

# SpeakOut

The newsletter of Oracle Cancer Trust

LEADING RESEARCH INTO HEAD AND NECK CANCER

SUMMER 2020

## Message from our Chairman, Peter Rhys Evans

The 22nd March 2020 was Mothering Sunday and also the first Sunday of the 'Coronavirus Lockdown' in the UK. I was in the car, taking the dogs for their (legitimate) daily walk, listening, as I invariably do, to Classic FM on the radio, when, for some reason, a small voice in my ear said: 'turn on to BBC Radio 4'. I dutifully changed channels, just in time to hear someone introduce their Sunday speaker on 'A Point of View'. I immediately recognised the mellow voice, which I have come to know, and love, over the past few years, the voice of our dear Patron, Sir Michael Morpurgo talking on 'Cause for Hope'. In that car journey, for the next 10 minutes I listened to his wonderful words of hope at this very difficult time of international crisis, urging reconciliation in our society, both nationally and internationally, to overcome this invisible adversity which has indiscriminately threatened all nations, religions and races without exception. Not only that, but it has highlighted the wide divisions in our own society between the rich and the poor, the north and south and the importance of equal opportunity and access to good education and health for all of us.

It is only through us all working together that we can hope to overcome disasters like this and I hope that when the world comes through this pandemic we shall be stronger and more united.

Apart from the 180 wonderful books that Michael has written over the past 50 years and his time as Children's Poet Laureate, many of you may not know that in 1976 Michael and his lovely wife, Clare, established the charity 'Farms for City Children', with the primary aim of providing children from inner city areas with experience of the countryside. The programme involves the children spending a week at a countryside farm, during which they take part in purposeful farm work. Many of these children have not seen a cow, a sheep or chickens before and some still think that milk and eggs come from the supermarket.

Some of you have heard him talk, and sing at our annual Christmas concert and other Oracle events over the last two years. Three years ago, when I first met Michael, the situation was quite different. He had virtually no voice, because a cancer was beginning to destroy his voice box. Fortunately, we were able to remove the tumour; he had further treatment to help prevent any recurrence and he is now cured. We have to thank Oracle and your generous support for our research work to make these treatments possible, curing cancers, restoring function and quality of life.

Because of the virus and closure of research units



and laboratories, much of Oracle's work has been delayed for the moment. Cancer treatment and surgery have also been affected and we have heard that many people have put off going to their doctor with worrying symptoms. The situation is now slowly improving with vital cancer services resuming.

Sarah Bender, Oracle's Head of Operations, has herself been very unwell in March with COVID-19 and we are thankful that she is now fully recovered. She reminded me of something I had written in my recent book: 'The Waterside Ape: An Alternative Account of Human Evolution', that survival of species depends on successfully combating and adapting to natural disasters. One third of the population of the UK and Europe was wiped out in the 14th century by the Bubonic plague and more recently many millions died as a result of the AIDS epidemic.

I speculated that the rapid extinction of our Neanderthal ancestors in Europe 30,000 years ago might also have been due to a similar pandemic for which they had no immunity or treatment. Fortunately for us, their Homo sapiens cousins, who had come over from Africa, survived through the end of the last Ice Age to establish a stronger and more robust society, which we must do, having faced this new challenge together.

This pandemic has demonstrated that we are still very vulnerable to unforeseen viral or other diseases, but fortunately, thanks to modern research and treatments, not only for head and neck cancer that you are generously supporting, but through advances in many other areas, the future of our children and further generations will hopefully be secured.

Please stay safe and well,

*Peter Rhys Evans*



BGC Charity Day



COVID-19 crisis



Tribute to John Wilkinson



# COVID-19 - your questions answered

On behalf of the Chairman, Trustees and the small team at Oracle Cancer Trust we hope that you are all keeping well during these very worrying times. We particularly extend our thoughts and best wishes to those who are undergoing or recovering from cancer treatment. We've put together a short Q&A to hopefully fill you in on where you can get support at the moment and how the COVID-19 lockdown is affecting us.

## ***Where can head and neck cancer patients get additional advice and support?***

If you have recently finished treatment for head and neck cancer and would like some friendly support during this time, our partners voluntary support group network Heads2Gether have established regional WhatsApp groups and will be shortly announcing a series of online support groups. As well as the groups there is also a 24-hour support line that can be contacted on Freephone 0800 0234 550.

## ***How much Oracle funded research is still underway?***

Oracle is currently funding 22 research projects at a cost of £2.4m at leading research institutions throughout the UK. Some of our medically qualified researchers have returned to support the frontline NHS effort, and we are proud that some laboratories are being repurposed to offer not only COVID testing but also using their equipment to manufacture necessities for healthcare teams. The majority of our funded researchers have been able to work remotely, completing their reports and carrying out other tasks until they can safely return to their laboratories.

## ***What impact has the crisis has on Oracle's financial position?***

Small organisations particularly like Oracle rely on our many generous and dedicated supporters to raise funds in the Spring; it's such a busy time for everyone running marathons, organising parties, charity dinners and much more. We are especially lucky that so many of you do this for us, and recognise and appreciate every single one of you.

But these are extraordinary circumstances and inevitably we and so many of our supporters have had to cancel or postpone fundraising plans until later this year or 2021. And sadly, at the moment charities in our field are not eligible for the funding made available by the Government so we are facing a significant shortfall of close to £200,000.

## ***What does this mean for our research programme?***

We are hoping that the events Oracle had been planning will take place in the Autumn, but as you can imagine this will have a huge impact on how much funding we can draw on both for the rest of 2020 and into 2021. As a result, Trustees have had to take the decision to delay starting some of the research planned for 2020 and currently plan to defer the next call for new research projects until March 2021 until the situation becomes clearer.

We are not alone though, and the disruption is being felt throughout the entire research community. The Association of Medical Research Funders – AMRC – have been monitoring the wider impact of how the COVID-19 crisis will affect medical research charities. Initial feedback suggests up to 70% of charities will be unable to fund future medical research due to the impact on fundraising income.

## ***How is Oracle adapting?***

Inevitably, we have had to look at ways to reduce our overheads despite operating a much smaller research portfolio. As a small team we have done as much as we can, and furloughed our one employed staff member, Natalie, and both our self-employed key team members Sarah, Teresa and Sally are working remotely on a significantly reduced timetable. We are keeping the outgoings to an absolute minimum however our core costs such as governance, accounting, insurance and premises cannot be reduced.

In normal times, it costs approximately £12,000 per month beyond our research grants to keep our lean operation running. Following a cost savings review we have been able to reduce this back to well under £9,000.

Finally, the Oracle team of Sarah, Teresa and Sally would be delighted to hear from any supporters – please don't hesitate to drop us a line for a chat or virtual coffee and catch up. Email or call us, we would be delighted to hear from you. Our contact details are below!

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## Contact details:

### **If you would like to get in touch with any member of the team here's how you can contact us:**

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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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# COVID-19: the impact on Oracle Cancer Trust

## Many small research charities that provide vital research are counting the cost of the COVID-19 crisis - and with no access to government support now face a fight for survival

Oracle Cancer Trust is just one of the hundreds of small charities that provide life-saving pioneering research to bring newer and kinder treatments for patients. AMRC (Association of Medical Research Charities) estimates that 148,000 patients currently on clinical trials have been affected - and for some of these patients these treatments are their only option.



Oracle's laboratory-based research has been paused for now and is due to resume in early June

For Oracle Cancer Trust this has been an extraordinary time that has tested our adaptability and resilience. We've all been so proud of how our researchers have responded to the crisis; repurposing their labs, returning to the front line and where possible, and adapting to working remotely from home.

Now that the COVID-19 pandemic appears to be over the worst, the funded research teams are looking forward to being able to return to their research. And the small team at Oracle are keen to pick up on the various fundraising initiatives so we can continue to plan for our 2021 funding of new scientific research.

Cancer hasn't paused for the lockdown even though our fundraising and some of our science had to. But, like so many other small medical research charities we need your support now so that we can continue our vital work and keep delivering the research to help head and neck cancer patients.

Dentists, often at the front line of referring suspicious ulcers, patches or lumps have now been closed for several weeks and it's feared that there will be a huge spike in oral cancer cases that may have been missed at an early stage. Oral cancer is now the most common type of head and neck cancer also sixth most common form of cancer overall in the UK and worldwide.

### The Bottom Line

- It costs £290 a day to keep the charity afloat
- £1,000 a week has been spent on research that has continued during lockdown
- Research leaders have had to delay the start of three projects until early 2021 due to the knock on effect of the crisis
- Current projects, particularly laboratory-based research face delays and will have no-cost extensions
- Delay our next grant round for new research projects to March 2021 at the earliest

We've also seen reports showing referrals from GPs for all kinds of cancer have dropped by over 70% during lockdown and we are very concerned that people who have early stage head and neck cancer may suffer as a result of delays in diagnosis.

And there have been cases of current patients and their clinicians having to make a choice between continuing treatment or pausing. With chemo-radiotherapy significantly impacting the immune system, some patients have had to make an awful choice between continuing their lifesaving treatment to reduce their chances of contracting coronavirus.

### Never More Needed

Spring is usually a busy time for our Oracle Family. For everyone running marathons, organising parties, charity dinners and much more. And, with the likelihood of mass participation challenges such as marathons being postponed to 2021, we need your support more than ever.

Donations have effectively ground to a halt and we are now facing a shortfall of around £200,000 that we had planned as income to the end of our financial year at the end of May this year.

### Revive Head and Neck Cancer Campaign

As we ready ourselves to reopen the doors to our labs and out office, we hope you'll help us kickstart our head and neck cancer research.

We'll be launching a crowdfunding appeal shortly and hope you'll consider supporting us and share it with your friends and family. Our community knows more than anyone what it takes to face head and neck cancer and with your help, we will be able to get back up and running as soon as possible: Watch out for more news on our website, Facebook, Twitter and Instagram pages.

## BGC Charity Day

Oracle were honoured to be welcomed as guests to attend the prestigious BGC Charity Day, a global fundraising event set up to commemorate those who perished in the 9/11 World Trade Centre Attacks

We were delighted to invite a very special family to join the Oracle team for the day. Bec Davies from Bridgend in Wales has raised an incredible £12,000 over the past year in memory of her father, Jeff who tragically lost his life to an aggressive form of head and neck cancer at just 54 years old. Bec, her family, friends and the whole community have joined together over the past year and taken part in challenges from walks to sporting events. Bec, husband Matt and their daughter Scarlett made the journey to Canary Wharf for the fun-filled day attended by a host of stars from the world of TV, film and music who all take trades, assisted by one of BGC's brokers who in turn donate their commission to support a range of good causes.

BGC Every year the charity team at BGC theme the day and this year hit movie "The Lion King" set the scene in the impressive lobby at BGC. Children of all ages, many of whom have life-limiting illnesses enjoyed a petting zoo, sweet shop, celebrity children's entertainers Sharky and George along with a host of caricatures.



Bec's husband Matt with Peter Crouch who was supporting a children's hospice at the event



Scarlett gets in on the action with a trade on the busy floor



Scarlett with pop queen Cheryl Cole



Traders don their colourful charity day waistcoats for the annual fundraiser

## London Research Evening report



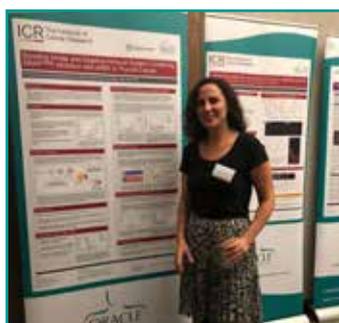
L to R Supporters Julian Gilbert and Steve Bergman

Our fifth annual research evening was hosted at the new Blue Orchid London Tower Suites Hotel, a new hotel venture by Vice-President Tony Matharu

Just 24 hours earlier, the venue was a frenzy of activity with workmen making the final touches to Tony's new five star all-suite hotel set in the heart of the City of London. Oracle were honoured to be the very first guests at the venue and guests enjoyed a champagne reception, a wonderful buffet as well as tours of the property for those keen to see the stunning development overlooking The Tower of London.



Guests mingle in the busy exhibition area speaking to the researchers



Oracle-funded researcher Eva Crespo-Rodriguez from The Institute of Cancer Research

As Oracle's research portfolio has grown, this year we welcomed over 20 researchers and their project leaders to the event who shared their work with our guests at the event.

Presenters included Prof Arturo Sala of Brunel University who is researching the rare cancer, Adenoid Cystic Carcinoma. Robotic surgery expert Prof Vin Paleri of The Royal Marsden Hospital shared the latest developments and Prof Kevin Harrington updated the audience with the latest news from his laboratory at The ICR, where Oracle are currently funding eight projects. We are delighted to announce that our London research evening will be held on **Tuesday 6th October 2020** and will be returning to The Blue Orchid Suites.



L to R Sacha Newall with Blue Orchid Hotels founder and Oracle Vice President Mr Tony Matharu

## Our 14th Glory of Christmas Concert

We were delighted to welcome so many friends and supporters to our annual Christmas Concert for a wonderful evening of music, readings including performances by leading Countertenor Theo Golden and award-winning Saxophonist Rob Burton.

Our Patron, Sir Michael Morpurgo performed a beautiful poem accompanied by the voices of the Choir of Christ's College, Cambridge. The audience enjoyed seasonal classics and carols with music by The Thames Chamber Orchestra under the musical directorship of Keith Marshall.

Thanks to the generosity of donors in our sponsored ticket appeal, over 80 nursing, research and support staff from head and neck units in London and Oxford joined us for the evening.

The concert also marked the beginning of our Big Give Matched funding campaign to support a new immunotherapy project. The response to the appeal was truly overwhelming and we are delighted that we exceeded our target raising over £16,000 to directly support our research efforts in this breakthrough area of cancer research.

Readers this year were all former patients who shared personal and seasonal readings, and this year we welcomed former BBC presenter Janet West, former Radio 1 DJ Pete Brady and leading hospitality expert Robert Walton MBE.

We would like to thank all our supporters who travelled from all over the UK to attend our annual concert, our solo performers who so generously gave up their time to for us as well as the teams of volunteers who helped us bring the event to life.

All photographs from the event are available to view at [oraclecancertrust.org/the-14th-glory-of-christmas-concert](http://oraclecancertrust.org/the-14th-glory-of-christmas-concert)

We are currently monitoring the current situation with regard to COVID-19 and will update supporters with further information regarding the 2020 concert.



Sir Michael Morpurgo with Peter Rhys Evans and performer Rob Burton



Robert Walton MBE with Jamie Newall

## 2020 Annual Golf Day

Our golf day, like so many events, was postponed due to the COVID-19 pandemic and we are hoping to go ahead with our new date of **Friday 9th October** at Cowdray Park Golf Club, which is set in the heart of the South Downs near Midhurst.



With current regulations golf is currently allowed in a two-ball format and we hope to be able to host our day possibly even with a reduced format. With the issues of social distancing it may not be possible to host a lunch and the usual entertainment. We will update everyone as soon as we know more.

## Oral Health Awareness Month

The team recently attended the official launch of Oral Health Awareness month at The House of Commons which kick-started a month-long campaign to raise awareness about one of the fastest growing types of cancers which has seen cases grow by over 90% since the 1970s.

More than 130 people from a variety of different organisations were in attendance and heard from a range of speakers reinforcing the need for greater recognition of mouth cancer along with its signs and symptoms.

Sir Paul Beresford MP, the event's parliamentary sponsor, brought the room to order and used his introductory speech to talk about the "vast improvements in prevention" in recent times in combatting mouth cancer risk factors like smoking and alcohol. Sir Paul also highlighted the success of the gender equality campaign with the introduction of the HPV vaccination for boys and the importance ensuring high rates of inoculation across all genders.

Guest speaker Karen Lisching-Schroder (pictured right) spoke movingly about her battle for over six months to get referred to a specialist following a suspicious ulcer on her tongue which was later diagnosed as tongue cancer.



Karen, a dedicated marathon runner, put her remarkable recovery down to her fitness and with the support of family and friends was able to resume her love of running after months of debilitating treatment.

## Giles Cuthbert's garden challenge

"Before our lives were turned upside down by the pandemic that is Coronavirus, I had signed up for 5 of 20 marathons, all of which have been cancelled or moved to later in the year. With the cancellation of the Reading marathon, I decided to continue the challenge by running the first in my back garden and then carry on the rest in and around my local village.

"I am fundraising for five charities close to my heart, one of them being Oracle Cancer Trust. Four years ago I was diagnosed with head and neck cancer and after going through chemotherapy and radiation treatment four years ago, I was given the all clear. I count myself as being extremely lucky."

To support Giles' fundraising please visit [uk.virginmoneygiving.com/GilesCuthbert1](https://uk.virginmoneygiving.com/GilesCuthbert1)



## Julian's virtual cycling challenge raises over £3k



With the cancellation of Julian's corporate golf day in support of Oracle as well as the annual Harpenden Carnival, the committee joined forces to recreate a Lands End to John O'Groats virtual cycling challenge. Julian has raised over £40,000 for Oracle Cancer Trust and is currently part-funding PhD student and fellow Harpenden resident Alex Rose who is researching a rare type of head and neck cancer at the ICR in London.

The 24-hour challenge involved 28 riders covering 1407kms taking 48 hours. Cyclists joined from their basements, garages, front rooms and even tool sheds with the keen riders all joining for three hour stints. We were delighted that Prof Kevin Harrington (pictured) from The ICR and Royal Marsden Hospital joined the challenge as well as long-term supporter Barrie Dawson and his friends as part of "Team Oracle".

You can support Julian's fundraising at [www.harpendencycleval.uk](http://www.harpendencycleval.uk).

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## Derek Miller raises over £7,000 at second fundraising gala



Tricia Collins and Dolly Edwards getting the hang of their jive moves

Over 85 family and friends joined former patient Derek Miller for his second Summer Charity Party held at Sand Martin Golf Club, in Berkshire. Guests enjoyed a three-course meal followed by some fun fundraising games and a highly entertaining auction with MC Mark Head. Some fantastic prizes were donated including holidays in Cyprus, glider flights, a private dinner by a celebrity Chef to the Celebrities and much more.

Then the party started! A fun, 'Ice Breaker', Modern Jive Dance Class conducted by Luci and Kerrin of Ginger Jive fame got everyone on the floor, even for the absolute beginners with two left feet. The superb 'Hillmans Blues Band' then took up the pace to keep everyone dancing through the night to classic rhythm and blues and rock and roll. The band were supported by Nick Breakspear, the 'silent DJ', who provided his Playlist selections from 60's 'Beat' to Motown, from 70's 'Disco' to music of the 'noughties'.

Says Derek "As ever, it is a case of attention to detail. We had a busy fun-filled evening, a great party, with everyone letting their hair down and yet, at the same time, doing their bit to support an excellent cause ...what more could I ask! I was overwhelmed with the generosity of everyone who came to support my evening and who gave such wonderful feedback.

I'd like to thank everyone who donated prizes and joined us for a great night. Here's to planning an event in 2021!"



Derek handing over a raffle prize to a lucky winner



Nick Breakspear the 'Silent DJ' assisting with the auction



Blues Band "The Hillmans" at work

# Remembering: John Wilkinson 1968 - 2019

“If you feel something isn’t right, please don’t give up and seek help. Insist to be referred if symptoms haven’t resolved themselves in three weeks. Had John been more insistent about his symptoms, things might have been a lot different. I want John’s legacy to raise awareness about head and neck cancer through his books and support Oracle’s pioneering research work in his memory.”

John’s cancer journey started with a slight numbness above his back molar teeth. After much flossing and brushing, the sensation continued so decided to pay a visit to the dentist. Following an examination and x-ray John was told there was nothing untoward and his symptoms were put down to old age and teeth grinding. As the weeks flew by with a whirlwind of work and travel commitments he realised the numbness had spread to his top lip and cheek. There was no pain so he concluded it was “nothing.” But on a routine visit to the Dr, a repeat visit to the dentist was advised. This dental visit proved to be the turning point which led to a referral and the news that there was an “unknown mass” in the sinus area. This was then diagnosed to be a 7cm, rare tumour and due to the complexity of the treatment John faced, was referred to The Royal Marsden Hospital in London who specialise in complex head and neck cases. What followed was over 30 hours of life-changing facial surgery, 400 stitches as well as radiotherapy and chemotherapy.

Following John’s first major operation, he said he wanted to help others facing cancer and give something back to everyone who had helped him on his journey. Says his widow Jane, “I remember the day John told me he was going to write a book. I listened to his reasoning and felt an inner strength almost exude out of him. I also remember my thoughts as I left his bedroom: doubt, disbelief, fear and a sense of angst as I wondered how he could rise to a challenge such as that and congratulated him on his bravery, his fortitude, his essence and all the other synonyms that could be associated with the word “hero.”

Following the publication of John’s book the couple embarked on a sold-out book tour throughout the UK to raise awareness about head and neck cancer and promote his new book. “Face Cancer” has received rave reviews for its raw honesty and at times, humour, is on sale and can be purchased by visiting the site [www.facecancer.org.uk](http://www.facecancer.org.uk) or online at Amazon.

John died peacefully at home on Christmas Day 2019. Jane continues, “When I broke the news to the children, you could feel the sense of relief that his battle was finally over and he was free from pain. To keep his memory going and continue his legacy I’m planning a series of fundraising events and am delighted that we will be supporting Oracle Cancer Trust and their pioneering research into one of the “forgotten cancers.” Whilst sinus cancer is thankfully still quite rare, it’s vital that dentists, doctors and the public understand the often confusing symptoms of head and neck cancer and, if necessary, get a second opinion.”

The team at Oracle Cancer Trust would like to thank Jane Wilkinson and her family for their ongoing support of the charity in John’s memory. There are a series of charity walks, lunches and dinners to raise funds in his memory. Due to the COVID-19 crisis many of these have been postponed to later in 2020 and 2021 and we look forward to sharing further details soon.



At the book launch with our children Max and Lois



John with ex-cricketer and TV pundit Phil Tuffnell at his book launch



Following the first surgery



With John in the Alps.



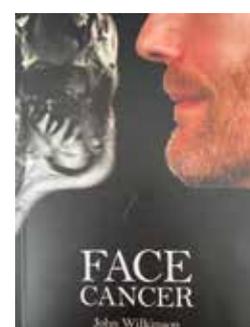
John and I at one of his book launches



In happier days enjoying one of our favourite pastimes, skiing in the Alps



John sharing his story at one of the many book launches around the country



## Donate

### Online

Help us get our research back on track. You can make a one-off donation or set up a regular donation directly via our website at [oraclecancertrust.org/donate](https://oraclecancertrust.org/donate)

### Regular Giving - Become an Oracle Friend

By becoming a regular donor you can help ensure that Oracle's research programmes get the funding they need to make advances in finding newer and kinder treatments for head and neck cancer. A direct debit form can be downloaded via Oracle's website at [oraclecancertrust.org/donate](https://oraclecancertrust.org/donate) or you can set up a regular donation online

### Become a Corporate Partner

Oracle is very keen to create mutually beneficial partnerships with companies who would like to support our pioneering cancer research work, a cause about which everyone can feel passionate. Pledge to fundraise for the charity and in return we can offer you bespoke fundraising support, volunteering opportunities and event invitations. We will work with your organisation to offer dedicated support throughout any partnership activity and keep you up to date with the charity's pioneering research work so that you can understand the impact of your fundraising.

Contact [teresa@oraclecancertrust.org](mailto:teresa@oraclecancertrust.org) for more information or visit [oraclecancertrust.org/fundraise/become-a-corporate-partner](https://oraclecancertrust.org/fundraise/become-a-corporate-partner)

## Dates for the diary

### Tuesday 6th October 2020, 6.30pm - Annual Research Reception

Our popular supporters reception showcases the current developments in our head and neck cancer research programmes and features presentations and the chance to meet the teams of research leaders and the scientists. This year's event is being held once again at Blue Orchid London Tower Suites, Minories, London EC3 and is conveniently located near to Tower Bridge in the City of London.

The evening includes a welcome reception and buffet kindly sponsored by our Vice-President, Tony Matharu. To register please visit [oraclecancertrust.org/events](https://oraclecancertrust.org/events) or email the team [events@oraclecancertrust.org](mailto:events@oraclecancertrust.org).

### Friday 9th October 2020, 9.30am - Annual Golf Day - subject to change

Our fun and informal golf day is a great day out and this year will be visiting the stunning Cowdray Park Golf Club near Midhurst in Sussex. The day includes breakfast, golf and entertainment and fun competitions. Individuals (£95) and fourball teams welcome (£380). If you'd like to join us please email the team [events@oraclecancertrust.org](mailto:events@oraclecancertrust.org).

### Monday 7th December 2020, 7.30pm - The Annual Glory of Christmas Concert

Due to COVID-19 and for the safety of our supporters, performers, staff and volunteers we are unable to confirm if this year's concert will be going ahead. We hope to update supporters shortly with further information.



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Leading research into head and neck cancer

