

SpeakOut

The newsletter of Oracle Cancer Trust



LEADING RESEARCH INTO HEAD AND NECK CANCER

AUTUMN/WINTER 2015

Restoring Voice after Laryngectomy



Some of our readers may remember the actor Jack Hawkins who is perhaps best known for his roles in "Bridge over the River Kwai", "Zulu" and "Lawrence of Arabia". In his aptly named autobiography "Anything for a Quiet Life" he describes how he developed cancer of the larynx from his heavy smoking and in 1966 had to undergo a total laryngectomy. In those days, only about 10% of patients who had had their voice box removed could achieve any sort of voice, by swallowing small amounts of air and producing what was called "oesophageal voice", which Jack Hawkins managed to do quite well. This allowed him to say a few short phrases in a softish voice, but he was determined to try and get a better voice.

In the early 1970's a new operation was pioneered in the USA using a rather complex "artificial voice-box" device and bravely he decided to go ahead with a chance of improving his voice. Sadly, he developed complications from the operation and died in St. Stephen's Hospital, now the Chelsea and Westminster Hospital, just along the Fulham Road from The Royal Marsden Hospital in July 1973.

Following his tragic death, all attempts at using these elaborate artificial voice-boxes were abandoned for several years. However, in 1979 a brilliant young speech therapist from Indianapolis, Eric Blom, thought up a simple concept of inserting a small one-way valve between the top of the trachea and the oesophagus to divert air from the lungs into the back of the throat and mouth, thus giving the potential of restoring a much stronger and sustained lung-powered

speech. Teaming up with an ENT surgeon, Mark Singer, they introduced the Blom-Singer valve which established the new era of modern voice restoration, transforming the lives of laryngectomy patients worldwide.

Shortly after, in 1982 I had the opportunity of spending some time with Eric Blom in Indianapolis learning and developing this new technique, which we brought back to the UK. Initially, there were hundreds of laryngectomy patients in this country who had been without voice, some for many years, who were thrilled to have their voice restored with a simple day-case procedure.

Especially gratifying was being able to go and carry out these voice restoration procedures in third-world countries where a large proportion of the laryngectomy population were unable to read or write and therefore had no means of communicating at all, even with family and friends. Hearing their loved-one speak for the first time in years in their own voice, moments after putting in the Blom-Singer valve was extremely emotional for everyone concerned, not least for the surgeon who had to double up as speech therapist and diagnostic radiologist in those early years! Soon after, we started to do the operation at the same time as the laryngectomy and now it is standard practice with about 90% of patients being able to talk well 3-4 weeks after their laryngectomy.

Over the last 10 years Oracle has already funded three PhD projects through the John Diamond Voice Research Laboratory at The Royal Marsden Hospital investigating quality of voice, speech and swallowing function following laryngectomy and radiotherapy, establishing recognised analytical indices which can be used universally for comparison of data.

However, without further funding and investment we are unable to incorporate these valuable tables and indices into routine practice. This would allow sequential analysis of these functions before and after treatment so that new techniques can be incorporated or modified in order to achieve optimum function. In time we hope that this will benefit all patients, not only at The Royal Marsden but at other centres as well.

Peter Rhys Evans
Chairman and Founder, Oracle Cancer Trust



Research round up



Join us at the tenth Glory of Christmas Concert



Supporting patients with speech and language



Remembering Oracle in your will

ORACLE
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Dear Supporters

Welcome to the Autumn issue our our newsletter. Thanks to the loyal support and generosity of our donors in 2014 and 2015, Oracle was able to launch four new fellowships in partnership with The Institute of Cancer Research and The Royal Marsden Hospital. I am also delighted to announce our new Supporters' Fellowship, which has been founded in recognition of all the donations we receive throughout the year. With increased scrutiny in the media about the Charity sector and responsible spending, I would like to reassure our donors that overheads to run Oracle are kept to an absolute minimum to ensure your donations go to where the need is greatest - our world class pioneering research projects. Many of our events and fundraising initiatives are managed by volunteers.

Our primary focus at Oracle is to increase our current research projects to 18 by 2018 - and to achieve our ambitious target we rely on your generous support. We were delighted to have met so many of our supporters at our recent Research and Innovation Event at The Institute of Cancer Research, where our outstanding team of clinicians and researchers showcased their existing projects and future plans.

Looking to the future, we will be focusing our efforts on raising funding from foundations and trusts as well as building up a solid flow of funding through the Oracle Endowment Fund. We are also highlighting the importance of legacy giving in this issue which will ensure the continuing future of our research work. Despite over 70% of us donating to charitable causes during our lifetime, less than 6% of people leave a gift in their will to a good cause. On page 11, we are looking at how leaving a gift in a will can be a lasting legacy to continue our fight against head and neck cancer and ensure Oracle's long term future.

We have held a number of exciting events over the past year, including our annual golf day, Rugby World Cup preview, and Walk the Test Way. This year we also look forward to our 10th Glory of Christmas Concert at St John's Smith Square in London, which is a true celebration for all our friends and supporters to join together at this special occasion.

In the meantime, I hope you enjoy reading our latest issue of SpeakOut, and if you have any comments or questions, please don't hesitate to get in touch.

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Oracle's Voluntary CEO, Anthony Sykes

By 2018 our target is to have 18 funded research projects to bring us closer to finding improved treatments and cure rates for head and neck cancer



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Twitter: @oracle_cancer

Oracle Head and Neck PhD Research Programme



Oracle Cancer Trust is delighted to announce its biggest research funding commitment to date with a new joint initiative with The Institute of Cancer Research. Although Oracle has been funding pioneering head and neck cancer research projects at The ICR for the past decade, this is our largest undertaking to date. This fully funded programme of PhD students will help to accelerate work to take new therapies into the clinic to help patients.

This new initiative will recruit up to two new students every September to undertake a three year research study, specifically for head and neck cancer. Recruitment is underway for our first student, and we have designated this the "Oracle Supporters' Fellowship" in recognition of donations we receive throughout the year (see below).

These new research projects will range from virus and drug therapies, immunotherapy, surgery and radiotherapy.

Oracle Supporters' Fellowship

We are delighted to announce our new Supporters' Fellowship which was launched in September this year in recognition of donors who so generously support Oracle throughout the year, either through regular donations, sporting challenges, the Oracle Endowment Fund or by one-off donations.

This first Oracle funded PhD student will be working under the guidance of Dr Simon Robinson. Dr Robinson is developing non-invasive magnetic resonance imaging (MRI) techniques to assess how tumours respond to treatment. He is internationally recognised for his studies in the use of blood oxygen level dependent MRI in detecting and diagnosing cancer.

Low oxygen levels, as often occurs within a tumour mass, can cause tumour cells to switch on a survival mechanism that results in them becoming more resistant to radiotherapy or chemotherapy. This is particularly prominent in squamous cell carcinoma of the head and neck.

New targeted agents that can influence the tumour oxygen levels for radiotherapeutic gain, or that target the resultant survival mechanisms are in development. But it is difficult to accurately assess how well such agents perform in laboratory models *in situ*. Within The ICR's Tumour Profiling Unit we are pioneering the use of cancer 'avatars' for head and neck cancers (as Professor Kevin Harrington talked about on the Panorama documentary). These avatars could help tailor cancer treatments to patients by matching drugs to a tumour's unique characteristics – because both avatar and patient have the same cancer type, down to the same mix of genetic mutations.

Dr Simon Robinson and the PhD student will use advanced imaging technologies (such as MRI, PET, CT), and a state-of-the-art radiation research platform within the new Centre for Cancer Imaging at The ICR, to develop ways of assessing tumour response to the new agents within these avatars, thus speeding up the time taken to get them into clinical trials for cancer patients.

By using high-precision imaging technologies they aim to assess, in a non-invasive way, how these new targeted treatments are working on the oxygen levels in the avatar first, and whether the tumour might become more sensitive to radiotherapy. The idea is that doctors can then judge which treatment will be most effective for each patient, and have greater confidence of success – particularly for head and neck patients where standard treatments for aggressive forms of the disease can still cause life-altering side-effects for those that survive.

This new Fellowship initiative has been funded thanks to the generosity of our donors, some of whom have undertaken sporting challenges in support of our research work

Events and Fundraising Update

Annual Research and Innovation Event

Over thirty five supporters joined the whole team from Oracle to learn about the projects being funded by the generosity of our donors.

Following an introduction by Oracle's CEO Anthony Sykes and Chairman Peter Rhys Evans, Professor Jim McCaul presented his robotic surgery project, that will transform



Professor Kevin Harrington updates the audience on the latest developments in virus and immunotherapies

the ability for surgeons to operate on hard-to-reach tumours in the mouth. The new robotic surgery project will focus on tonsillar cancer, which is one of the fastest growing groups of cancers. Professor McCaul explained that surgery is still considered the "gold standard" when treating cancers.



A guest bravely challenges ex-Samoan International Freddie Tuiliagi to an arm wrestle



Over 200 guests enjoyed an evening including previews from former England International Julian White



Freddie Tuiliagi entertains in a barely there national costume



Head and Neck Dietitian Laura enjoys some Samoan dancing



Guests had the opportunity talk to the Oracle funded research teams about their individual projects

Professor Chris Nutting spoke about advances in the delivery of radiotherapy treatment and how following Oracle funded research, common symptoms such as dry mouth can be dramatically reduced. A new larger scale study is currently underway at The Royal Marsden Hospital. Oracle initially funded an early stage trial that has led to CRUK funding a multi million pound research programme.

Professor Kevin Harrington's work on virus and immunotherapies is known throughout the world. These targeted therapies attack cancer cells and recent studies are yielding some remarkable results. Following the presentations, guests mingled with the research teams who talked through their projects.

Our research and innovation evening is set to be an annual event and we are looking to organise our next presentation in Autumn 2016.

Rugby World Cup Party Night

Over 200 guests enjoyed an evening all things rugby in support of Oracle Cancer Trust, two days before the kick off in the Rugby World Cup. Ex-Samoan International Freddie Tuiliagi demonstrated not only his arm wrestling skills, but also his proficiency in dancing in his native Samoan national costume.

Dancing aside, several female professional rugby players talked about life in the training camp in preparation for Rio 2016 for their debut in Rugby Sevens. Guests also enjoyed insights from several of the England World Cup winning rugby team of 2003 including George Chuter and Julian White ahead of England's first game just three days later.

Between dancing and rugby, the evening was all in support of charity, with a silent and live auction running that raised just over £10,000.

We are very grateful to supporters who so generously provided auction prizes for the evening.

Events and Fundraising Update

10th Glory of Christmas Concert Monday 7th December 2015 7.30pm

Our 10th concert is fast approaching and we look forward to welcoming all our supporters to join us for a joyful evening of music, readings and reflection to start the festive season. We once again welcome the acclaimed Thames London Chamber Orchestra and The Choir of Christ's College, Cambridge at the beautiful concert venue, St John's Smith Square in London's SW1.

Ticket prices range from £45, £30, to £10 with a special "4 for 3" offer on £30 price banded tickets.

Tickets can be booked as follows:

Select your seats online at: www.oraclecancertrust.org/boxoffice

Email events@oraclecancertrust.org

Call us on 020 7922 7924

LAST TICKETS AVAILABLE

Book online at

www.oraclecancertrust.org/boxoffice



Why not combine the concert with an overnight stay at The Sloane Club? The Sloane Club is located in the heart of Chelsea and has double rooms available for the special rate of £266 (£256 for double room for single occupancy) including VAT, Wifi, continental breakfast and temporary membership of The Sloane Club for the duration of your stay. Reservation enquirers must be sent in writing to reservations@thesloaneclub.co.uk and quote "Oracle Cancer Trust".

The whole team look forward to seeing you on the 7th December.



uk.virginmoneygiving.com/KevinHarrington



Barrie Dawson on his 14th bike ride for Oracle

Professor Kevin Harrington to run the Virgin London Marathon in support of Oracle Cancer Trust in 2016

Better known as a Consultant Clinical Oncologist and Professor of Biological Cancer Therapies at The Institute of Cancer Research, Professor Kevin Harrington has started training for the biggest physical challenge of his career - the London Marathon. Professor Harrington recently completed The Royal Parks Half Marathon, and was keen to take up the challenge in support of Oracle Cancer Trust.

Says Kevin "When Oracle was awarded a charity ballot entry for the Marathon I jumped at the chance to run. I've recently completed The Royal Parks half marathon and I'm now ready to take on the challenge of 26 miles. I already have a target time of completing the 26 miles in under 4 hours and am looking to beat my fundraising target of £25,000. Please do visit my page and pledge your support! All funds raised will be specifically used to support my head and neck research programmes at The Institute of Cancer Research."

Barrie Dawson completes his 14th annual bike ride for Oracle raising over £5,000 - bringing his total raised for Oracle to over £66,000!

Barrie and his team disembarked at Caen at 5.30am facing a 96 mile ride to Evreux, commencing Day One of his five day ride through France. The scenic route took Team C through Versailles, Rouen and Le Havre covering over 400 miles, with temperatures soaring to 39 degrees throughout the gruelling ride, which they finished at the famous Pegasus Bridge in Caen.

Barrie would like to thank his cycle team. Without their motivation and navigation skills he would not have been able to complete the ride. And, also not forgetting his very generous and loyal sponsors. But most of all the person who made it all possible, his surgeon, his hero - Peter Rhys Evans.

10am, July 4th 2015, Seaford Beach, 30mph wind, 4ft waves



Morgan: 'Looks quite choppy, don't you think?'

Paul: 'Uh-huh'

Morgan: 'Rescue boat is busy....'

Paul: 'Uh-huh'

Standing on the Seaford shingle, cupping polystyrene beakers of scalding tea as the waves rolled and crashed before us, we were

contemplating our first triathlon (750m swim/20km cycle/5 km run). The wind hampered our chat. The swarm of yellow-capped swimmers taking part in the race before ours disappeared into the troughs of the waves, then reappeared as the waves broke over them. Some were retiring, swamped and exhausted. A helpful gentleman standing next to us declared himself a local. "I come down every year to watch. Last year, they cancelled the swim because it was too rough. I expect they'll keep it going this year. They wouldn't want to cancel twice." We both took a gulp of tea.

Morgan: 'Just doing the sums. If we pull out now, it'll cost us £750 each to cover the pledges'

It seemed a reasonable price and a sensible option. Paul's phone pinged in his pocket.

Paul: 'Make that £755. We just got another tenner on JustGiving.'

Then we remembered why we were doing this. Three years earlier, Morgan had finished his treatment at the Royal Marsden for cancer of the tongue. He had been put forward for a new type of treatment, in the hope of saving some of his salivary glands. He didn't let go of his hope of returning to work as a teacher.

Morgan: 'If you were a real friend, you wouldn't have signed me up for this.'

Paul: 'If you hadn't given me a job 32 years ago, we wouldn't be here at all'

And that's why we were there: to celebrate friendship, family and longevity, and to thank those who put their hearts and souls into researching, treating and supporting patients with cancer. Morgan also wanted to give hope to others starting out or midway through their treatment.

Morgan: 'That day you signed us up, I was exhausted; I couldn't imagine I'd be anywhere fit enough for this'

That was six months earlier, sitting in Morgan's front room. Morgan had been diagnosed in 2012. After the treatment, his weight had dropped to 9st 6lb. Paul had been dropping round to help with those tasks that become such big

challenges during the treatment and recovery period. We thought back to where our friendship had begun. We'd been introduced by Paul's sister in 1983 and spent the next 20 years running the outdoor charity, Adventure Unlimited, together. At 63 (Morgan) and 53 (Paul), we were certain this was our greatest adventure.

Morgan knew he wanted to do something to mark his recovery, and to thank those who'd cared for him. He'd always been a strong swimmer. His six-pack felt more like Lurpak these days; it felt great to be 12 stone again but a triathlon seemed to be a distant dream. Yet, here he stood. Here we stood, on Seaford beach.

Paul: 'When we get in the water, we'll try and stay together'

We'd trained for weeks. We were like two finely tuned and well oiled machines – ready to break down at any moment.

Morgan (full of apprehension): 'Let's do it'. We confidently tip-toed into the water. Two hours of puffing and sweating later, we crossed the line 108th and 109th out of 110 in our class. Cheered on by family, and reassured by the presence of Paul's wife, a GP, amongst the crowd (Morgan had marked the spot where he was going to collapse if it came to it!) we'd done what we set out to do. We didn't drown, we didn't crash and we didn't walk.

We didn't win but we did finish. The challenge was about friendship, thanks and hope – and making some money for Oracle Cancer Trust.



Three years earlier, Morgan had finished his treatment at The Royal Marsden for cancer of the tongue. He had been put forward for a new type of treatment in the hope of saving some of his salivary glands. He didn't let go of his hope of returning to work as a teacher

Living life to the full

In August this year I celebrated my 65th birthday. On several occasions in my late forties, I was not expected to reach the age of 50. I was only able to live longer thanks to the skills, experience and determination of Peter Rhys Evans and his marvellous team at The Royal Marsden Hospital.

In August 1997 a lump appeared on the side of my neck. Much to the surprise of my GP in Southampton and the local Consultant, squamous cell carcinoma was diagnosed at the base of my tongue. I underwent 30 sessions of radiotherapy over six weeks and we were told that the tumour had disappeared. Seven months later, however, in March 1998 a lump reappeared in my neck. Surgery was required to remove a tumour from the wall of the pharynx and the neck. The operation was carried out in Southampton and went well. After a week I had recovered enough for our daughter Carine aged 5 to visit me. As my wife Nadine recalled "On entering hospital, Carine spotted a pink rabbit balloon in one of the shops which we bought to tie to the end of Daddy's bed", see photo.

I recovered well but in August another lump appeared near the jawline on the same side as previously. My consultant said surgery would not be possible and recommended palliative chemotherapy which would not be curative. Fortunately my sister-in-law Ludmila, a GP in London, suggested I see Mr Rhys Evans at The Royal Marsden Hospital. After careful examination he explained that he could do surgery even though the tumour was close to the carotid artery and would also insert plastic tubes into the wound at the time of the operation through which radium implants would be inserted a few days later to clear up any remaining cancer cells.

In April 1999, although the original tumour sites were clear, a further lump appeared lower down in my neck involving my voice box. Mr Rhys Evans said that the only curative option

was a total laryngectomy to remove my larynx together with the tumour.

In September 1999 a nodule appeared in the front of my neck and it was initially thought that the tumour had come back in several places which was not curable. However, after some chemotherapy, Mr Rhys Evans carefully reviewed all my recent scans, which were difficult to interpret after all the previous reconstructions, and decided there was just one site of tumour remaining, which he removed on 24 February 2000. As he said, no matter how bleak the outcome may seem, never give up hope. That was 15 years ago.

Six months later in August 2000 I celebrated my 50th Birthday on a family holiday and was fairly optimistic that no further treatment would be required. I was able to lead a fairly normal family life. I was not able to return to work full time but was able to spend more time with Nadine and Carine, then aged 7. I had taken readily to speaking through a voice prosthesis and in my voluntary work, I facilitate Self-Management courses for people with Long Term Health Conditions.



Carine, aged five visiting me in hospital following my first operation in 1998

The photo of us on Carine's 21st Birthday last year is a special "After" photo, in sharp contrast to the "Before" photo above.

With many thanks to Peter Johnson for sharing his story



With my daughter Carine on her 21st birthday and wife Nadine

If you have a treatment journey you would like to share with us please do get in touch

The voice

If I were to let them, my three children (twins aged 11 and a coming-up-to-seven year old) would watch 'The Voice' all the time. Apart from the power of the singing it seems to be the competitive element that they love. Each of them quickly latches on to a favourite performer and supports them fervently until they drop out – at which point they are seriously disappointed.

For me though, the title of the TV show has very different connotations. It was 14 years ago (on August 2nd, 2001 to be precise) that I underwent a ten-hour operation, the outcome of which I knew beforehand was completely unpredictable. I was first diagnosed with throat cancer in July 2000 while working for the British Government's Department for International Development in Uganda. After being flown straight home, I spent three months in Guy's Hospital, where I had the full dose of radiotherapy and chemotherapy. To no effect. I was released on December 15th 2000 (you will see that I know these dates intimately), and was told that I was "incurable and inoperable". I was



The family at Great Barrier Reef in Australia. Although I was only photographer on this occasion, snorkelling is now possible following a laryngectomy

handed over to palliative care at St Christopher's Hospital in South East London and to this day I believe I am one of only a few patients to be taken in to St Christopher's and to be alive 14 years later and cured of cancer.

For seven months I lived at home, not able to speak or eat – I had a tracheostomy and was machine-fed overnight by a direct tube into my stomach. By June 2001 my GP was wondering why I was still alive. So was I. He referred me to The Royal Marsden Hospital in the Fulham Road and to the care of Mr Peter Rhys Evans and his remarkable team.

Scans indicated that the primary tumour obstructing the larynx was large (about the size of a large plum) and that it had extended into the base of the tongue as well and had also spread to involve the lymph nodes in both sides of the neck. Mr Rhys Evans admitted that no specific outcome could be guaranteed by an operation, but an operation

would undoubtedly improve the quality of my life by reconstructing my throat with skin and muscle from my back, and if he was able to remove all of the tumour it was the only way of possibly offering me a chance of cure. I decided to go for it. There was, quite literally, no future in doing otherwise.

I very clearly remember coming around the next morning, feeling very groggy, and seeing a bunch of indeterminate shapes in white coats around my bed saying how "wonderfully well the operation had gone". Those words still ring in my ears all these years later. The primary was large and similarly the secondaries in either side of my neck, but it had not metastasised elsewhere and, as the scans had optimistically suggested, it was possible to dissect the tumour safely from the vital carotid arteries. So I was on my way. In November I was re-admitted to The Royal Marsden where Mr Rhys Evans inserted a small plastic valve in my throat which would allow me to talk again. I now have a small white plastic button-like object in my throat which I depress to divert air from my lungs, into my throat, thus enabling me to speak – it is my voice, although a little deeper than before. After 14 years I love my "lary button".

I returned to work in DFID headquarters the following February (February 5th, 2001: another unforgettable date). I must admit I was terrified. I felt like a five-year old boy going to primary school for the first time. But of course everybody at work was wonderfully supportive. DFID provided access to a psychologist for the first couple of months, and – quite quickly – my confidence returned and colleagues just got used to "Graham's new voice". It became a non-issue.

In the darkest days of early 2001, at home, sitting and waiting for the haemorrhage from the throat that I was told would kill me, I had of course absolutely no idea of the future that lay in store for me. If I had been told then that I would return to work, get promoted to the British Government's Senior Civil Service, have three children, move to Washington DC in the USA for three years to work for the World Bank, and then in September 2012 on to Canberra, Australia, to work for the Department of Foreign Affairs.... well, I would have laughed. (Although of course with no voice it would have been a silent, rather dejected and ironic laugh).

In the intervening years I have been able to continue doing what I have always loved doing: working on the challenges of poverty reduction and development in some of the most challenging country contexts in the world: Zimbabwe, Kenya, Tanzania, Timor Leste, Papua New Guinea, Solomon Islands, Vanuatu, Fiji, Indonesia, Myanmar and the Philippines. I have become used to speaking at conferences in front of hundreds of people. The mere thought of doing this in the days immediately following my return to work all those years ago would have been unthinkable.

My life after a laryngectomy

But why, in those early days, was it so unthinkable? It all comes down to The Voice. Why does The Voice matter so much? I have reflected on this many times over the years. In many ways my disability is a very minor one. I can walk, run, do just about anything really apart from singing (I could never sing anyway). Even swimming is now possible with a special snorkel. Compared to other disabilities – those which severely limited mobility or participation in life - mine is trifling. But in other ways, I feel my disability is profound.

**One's voice is partly of who one is: it is part of how one presents oneself to the world.
Suddenly to acquire a new voice is disturbing.
Even today, despite being thoroughly accustomed to using my voice, I still do not care much to hear it on a telephone voice message or on a recording. It upsets my equilibrium: this surely is not me? But it is me.**

But absolutely the most positive thing about my experience is the reaction from everyone I have ever met: all have been unfailingly helpful and accommodating.

I have followed Mr Rhys Evans's advice, given to me the morning of November 23rd 2001 (another memorable date) when he gave me my new voice: "Graham" he said. "If you are embarrassed by your voice, everyone else will be too. If you are not, and you explain, you will be amazed by the reaction".

This I have found to have been overwhelmingly the case; when I go to meetings or speak at conferences and meet new people, I always start with a brief explanation. The response is gratifying, and it has reaffirmed my faith in the basic goodness of human nature. As I noted above, after people have heard me once, my voice quickly becomes 'normal'. Colleagues tell me they don't even notice it. "That's just Graham's voice". This provides the greatest testimony to just how normal life has become.



With my wife Jane, twins Geordan and Molly and our youngest daughter Rose in Sydney, Australia

With thanks to Graham Teskey for sharing his inspirational story with our readers.

Health and Wellbeing Event in 2016 for Head and Neck Cancer Patients

The team at The Royal Marsden Hospital are organising a Health and Wellbeing Event specifically for patients who have undergone treatment for head and neck cancer at the Fulham Road hospital on **March 18th 2016**. Patients and carers are welcome however they must be at least six months out of treatment.

Following a series of presentations by the team, dietitians, clinicians, specialist nurses and other support staff will be on hand to discuss any concerns or issues.

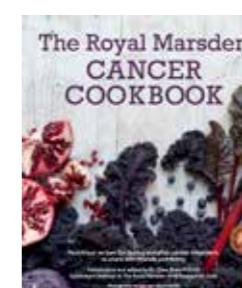
If you would like more information on Health and Wellbeing events in your local area contact Macmillan Services or if you have been treated at The Royal Marsden Hospital, Charing Cross Hospital or St Georges Hospital and would like to attend, please contact your Clinical Nurse Specialist who will send details for registration.



Dietitians will be on hand to offer support and advice



Butternut squash lasagne from the Royal Marsden Cancer Cookbook



Photos courtesy of Kyle Books



Blueberry and avocado smoothie from The Royal Marsden Cancer Cookbook

The work of the Speech and Language Department at The Royal Marsden Hospital is known throughout the World, particularly with the advances in delivery of care to patients undergoing treatment for head and neck cancer

The introduction of Speech and Language Therapy Research at The Royal Marsden Hospital was only made possible with the opening of the John Diamond Voice Research Laboratory in 2001, the first of many varied research projects funded by Oracle Cancer Trust. Since then Oracle has funded three PhD Research Fellows in the laboratory, including Dr Justin Roe who is now joint head of the Speech Therapy department and leads ongoing research. Recognised as a UK Centre of Excellence, the team works closely with the team of Surgeons and Radiotherapists delivering care to patients from diagnosis, through treatment and beyond.

Dealing with a cancer diagnosis is difficult enough but once the effects of the treatment start, battling the cancer often comes secondary to the challenges of eating and drinking

Some patients, particularly those who have undergone a laryngectomy (surgical removal of the voicebox), remain under the care of the team for the rest of their lives.

Preservation of the swallowing function is essential during surgical and radiotherapy treatment. Towards the end of chemo-radiation treatment the throat becomes extremely sore and it is very difficult for patients to maintain an adequate oral diet. Gastrostomy or nasogastric feeding tubes may be recommended in those with pre-existing swallowing difficulties or problems with nutrition or hydration during their treatment. Previously gastrostomy feeding tubes were often inserted prior to the onset of radiotherapy but research has shown that it is essential to try to keep the pharyngeal muscles working as long as possible during treatment and that insertion of a feeding tube should be considered as a last resort.



Dr Justin Roe with Sarah Adams from the Speech and Language Therapy Department at The Royal Marsden Hospital, Chelsea

The pharyngeal muscles are a group of muscles that contract and push the food into the oesophagus. By keeping this group of muscles active throughout treatment, the after-effects of chemo-radiation treatment have been shown to be greatly reduced. Speech therapists aim to see patients before treatment starts and they may recommend swallowing exercises to maintain function during radiotherapy.

One of the major shifts is the age profile of the head and neck cancer patient that Dr Roe and his team see in their clinic. Typically patients affected by head and neck cancer were the older 60 plus generation, who were often smokers and heavy drinkers. Due to the sharp increase of HPV virus-related head and neck cancers over the past ten years, the team are now seeing much younger patients. This younger group of HPV patients are often suffering from cancer of the tongue or tonsils and are generally health conscious.

These patients often have young families, and the psychological aspect of swallowing and eating difficulties during treatment can often leave patients depressed and withdrawn from family life. The team take on a counselling and therapeutic role in supporting these patients through the often complex psychological difficulties of not only changes in their physical appearance, either through surgery and weight loss but also coping with drinking and eating in social situations, things we all take for granted in our everyday lives.

Dr Roe and his team work very closely with the Dietitians and Clinical Nurse Specialists at The Royal Marsden. Family members and carers are key to the success of ensuring patients maintain their wellbeing as much as possible through the rigours of treatment. An important part of maintaining health and vitality through treatment is engaging with carers and family from the start so they are supported with all the available information on how to support patients with swallowing problems as well as the very common symptom of dry mouth.

The month of September marked “Remember a Charity in your Will” week

In the UK as a whole, legacies form a huge part of charitable donations - in 2014, the legacy market was worth around £2.4bn. Although a huge sum, it only represents 3% of all money left in estates. And with 74% of us donating to charities during our lifetime, there is a large disconnect between those who give during their lifetime and those who choose to leave a gift in their will.

Oracle Cancer Trust are truly grateful for the compassion of anyone who leaves a gift in their Will, whatever its value - today's legacy gifts will help us find better treatments and new cures for future generations of patients suffering from head and neck cancer. Here is some outline information outlining some ways in which you can leave a gift in your will.

Types of legacy

Legacies can be separated into three categories:

A fixed sum of money (Pecuniary)

This may seem like a simple option but bear in mind that the effects of inflation could mean that the true value of this gift could become less than you intended. To plan for this, either update your will regularly or link your legacy amount with inflation.

A percentage of the net value of the estate (Residuary)

A residuary legacy means you can leave a set proportion of your estate to charity after other beneficiaries are taken care of.

Individual possessions (Specific)

This could be anything, but typically land, property or shares. If you're not sure about what kind of gift you would like to give, talk to your solicitor who will be able to advise you further. If you have already made a will but now want to leave a legacy, you can make an addition or change it without rewriting your current will. This addition is called a codicil and a solicitor can advise how to add this to an existing will.

Tax benefits

As well as helping a good cause, leaving a gift in your will also have financial benefits for your friends and family. By leaving a gift in your will to Oracle, its value will be deducted from your estate before inheritance tax (IHT) is worked out. In some cases leaving a legacy may help bring the total value of your estate below the taxable threshold. It is possible for the inheritance tax rate to be reduced to 36 per cent if 10 per cent or more of an estate is left to charity. Taking advantage of this reduced rate would require advice from a solicitor. Gifts made up to seven years before your death may also qualify for exemption.

Some common questions

Why should I leave a gift in my will to benefit Oracle?

- A wish to make a contribution to benefit future generations in the fight against head and neck cancer and ensuring the continuation of our valuable work.
- A way to donate more generously that would have been possible during your lifetime.
- Reducing or eliminating your inheritance tax liability.

How do I know my gift won't be swallowed up in administration costs?

- Oracle includes any gifts in wills in a restricted fund, meaning that 100% of your legacy will fund research.

Will my legacy be remembered?

- Gifts can be acknowledged in a variety of ways, for example naming a research project or fellowship. We would be happy to discuss any thoughts or ideas on how you would like your legacy to be used.

Will I have to re-write my whole will?

- No, you can simply add a codicil to an existing will, which your solicitor can advise you how to write.

By leaving money to Charity I won't be supporting my loved ones?

- Often discussing your wishes with your loved ones will make them feel part of your decision to leave lasting legacy for a cause that meant a great deal during your lifetime.

Can I specifically instruct how I wish my legacy to be used?

- The best way to do this is by an Expression of Wishes. This will give us the flexibility to utilise your legacy in the best possible way. Oracle follows the Institute of Fundraising's code of conduct.

Where can I go for advice about leaving a gift in my will for Oracle Cancer Trust?

- Your solicitor will be the best place to start with discussing ways to make a gift. Oracle cannot provide independent advice in this regard.

Events in 2016

EVENTS IN 2016

"HEADS" - Wednesday 20th April 2016

This exhibition has been the result of over two years work by Karen Mulville, wife of Oracle's President Jimmy Mulville. The exhibition will feature over thirty of the world's leading names from sport, TV and entertainment and has been produced to raise awareness about head and neck cancer and be a major fundraiser for Oracle.

WINDSOR CHARITY RACE EVENING - Monday 9th May 2016

Enjoy an evening at the races at one of the UK's most beautiful racecourses set beside the banks of the River Thames in support of Oracle Cancer Trust. We have reserved the marquee which overlooks the parade ring and have a host of tipsters, jockeys and trainers from the world of horseracing to join us. We also have some exciting sponsorship packages available, from sponsoring races to best turned out horse.

ANNUAL GOLF DAY - Thursday 23rd June 2016

Our popular golf day will once again be held at Burhill Golf Club in Surrey on the Old Course. We look forward to once again welcoming golfers of all standards to join us for a great day's golf followed by some sporting entertainment.

GLORY OF CHRISTMAS - Monday 5th December 2016

Put your dates in the diary for our annual celebration concert at the usual venue, St John's Smith Square in London SW1.

HOW TO DONATE

ONLINE via CAF BANK

Donating directly via Charity Bank CAF is the most cost efficient way of sending funds to us. All you need to do is complete the online form and the rest is done automatically. www.cafonline.org

PAYROLL GIVING

Payroll giving is easy to set up. There's no direct debit, no gift aid, and just one form to complete. Payroll giving will let your payroll department, and us, know that you want to start giving and within 4-6 weeks it will start.

VIRGIN MONEY GIVING & JUST GIVING

Virgin Money giving is one of the few online websites which does not make a profit on your donations. To donate, visit the Oracle Cancer Trust webpage on uk.virginmoneygiving.com or www.justgiving.com

SHOPPING ONLINE

Did you know that you can shop online and raise funds at the same? Easyfundraising has joined forces with thousands of well known retailers who in turn have agreed to pay a small commission towards the charity of your choice, at no extra cost to you. See www.easyfundraising.org for more information.

TEXT ORCT15 TO DONATE £5 to 70070

Have you visited our website recently? We have some new patient case studies as well as information on forthcoming events, patient videos and updates from the Oracle funded team of researchers.

FIND US ONLINE: oraclecancertrust.org

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Registered charity 1142037

Leading Research into Head and Neck Cancer