In this issue, find out why you should stand behind Pancreatic Cancer UK’s ground-breaking research; to have a simple test to detect pancreatic cancer by 2024.

Unite-Diagnose-SaveLives
UniteDiagnoseSaveLives.org.uk

5. Patient Survey
We’ve launched the results of our Patient Survey, unveiling the unmet needs of patients.

6. Petition hand-in
Our Demand Faster Treatment petition has been presented to politicians across the UK.

9. Something positive
Read Rebecca and Niamh’s heart-warming story of fundraising in their local community.

11. Paul Ainsworth
Michelin-starred chef Paul tells us how he felt before the Virgin Money London Marathon.
Up and coming

July 2019

Join Sir Michael Parkinson at The Guy Barker Jazz Orchestra Gala Concert

Thursday 11th July 2019

Venue: Cadogan Hall, 5 Sloane Terrace, Belgravia, London, SW1X 9DQ

Hosted by Sir Michael Parkinson, the brilliant Guy Barker (pictured) and his Jazz Orchestra present an evening of jazz favourites in aid of Pancreatic Cancer UK.

For more information and to book tickets, please visit pancreaticcanceruk galaconcert.com

Pancreatic cancer is tough to diagnose. There’s no simple test for it, and nearly half of people with the disease are diagnosed in A&E or other emergency care. For many, that diagnosis tragically comes far too late.

Researching and improving early diagnosis is critical to saving lives, and that’s why we’ve launched Unite-Diagnose-SaveLives. You can read about this on the page opposite alongside details of the amazing Pancreatic Cancer UK Early Diagnosis Research Alliance. Our mission to tackle early diagnosis doesn’t stop there, and we need your continued support. So please take a stand with us and unite in the fight for early diagnosis.

Inside you can also find the results of our 2018 Patient Survey. Shockingly, close to half of the people questioned told us they aren’t getting the help they need. That’s simply unacceptable, and at Pancreatic Cancer UK we won’t rest until everyone with the disease receives the diagnosis, support and treatment they need to live well.

But we can’t do it alone. So I want to say a personal thank you to every one of the 100,600 people who supported our Demand Faster Treatment campaign. On page 6 you can read about our petition hand-ins and find out what happens next in our campaign to get people with pancreatic cancer their treatment fast.

Erika, who so bravely shared her story as part of Demand Faster Treatment, sadly passed away recently. Our thoughts are with her loved ones at this difficult time – as they are with everyone who is living with, or who has been affected by, pancreatic cancer.

Thank you for uniting with us to take on this tough disease.

Diana Jupp
Chief Executive, Pancreatic Cancer UK
Early diagnosis: the key to survival

Often pancreatic cancer isn’t detected in GP surgeries at all. Shockingly, nearly half of all pancreatic cancer patients are diagnosed in A&E or other emergency care.

Just like Ann’s son, Robert. He had been suffering with fatigue and back pain for years but was only diagnosed when he was rushed to A&E. Robert’s diagnosis came too late for treatment, and he died, aged 26, just four months afterwards.

Sadly, we hear stories like Robert’s time and time again. That’s because, unlike other cancers, doctors have no simple way of spotting the disease. No blood test, no screening, no simple test.

People shouldn’t need to wait until they’re in emergency care to be diagnosed.

That’s why we are bringing together some of the best researchers in the UK to find a simple way to diagnose people earlier and save lives from pancreatic cancer.

With your support we can tackle early diagnosis.

Stand behind Pancreatic Cancer UK’s ground breaking research; to have a simple test to detect pancreatic cancer by 2024.

Unite-Diagnose-SaveLives

The Pancreatic Cancer UK Early Diagnosis Research Alliance

We have always been determined to drive up early diagnosis rates. But research into pancreatic cancer has been underfunded for decades, and previous investments in early diagnosis research have been too small, infrequent and isolated. They haven’t made the breakthroughs patients so urgently need.

To solve this problem, we’re taking a different approach. For the very first time in the UK, we have brought together scientists to collaborate on a major early diagnosis research project: the Pancreatic Cancer UK Early Diagnosis Research Alliance. Leading the large team of researchers that form the Alliance is Professor Steve Pereira, University College London.

As the single biggest investment in early diagnosis within pancreatic cancer in the UK, the Alliance supports dozens of the UK’s brightest research minds, all focused on driving down the time it takes for people with pancreatic cancer to be diagnosed.

By sharing information and coordinating efforts, the different work areas of the Alliance will be enhanced by one another, speeding up progress and ultimately changing the story for families like Ann’s.

Thanks to supporters like you, with this initiative, we will make great strides in early diagnosis research. But we mustn’t stop there. More work will be needed to bring any breakthrough out of the lab and into the local hospital and your support will once again be critical to spearhead the next stage of ground-breaking research into early diagnosis.

Take a stand with Ann, and thousands of others like her. Unite to fight for early diagnosis and save lives, visit UniteDiagnoseSaveLives.org.uk
What NHS England’s long term plan means for people with pancreatic cancer

Georgia Papacleovoulou, Senior Policy and Intelligence Manager, Pancreatic Cancer UK.

Over the last 18 months, we’ve worked tirelessly to ensure that NHS England understands what needs to be done in order to transform the future for people with pancreatic cancer.

The new long term NHS plan was published in January 2019, setting out the strategic priorities over the next 10 years in England.

Here’s just some of the things we called for, and how they compare with the plan.

A commitment towards levelling up pancreatic cancer survival with other cancers

We’re pleased to see a focus in the plan on early diagnosis, including the ambition to diagnose 75% of cancers at stage 1 or 2 by 2028. This is critical for pancreatic cancer, which is often diagnosed late, but achieving it will be challenging.

We will keep the pressure on NHS England to ensure that those affected by pancreatic cancer benefit from the ambition that more people are diagnosed early.

Faster treatment of pancreatic cancer across England

In October 2018 we launched our Demand Faster Treatment campaign, calling on NHS England to commit to our ambition that people with pancreatic cancer will be treated within 20 days from diagnosis.

Although the plan acknowledges that reducing waits can save lives, it doesn’t go as far as we’d like. We will continue to argue for and ensure that NHS England prioritises developments that enable people with pancreatic cancer to access treatment faster.

Rapid Diagnostics Centres across the country to diagnose pancreatic cancer faster

Rapid Diagnostic Centres (RDCs) enable people to have a range of tests in one place rather than repeatedly visiting their GP, and they’ve shown promising results for pancreatic cancer. We are very pleased the plan confirms a nationwide roll-out of RDCs.

More investment in research and incentivised clinical trials

We welcome the changes that will enable more research and increase participation of cancer patients in experimental treatments.

7 in 10 people with pancreatic cancer still aren’t receiving any treatment. We will continue to call for more clinical trials and help ensure that everyone who might benefit from them is encouraged to take part.

We will continue to influence NHS England and the Government to ensure that people with pancreatic cancer aren’t forgotten as the long term plan is delivered.

We want to see specific targets on early diagnosis and survival for the disease. And we won’t stop fighting until everyone with pancreatic cancer can live long and well.

To find out more about changing the the future for people with pancreatic cancer, visit pancreaticcancer.org.uk/policy
Uncovering the unmet needs of patients

On 14th March, we welcomed people from across the pancreatic cancer community to our Annual Summit 2019: Accelerating Success.

An unmissable event, our Summit gave health professionals, researchers, policy makers, patients, carers and our supporters the chance to come together to share, learn, network - and ultimately transform the future for people affected by pancreatic cancer.

Professor Eila Watson from Oxford Brookes University was one of the many experts who spoke at Accelerating Success. In a lively and informative session, she presented the results of our 2018 patient survey.

Professor Watson, why did you want to undertake the patient survey for Pancreatic Cancer UK?

The patient survey felt like an important area of research. There is a real lack of information about the experiences and needs of pancreatic cancer patients in the UK, yet this is a group with a poor prognosis and a complex range of needs.

Plus, we knew that Pancreatic Cancer UK wanted to use the findings to drive change in policy and practice to ensure that patients and their families get the support they need, when and where they need it the most.

What were the survey’s main findings?

The survey revealed that patients with pancreatic cancer have unmet information and support needs, irrespective of whether they have been diagnosed recently or several years ago. Psychological and physical support appear to be the biggest gaps in care.

Although care received was generally reported positively, 29% of respondents felt they did not receive enough information at diagnosis.

One in ten respondents felt they were not involved in decisions about their treatment but would have liked to be. This was more so for patients who were ineligible for surgery.

Almost half of the respondents reported one or more moderate/high unmet need within the last month, of which the most frequently reported were:

• problems dealing with uncertainty about the future
• fears about the cancer spreading
• not being able to do things they used to
• concerns about those close to them
• lack of energy
• anxiety
• feelings of sadness and feeling down/ depressed.

These unmet needs were also more commonly reported in people ineligible for surgery.

What was the number one thing that people wanted to see change about the care and treatment of pancreatic cancer?

Better psychological support for patients and their families.

For more information and to view photos from our Annual Summit 2019: Accelerating Success, please visit pancreaticcancer.org.uk/summit

Our Support Line is here for you

If you’ve been affected by pancreatic cancer and would like to speak to one of our specialist nurses, please call our free Support Line on 0808 801 0707 or email nurse@pancreaticcancer.org.uk
You helped us to Demand Faster Treatment

Pancreatic cancer is the deadliest common cancer. Patients can’t afford to wait for treatment. That’s why we launched our Demand Faster Treatment Campaign last year and asked you to join us in petitioning UK governments to ensure that people with pancreatic cancer receive treatment within 20 days of diagnosis.

An incredible 100,600 of you heard our call and signed our petition! Thank you for helping us make change happen.

With your support, we presented the petition to politicians in England, Scotland, Wales and Northern Ireland. We highlighted the appalling survival statistics - and we called on politicians and health services to recognise pancreatic cancer as a cancer emergency.

In memory of Erika

We are sorry to announce that Erika Vincent, who championed our Demand Faster Treatment Campaign, has passed away.

When Erika was diagnosed with pancreatic cancer, she expected her cancer would be treated as an emergency, and that she’d be given treatment fast.

But it didn’t happen.

Erika fought for change so that no one in the future would have to wait for treatment like she did. She was exceptionally brave in sharing her story.

Our thoughts are with Erika’s family at this difficult time.

The petition numbers by country

Scotland
8,300

Wales
9,000

Northern Ireland
3,000

What’s next

You’ve helped us shine a spotlight on this critical issue, and although the petition has closed, our campaign is far from over. We will continue to seek meetings with Ministers and NHS policy makers across the UK to push for change. As well as continue to work with clinicians to ensure patients are treated faster. We will keep you updated on how we’re building on the incredible start you’ve given us.

Thank you once again for all your support.

pancreaticcancer.org.uk/demandfastertreatment
Putting you in touch with people affected by pancreatic cancer

Living with pancreatic cancer can be tough. But talking to people who know what you’re going through can really help. That’s why at Pancreatic Cancer UK we have two different services that enable you to meet others affected by the disease and share your experiences of it.

**Living with Pancreatic Cancer Support Days**

Run by specialist nurses, our Living with Pancreatic Cancer Support Days take place across the UK. They include talks and sessions on topics such as managing dietary symptoms and give people with pancreatic cancer and their carers the opportunity to get to know one another.

Karen recently attended a day with her parents.

“In the year since my dad’s diagnosis, no one in our family had met anyone with pancreatic cancer. So, for us, the day was a chance to meet other families and hear from specialists in this type of cancer.

The organisers were friendly, kind and supportive. They presented a lot of helpful information with booklets to take away. And being able to share our experiences and talk to other people affected by pancreatic cancer was invaluable.”

**SIDE BY SIDE**

Launched in 2018, Side by Side is our telephone support service for people who have had, or are likely to have, surgery to remove their cancer. It’s delivered by trained volunteers, who all have experience of living with the disease, and it’s completely free to use.

Isobel first contacted Side by Side after having chemotherapy following her Whipple’s operation.

“When you’re diagnosed, everything can seem really negative. But thankfully my Side by Side volunteer is there to reassure, encourage and empathise with me. She doesn’t think I’m being silly when I ask questions or share my fears because she has been there. She knows what I’m going through, and she’ll always listen to me when I moan.

Side by Side has helped me get through some very low times. I always feel so much better after the calls. It’s a vital service - and one I can’t recommend highly enough.”

For more information about Side by Side and our Living with Pancreatic Cancer Support Days, visit pancreaticcancer.org.uk/getsupport
Fundraise for us

We couldn’t continue our vital work without your support. Get involved today and help us take on pancreatic cancer.

Bake Off
Holding a bake sale, coffee morning or even a Prosecco party is a great way to support us.
And we’ve got everything you need for the perfect event, including invitations, balloons, posters and more.

Challenge 24
In the UK, 24 people die every day from pancreatic cancer. But you can change that by taking on Challenge 24 and walking, running, swimming or cycling 24 miles, kilometres, lengths or metres in support of our work.

Celebrate
Whatever your special event, we would love to be part of your day!
You could ask for donations instead of gifts or cards, or use our special pin badges as wedding favours.

Fundraise on the Fairway
Supporting us at your golf club is easy, you could nominate us as your charity of the year or host a charity golf day.
We’ve got the balls, tees and pencils you’ll need to make your fundraising a success!

Special events
Hold a gala dinner, ball or concert and have a night to remember by supporting Pancreatic Cancer UK.
Our team will be with you every step of the way.

Do your own thing
If our ideas aren’t for you, feel free to fundraise in whatever way you can think of!

“We are here to support you and your fundraising efforts and every penny really does count. To let us know what you’re thinking of doing or to find out more, please get in touch. We would love to hear from you!”

Megan and Laura, Pancreatic Cancer UK

To contact Megan and Laura, email fundraise@pancreaticcancer.org.uk or call 020 3535 7090
We fundraise because we want to do something positive

by Rebecca Sharp Phillips

“My husband Viv was diagnosed with pancreatic cancer the week our daughter, Niamh, turned three. He was in his forties and he passed away in March 2013, just six months after diagnosis.

Niamh and I were absolutely devastated by our loss. But when Viv’s boss, Steve Hoskin, dedicated his Annual Golf Day to Viv the following September and raised a massive amount of money, it made me realise that we needed to do something positive, too.

So we began fundraising for Pancreatic Cancer UK in our local community.

One of the ways we raise money is through collection tins. I noticed that the local shop had several tins on their counter, so I asked if they would include one for Pancreatic Cancer UK. Happily, they said yes and since then we have had a few in other shops, pubs, hospitals, hairdressers, ice cream shops and other local businesses.

Every month I collect the money from the tins and pay it into the bank. I must have made over 50 deposits in the years we’ve been fundraising - and people are so generous. One village shop has raised almost £1,500 on its own, which is just fantastic.

Through the golf days, collection tins and our other fundraising activities, Niamh and I have raised over £10,000 for Pancreatic Cancer UK, but we’re not done yet. We don’t have a financial target in mind, we just want to do as much as we can to raise awareness of pancreatic cancer and support a charity that is leading the fight against this silent killer.”

“From the whole team at Pancreatic Cancer UK, I want to say a huge thank you to Rebecca, Niamh and everyone in their local community in Cornwall for helping us take on pancreatic cancer together. They’re true superstars!”

Sue Collins, Director of Fundraising and Marketing, Pancreatic Cancer UK

To find out more about fundraising in your local community, please contact our community fundraising team on fundraise@pancreaticcancer.org.uk or visit pancreaticcancer.org.uk/fundraiseforus
Progress/Fundraising

Join our team for Prudential RideLondon-Surrey 100

There’s still time for you to get pedalling for Pancreatic Cancer UK and take on this year’s Prudential RideLondon-Surrey 100.

As a member of our team, you’ll get an exclusive cycling jersey, expert tips on training and fundraising, and an invite to our very special post-ride reception.

When: Sunday 4th August 2019
Where: London’s Queen Elizabeth Olympic Park to The Mall via the stunning Surrey countryside
Registration fee: £30
Fundraising Pledge: £500
Find out more at pancreaticcancer.org.uk/ridelondon

“I want to help other people with pancreatic cancer”

Pancreatic cancer survivor, Chris Davey will be doing more than taking in the beautiful scenery when he hikes the Jurassic Coast Challenge this June. He’ll be helping to change the future for people affected by the disease.

“I class myself as a really lucky man because I was able to have surgery and then chemotherapy in 2016.

Now I want to try and give something back if I can. I’ve already taken part in some clinical trials. But, by taking on this Challenge, I can hopefully raise lots of money for Pancreatic Cancer UK - and prove to myself and others what you can achieve after a severe illness.

My training isn’t going too badly so far. I did 12km recently. That’s half the distance I’ll be doing in the Challenge, but I found it really enjoyable walking around Bristol docks and seeing all the houses painted different colours.

I’m sure the coastal views along the route are going to be lovely, too. I’m really looking forward to the atmosphere on the day, of being part of it all.

I know I’ll feel a huge sense of achievement when I finally cross the finish line and think about the difference I’m making to people with pancreatic cancer and their families. I can’t wait to get started!”

“If you’re feeling inspired by Chris’s story, why not sign up for one of our Ultra Challenges? We can help you find the one that’s right for you, and we’ve got lots of training and fundraising tips to help get you started.”

Caitlin, Events Officer, Pancreatic Cancer UK

For more information visit pancreaticcancer.org.uk/events today
Nominate us as your charity of the year!

Leading health lifestyle service provider, Thrive Tribe has been supporting our work since July 2018. Emma, their Employee Experience Manager, explains why:

“A member of our team, Fiona Harding, lost her husband to pancreatic cancer in 2015. The disease had a devastating effect on her and her daughter. So when Thrive Tribe was looking for a charity partner and Pancreatic Cancer UK’s name was put forward, it seemed a natural choice for us. It was our way of supporting both Fiona and helping to change the story for families like hers - now and in the future.

So far, we have raised nearly £6,000 through activities such as a reverse auction and The Brecon Beacons ‘Fan Dance’. One of my colleagues even shaved her head at our away day!

We are so proud that our fundraising is helping Pancreatic Cancer UK to continue their vital work. We are having fun and getting to know our colleagues so much better. I hope you will join us by making them your company’s charity of the year in 2019. You won’t regret it.”

To find out more about nominating us as your charity of the year, email Amy on amy@pancreaticcancer.org.uk or visit pancreaticcancer.org.uk/workplace-fundraising

Thanks Paul!

Michelin-starred chef Paul Ainsworth swapped his chef whites for a Pancreatic Cancer UK running vest and took on the Virgin Money London Marathon 2019.

We can’t thank Paul - or the other members of Team Pancreatic Cancer UK - enough for taking part in the marathon. It’s not too late to sponsor Paul (uk.virginmoneygiving.com/Paul-Graham6), your family or friends via their fundraising pages.

Ahead of the event, Paul told us about his motivation:

“l lost my hero when my dad died from pancreatic cancer in 2015. He was my world, he made me the man I am today and taught me the true values of life. Last year I decided to run the London Marathon in support of Pancreatic Cancer UK and in memory of my incredible dad.

My good friend Graham will be running with me too, he was very close to my dad. It’s taken me years to get to a point where I can run longer than 10 minutes, so to be able to complete a marathon and support such an important charity will be up there with my greatest achievements. I hope I’ll do my dad proud.”

Why not follow in Paul’s footsteps and take on the Virgin Money London Marathon in 2020? Find out more at pancreaticcancer.org.uk/londonmarathon2020
Progress

Transform the future with a gift in your Will

“Having lost my mum to pancreatic cancer, I am extremely passionate about the cause and I can see the potential for gifts in Wills to transform the lives of the next generation. That’s why I decided to leave a gift in my own Will to Pancreatic Cancer UK. And if it feels right to you, perhaps you might consider doing the same.”

With your gift, you could help us invest in ground-breaking research long into the future.

Caroline Purewal

To find out more and download our free guide to leaving a gift in your Will to Pancreatic Cancer UK, visit pancreaticcancer.org.uk/legacies

Alternatively, you can contact Caroline, our Gifts in Wills and In Memory Manager, who would be happy to answer any questions you might have. She’s on legacies@pancreaticcancer.org.uk or 020 3872 6075.

Your contact preferences

We’re sending this communication to you because we think you’ll be interested in hearing about how we’re taking on pancreatic cancer. If you don’t want to receive any more mailings from us, please call 020 3535 7090, email dataprotection@pancreaticcancer.org.uk or fill in your contact preferences online by visiting pancreaticcancer.org.uk/contactme. To read our privacy policy please visit 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

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