

SpeakOut

The newsletter of Oracle Cancer Trust



LEADING RESEARCH INTO HEAD AND NECK CANCER

WINTER 2020

After a challenging year we will still celebrate Christmas



Message from our Chairman

This year has proved to be very difficult for almost everyone around the world because of the COVID-19 crisis and we have had to make a lot of sacrifices and adjustments to our lives.

These have affected and dominated, not only our family lives, our businesses and the economic situation, but have disrupted our enjoyment of social events and entertainment.

Our Oracle 'Glory of Christmas' concert has become the main focus of our charity's year, where 500 supporters from throughout the UK travel to join the Oracle family for a wonderful celebration at St John's, Smith Square enjoying the wonderful voices of Choir of Christ College, Cambridge and music performed by the Thames Chamber Orchestra.

Sadly due to the COVID pandemic our concert and other charity events have inevitably been cancelled. But we wanted to celebrate an evening on the first Monday in December, a night for the past 14 years where we have traditionally joined together to celebrate the start of the festive season. This year we are delighted to be able to share an evening of music, carols and special performances on Monday 7th December at 7.30pm which you can watch the concert on YouTube from the comfort of your homes.

I do hope that you will be able to join our celebration of Christmas with carols, music, readings from former head and neck cancer patients and two contributions from our

wonderful Patron, Sir Michael Morpurgo, and a fabulous musical solo from Rob Burton, former Young Musician of the Year finalist.

The small team at Oracle have collaborated with St. Paul's, Knightsbridge who are supporting a number of charities to provide a virtual concert. Oracle have pre-recorded some special readings from patients who have been through head and neck cancer - including Prof Anson Mackay who was diagnosed with head and neck cancer at the start of the first lockdown in March and was treated when all London hospitals had been placed on COVID lockdown. You can read more about Anson's inspiring treatment journey on page 7.

Please register for the event which will take place for one night only, Monday 7th December at 7.30pm via our website at www.oraclecancertrust.org/glory2020

If you are able to make a donation, we are launching our "Missing Cancer Patients" fundraising appeal with the Big Give - any donation made between the 1st to the 8th December is matched - please see the back cover for more details on how to support this important fundraising initiative for Oracle.

I would also like to take this opportunity to wish you all a peaceful Christmas and best wishes for 2021.

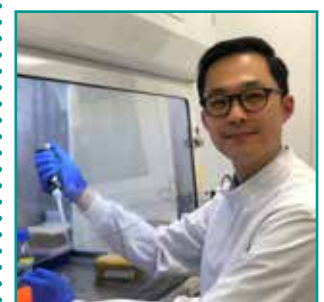
Peter Rhys Evans, Chairman



Anson runs the virtual Virgin London Marathon for Oracle



Olivia donates her hair for charity



Research update



Welcome to our new Voluntary CEO

Nicola Ridges-Jones joins Oracle as interim voluntary CEO

After four years of invaluable support and leadership of Oracle Cancer Trust, Voluntary CEO Jamie Newall steps down from his role at Oracle

Jamie helped the Oracle achieve AMRC membership, negotiated the Charity's first Intellectual Property income from funding early-stage research and has steered the charity through the challenging COVID-19 crisis.



After a productive time as CEO, Jamie has decided to concentrate on his career and has returned to the business world full time, so Oracle is starting the search for a permanent CEO. In the meantime Board Trustee Nicola Ridges-Jones, has agreed to accept the role as interim Voluntary CEO. Former Managing Director of a leading warehousing and logistics firm, MSX, Nicola also holds a number non-executive Directorships as well as running a commercial and residential property company.

Nicola has supported Oracle Cancer Trust and been a Trustee for many years raising over £100,000 in memory of her father, Fred Ridges who died of throat cancer.

Nicola takes over the role of CEO of the charity at a very challenging time for medical research charities who have

all suffered substantial drop in income due to the COVID-19 pandemic.

The charity has already made the difficult decision to make a staff member, Natalie, redundant. Natalie was managing Oracle's research portfolio and overseeing relationships with AMRC, NCRI and other various cancer organisations to support its position in the charity-funded research arena.

Says Peter Rhys Evans, Chair of Oracle, "On behalf of the Trustee Board I would like to thank Jamie for his incredible enthusiasm and energy to support the Charity over the past four years, and welcome Nicola who has kindly volunteered to take on the role.

"We are facing the worst funding crisis in the charity's 30 year history and our urgent priority is to ensure we can fund new projects in 2021 to maintain the momentum to drive forward Oracle's nationwide head and neck cancer research programme. COVID has resulted in many delayed diagnoses and treatments and funding new research is vital."

Says Nicola, "I am delighted to continue to support Oracle and become CEO through this period of transition until a permanent CEO is found. With the support of the Board of Trustees we have set some robust targets to ensure that Oracle continues to meet its objectives of funding early-stage research."

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Please note if you wish to telephone us we have a 24-hour answering service in place and messages are forwarded straightaway.

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Head and neck cancer in the news

Radiotherapy for head and neck cancer kinder than ever before following IMRT study



Oracle Honorary Trustee and leading radiotherapy expert, Prof Chris Nutting has dedicated his research spanning nearly two decades discovering kinder radiotherapy techniques for head and neck cancer patients. Prof Nutting presented results of the trial at the virtual American Society of Clinical Oncology

virtual conference in May sharing that 40 per cent of patients treated with the optimised IMRT (intensity-modulated radiotherapy therapy) reported significant improvements in swallowing one year after treatment, compared with only 15 per cent of those who received standard radiotherapy treatment.

During the trial, half the patients were given standard IMRT, while the other half received optimised IMRT. The same strength of radiotherapy was used in both groups. All the patients underwent treatment every week day for six weeks. They were closely monitored afterwards and swallowing ability was assessed 12 months after completing treatment.

Says Prof Nutting, “If the swallowing muscles get damaged and never recover, this has a huge impact on someone’s life. Patients with swallowing issues can eat only softer foods — or have their food liquidised, with a small number of people end up having to use swallowing tubes. This is a game-changer. In our clinical study of 112 patients from 23 UK cancer centres, 25 per cent fewer patients suffered with swallowing issues when they got the optimised radiotherapy, compared with those who received it via the standard technique. It means many patients will be able to return to eating normally again after treatment.”

Oracle was involved in funding early-stage studies that helped develop IMRT which has been the gold-standard radiotherapy treatment since 2011.

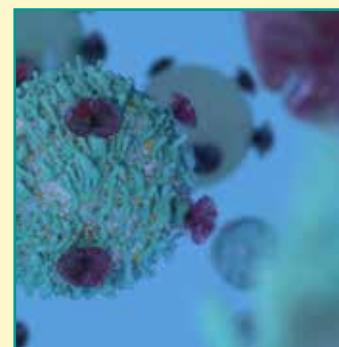
Research has shown that “optimised IMRT” bespoke radiotherapy allows patients to swallow normally following treatment giving back quality of life. The treatment should be rolled out across NHS centres next year.



Patients undergoing treatment for head and neck cancer will now have access to immunotherapy drug pembrolizumab (Keytruda) on the NHS in England.

This new immunotherapy drug was initially rejected in January 2020 but has now been approved by NICE - who estimate that around 950 people will be eligible for the treatment.

Pembrolizumab will now be a treatment option for patients who have relapsed and cannot be treated with surgery, or their cancer has spread. The drug aims to boost the patient’s immune system to recognise and kill cancer cells by blocking a molecule called PD-1.



Professor Kevin Harrington, Professor of Biological Cancer Therapies at The Institute of Cancer Research, London, and Consultant Clinical Oncologist at The Royal Marsden NHS Foundation Trust, led the UK arm of the KEYNOTE-048 trial looking at the benefit of pembrolizumab as a first-line treatment for advanced head and neck cancer, said, “There is clear evidence that pembrolizumab has survival benefits for patients with head and neck cancer, and it is also a much kinder treatment than intensive chemotherapy.”

Dutch scientists have made a breakthrough discovery of previously unknown salivary glands located at the back of the nasal cavity

This exciting new discovery, the first in over three centuries could help enhance radiotherapy treatment even further for head and neck cancer patients.

Says Prof Nutting, “This study is a very interesting new observation that there may be some previously unidentified salivary tissue at the back of the nose. This could be specifically preserved with new radiation techniques to see if it improved dry mouth which remains a problem for some head and neck cancer patients after treatment.”



The impact of COVID-19 on charity-funded research in the UK



Medical research charities in the UK have faced a huge drop in income due to the COVID-19 pandemic and expect to reduce their spending on research by £310m in 2021. The UK is a world leader in life sciences, generating over £74 billion in annual turnover and supporting nearly 250,000 highly-skilled jobs.

Vitality, medical research charities invest £1 in every £5 that goes into life science research, and Oracle's early-stage research is largely unseen in the hard work that makes these scientific discoveries.

Medical research charities have played a defining role in creating treatments that save lives. Oracle is proud to have played a part in early-stage advances in head and neck cancer including advances in radiotherapy, immunotherapy and virus therapies, combination drug studies and quality of life research including taste and swallowing studies. But for many medical research charities, the COVID-19 pandemic has posed a risk beyond anything the charity-funded sector has ever faced.

With fundraising events cancelled and financial uncertainty for many donors, the impact on research is far-reaching. The Institute of Public Policy Research revealed that the COVID-19 pandemic has put £7.8 billion of medical research at risk between now and 2027. Of that sum, £5.7 billion is down to lost charity income - meaning around 35,000 fewer PhD students undertaking vital, early-stage research.

This loss of PhD early-stage research innovation will have far-reaching consequences for new treatments but also affect the employment for early-stage opportunities funded by medical research charities. Oracle is the only UK charity that is dedicated to funding research into head and neck cancer - our role is vital in funding treatment breakthroughs, and without our investment into research there would be less diversity, less patient involvement and a weaker link between what people want and what research we do.

AMRC (Association of Medical Research Charities) have been lobbying the government to save the sector with a three-year life science charity partnership fund offering public funds to supplement charity research investment over a period of three years. This initiative would make the government step in and make up the funding shortfall, giving medical research charities the time to adapt, innovate and recover.

Oracle faces a period of huge uncertainty. If things don't improve, we don't think we'll be in a position to fund more research until the end of 2021 at the earliest. Without embarking on a new way of fundraising we won't be able to plan for our future as a charity and major funder of head and neck cancer research in the UK.

We'd love your help to turn this bleak situation around by supporting the Missing Cancer Patients Appeal. This December, we're launching an appeal to raise £100,000 so we can reach people who may delay seeking help with symptoms and find treatments that are more effective and humane. You can give at any time, but between midday 1st – 8th December, your gift will be doubled by the Big Give. This is a great opportunity to give once and double the impact - please see the back cover of the newsletter for further details.

Oracle's latest projects to join the research portfolio

Oracle's last research grant round was held in September 2019 where the committee reviewed and approved a total of five new projects. The research committee comprises four leading head and neck cancer consultants and is chaired by non-clinician and Trustee Keith Jones.

The committee review projects from leading research centres throughout the UK and teams present their projects to the committee followed by a series of questions. Some project require additional scrutiny from our team of peer reviewers that vet projects in great deal and provide important insight for the committee before meetings.

Oracle adheres to stringent guidelines as set by the Association of Medical Research Charities (AMRC).

On the following page we are delighted to share details of four new projects taking place at Newcastle University, The ICR and The University of Derby.

Improving outcomes in Immunotherapy



Immunotherapy represents a revolutionary approach to treat cancer, but many cancers are resistant to immunotherapy, for reasons not fully understood.

Many head and neck cancer patients develop recurrent disease and there is a pressing need to find new and better treatments to eradicate it. Immunotherapy has

proven promising for head and neck cancer, but we need to understand how it works so that we can improve it and provide effective treatment to the majority of patients for whom it does not work at present.

In this project, scientists will characterise the proteins shown on the surface of cancer cells for inspection by the immune system (the so-called immunopeptidome) in model cell lines and from patient samples. These molecules provide direct communication between the tumour and immune cells and the nature of the immunopeptidome repertoire in different tumours is thought to play a key role in determining whether, or not, immunotherapy will be effective.

The resulting data will provide new information about HNC that will help in the development of new immunotherapies and provide patient classification to enable personalised therapy. Miriam Melake (pictured) started this four-year PhD project in January 2020 under the supervision of Dr Jyoti Choudhary and Prof Kevin Harrington.

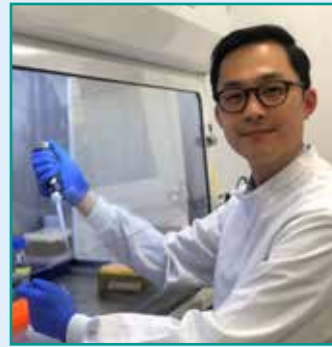
Modulation of the immune tumour micro-environment

Head and neck cancer is a disease that is very frequently treated by radiotherapy with curative intent. Unfortunately, in many patients it fails to achieve durable tumour control and, in those in whom it is successful, there are often long-term severe side effects. In this research, we aim to use drugs to make radiation more effective in killing cancer cells, but also to alert the immune system to their presence.



In this research, the aim is to use drugs to make radiation more effective in killing cancer cells, but also to alert the immune system to their presence. In this way, the study aims to make radiation work better against hard-to-treat head and neck cancers (eg HPV-negative tumours), but also to reduce the side effects of treatment by needing to use less radiation dose to control more sensitive cancers (eg HPV-positive tumours). Emanuel Patin (pictured) is starting his two-year project in December this year at The ICR funded by donor DPS Limited.

Exploring IDO immune status



Existing treatments for head and neck cancer have lasting effects on patients' quality of life. The head and neck region is a site of intense immune cell interactions and understanding the changes in these cellular signals throughout treatment provides a basis for modifying existing treatments and personalising future therapies. Indoleamine 2,3-dioxygenase

(IDO) is an important enzyme which allows tumours to evade elimination by the body's own immune system. The activity of IDO can be measured locally at the tumour and peripherally in blood.

This study aims to research IDO activity at baseline and mapped throughout treatment to establish IDO as an indicator (biomarker) of the function of the patient's immune system (immune status). This will be achieved by testing the IDO activity in existing collected and stored blood and tissue specimen from a preliminary study and collecting further specimen during the research to support initial findings that IDO activity varies significantly during therapy. This work to establish IDO as a biomarker will support a more personalised, stratified approach to treating this condition in the future and aim to improve outcomes for the patients affected. Dr Daniel Lin (pictured) commenced this two-year project in September at Newcastle University.

Understanding HPV

Human papillomavirus (HPV) predominantly causes cervical cancer, however, HPV also causes a subset of head and neck cancers, particularly in younger men. The disease is often diagnosed very late, and treatment challenging. Dr Elizabeth Marsh (pictured) from the University of Derby is supervising a three-year PhD project commencing in January 2021.



It is currently not understood how HPV causes head and neck cancer and this project intends to understand the lifecycle and development of HPV infections within the mouth to determine how HPV causes cancer, in order to develop new treatments.

This clinical study will examine tonsils (the site of HPV-positive cancer) for HPV infections and disease, and identify any pre-cancerous changes which may act as predictive biomarkers of dangerous HPV infections that could influence the development of cancer.

Supporter fundraising

Jane Wilkinson establishes The John Wilkinson Face Cancer Charitable Trust

"We can't believe it's almost one year since John passed away - 25th December 2019. It's a reminder to us all that life moves quickly and we must enjoy what we have, even in these challenging times. In John's memory we established The John Wilkinson Face Cancer Charitable Trust so we can continue to raise awareness of head and neck cancer as well as support research into head and neck cancer.

"With the support of family, friends and John's former employer HSBC, fundraising has continued in earnest. In August this year family friend Olivia visited the hairdresser to have 15 inches of her hair cut to raise funds in John's memory. Olivia donated her hair to the Little Princess Trust, a charity that provides free wigs for children with cancer. I'm so proud that Olivia raised over £1,000 in John's memory for Oracle.

"NEWFS - a wonderful voluntary fundraising group of Newfoundland dog owners organise fundraising events throughout the year supporting good causes. Due to lockdown members came up with the idea of creating a natural doggy treats recipe book, tested by their grateful canine friends, raising over £750.

"On a very hot summers day, June 25th, six months to the day when John passed away, colleagues from HSBC Thames Valley as well as friends from around the UK set out on a socially distanced series of walks from their homes. The idea was brought to life by John's former colleague Matt Povey just as lockdown had been lifted and I was humbled that even friends from France and Spain took part to remember John. The walk raised over £7,000.

"This Christmas we would like to open a Christmas appeal to raise money for Oracle Cancer Trust and would love all supporters to join in! "Decembeard" is an annual charity initiative organised by Bowel Cancer UK but this year we would like to create our own "Face Cancer Decembeard" campaign and set the men a challenge of growing beards for December. Show us what beard you can grow! Bumfluff or beardy bush, we can't wait to see. Follicly challenged or Female? No problem, you can join in too by buying John a "virtual pint" and donating that drink instead.



Olivia Gowland's hair cut for charity



NEWFS present their fundraising cheque from their canine cookbook



Matt Povey with his partner Eve



"All donations will be **DOUBLED** by The Big Give Christmas Challenge so it is a great time of year to donate."

Jane Wilkinson

If you'd like to join in and support "Decembeard" visit the JustGiving page:

www.justgiving.com/fundraising/the-john-wilkinson-face-cancer-charitable-trust



Katrina's virtual quiz keeps everyone guessing



Former patient Phil and Katrina have fundraised for Oracle for over a decade

Quiz supremo Katrina created a virtual "Cranial Conundrums" challenge to replace her postponed quiz night. The questions were challenging - and not the kind that could be answered by looking on Google either - lateral thinking and powers of logical deduction were key to coming up with the answers!

"The quiz was a great success raising £480 for Oracle. It threw up a few challenges for me when marking the answer sheets as there was more than one correct answer to some of the conundrums that I hadn't realised. I'd like to thank everyone who took part in the quiz and hope that in 2021 we will be able to once again meet up at our village hall to host our fun and informal quiz night." Katrina Doubleday

Anson takes on the Virtual London Marathon

"I was diagnosed with stage 3 HPV-positive tonsil cancer on my birthday earlier this year, just a few weeks before lockdown in March. I underwent seven weeks of, at times quite brutal chemo-radiation therapy and I was just grateful to be able to complete my treatment during the very challenging period when hospitals were on lockdown and dealing with a surge in COVID-19 cases in London.

"I've always been a passionate runner and after researching the huge mental and physical benefits of exercise and cancer was more determined than ever to start running again and keeping fit. I slowly built up to running 10kms but this in itself presented more challenges as I was told to eat around 2,500 calories a day - and, with a whole host of foods now off the menu and the new norm of dry mouth after radiotherapy it became a real struggle at times.

"The day before the Virtual London Marathon was memorable for the fact it was the wettest day for decades and runners battled horrendous conditions up and down the country. For the marathon my running buddy Michael joined me and we completed the marathon in under five hours. The running felt so good I decided to carry on alone and run another 10kms to complete my first ultra marathon. Charities have been so badly hit by the pandemic and COVID-19 losing vital sources of funding and I was delighted to support Oracle's pioneering research.

"With the support of family, friends and colleagues I was overwhelmed to raise £2,300 - I'm delighted that my oncologist has given me the "all-clear" for now and am dedicated to raising awareness about the signs and symptoms of head and neck cancer. My only symptom was a painless neck lump and it's vital that men, in particular over the age of 45 seek help early." Professor Anson Mackay

Anson has written a thought-provoking blog about his cancer treatment and recovery at www.ansonmackay.com/blog



Darren raises an incredible £8,500 in memory of Mikey

"In August last year, we lost our great friend and brother in law, Mikey to head and neck cancer just days before his 46th birthday. Mikey was a father, husband, brother and friend that was sadly taken from us before his time. In his memory I decided to take on the challenge of a lifetime - by Everesting Cairngorm Mountain to support Oracle's research work. By advancing research we can only hope that other families won't lose loved ones like Mikey's have.

"Everesting is regarded as the most difficult challenge in endurance cycling - simple yet brutal. To complete the challenge, the cyclist repeat climbs a single hill until the combined elevation gain reaches 8848m or in other words - the height of Everest. This means I took on riding 31 laps of Cairngorm and around 176 miles to complete in total.

"I was overwhelmed by the support of family and friends who set up a basecamp to support my challenge - and I'd like to thank Eve Murray, Suzanne Gillespie, Holly Gillespie, Josh Gillespie, Lynn Hankinson, Maria Lawson, Lorraine Buttenshaw, Leigh-Ann Little Gillian Sutherland, Jennifer Mentipty, Andrea Pittner, Helen and Stevie. Without their bonkerness, baking and un-wavering support none of this would have been possible.

"In addition to the base station crew I'd like to give a huge shout-out to the "Sherpas" that rode with me - Colin, Derek, Craig, Stuart, Neil, George, Alan, Isla, Paul, Craig, Scott and Keith. They each took turns to ensure I never rode a lap up and down alone through the course of the 31 laps. I couldn't have done it without them or the base station crew. The picture on the right was our final lap on what couldn't have been a more beautiful day." Darren Murray



Missing Cancer Patients Appeal Powered up by



theBigGive
CHRISTMAS CHALLENGE
1—8 DECEMBER 2020

Please help lockdown's missing head and neck cancer patients receive a swift diagnosis and treatment. Lockdown meant 350,000 fewer people were referred to a cancer specialist between April and August, a drop of 70%. Survival is hugely improved by a speedy diagnosis and prompt, expert treatment.

On 1st December Oracle launches our £100,000 Missing Cancer Patients appeal, named for the thousands who missed being diagnosed and treated during the first lockdown of 2020. Help us ensure no-one else delays seeking help for symptoms and keep breakthroughs coming in treatments for head and neck cancer.

While you can donate at any time, we're delighted that once again your donations will be doubled if you give between 12 midday Tuesday 1st December - 12 midday Tuesday 8th December thanks to the Big Give Christmas Challenge. If you like to support our campaign please visit www.oraclecancertrust.org/biggive2020 to help.

What was the impact of Lockdown for head and neck cancer patients?

Lockdown led to cancer patients missing out on an early diagnosis and treatment. 350,000 fewer people than normal were referred to a cancer specialist between April and August. At one point, referrals dropped by over 70%. With 12,000 people diagnosed with head and neck cancer a year, speedy diagnosis for this often rapidly developing cancer can be important. Survival is greatly affected by speed of diagnosis and prompt, expert treatment.

Oracle Cancer Trust is worried thousands of people should be in treatment for head and neck cancer now but have not been diagnosed. We want to ensure people seek help for any subtle symptoms of head and neck cancer as soon as possible, as we continue to face restrictions due to COVID-19. We will run a campaign to raise awareness of the sometimes subtle symptoms of head and neck cancer. We'll encourage people to seek medical advice asap, no matter the restrictions in place. And we'll fund research to improve treatments to give better options for people who may have more advanced cancer due to a delayed diagnosis.

While much medical research paused during Lockdown, Oracle researchers are now back up and running with social distancing in labs. Your gift towards the Missing Cancer Patients Appeal can help us ensure people receive the best treatment as quickly as possible. You can support us at any time, but we have a brilliant opportunity to double your gift between midday 1-8 December thanks to the Big Give.

£5,000 – could fund an awareness campaign run through social media and with dental and primary care networks to encourage people to seek advice if they have any symptoms that could relate to head and neck cancer

£10,000 – could provide a pot of innovation funding for researchers improving diagnosis and treatment planning tools so more people benefit from personalised treatment

£20,000 – could fund developing gentler treatments that avoid disfigurement and life-changing side effects with speaking, eating, tasting and swallowing.

We'd also love to see you at our special Glory of Christmas virtual concert; it's the perfect way to kick start festive feelings in this strangest of years. All funds raised will go towards our Missing Cancer Patients Appeal too. See the front cover for more details of how to reserve to reserve your ticket.



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Leading research into head and neck cancer

