



A M M F

THE CHOLANGIOCARCINOMA CHARITY

Facebook Guest Posts

Cholangiocarcinoma Awareness Month

February 2015

www.ammf.org.uk

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Introduction

Thank you to each person who took their courage in both hands and contributed a Guest Post for AMMF's Facebook page during Cholangiocarcinoma Awareness Month 2015.

What incredibly moving stories were shared by those who have lost precious people to cholangiocarcinoma, from those currently undergoing treatment, and from all too few "survivors".

It was heartwarming to see the kind and supportive comments coming in on all the posts, and especially so to see the generous support and, yes, rejoicing, for those fortunate enough to have benefited from surgery and now living their lives normally once more.

The recurrent message coming across loud and clear is that there is still a desperate need for earlier and more accurate diagnosis, and for more effective treatments...

All the 2015 Guest Posts now appear here – collated in one special brochure. Photographs and external links have been included and are live in the download version*. Comments to the individual posts are not included although these, of course, remain on Facebook.

"This is not one of the cancers that has glossy adverts and famous people suggesting you check yourself for lumps and bumps..." Nikki Greenall

"Dad's journey with Cholangiocarcinoma was mercifully brief, mine has only just begun."
Samantha Parmar

"We are all part of a family... A family linked by one word; Cholangiocarcinoma."
Claire Bradburn

"Stories of CC survivors gave us cause for hope during Derick's illness and now bring us so much joy. They are proof that, if caught early, this disease CAN be beaten."
Margaret McRobert.

* A small quantity of these brochures have also been printed, and are available on request.
(Obviously, the links will only work when the download version is viewed online.)

CC DAY 1 – GUEST POST *from Tom Morement*

We are family.

Just before Christmas 2000, at the end of that fantastic millennium year, I lost an incredibly important member of my family to cholangiocarcinoma – my father.

During the weeks and months after my Dad's death I often wondered if there was anyone who could possibly understand what it was like to lose someone so strong, someone who made the toughest things in life seem easy, who answered all my questions, and always made things better, to a disease none of us understood.

When my mother founded AMMF (Alan Morement Memorial Fund – www.ammf.org.uk), initially running it through and with the resources of her business, she knew there was a need to raise awareness and a need to share information. What she didn't know then was the enormity of that need, nor how the charity would grow year on year. It's still a small charity, but one that now has connections with specialists, professors and medical trials all over the world, one that is putting cholangiocarcinoma on the map, and has hundreds upon hundreds of supporters that have become the life blood of the charity, brought together by that word, cholangiocarcinoma.

So when I look back now and remember thinking who could possibly understand what it was like to lose someone special to cholangiocarcinoma, I know the answer – all the people in AMMF's CC Family, who are now there for each other and will help support anyone who is struggling. With AMMF's support nobody needs to feel there is no one who can understand.

I look forward to reading all the posts from AMMF's family and wish everyone strength for the year ahead.



Photo: My Dad and me in those far off days...

CC DAY 2 – GUEST POST *from Rachel Munns*

I am honoured to be running the London Marathon 2015 in memory of my Dad and as the privileged holder of the AMMF Silver Bond Runner place. For that reason, I would like to dedicate Day 2 of AMMF awareness month to John Munns.

My Dad was first admitted to hospital on June 14th 2014 – the same day on which he had, seemingly in full health, moved me and my belongings back from Leeds following the completion of my degree. The following week, as if from nowhere, he was diagnosed with cholangiocarcinoma.

At the end of July it was confirmed that his cancer was terminal and from that point onward his health deteriorated rapidly. On 17th September 2014, less than 3 months from his original diagnosis, he passed away.

It is impossible to sum up a life in words. My Dad was my loyal supporter, there was never a time when he was not rooting for me to succeed. He was selfless, working without complaint to provide and support my family. And, his intelligence and great sense of humour meant he was loved, and is missed, by many.

The reality is that my father's death came too soon. At only 60 years old and approaching retirement, he had so much more living to do. Yet, despite his devastating diagnosis he handled his illness with fortitude, courage and dignity. A man of unfaltering faith, his wisdom has led me to success and his courage has taught me to be strong in the face of adversity.

To live in hearts we leave behind is not to die.
I love you Dad.

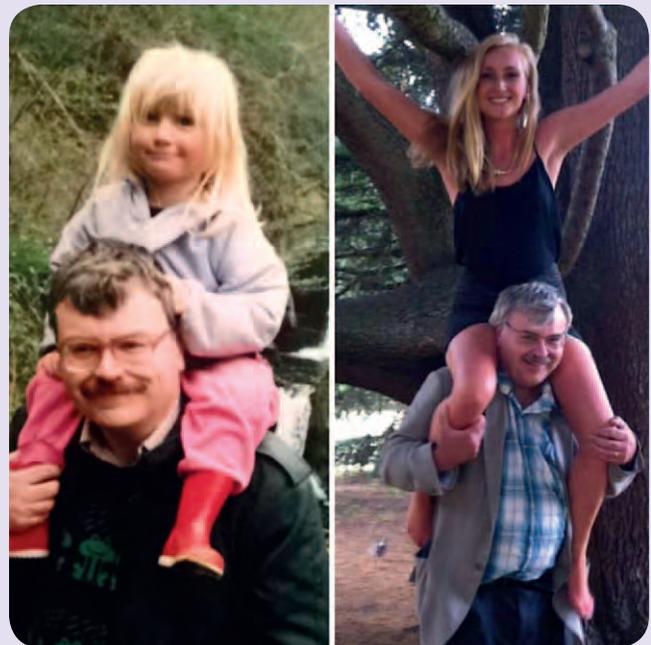


Photo: Rachel and her Dad.

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www.justgiving.com/LondonMarathon-Rachel

CC DAY 3 – GUEST POST *from Gavin Strachan*

For my Dad, Ronald John Strachan (12.7.44 – 10.12.09)

My Dad was diagnosed in the summer of 2008, a summer I will never forget. He was a relatively healthy guy. Could do with losing a pound or two but who couldn't! Never smoked and didn't drink much and never in excess when he did. He had recently retired from his job and was looking forward to retirement.

To say that not just cancer itself came out of nowhere, but Cholangiocarcinoma, would be a huge understatement to say the least. A cancer that we and I'm guessing all of you reading this, had never heard of before. I still remember hearing the diagnosis that day and the look on my Dad's face when we got the news. A very rare cancer, inoperable at his stage. Baseball bat to the head sums things up well I would say.

He had PDT as his treatment with a metal stent for the jaundice. That helped a bit but surgery was deemed too risky and chemo was ruled out at a later date. The jaundice had come back and chemo was not possible then. That was in 2008 when treatment options were not so many. Now in 2015 things are getting better, not as much or as fast as we would like but they are improving.

My Dad fought a tough fight with a ton of ups and downs along the way. He learned how to horse ride, something he had wanted to do all his life, thanks to the Riding for the Disabled Program. That gave him and I so many happy memories and I will never forget him on Paddy, his horse. Paddy was big and he had to be to carry my Dad but like my Dad, he never complained!



Photo: Gavin's Dad, Ronald Strachan.

I would like to thank Helen, AMMF and all involved for all the work they do in taking the fight to CC. I would also like to thank all involved with the Cholangiocarcinoma Foundation for their part in the fight too. For those who know me, you will know that both organisations are so very dear to my heart and always will be. Much has been done and achieved in the years since my Dad passed away, but so much still has to be found, the cure.

We will get there.

Rest in peace Dad and know that you are much loved and missed.

Gavin

CC DAY 4 – GUEST POST *from Kellie Hadfield*

Hello, my name is Kellie and this is my first guest post for AMMF during cholangiocarcinoma awareness month. I discovered this wonderful charity and the lovely Helen Morement after my dad (who I love with all my heart) was given the devastating diagnosis that he had bile duct cancer (cholangiocarcinoma). We received this news on 30th July 2014, which was only the very beginning of an emotional roller coaster journey which we are still on today.

I knew as soon as I found AMMF that I wanted to do something positive to help raise money so on Saturday 30th August 2014 I challenged myself and my fear of heights by going down the largest zip line in Europe at Zip World in Wales. The response from friends, family, colleagues and even complete strangers was humbling and I managed to raise over £1500 on my Just Giving page – www.justgiving.com/Kellie-Hadfield2

JustGiving™

We were told that my dad was not a candidate for surgery but was able to have chemotherapy treatment which he commenced at the end of September 2014 at The Christie hospital in Manchester. The doctors there have been amazing and the fact that we were given some hope was instrumental in strengthening my resolve to do everything in my power to support my dad in his fight.

I have learned to take one day at a time along with all the ups and downs... my dad had very few side effects initially from the chemotherapy (up) then it was low platelets so no treatment (down), the week after his platelets were back to normal (up). In November he was admitted to hospital with an infection (down) which he recovered from and managed another couple of treatments (up). In December my dad was back in hospital with another infection which hit him hard (down). A CT scan on 30th December showed the cancer has stopped growing and even shrunk a bit (up) so the doctors want to resume chemotherapy, which we are hoping will be in the next week.

I have devoted every ounce of energy to being there for both my mum and dad; attending every appointment including chemotherapy treatments and helping with household chores and shopping. I find it hard working full time whilst trying to maintain some semblance of a normal life (the new normal which began on 30/07/14 not the old normal; that is gone forever) but we are lucky and have been blessed with lots of caring family and friends, support from them is vital.

We have to fight the good fight and it's almost impossible at times. However anything is possible, and there is nothing wrong with us hoping and believing things will get better.

Today's battle is done with and every day is a battle so I dust myself off and fight again because I love my dad. Some battles are easier than others but what a difference a day makes.

We are strong together!



Photo: Kellie with her Dad.

CC DAY 5 – GUEST POST *from Helen Tanner*

Initially I found it difficult to choose what to write about this year – until I realised why I had been struggling – and that was the realisation that I am suffering from a mild form of what is commonly called “survivor guilt”. Many of you become involved with AMMF because a loved one has died – sadly there are far fewer of us who are here because we had successful surgery for our CC!

I had my own surgery in November 2010, and thus this year I am heading towards that oft-quoted 5 year survival date. This has raised some questions for me personally. Given the discouragingly low rates that we can all find easily on the internet, how have I been lucky enough to get this far without recurrence? What did I do to deserve such privilege? And is it ok to say that I am feeling ok (if that makes sense) or do others hold that against me?

Hopefully the practical person that I am will sort all this out – I realise that thinking about this post has helped me to see that comparing myself with others isn't very productive. Doing what I can to help raise awareness of CC, and to continue to raise funds to help with research into a wider range of diagnosis and treatment options so that there will be more people like me in the future is what really matters!

Helen and all those at AMMF will, I am sure, be there to help all of us do just that!

At our daughter Clare and son in law Martin's recent wedding, with husband and daughter Nicola. Note the bridesmaids, cravats and flowers in glorious AMMF purple!

Thanks

Helen



CC DAY 6 – GUEST POST *from Margaret McRobert*

“I’m afraid the lab reports show cholangiocarcinoma.” I just sat there rooted to my seat, staring at the consultant, my hand instinctively grasping Derick’s. I didn’t even have to ask the question the consultant was obviously expecting, namely, what’s that? I knew only too well what cholangiocarcinoma was – a friend’s wife had died of the very same cancer only months before and I had turned then to the Internet for information.

Oh well, I thought, once I had recovered from the shock, it can’t be too advanced – it’s only 6 weeks since he had his annual full Well-Man check and blood-count and all was well then...

There’s been no delay... He had his initial scan and the operation, all within a fortnight... They removed the bile duct with the tumour in it. He looked and felt fine... yes, it will have been caught early enough. I seized on any kind of hope.

A conversation with the consultant later in the day, however, floored me, when he revealed that the prognosis was poor, as CC had already spread to Derick’s lymph nodes. As the two of us had been getting on with life, relaxing, relishing retirement, enjoying the grandchildren etc., this insidious disease had been spreading through his body and neither of us had had the slightest clue.

Derick fought CC for 22 months from diagnosis with courage and amazing optimism. We have a huge void in our lives... After nearly two years, we still miss him so very much, but memories of the good times, so painful in the early days, are now a great source of comfort. He lost his fight but, as a family, we feel we owe it to him to take every opportunity to support AMMF in spreading awareness of this terrible disease. We will be eternally grateful to AMMF – for personal support, through Helen, and for allowing us to feel part of the CC family. It was such a comfort to know we were not on our own during Derick’s illness, nor since he died.



Photo: Derick McRobert.



*Derick’s grandchildren, his ‘Magnificent 7’.
From the left: Amelie, behind her, Hannah, then Aoife, and in front of her Fergal, and then Fraser, Laura and Kirsten.*

Stories of CC survivors gave us cause for hope during Derick’s illness and now bring us so much joy. They are proof that, if caught early, this disease CAN be beaten – but, given Derick’s case, just HOW EARLY does that need to be? The updates from AMMF on research to identify sufferers early are heartening and we will support AMMF at every opportunity so this valuable research can progress. After all, we owe it to Derick to continue his brave fight against this dreadful disease, which so cruelly robbed us of such a special and much loved, husband, dad and grandad.

CC DAY 7 – GUEST POST *from Rebecca West*

My closest friends and I were all born in 1974 or 1975 which means that we have recently become, or will very soon be, 40 years of age. This has been a bittersweet time for me, as whilst we have all recently had a wonderful adventure for one of our friend's 40ths, taking part in a very muddy endurance race to raise money for AMMF, I am also filled with a profound sadness because the reason we ran for AMMF is because my best friend, Helen, died from cholangiocarcinoma in 2010, aged 35.

I am devastated that we will not be able to celebrate Hel's 40th, that Nikki and I won't have to follow her around a hundred shops finding the 'perfect dress' – then take it back twice! – That we can't plan a fabulous party and dance all night, and most of all, that our little daughters can't run around together next to both of us.

The grief that I still feel at the loss of Helen can be best imagined as water: sometimes it floods and knocks me down, yet sometimes it just trickles past me. Currently, I am trying to let it flow through me and accept that, as well as the pain, there are moments of pure love and happiness when I think of her.

The other day, I heard a song on the radio by Frankie Valli and I immediately stopped, remembering Hel. Often, when we were younger and after we had all been on a night out, having a few vinos, Helen would leave me an answerphone message, singing the chorus down the phone, laughing her head off. "Hey Bec, guess what?... I love you babbbyyy!!"

Well Hel, I still love you too. Cancer may have taken you from us all but you remain in my head and heart every day. We shall raise a glass to you on your 40th in May and continue to support AMMF in their outstanding work.

One day cancer will be beaten.



Photos: Me on my wedding day in 2007 with Helen as my Matron of Honour and 'Team AMMF Animals' after the Monster Race in November 2014.

CC DAY 8 – GUEST POST *from Claire Bradburn*

We are all part of a family. A family that nobody had a choice to be in. A family that provides strength and advice through the darkest and toughest of times, despite many of us not really knowing each other. That family links us all by one word; Cholangiocarcinoma.

Today marks the second anniversary since my wonderful Dad, Alan Bradburn, was taken away from us after a short battle with Cholangiocarcinoma. A battle that lasted only 9 days after a diagnosis.

It seems strange to think it has been two years. One minute it doesn't feel that long since I last saw him. But then, in that instant, it feels like a lifetime. The pain never fades but you learn to cope and cherish the memories you have been blessed with.

I feel privileged to be writing my second annual post for AMMF's awareness month. Honoured to be a part of a family that is united by one main objective; to raise awareness of the rarer cancers, specifically CC, so that one day others can be more fortunate than those we have all loved and lost.



Photo: Claire Bradburn's Dad, Alan.

That day will come. The efforts of AMMF and its supporters will not be in vain. This will be achieved for the legacy of our CC family. We have too many guardian angels willing it to happen and the tenacity of our fundraising family undertaking a wide range of challenges (some weird, some wonderful!) so that treatment can one day become more curative than palliative.

In the last twelve months we have seen Cholangiocarcinoma claim the lives of Tommy Ramone and Elena Baltacha. Although, it was often referred to within the press as liver cancer or simply, just cancer. This proves we must continue to raise awareness of this seemingly unknown form of cancer.

I had never heard of Cholangiocarcinoma prior to my Dad's diagnosis. I never knew that it could be so aggressive and claim the lives of the strongest willed sufferers. It's a lesson learnt hard and fast. My Dad was strong. He fought with every ounce in his body. It simply wasn't enough.

So much emphasis is placed on other forms of cancers, especially the 'big four', despite the majority of lives being claimed each year by the rarer cancers and this is why we must continue to campaign.

We are all touched by the plight of those affected by CC. It universally binds each and every one of us. I lost the greatest man I will ever know, but am so grateful that I gained a new family. A family that understands. That shares my pain and anger and realises that more needs to be done. A family that is an army, in combative mode, fighting until the battle is victorious. A family that will never surrender until there is hope and light.

For my beautiful Dad, and all those affected by CC. We will not give up. Please know that you are loved and missed each and every day. You are all the driving force for AMMF and our CC family. We hope you are incredibly proud. To the amazingly brave who continue to fight against CC, you are truly inspirational.

'I keep dreaming of a future, of a long and healthy life, not lived in the shadow of cancer, but in the light...'

CC DAY 9 – GUEST POST *from Julia Wise*

Two and a half years after my sister's death, the pain of losing her is no longer all pervasive. I think of Susan every day and she visits me regularly in my dreams, but the great memories are getting stronger and the nightmare grip of the awful ones is gradually weakening.

Cholangiocarcinoma has embedded itself so deeply into my psyche over the past 5 and a half years, though, that my desire to raise awareness of it and to do what I can to help eradicate it has strengthened with time, not diminished.

For Cholangiocarcinoma Awareness Month 2014, I wrote about how I started iPad drawing and how www.dfpportraits.co.uk (my website, through which an iPad drawing of your pet can be commissioned in exchange for a donation) came to be. Last summer, one of my earliest pieces of artwork, created in the weeks after Sue died, was displayed at the Royal Academy Schools, Burlington Gardens as part of the RA Schools/Marie Curie "Life Embraced" art exhibition. Then, in November, one of my iPad portraits won a competition to be featured in an international calendar (the 2015 calendar of internet-sensation, Henri le Chat Noir). In each case, I was able to broadcast the name of Cholangiocarcinoma and to advertise DFP Portraits' website, via word-of-mouth, business cards, publicity material, brochures and web-links. Anyone following the links will be able to discover more about this dreadful disease and to donate to AMMF.



Photo: Susan (l) and Julia.

Over the past year, DFP Portraits has raised £1,285 for AMMF and £390 for Edenhall Marie Curie Hospice (both of which supported me so compassionately during Sue's illness and after her death) plus £140 for other charities. Raising the money has been an immensely satisfying experience but, even more satisfying than that is the knowledge that, with every Facebook share, with every tweet and every retweet, the name of Cholangiocarcinoma gets out there. The more we talk about it, the more awareness we raise, the greater our likelihood of beating it.

"Do YOU know a pet in need of a portrait?"

CC DAY 10 – GUEST POST *from Jackie Pinfold*

This is the first time I have contributed to AMMF's Cholangiocarcinoma Awareness Month. In fact, this past year my family and I have had a lot of firsts. A year ago, we'd never heard of cholangiocarcinoma though we were soon to learn.

Mum had been diagnosed with gallstones, "the worst case" the radiographer had ever seen, back in November 2013 and told she needed an op; we had a wonderful Christmas, though she was clearly not quite herself and mentioned that she was in some pain once or twice; in January she started to struggle so went back to see her GP to try to get her operation more quickly; but mum suddenly lost lots of weight, was unable to eat properly and went downhill fast.

In February, she managed a trip to Plymouth to mark grandson Ben's 21st and she had my youngest son, Freddie, to stay over half term but, again, she wasn't herself. Her GP was becoming alarmed at this point and expedited various tests. In early March, mum was told she had cancer and that it was probably in her stomach. She was allowed out of hospital. After the MDP meeting she went back, on 13 March, to hear the horrendous diagnosis of cholangiocarcinoma and duodenal cancer. To hear that she had just weeks to live. That day is marked in all our memories.

There followed three weeks of mum putting her affairs in order, making sure she did everything she possibly could to ensure dad would be OK, all of us – dad, my sister Gina, me, our three boys and other friends and family important to mum – saying our goodbyes and telling her just how very much she was loved, then nursing her through to a peaceful end. The end that she asked for, in her own lovely home amongst all of us. Our final gift to our very beautiful, loving and loved mum.

Since then, we've all had a birthday without her, Christmas without her, too many uninvited firsts. We're all moving on but discovering cholangiocarcinoma in this way changes you. We have become involved to do our little bit to help. AMMF has played a enormous part in helping us to move on, reading other people's stories, being inspired by, and so happy for, the survivors of this vicious disease, altogether a source of information and inspiration.

My eldest son, Tom, did an open water swim in the Summer to raise money and has other fundraising ideas up his sleeve. In September, I'll be trekking Morocco's highest mountain, Mount Toubkal, with my partner, to raise money for AMMF and we follow its good work with interest. Thank you AMMF, for making a difficult year bearable.



Photo: Jackie with her Mum, Dad and Sister.

CC DAY 11 – GUEST POST *from Wendy Clarke*

On Friday 11th April 2014 at precisely 2.30pm I received a phone call telling me, that following my MR scan earlier that morning, I have what looks like cholangiocarcinoma and I was admitted to North Manchester General Hospital on Sunday 13th April. After a few ups and downs and a ridiculous amount of stents inserted to release the bile that was making me yellow, and having spent nearly seven weeks in hospital I had my surgery on 2nd June 2014 (the day after my 43rd birthday).

I had two thirds of my liver removed as well as one lymph node that the cancer had spread too. Like everybody else I had never heard of this horrible disease and cannot put in to words the devastation it brings, not only to the person diagnosed, but also friends and especially family members.

After being off work for 22 ½ weeks I went back with a huge smile on my face and an even bigger scar on my stomach, but as the saying goes, never be ashamed of a scar, it simply means you were stronger than whatever tried to hurt you.

I am nearly at the end of my chemotherapy now and will have another CT scan when that has finished and fingers crossed, nothing nasty has returned. I have been told that if it does return, and there is a 60% chance that it will, then my life expectancy will be within a year of this horrible disease returning. How do you comprehend being told something like that, it was bad enough being told I had it in the first place, but you have to carry on living day by day. Hopefully positive thinking and having a loving husband and 3 amazing children as well as great friends helps you get through the bad days and keeps you smiling...



Photo: Wendy Clarke.



I found it quite difficult to write this as how do you put down in words the feelings you have when you are diagnosed not only with cancer but a cancer that is very rare, but with all the new trials and further investigations, hopefully a cure will be found for this terrible disease and I for one am very hopeful that I am still around to see the day.

CC DAY 12 – GUEST POST *from Liz Heywood*

My Dad's journey with Cholangiocarcinoma – John Smith.

As I read through all the amazing, inspirational, sad, moving and reflective posts again this year, I realise another year has passed without my wonderful Dad.

Bank Holiday Monday 4 May 2009 is a date I will never forget, but for all the wrong reasons. Because that is the day my precious Dad rang me from his home in Florida to tell us he had been diagnosed with CC and had been given around 12 months to live...

Twelve months to live? "But you aren't ill, Dad" I said through my tears, and he hadn't been. No classic signs of weight loss, jaundice, itching or pain, just raised blood tests detected at a routine cardiac follow up, years after having a heart bypass and pacemaker fitted.

As an experienced paediatric nurse, cholangiocarcinoma meant nothing to me. I guess I was in denial, but have to admit to a quick google search, the findings from which, as we all know, were bleak. But, I reasoned, my Dad was being treated in America, surely if anyone could save his life they could...?

What followed was a roller coaster, because a mere 24 hours later, after I had made plans to go over to the States and spend time with my Mum and Dad, I received another phone call to say the surgeon had called back and was now willing to offer surgery which could potentially save my Dad's life. Without a second thought, my Dad had total faith in his surgeon...

Two days later I was with them, as the journey towards surgery began. The whole preparation procedure took five weeks, with a lot of difficult times for Dad. I went back home to my family and work whilst this was going on, and returned to Florida to be with my Dad as he faced what is the most major surgery a person can face, a liver resection...

The day before his surgery is a day I will treasure forever, enjoying time together doing normal 'stuff' before my Dad drove himself the 100 miles to the hospital, at his insistence I must add! Sadly, Dad's surgery didn't go as we hoped and after a stormy 9 days my Dad passed away in peace and dignity with my Mum, brother and myself at his side.

A mere 7 weeks from the day he was diagnosed... Unfortunately, it wasn't until I was back in England some weeks later that I discovered AMMF and the wonderful Helen and her team. Since then we have continued to raise money through my Justgiving site and I have had the pleasure of meeting with Helen, representing AMMF at the Christie Hospital in Manchester with Professor Valle.

Through AMMF I have also made some friends who share our common aim to continue to raise the awareness of CC. I realise my Dad's story didn't have the ending we all prayed for but hope, with earlier detection and continued research and awareness raising, the journey for others may have a different outcome.

Love you Dad xxxxx



Photo: John Smith.

CC DAY 13 – GUEST POST *from James Odell*

I think about my Dad every day and I choose to make sure I only remember the happy times. My Dad passed away on the 21st August 2013 and today would have been his birthday. I was privileged enough to have been able to write a guest post on Dad's birthday last year and I really wanted to write something again this year but, if I'm honest, I have struggled to find the words.

People say that when you lose a loved one, as time goes on it gets easier. For me, that is not the case... yet. It's got harder; thinking of the good times is a reminder that there will be no more good times for us together. It also angers me that his life was taken by cholangiocarcinoma and that no one in the medical profession could offer us any real explanation as to what it was, or what treatment was available to him.

I was with my Dad on the worst day of his, mine and our family's lives, the day he was told he had bile duct cancer. We were given basic information regarding what needed to happen in order to operate, and the various chemotherapies, yet even those details were not definite as they seemed to be trialing all sorts of different combinations. In hindsight, the enormity of what we'd just been told probably affected my ability to take everything in that day.

I remember walking away from hospital, my Dad being so positive about not letting it beat him or get him down, and me knowing I needed to find out more about what was happening. I found AMMF through the internet, picked up the phone and spoke with Helen. It was one of the best calls I have ever made, she was so understanding and informative with regards to CC.

I'll never forget how I felt after that call, knowing I could speak to Dad and let him know that I'd spoken to this wonderful lady and that she and her team were doing great things. Dad also made contact with Helen. He met friends through AMMF – those who had been diagnosed with CC or those who had been affected by someone who had it.

During his treatment, he did his bit with fundraising. At any opportunity, he'd do what he could to try and raise money for AMMF, even getting in contact with the cholangiocarcinoma foundation in the US and having their wristbands shipped over from America so he could sell them.

Dad was determined to fight, he followed his consultant's advice religiously and made it all the way to 'the operation' that, at the time of diagnosis, felt so far away. Like so many others, even after all the effort, hope of curing him was taken away from us and the following prognosis seems all too familiar. Even when faced with this information, my Dad made the best of the time he had left. He never let things get him down and I need to remember that when I'm feeling angry or upset so I can turn those feelings into doing something positive, because that's what he'd want.



Photo: Dad (Peter Odell) with Steven (r) and James.

Knowing Dad is not here to celebrate today with his family and even more so his two young grandchildren is so painful, but he would be proud to know that a lot of good people are doing great work in order to make sure less people need to deal with the sadness of losing loved ones to CC. One thing my parents always taught me is that manners cost you nothing so, on behalf of Dad, all my family and I want to thank Helen, all the team at AMMF and everyone who does wonderful and crazy things to raise money and awareness, your efforts will one day give us a cure for this terrible disease.

Happy Birthday Dad, you are missed more than you'll ever know. We'll raise a glass or two to you tonight. We love you. XX

CC DAY 14 – GUEST POST *from Clare Henderson & Kirsty Mackay*

The light of a star continues to shine, long after the star itself is gone.

This is our second year without Nikki and our second year of writing for Awareness Month. As much as we want to, we can't re-write our sister's past but our thoughts have turned to hope for others with CC and the influence that AMMF can have on changing the future for those that are diagnosed.

Two weeks before she died, Nikki asked her doctor to learn from her. If she couldn't be cured then he should take what knowledge he could from her case and use it for the greater good. So learn from her we have and by the time you are reading this we will have been to AMMF's awareness day in London, looking towards a time when the February tributes are full of survival stories.



Photo: Nikki.



"Somewhere over the Rainbow"
by Israel "IZ" Kamakawiwo'ole

Today, on St Valentine's day, at a Coffee and Cake Morning, we are remembering and celebrating Nikki's life as a Mum, wife, daughter, sister, aunt and friend. Please join us and grab a coffee, some cake and take a few moments to celebrate the love and bravery of those that have crossed paths with CC. We have Nikki's music playing in the background, so as you enjoy your cake, we'll leave you again with another of her favourite songs.

Shine bright Nikki x

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www.justgiving.com/Kirsty-Mackay2/

CC DAY 15 – GUEST POST *from Nikki Greenall*

Last February when AMMF launched the GP awareness letter, it appealed to me as it was something that I could practically do to help. So I started by sending the letter to the 3 GP practices in the town where I live. And feeling pleased that the people local to me might be lucky if they displayed any symptoms as the GP's had received copies of the awareness letter, it made me think about the other towns and cities in the UK. What about the people who lived in the Outer Hebrides, or on the Isle of Man? What if a prompt to the GP practices there helped someone to get an early diagnosis? And so it began. Armed with a spread sheet with details of all the GP practices in England, nearly 9000, I started trying to get hold of email addresses of the GP Practice Managers. Believe you me; trying to get hold of an email address for this particular group of people is like trying to get blood out of a stone! To date, I have managed to contact a total of 2511 GP practices in the UK, 134 in Wales, 294 in Scotland, 28 in Northern Ireland and 2055 in England. But there are still thousands more to be contacted. I have received varying responses to the emails sent out, some Practice Managers confirm that they have forwarded the letter to the GP's, others say they will raise it at their next practice meeting. I have received a prayer from one GP who was sad to hear about my friend Helen Smith, 2 GP's emailed to say that they had also lost loved ones and were glad to see an awareness campaign was in progress. One GP helpfully suggested a slight change to the wording. And sometimes you don't get any response at all and you have to hope that the information has been passed on and shared.



Photo: Nikki's best friend Helen on her wedding day.

So, your mission, should you decide to accept it, is to stick a pin in a map of the UK, locate the GP practices in that area, contact them, and send them a copy of the AMMF awareness letter. It might land in the inbox of a GP who reads it and decides that one of his/her patients might be displaying the vague symptoms of Cholangiocarcinoma and decide to investigate the possibility. If you are reading this and are not aware of the symptoms: Cholangiocarcinoma starts in the bile ducts and the commonest symptoms are due to blocking of the flow of bile – jaundice, dark urine, pale stools, a pain under the right ribs and sometimes itching. There may also be unexplained weight loss, general malaise and fatigue. Wouldn't it be fantastic if the letter you have sent out leads to an early diagnosis and saves someone's life? So do me a favour, pick a town or city, and send out a letter. The letter is available on the AMMF website:

www.ammf.org.uk/wp-content/uploads/2015/01/AMMF-Letter-GP-WEB-15.pdf

The Facebook page has over 2000 likes, and rising, so if each one of those people contacts a surgery then that is potentially another 2000 GP practices contacted. I know I sound a bit like Bob Geldof – but it is something that I feel very passionate about! I have contacted every surgery in Dorset but I know there are parts of the UK that have not been contacted at all yet. Let's raise awareness as far and wide as possible so we hear more happy, success stories from people who have been diagnosed early and treated successfully.



AMMF's GP Awareness Campaign map as at February 2015.

Now for the serious bit. The reason why I have spent so many hours working on this over the last year is because I lost my best friend Helen Smith in 2010 to Cholangiocarcinoma. She was 35, in the prime of her life, having the time of her life (*Dirty Dancing* was one of her favourite films), she had recently returned to work after maternity leave following the birth of her daughter Ella. She was a deputy head teacher at a local primary school and it was a job that she was passionate about. I can honestly say that I had never seen her happier, and then the devastating diagnosis of Cholangiocarcinoma turned her world upside down. In the 13 months she was alive, following the diagnosis, the disease and drugs she was taking left her virtually unrecognisable from the Helen that we knew and loved. No-one should have to watch this happen to someone that they love, it is devastating. Throughout the whole terrible journey we all felt totally helpless and unable to do anything practical to make things better which was incredibly frustrating.

The whole point of AMMF awareness month is to do just that – raise awareness. I had never heard of Cholangiocarcinoma before Helen's diagnosis. It is not one of the cancers that has glossy adverts and famous people suggesting you check yourself for lumps and bumps. So unless you or someone you know has had this type of cancer, then the chances are that you won't have heard of it. So my request if you are reading this, is to share this page on your facebook page so it might reach people who don't know about Cholangiocarcinoma and AMMF.

CC DAY 16 – GUEST POST *from Emma Brown*

I'd like to start by saying "Thank you" to Malcolm and his wife Susan for giving up their day to let me share Nick's story.

Mid October 2014 Nick came home complaining of back pain, he'd been tutoring a swimming instructor course so we put it down to standing all week. As the week went on and endless efforts of heat packs, cold packs, creams and tablets, it was still there and was getting worse. We'd noticed a lump on his back now and went straight to the doctors.

They said it was a lipoma (which was true) and they said to have an ultra sound just to be sure. A couple of weeks later he was still in pain and following the ultra sound, the doctors, due to another illness – Nick had (PSC), were concerned and admitted him to hospital for a CT scan.

After two weeks of tests we got the awful news of bile duct cancer. I didn't even know what a bile duct was let alone anything else. It was a frightening time but Nick as always handled it with great dignity. We were told he would go in to hospital to start chemo the following Monday. As that week went by things went downhill, Nick got really poorly and after more tests we were told there was nothing they could do.

They said he only had a couple of weeks at best and that the chances were he wouldn't see Christmas! This was the most heart breaking news for all that love him. 5 days after this on Thursday December 4th 2014, Nick lost his battle.

That's just 3 short weeks from being diagnosed!! Nick was only 33!!! Please remember this disease can affect anyone of any age.

Throughout this whole process Nick was incredibly brave and still managed to make us laugh right until the end. We've already had many difficult days without Nick, Christmas, New Year and now Valentine's Day, all of which he has been missed deeply by all.

I've never known anyone so brave, so true and so loving. A very special son, brother, friend and soul mate Nick will never be forgotten.

The pain Nick's family, friends and myself are going through is awful. He's in our thoughts and hearts and we miss him more and more with each passing day. But his memory will live on and many fundraising efforts will be made in his name.

Sleep tight my darling Nick.
I love you always and forever. Xxx



Photo: Emma & Nick.

CC DAY 17 – GUEST POST *from Emma Hirst*

It's what Friends are for...

How do you react when a beautiful friend tells you they have cancer? What do you say and what do you do? At 24 years old you don't expect to hear news like this from one of your 'besties'.

I spent time feeling sad, angry and bitter but after a while you realise that negative feelings are not the way forward. You need a positive mental attitude in order to listen and understand, to support, encourage and love those that matter to you.

My friend is in a personal battle with CC. It is difficult to know what to say and do. I don't want to ask, 'How are you?' and 'What's the latest?' yet I want to because I care. You want to keep things 'normal' but how can you when it's not?

I read an analogy recently that sums up my friend... She stood in the storm and when the wind did not blow her way she simply adjusted her sails.

The overwhelming love I have for my friend cannot be conveyed in words or actions. Seeing her deal with adversity in such a modest, dignified and beautiful way has really inspired me to do something positive. The only thing I want to do is take the Cancer away and I can't physically do that, but I can raise money to help AMMF.

There is a 'can' in Cancer because we can beat it and nothing is impossible, the word itself says 'I'm possible.' These are the sayings I stick to and ones which I believe we can all take something from.

AMMF is a wonderful charity doing all the right things in memory, and for those affected by CC. They have been brilliant to my friend, her family and me.

Lucy, I love you, you're incredibly strong, brave and a total babe!
Keep fighting, remain strong and focused. I'm right behind you all the way.
You are a true inspiration and a wonderful person. Life isn't about waiting for the storm to pass, it's about learning to dance in the rain xxx

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[www.justgiving.com/
Emma-Hirst1/](http://www.justgiving.com/Emma-Hirst1/)



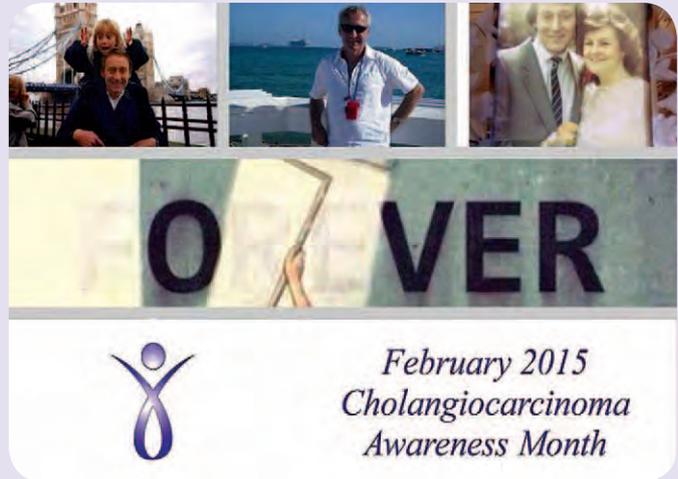
Photos, left to right: Emma Hirst with her friend Lucy-May at Lucy's Hen Party; Wedding in October 2014 and at Emma's recent 10K challenge.

CC DAY 18 – GUEST POST *from Marcella Smith*

Stewart Smith (14.05.56 – 05.09.11)

Stewart's battle with Cholangiocarcinoma has been well documented since his death in previous Guest Posts, local Newspapers and also local radio in an effort to support AMMF and to raise awareness and funding for research into Cholangiocarcinoma.

Our story will resonate with most other patients and carers; itching, jaundice, stents, and then the devastating diagnosis. Stewart's operation was unsuccessful and after fourteen months from him becoming ill he passed away.



Cholangiocarcinoma is a hideous disease, it is ruthless and unpredictable. We would reel from one dreadful situation to another. We never had any positive news and were not on an even keel so apart from dealing with the fact that we were losing a loved one, our lives were turned upside down with endless Consultant appointments which usually ended up with Hospital stays, pain relief that rarely worked consistently and side effects, all of which still fills me with complete horror at the recollection of it. During that time we tried to lead a normal happy life with hope for our future even though I knew that deep down we both realised that really there was no hope at all.

A month after Stewart's death, his Consultant wrote to me and said "I hope you will understand that everyone on the team here at Warwick Hospital was deeply saddened by Stewart's death. He managed a very complex and severe illness with great fortitude and dignity."

Since Stewart's death, our daughter, Lucy, celebrated her 21st Birthday, graduated from University and is now a teacher. His Goddaughter is getting married this year and Lucy is a Maid of Honour. We often talk about our memories, how much we miss him; wishing that this had not happened and we were still enjoying a family life together. The walks and holidays without him, the empty chair at meal times how sad it has been and always will be that he is not here to share the milestones with us.

We feel very privileged to have had Stewart in our lives. He was a wonderful Husband and Father, always putting us first and making us feel happy and safe. He said to Lucy "try to think of all the lovely places we have been to" and I always remember as the Bank Holidays were approaching, he would watch the weather forecast and tell Lucy we were going to chase the Sun.

As Lucy and I continue with our lives, Stewart's memory is never far away, I am sure he would raise an eyebrow at my DIY efforts and also the time I was footing the ladder whilst Lucy was trying to rescue the Cat and I intervened which nearly ended up with me killing both of us!

We as a family support AMMF in Stewart's memory and my hope is that early biomarkers for this cancer can be found so that others can benefit from better treatment and hopefully a cure for this "complex" disease.

We love and miss Stewart every single day.

CC DAY 19 – GUEST POST *from Andrea Fear*

For my Dad, John “Mac” Clark (11.12.47 – 19.02.11)

Saturday 19th February 2011, 2.45am, my life changed forever. My wonderful, kindhearted Dad, the man who had always been there to protect and love me unconditionally, finally lost his fight against Cholangiocarcinoma. As I sit here, trying to put pen to paper for my guest post, I can't believe four years have gone by, it still seems like only yesterday. Five years ago my family and friends had never heard of CC. So much can happen in a year.

Dad was officially diagnosed in April 2010 after being hospitalised with jaundice in the March. Numerous tests were carried out and at first his GP suspected Gallstones. Dad had battled cancer most of his adult life, he'd had bowel cancer three times and was just coming up to his ten years of being cancer free. This time was different, this time the word terminal was used, my heart broke.

As a family we gained our strength from Dad, he was never one to feel sorry for himself, he carried on each day smiling and determined to get on with his life, never giving up hope that some sort of miracle would come our way. I remember a few weeks after he came out of hospital he insisted on decorating my hall, if anyone had fighting spirit it was my Dad. Chemo was suggested to help prolong the time he had left but his bilirubin level never came down to the magic number fifty. We travelled to Leeds for a second opinion in the November, but all our hopes were finally shattered when we were told Dad's cancer had spread too far.

That day the reality that nothing could be done broke my heart all over again, every bit of hope cruelly snatched away. Dad remained at home and pain free until the end, something I will always be grateful for.

Death changes you, it reshapes who you are and how you see the world. One lesson Dads death has taught me is life really is short and you never know what is round the corner, which probably is a good thing at times. Life is for living, so grab it with two hands and make the most of it, as my Son would quote, YOLO....you only live once!

We can all make a difference in this world. When Dad died I wanted to help raise money in his memory for AMMF. Hopefully one day it will help make a difference to someone fighting for their life, to someone living in hope, to someone like my Dad.

Miss you Dad, always and forever. To the world he was one, to us he was the world xxxxx



CC DAY 20 – GUEST POST *from Phil Pointon*

This is my first post for AMMF. In Memory of a much missed Son, Brother, Father, Husband and Uncle.

Nigel turned 50 in September 2013 and was still playing football, running and following a healthy lifestyle including only ever having half a lager when he went out (a standing joke). Prior to his diagnosis Nigel never had a reason to visit his GP.

The picture is of my brother Nigel (left) wishing me a Happy Birthday on a night out on 15th December 2013. 10 days later Nigel presented himself at A&E with Jaundice. Nigel shared what he had been told at the Hospital “It might be a blockage or, at worse case, cancer”. Numerous trips between his GP and the Hospital followed along with a rapid deterioration in his health.



Nigel’s diagnosis came in early February 2014 and we were all trying to understand what was happening to Nigel and what could be done. His health continued to deteriorate but he remained hopeful of finding answers and clung to the hope that Chemotherapy would prolong his life whilst worrying about the Chemotherapy process itself. But Nigel was only well enough to have one session.

Nigel had one set back after another and, along with his family, was still uncertain as to what was happening. Nigel spent more time in Hospital than at home having stents fitted and treating repeated infections. Nigel, along with his family were informed that he would not be able to receive any more Chemotherapy and discussions focused on the need to access a Hospice.

Nigel remained very dignified and continued to worry about all those around him, including the nursing staff. Nigel fought to the end and was taken away from his loved ones on the 7th May 2014.

A few days after trying to find answers and looking for charities we came across AMMF. We cannot thank AMMF enough for the continued support and wish we had found them sooner, for Nigel.

Doing our bit for AMMF various fundraising has taken place, and on June 6/7th 2015, I along with friends, will be taking part in the Nightrider 100km cycle ride again on behalf of AMMF. Please visit my Just Giving fund raising page ‘In Memory of Nigel’.

God bless Nigel and keep dancing xxx

JustGiving

www.justgiving.com/Phil-Pointon/

CC DAY 21 – GUEST POST *from Beryl Jones*

It was seven years ago on 23rd January that I had an operation to remove the tumour that had been discovered in my liver...

I know now that early diagnosis and surgery is the key to beating cholangiocarcinoma, but if I could have heard a positive story and believed CC could be beaten it would have helped me through the difficult days after my operation, when I was afraid and my emotions were in overdrive. So I hope my positive story will be of comfort to those like me, who have had surgery and may be struggling emotionally.

It was hard, but I did get through that first difficult year after surgery, and gradually regained control of my life. Finding AMMF helped me to turn my negatives to positive, and I now feel I have a family to turn to who are committed to finding a cure for this ghastly cancer and I can also hear of others who have fought a battle with CC and WON.



Photo: Bill and Beryl in the Tenerife sunshine.

Today, my husband Bill and I have just completed a 10 mile cliff walk here in sunny Tenerife. As you can see from the photo, I am very well and leading a full and active life.

And, as much as I dislike having my photo taken, I think anyone seeing me will be reassured that seven years down the line my quality of life is “simply the best” – and with early diagnosis and surgery, CC can be beaten.

CC DAY 22 – GUEST POST *from Stacey Walker*

Christopher Andre Jackson – Lover of photography, food & wine and all things speed!

Chris was my boyfriend Matt’s Dad, but in my heart he felt a little like mine too. Bearing in mind I had only met my real father two years prior to meeting Chris in 2004, and seeing more of him and Nicki than my own family whilst at university, I had truly embraced the Jackson family.

Prior to Chris being diagnosed in 2011, we had moved away and were seeing a lot less of him. When we did catch up, Chris would say how tired he was but we all put it down to the stress and daily commute to work. His poor liver function, which had been highlighted shortly after that, was blamed on his love of fine wine. His true condition remained undetected for months.



Photo: Chris and Nicki on their wedding day.

The day Matt told me Chris had cancer I was instantly angry at the world – how could one of the nicest men on earth have this awful disease? The following year saw Chris go through some grueling treatments, with the best that money could buy. I would scare myself by reading the depressing statistics online which promised 5 years prolonged life at best, but all the while trying to summon up hope that he would beat this thing. Unfortunately Chris lost his battle with Cholangiocarcinoma on 24th June 2012 – just over a year after his diagnosis.

Since then as a family we have raised money for AMMF by doing various running events, climbing in the UK and Nicki walked the Great Wall of China with her son Adam. We even talked about fundraising whilst Chris was alive and I told him I wanted to climb Mt Kilimanjaro to raise funds and awareness for AMMF – and in September last year I did just that. It was the toughest challenge I have ever put myself through, but that was the point. Not only did I want to support AMMF, I also wanted to experience part of Chris’ struggle. The painful body and negative thoughts telling you “you can’t go on”. I saw Chris take his last breath and how brave he was until the end – and I carried that thought with me to the top of Africa... as well as my AMMF t-shirt!



I miss Chris so much still, and I can only imagine the hole that is left for Nicki and his children. The only consolation I can take is that I feel so blessed to have been part of his short life and in his memory; I will endeavour to live my life to the fullest and be the best that I can be.

Final thought – early diagnosis is key! Let’s continue our GP Awareness Campaign as well as raising funds for research purposes.

Photo: Chris & Nicki, with (r) Matt and Stacey.

CC DAY 23 – GUEST POST *from Matt Sheppard*

Susan Frances Sheppard (16.09.69 – 09.04.14)

My beautiful and radiant wife, glamorous and full of style was such an important part of so many peoples' lives. As a mum to our youngest Lily and to Louise, to me as her husband, to her brother and grandparents and to the countless friends who sought her wisdom, guidance, fun and companionship. She will never be forgotten and her sparkly, twinkling memory, shimmering as a diamond will burn bright forever.

Sue ran her own businesses and became our town's Vision Manager, typical of her, ensuring facilities and infrastructure benefited everyone. And what made her so special, she did it all effortlessly.



Photo: Matt & Susan.

My wife complained of being tired and cold, but not the normal chill of winter, a chill that went to the core as if it was emanating from deep inside. Stabbing pains and the first signs of how things had spread to the lungs manifested themselves in breathlessness. Sue was not the fittest, but having to stop to catch her breath after just walking was not normal. Neither was the diagnosis. "You have a cancer of the liver that is metastatic to the lungs." A terrible, despicable announcement amidst a sea of 'normalness'.

Chemo followed drugs, home visits followed endless trips to the hospital. Palliative care and then the treatment termination. My wife smiled to the end and soothed me when I could take no more.

Sue never wanted to know the full prognosis of her illness. Her fighting spirit remained until the very end, fiercely clinging to the hope that she could get through this, to see Louise prosper in her work and Lily progress at school. She faced adversity in her typical ebullient manner

The work of Helen and all at AMMF is vital in funding research into this wicked and devious of all cancers. Sue's friends and family continue to keep her memory alive by raising much needed funds to help AMMF find ways to overcome this terrible illness.

Fetes and 'Danceathons', runs and cycle rides continue to put something back into what has been taken away.

Shine bright like a diamond...

CC DAY 24 – GUEST POST *from Chris Allum and Nic Othmani*

When we discussed what to write about for this year's guest post it quickly became clear that we would like it to be about our experience at the recent AMMF/Imperial College event in London.

We have spent the best part of four years since losing our lovely Dad, Charlie, looking back and remembering the pain of losing him whilst also recollecting the lovely times that we had with him. This year, 2015, would have been a big year for Mum and Dad with them both becoming 60 years of age and it being their 40th wedding anniversary. However, we want our guest post to be about looking forward with hope and positivity for the future in the search for a cure so that there are more survivors of this awful disease.

We felt so privileged to be asked by Helen to attend the event on the 11th February and are so pleased that we decided to attend together. Whilst we know we have played our part in helping the charity over the last five years with several fundraising events which range from Nic's slimathon, to my two London Marathons and the three memorial football days that have been arranged by the family, what we do also realise is that there are also hundreds of other people that are raising money for one common goal.

The day at Imperial College London was amazing and provided us with a real and informative insight into where the fundraising money is being invested, not just here in the UK but also in projects in Thailand and America. From funding to help employ a technician to log samples for the biobank at the Imperial College, to hi-tech research into imaging equipment to assist with early diagnosis which will ultimately mean more people will be eligible for the only current cure which is surgery. Supporting AMMF over the last few years has personally given us a much needed focus and has formed part of our grief journey and will continue to do so.

During the day we got to spend time with a huge spectrum of people who ranged from the professor, to scientists, to doctors, to the AMMF team and to the fellow charity supporters who also included two amazing survivors who are beating this disease.

Without doubt the day made us understand that there is a huge amount to still be done in order for the survival rate to be improved but what is also clear is that without Helen and the rest of Team AMMF, this amazing progress would not have been made thus far.



It is our family's understanding that around ten years ago there was no research whatsoever being done into cholangiocarcinoma and it is thanks to team AMMF and all of its supporters that this situation has been rectified.

'TEAM' AMMF – Together Everyone Achieves More, so let's keep up the fight!

Photo shows our Mum, Julie, Dad and our brother Andy from November 2008 at Andy's wedding in the Dominican Republic. Such happy times!

CC DAY 25 – GUEST POST *from Sandie Gapper*

Journeys...

Cholangiocarcinoma, like other cancers, can rule your life... if you let it! You can find yourself embroiled in endless hospital appointments, treatments and the journeys that brings and still have to deal with your “normal” journey in life.

My year began with six months of harsh chemotherapy and all the horrid side effects that journey beholds and there were times when I just wanted to give up and leave that journey and let life take it’s own course. However, I promised myself some new journeys and experiences if I got through. I did get through, with the support of a loving family and a circle of wonderfully supportive friends and having recovered I set out on the journeys I had promised myself.

With my Little Bear, I went to Palermo wandered around the botanical gardens and dined out on chicken and chips. I went to Turkey celebrated my birthday on a boat and dived with my precious son. I went to New Zealand and bungee jumped, saw dolphins and geysers, sat in a Polynesian spa and body boarded the waves for the first time. In Australia I dived in the Great Barrier Reef and saw Madame Butterfly at the Sydney Opera House. In South Africa, I tasted delicious wines, sunbathed with penguins by my side and went on an amazing safari.

I know I was lucky to be able to take these amazing journeys. Life is a journey and only you can decide which paths you take. Use your strength and will to make the most of your journeys and create memories which you can draw upon during your tough journeys.

Sandie x

JustGiving™

www.justgiving.com/LittleBearAdventures



Photo: Sandi and Little Bear brave the bungee jump!

CC DAY 26 – GUEST POST *from Samantha Parmar*

Today it will be 42 days since my Dad spoke his last words to me whilst lying in his intensive care bed, “give me a kiss”. A quick kiss on his forehead and a “bye, see you tomorrow” from me, little realising then that the next day would be his last and I would only spend a little more than half an hour with him before he passed away, peacefully with his family by his side.

Dad’s journey with Cholangiocarcinoma had only begun two months earlier, although we didn’t know it then. It was a month later having been admitted to hospital with jaundice, two weeks before Christmas, that the reality of the situation was laid bare. Dad had cancer. We still didn’t know the full picture at that time, but that didn’t matter, we wanted him home for Christmas. We would deal with whatever we needed to later.



In fact, we got Dad home three times prior to his death, Christmas, New Year and crucially his last weekend, spending time with my Mum and his beloved dogs. Mutley, technically my dog but Dad had been his master for the past 14 years, died two days before my Dad. It was as if Mutley knew that Dad would need a companion.

Information was fed to us over the next couple of weeks but the final diagnosis and ultimately, the devastating prognosis, were delivered to us one week into the New Year. Dad died 9 days later.

I knew Dad was seriously ill before he did, having researched his symptoms. Despite extensive searches, Cholangiocarcinoma did not come up, not once! The symptoms only surface when advanced, but what if there were earlier signs that had been ignored, dismissed? Awareness is key, if only we had known the warning signs, maybe I wouldn’t be writing this now.

Dad’s journey with Cholangiocarcinoma was mercifully brief, mine has only just begun.

CC DAY 27 – GUEST POST *from Terry Matthews*

Tomorrow would have been Mark's 57th birthday. To say how much we miss Mark would be an understatement and, like so many others, we are learning how to cope with all the firsts. But it's when you least expect it a memory will emerge and catch you out, causing you to feel that familiar sharp pain and wipe away the tears. It happened to me this morning while I was cleaning my teeth. I had a very clear memory of how I used to get exasperated when Mark would speak to me and expect an answer when my mouth was full of toothpaste. I knew in that moment I would give anything to have that time again but sadly I can't. However, maybe with the help of AMMF, all the fundraisers and supporters, we can help change the outcome for others.

Like so many of the stories I have read this month on the AMMF Facebook page, by the time Mark was finally diagnosed in October 2012 – 6 months after we noticed things were not right – we were told those dreadful words “you have a rare terminal cancer, cholangiocarcinoma”. The cancer was already at stage 4 and Mark was given months to live. With true grit, determination and the desire to prove his doctors wrong, we all had eighteen months of making memories, happy and sad until he lost his battle on the 14th April last year.

Mark found out about Helen and her wonderful charity, AMMF, quite soon after he started treatment. Helen listened and dealt with Mark's deepest and darkest fears in that wonderful way she has, giving him just the information he required each time and being so very supportive and encouraging. I also have had many times during and since when I needed to speak to Helen or exchange emails and she has always found the time to listen and reply and for that I want to say ‘Thank You’ from the bottom of my heart.

Early last year Helen and her team sent an email requesting if anyone would be interested in contacting their local radio station to help with the February awareness month for AMMF. Mark was very keen to help but, unfortunately, he became quite unwell so it took a while to arrange. Finally on the 26th March, just weeks before Mark passed, he found the courage and strength to climb out of bed and give an interview to both the local BBC radio and TV station. This was to help highlight how the type of liver cancer that was going to take his life was also taking more lives each year than cervical cancer, but so few knew of it. He also went on to explain about the research into a simple urine dip test that AMMF are funding. This dip test could help diagnose not only cholangiocarcinoma, but many other types of cancer much earlier, helping to prolong and save people's lives.



Terry's favourite wedding photo.



Photo: Mark and Terry with friends and family at their wedding four years ago – 26 years after first meeting!

AMMF Note: The BBC have given us kind permission to share the video of the interview Mark & Terry did in February 2014. Terry has asked, “Please take the time to watch and then share with as many people as you can to raise awareness in Mark's memory”:

www.youtube.com/watch?v=OwfcMQLmVO0&feature=youtu.be

A link to the video and to Mark & Terry's radio interview can also be found on Mark's section of Our CC Family on AMMF's website:

www.ammf.org.uk/photo/?photoid=31

CC DAY 28 – GUEST POST *from Susan Bremner*

Today, 28th February 2015 my husband Simon is celebrating his 41st birthday. There was a time when I wasn't sure if he would even make it this far. In October 2011 he wasn't feeling well while we were on holiday, after many tests the hospital weren't sure what was causing his problems and said the only way to diagnose properly was to operate.

It was a huge operation and we were told that there was a chance he may not come out the other side, but we took a leap of faith and decided that in order to get better he'd have to have the operation. After a whole day of surgery my phone rang to say that he was out of surgery and in intensive care, they had to remove over 80% of his liver. This was when we found out that it was cancer, cholangiocarcinoma to be exact.

They were confident however that they had removed all of the tumour. After a few weeks he was well enough to come home and after only a few months recovery he was back at work and doing brilliant. Until December 2012 when he started feeling unwell again, after scans they decided chemotherapy would be the best option for him. After 6 months of chemo he was told that he was in remission. I can't begin to tell you how relieved we were.

Simon is my best friend and my hero, he is an amazing dad to our 2 boys. He has overcome so much and still remains positive even when there have been a few curve balls thrown along the way. I definitely think his positive attitude has had a lot to do with his recovery, he is an inspiration and I love him with all my heart.

I just wanted to write this little piece to let people know that even when life deals you an awful hand there is still hope and to always stay positive.

Someone has got to beat the odds, why can't it be you?



Photo: Susan and Simon with their boys.



AMMF is the UK's only cholangiocarcinoma charity, and is dedicated to raising awareness, supporting research and providing information on this disease.



www.ammf.org.uk
info@ammf.org.uk
Tel: +44 (0)1371 811811

Registered charity no 1091915