Half Marathon

26th May

Take on this beautiful and flat half marathon, and accomplish the challenge of a lifetime!

pancreaticcancer.org.uk/ehm



Taking It On for Pancreatic Cancer Awareness Month

Pancreatic Cancer Awareness Month is now only a month away, and we're gearing up to make it the biggest and best ever.

With survival from the disease little changed over the last forty years, we believe pancreatic cancer is an emergency and we need change fast. So we hope you will join us to Take It On this November. Show your support, campaign for change and help to raise vital funds for research that will lead to earlier diagnosis and faster treatment, saving more lives.

But this edition isn't just about Pancreatic Cancer Awareness Month.

Andrea Kearns, our Northern Ireland Community Coordinator, is featured on page 3, and explains how she delivers support and information to patients, families and carers. She's also embarking on her own personal challenge by trekking to Machu Picchu next year!

Professor Andrew Hart and his team at the University of East Anglia have secured a £147,000 grant with the help of our Research Involvement Network for their work into a new type of painkilling treatment for pancreatic cancer. Find out how on page 8.

There's also the wonderful story on page 9 of how three fantastic youngsters are helping us take on pancreatic cancer through their amazing fundraising. I'm sure you'll agree it is incredibly heart warming to read their stories.

I hope you are inspired after reading this edition of our newsletter and will join me this November to Take It On.

Thank you so much for your support.

Diana Jupp

Chief Executive, Pancreatic Cancer UK

60 second interview

Andrea Kearns, Northern Ireland Community Coordinator for Pancreatic Cancer UK.

Who are you?

I'm a 46-year-old mum-of-two from Belfast, who's also now a doting grandmother – but most of the time, what keeps me particularly busy and inspired is helping people with pancreatic cancer across Northern Ireland.

Tell us about your role?

I'm on the front line. A friendly face of the charity. My role is to go out to hospitals delivering support and information to patients, families and carers, including letting them know about the Specialist Nurses who work on our Support Line and the other support we offer.

I also work with healthcare professionals, members of the Northern Ireland Assembly and others to raise awareness of pancreatic cancer helping to make sure that everyone with the disease gets the care and treatment they deserve.

What's a typical day?

Every day is different! I could be running one of our information stands at local hospitals, talking to people directly affected by pancreatic cancer. Or speaking to local health professionals about the free support and training Pancreatic Cancer UK offers. Or even attending a local fundraising event on behalf of the charity. Sometimes I do all three on one day!

What inspired you to get involved?

I lost my dad to cancer and I always wanted to get involved like this and give something back.

What inspires you?

Well I'm now preparing to trek the Inca Trail to Machu Picchu next year to help raise funds for Pancreatic Cancer UK. It's great to have the chance to go that extra mile – literally!



Tell us about a highlight during your time at Pancreatic Cancer UK?

In October last year, Abraxane was approved for use in the NHS in Northern Ireland. This was a huge step forward because Abraxane can give people with advanced pancreatic cancer two more months or sometimes even longer with their loved ones. So I'd like to say a big thank you to our supporters in Northern Ireland and the rest of the UK for their help campaigning to make this happen.

What else can people do to support us?

Well, they can always do the Inca Trail with me! Or there's lots of other ways to get involved with the charity in Northern Ireland. Anyone interested can find out more at pancreaticcancer.org.uk/northernireland

The psychological impact of a pancreatic cancer diagnosis

The impact of receiving a pancreatic cancer diagnosis often has an emotional and psychological effect as well as physical. Recent NICE guidelines acknowledged the importance of addressing psychological needs of pancreatic cancer patients. We spoke to Helen Miller, a specialist Macmillan Psycho-oncology nurse at The Christie Hospital in Manchester.



What impact can a diagnosis of pancreatic cancer have on a person's mental health?

A cancer diagnosis can be devastating for patients, their families and friends. Patients often describe feeling like they are on an emotional roller coaster, as if they are out of control and like their life has been taken over. Patients commonly experience a period of adjustment where they describe mood changes and an increase in worry and anxiety. If they receive treatment, their journey can be physically and emotionally demanding with frequent appointments which can lead to them feeling like they have lost their sense of self.

What support do patients need if they are suffering psychologically?

Most patients will need time to adjust to their diagnosis. It is important to acknowledge how devastating a diagnosis is and to offer support and information whenever we have contact with them. Asking how they are coping and offering support early if we think they are

struggling is very helpful. Using tools such as the Holistic Needs Assessment can help to highlight whether extra input is required to support their emotional and mental health needs. There are lots of services available for people to access support through the NHS and charitable organisations.

Why is it so important that they get that help?

We know that patients who have symptoms of depression and anxiety do less well with treatment. Depression and anxiety are strongly associated with increased morbidity. Mood changes and anxiety can make it difficult to engage with the treatment process or supportive care. Getting to appointments can become impossible and they can be less inclined to report any side effects or concerns about their health or wellbeing which can delay intervention.

What more do you think nurses and other health professionals need to do in order to meet the psychological needs of their patients?

In the past few years there has been increased awareness of mental health issues and the impact that they can have on people's lives. The most important thing we can do is to ask how patients are coping and to provide care for mental health as part of the treatment we provide. Early diagnosis of mental health problems and appropriate intervention from specialist services is crucial in providing good care. Helen will be speaking at the National Study Day for Clinical Nurse Specialists and dietitians on Monday 15th October in Birmingham.

If you need help or support, whether you have the disease or know someone with it, you can always call our Support Line on **0808 801 0707** or visit **pancreaticcancer.org.uk/getsupport** for more information.



We've updated our Patient Charter

When we launched our Patient Charter in 2016, our aim was simple: we wanted to make sure that everyone with pancreatic cancer got the very best level of care - because time and time again families told us that theirs simply wasn't good enough.

We worked with people affected by pancreatic cancer to create a Patient Charter that outlined the support and treatment that people with the disease should expect to have while they are being diagnosed and treated. And we encouraged people to talk to their doctors and nurses if they felt they weren't getting the care they needed.

Two years on, our Patient Charter is as important now as it's ever been. We have recently updated it to include the new guidelines from the National Institute of Health and Care Excellence (NICE) on the diagnosis and management of pancreatic cancer.

The NICE guidelines have been produced for health professionals in England, Wales and Northern Ireland, and provide, for the very first time, guidance on how to diagnose, treat and look after people with the most common type of pancreatic cancer, pancreatic ductal

adenocarcinoma. Although doctors don't have to follow the guidelines in all situations, they must take them into account when deciding how to care for their patients.

You can download your copy of our Patient Charter and read our guide to NICE's guidelines on our website. Use them both to speak to your doctors if you have any questions or concerns about the care you're getting.

"The Patient Charter and Pancreatic Cancer UK's guide to NICE's guidelines are a very useful summary. They explain what has been recommended as well as providing an explanation of why that recommendation was made. I think they will be very helpful for anyone with pancreatic cancer as they provide a guide to the current standards and a basis for discussion between a patient and their healthcare professionals."

Professor Derek O'Reilly, Consultant Hepatobiliary and Pancreatic Surgeon, Manchester Royal Infirmary

Visit pancreaticcancer.org.uk/justdiagnosed for more information

Pancreatic Cancer UK

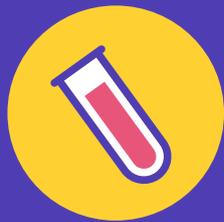


November is Pancreatic Cancer Awareness Month and we are on Purple Alert.

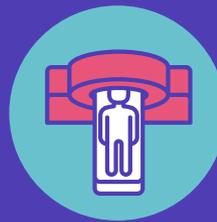
Pancreatic cancer: the toughest cancer to diagnose, treat and survive.

1 in 4 people won't survive for a month. 3 in 4 won't survive for a year. This is an emergency. We need change, fast.

It's time to Take It On. With your help we can fund research that saves lives, by:



Identifying a blood test for quick diagnosis



Developing better imaging equipment



Developing a fast track to surgery



Personalising medicine to make it more effective

You can hold a **Bake Off, Stand Out** from the crowd, take on **Challenge 24** or **Do your own thing**. To sign up, or for more information, visit pcam.pancreaticcancer.org.uk or call **020 3535 7090**.

Sign up today to **Take It On**

Will you **Take It On** this Pancreatic Cancer Awareness Month?



Sharon wanted to make a big impact in Pancreatic Cancer Awareness Month by standing out as much as possible. Sharon dyed her hair purple and took on a new look to raise awareness and an amazing £284! Stand out like Sharon this November.



The Downshire Hotel in Northern Ireland have supported us since 2016 by taking on challenges and organising coffee mornings. However last year they decided to take things to another level and got everyone hula-hooping! They filmed videos every day of them practising which went viral in their local area. Together as a workplace and community they raised over £3,000!



The fantastic Charlie (age 5) and Finley (age 3) wanted to make a difference to pancreatic cancer and be the biggest supporters of their grandad by cycling for **24 miles** in November. Charlie and Finley were amazing and raised £665 for Pancreatic Cancer UK!

Naomi, Andy, Lottie and Tom took on pancreatic cancer last November by walking **24 miles** over the month in memory of Kath, an amazing mum, mum-in-law and grandma. They walked through some of the most beautiful parts of Devon to make



a difference to the statistics of pancreatic cancer, raising £560. Kath had only 4 months from her diagnosis to when she passed away – so they were really happy to be able to do something positive to celebrate and remember her - and create wonderful memories for the children. Take on pancreatic cancer with your family this November and make a difference like Naomi and her family.

Professor wins grant thanks to our support

With the help of our Research Involvement Network, Professor Andrew Hart and his team at the University of East Anglia have been awarded a grant from the National Institute for Health Research for their work into a new type of painkilling treatment for pancreatic cancer.



Professor Hart's research is exciting because people with pancreatic cancer often suffer from severe abdominal pain, which lowers their quality of life and makes undergoing treatment harder. At the moment, when pain first occurs, the only proven treatment available to patients are strong painkillers containing morphine, known as opioids. But these can cause side effects and don't always relieve the pain completely. New treatments that can be given instead of opioids and which won't cause side effects are urgently needed.

Professor Hart's team are assessing two types of endoscopic treatments for treating pain when it first occurs. These involve swallowing a small tube so doctors can reach the nerves in the pancreas involved in pain. These pain nerves can then be blocked by injection which may relieve pain more effectively than by taking opioid tablets.

But, before he and his team designed the study, Professor Hart wanted to speak to people affected by pancreatic cancer to see whether they thought this research was needed. And, if there was anything in particular he should keep in mind when undertaking this research.

And that's where our Research Involvement Network came in.

Members of the Network helped Professor Hart's team with various aspects of the research planning. These included emphasising just how vital good pain relief is for patients, who often worry about their pain not being fully controlled.

Professor Hart said: The Research Involvement Network's input was key in the development of our study and the comments we received, such as how and when to approach participants were invaluable. I am sure their help contributed to our team being awarded the grant."

This is the first stage of Professor Hart's research. Their ultimate aim is to see if endoscopic treatments given when pain first develops can improve patients' quality of life and make undergoing treatment easier. This research has the potential to dramatically improve the lives of people with pancreatic cancer - and we are proud of the part our Research Involvement Network played in helping Professor Hart and his team secure funding.

Our Research Involvement Network explained

The Network is a group of 130 people who have been directly affected by pancreatic cancer. They share their unique experience of the disease to help scientists design and deliver research that could transform the future for people with pancreatic cancer.

Visit pancreaticcancer.org.uk/rin for more information on the Research Involvement Network.

Meet our amazing young fundraisers

Age is no barrier to fundraising for us and we are thrilled to introduce three fantastic children, who are helping us take on pancreatic cancer.

Matthew

At just 11 years old, Matthew organised his own 5k run to raise money in memory of his grandmother who died from pancreatic cancer. Over 80 people pulled on their trainers and hit the ground running at the event in Carrickfergus, Northern Ireland, and together they raised a whopping £1,500.

"My nanny was a VERY special lady and I miss her desperately every day. I organised the race to help stop other families feeling the sadness that we did."



Emily

Emily's grandad loved gardening, so when the nine-year-old was thinking of ways to support our work, hosting a garden party in his name seemed like the perfect tribute. But first, she and her grandmother had to get the garden ready. The pair spent hours planting flowers together. Then, this summer, when everything was looking its best, Emily invited her friends and family over for afternoon tea, raising £215 in the process.

"I fundraise for Pancreatic Cancer UK because Grandad's passing was the most painful thing I've ever had to go through and if I can raise money for research, I can help prevent other families from losing their loved ones, too."



Kiaragh

13-year-old Kiaragh started fundraising for us after her grandad, Poppa Jim, sadly lost his 12-week battle with pancreatic cancer. And in just a few months, she's done so much. Kiaragh has organised a purple cake sale, hosted a purple weekend and even convinced her local supermarket to set up an awareness stand. She's raised over £1,000 so far – and we can't wait to see what this special teenager does next.



Feeling inspired? Visit pancreaticcancer.org.uk/fundraising-and-events to find out how you can support our work

An Evening with Suggs and Friends 2018

This year, we're kicking off Pancreatic Cancer Awareness Month with a bang!

An evening with Suggs and Friends is back for its sixth year, raising funds for Pancreatic Cancer UK.



Join us on 1st November at the majestic Porchester Hall in London for a fabulous evening of live music, exciting auctions and top-notch entertainment, hosted by none other than Madness frontman, Suggs.



This year Suggs will be joined by UB40 featuring Ali, Astro and Mickey.

In 2012, Suggs lost his sister-in-law Alanah to pancreatic cancer only a couple of months after diagnosis. Ever since, Suggs has hosted this fabulous event to raise much-needed funds for pancreatic cancer research.

Why not Take It On in style at our flagship fundraiser? We'd love to see you there!

There are only 400 tickets available and they're selling fast. Get yours now at aneveningwithsuggs.com

Follow the event on Twitter [@SuggsAndFriends](https://twitter.com/SuggsAndFriends).

Thanks Oakleaf!

Our amazing corporate partner, Oakleaf Partnership, has smashed its £5,000 fundraising target in just four months, after hosting a glittering summer party at The Elysee restaurant in London.

The night was just one of the many brilliant fundraising activities that Oakleaf has done for us since April. They've organised regular dress-down Fridays, run a football sweepstake and even put on a royal tea party. In a few weeks' time, eight brave individuals will also be pulling on their trainers and taking on a Tough Mudder challenge for us.

Good luck team and thanks for everything!

"We began supporting Pancreatic Cancer UK because theirs is a cause close to our hearts. Not only have many members of our team lost loved ones to pancreatic cancer, but one of our Senior Managers, Zoe Bradley, was diagnosed with the disease in 2017 - and has only recently been given the all-clear.

Our fundraising has been a real team effort - it's brought us closer together and with Pancreatic Cancer UK's support, it's been really easy to do.

I'm so proud that Oakleaf can play its part in the fight against pancreatic cancer."

**Richard Colgan,
Founder and Chief Executive**

To follow in Oakleaf's footsteps and support us in your workplace, contact Amy in our fundraising team today on amy@pancreaticcancer.org.uk

Every mile you ride helps the fight against pancreatic cancer

Paul Foster loves the Prudential RideLondon-Surrey 100 bike challenge and has Taken It On for Pancreatic Cancer UK no less three times. Paul explains how he found this year's 100 mile cycling challenge.

"I wasn't going to do RideLondon-Surrey 100 in 2018, but when I got an email about it from Pancreatic Cancer UK a few days after my wife, Denise, passed away from pancreatic cancer, it seemed like the perfect way to honour her memory.

I had no idea it was going to chuck it down on the day though!

The rain began on the day even before I climbed on my bike and by the time I set off, I was already soaked to the skin. But despite the horrendous weather and the fact that I'd only been able to train for eight weeks because Denise had been so ill, it was still a great, albeit emotional, day.

So many people braved the wind and rain to come out and cheer us on. And cycling

through the Surrey countryside and passing some of London's most iconic landmarks really helped take my mind off how cold and wet I was. Riding down the Mall and meeting my children at the finish to celebrate their mum's memory together was also really special.

And anyway, it can't have been that bad because I've already signed up for next year!

I'd recommend RideLondon-Surrey 100 to anyone who wants to do something to help the fight against pancreatic cancer. It's not easy, but if you put in the training, it's a fantastic event. And at the end of the day, it's not a race – it's all about having fun and changing the story for people like Denise in the future."



Paul Foster

To join Paul in 2019, visit pancreaticcancer.org.uk/ridelondon today.

Take on a half marathon and do something amazing in 2019

London Landmarks Half Marathon

When: 24 March 2019

Details: Central London half marathon which takes in the grand, the quirky and the hidden sites of the City

Registration fee: £35

Fundraising target: £350

: Great North Run

: When: 8 September 2019

: Detail: The largest half marathon in the world is one not to be missed

: Registration fee: £35

: Fundraising target: £350

For more information on running for Pancreatic Cancer UK, visit pancreaticcancer.org.uk/runs

Set up a monthly donation for us

“My brother, Ian, died from pancreatic cancer in 2011. He was 44 years old, with two young children. I understand the devastation of living in the shadow of this disease – I watched Ian having to face his own mortality, frightened and overwhelmed; his children watching their father suffer and not really understanding what was going on; and my parents watching their child die, unable to protect him.

The loss of Ian broke all our hearts, and I’m determined to stop other families in the future going through the same thing. That’s why my husband, Alan, and I give regularly to Pancreatic Cancer UK. And I hope you will too.

By supporting Pancreatic Cancer UK with a monthly donation, we can fund ground-breaking research and vital services for patients and their families. And together we can change the terrible outcomes for pancreatic cancer.

Please set up your monthly donation today.”

Linda Dyson



To set up a monthly donation call **020 3780 5672** or visit pancreaticcancer.org.uk/monthlydonation

We’ve updated our Privacy Policy

We wanted to let you know that we’ve recently updated our Privacy Policy to give more information about how we use the contact details of our supporters to stay in touch with them through social media. This helps us to deliver cost-effective and more engaging campaigns which means that we have more money available to take on pancreatic cancer. To find out more, please visit www.pancreaticcancer.org.uk/privacypolicy.

Pancreatic Cancer UK

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Connect with others in our **Forum:**
forum.pancreaticcancer.org.uk

Talk to a specialist nurse via our **Support Line:**
0808 801 0707 (Freephone)
nurse@pancreaticcancer.org.uk