



# News



## Amazing Fundraisers!

See pages 4 and 5

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## Welcome to this edition of AMMF's newsletter.

Looking back over 2014, it is incredible to see that, yet again, AMMF's outlook and reach continues to broaden – with the launch of our ongoing GP Awareness Campaign during February's Awareness Month; participation in the Cholangiocarcinoma Workshop in Khon Kaen, Thailand, in March; and working with the National Cancer Intelligence Network and Cancer52 on a rarer cancers project (due to be published in the summer of 2015).

AMMF continues to support a variety of research projects, and the charity is now definitely recognized as the UK's cholangiocarcinoma 'go to' organization, with requests for reviews and cooperation coming in from a wide variety of professional bodies.

As I write this, we are looking forward to an incredibly busy 2015, including attending the US Cholangiocarcinoma Foundation's conference in Salt Lake City, and AMMF's supporters' day at Imperial College – both during February's Awareness Month; more fundraising events in the diary than ever before this early in the year; and several requests for research funding on the table.

Heartbreakingly, we see the incidence of cholangiocarcinoma continuing to increase, and the age of those affected getting lower – and for those reasons AMMF remains dedicated to raising awareness, to encouraging and supporting research and to providing information to those who need it.

Thank you to all AMMF's amazing fundraisers and loyal supporters. Put simply, without you the charity could not exist – but with your help, we hope to achieve a far better future for those diagnosed with cholangiocarcinoma.

**Helen Morement**  
Founder & CEO  
[helen@ammf.org.uk](mailto:helen@ammf.org.uk)

## New on the Website – AMMF's Online Shop

Launched to coincide with 2014's Awareness Month – AMMF's online shop provides fundraisers' and supporters' merchandise to help raise awareness and support the charity.

For those planning events there are balloons, banners, collection boxes and buckets all available at no charge (other than p&p). There are enamel lapel pins showing AMMF's icon, our 'symbol of hope', as well as ribbon pins and wristbands. And for those taking part in sporting events, or supporting them, there are vests and t-shirts with AMMF details back and front – great for awareness raising.

[www.ammf.org.uk/ammf-shop/](http://www.ammf.org.uk/ammf-shop/)

*\* Look out for our new, bespoke vests, t-shirts and cycle tops, coming in Spring 2015!*



Wristbands, ribbons and pins

## GP Awareness Campaign

One of the major difficulties with cholangiocarcinoma is the lack of awareness at primary care level of its insidious and, admittedly, often vague and non-specific symptoms which can lead to late diagnosis. During Awareness Month, February 2014, AMMF launched a GP Awareness Campaign to address this problem, and the campaign has been ongoing since.



GP practices approached as at February 2015

To enable as many supporters as possible to take part in the campaign, AMMF produced a letter for GPs listing the cholangiocarcinoma symptoms they should be aware of. The letter also draws attention to the fact that slightly abnormal liver function test results may be the earliest sign, so urgent assessment is needed if the window of opportunity for surgery is not to be lost.

As can be seen from number of pins on the map as at February 2015, increasing areas of the UK have been covered, but there is still more to be done!

If you would like to take part in the campaign, please take or email a letter to your own GP practice. Further information on the campaign and what to do, along with a downloadable letter, is available on AMMF's website.  
[www.ammf.org.uk/gp-awareness-campaign/](http://www.ammf.org.uk/gp-awareness-campaign/)

## Meet Debbie...

Working tirelessly offering advice and support to all those taking on fundraising events or thinking of doing so, is Debbie Nicholson, AMMF's fundraising co-ordinator.

Debbie joined the team early in 2014, loves getting out and about at events like the London Marathon and NightRider, where she's always ready with unfailingly cheerful support and encouragement for the charity's participants, and is great at building up a rapport with all our fundraisers, no matter what they are involved in.

If you are thinking of taking on a fundraiser for AMMF during 2015, make sure you let Debbie know! [debbie@ammf.org.uk](mailto:debbie@ammf.org.uk)



## International Cholangiocarcinoma Workshop – Thailand

After meeting with a Thai cholangiocarcinoma delegation at Imperial College in London in the summer of 2013, AMMF's Helen Morement was invited to attend an international cholangiocarcinoma workshop in Thailand in March the following year to give a presentation on the work of the charity.

This 3-day workshop, the first of its kind, was appropriately held in Khon Kaen, the area with the highest reported incidence of cholangiocarcinoma in the world.

With presentations and discussions on the major CC projects underway in the UK and Thailand, including workshops on biomarkers, diagnosis, surgery, patient support and patient care, many opportunities were provided for UK and Thai researchers to share perspectives and experiences.

AMMF's Helen was a keynote speaker at the Patient Support workshop, presenting



Researchers and specialists at the Mekong river (with AMMF's Helen back row, 5th from left)

the work of the charity. This was of special interest to members of the new CCA Foundation in Thailand – which has only recently been established and is seeking the best ways to bring about much needed social awareness of the disease.

A field trip to the Mekong River, through the rural areas of the north east Thailand with the world's highest incidence of CC, was a valuable experience, providing local and in-depth information on conditions in the area, leading to a better understanding of the problems the Thai rural population face.

Helen commented: "There is no doubt, cholangiocarcinoma is a global problem. We need access to higher numbers, to more samples, to effective research – collaboration with Thailand should enable this and, it is hoped, the results achieved in this way will then lead to improvements for the UK, Thailand and the world."

A full report on the Thai workshop, including AMMF's presentation is on the website [www.ammf.org.uk/2014/03/24/thai-cholangiocarcinoma-workshop-report/](http://www.ammf.org.uk/2014/03/24/thai-cholangiocarcinoma-workshop-report/)

*The workshop was supported by the British Council and the Thailand Research Fund, and organised by the Faculty of Medicine, Khon Kaen University.*

## MDT – the Patient's Perspective

AMMF's Helen Morement was invited by Mr Hassan Malik, Consultant Hepatobiliary Surgeon and Clinical Lead at University Hospital, Liverpool to speak to an audience of surgeons at the Esso Baso Cancer MDT Course, on 01 November 2014, on the subject, "MDT – The Patient's Perspective."

Knowing this to be a very fraught area for many cholangiocarcinoma patients and their families, AMMF supporters were invited to answer, comment on and give their thoughts on a series of questions, so that theirs would be the perspective used in the presentation.

The feedback after this presentation was immediate and remarkable. Several surgeons commented that this information would definitely make them take a fresh look at their approach, one mentioned that some of the comments actually brought tears to his eyes, and another said he felt that it

had been like, "an anchor pulling him back into the harbour where he should be..."

The comments from those who agreed to share their information were prepared as a handout and circulated to all at the course. You can see the questions asked, the comments handout and AMMF's presentation slides on the website:

[www.ammf.org.uk/2014/12/01/mdt-the-cc-patients-perspective](http://www.ammf.org.uk/2014/12/01/mdt-the-cc-patients-perspective)

*Mr Hassan Malik has since contributed an article for AMMF's Specialist Viewpoint series, entitled "Demystifying the MDT", and this is also available on the website: [www.ammf.org.uk/article-7-demystifying-mdt](http://www.ammf.org.uk/article-7-demystifying-mdt)*



Mr Hassan Malik

## Our Grants Portfolio

In line with one of its major objectives, AMMF encourages and supports research into cholangiocarcinoma. As at the end of 2014, the charity was supporting CC research teams at the University of Edinburgh, the Cambridge Research Institute, the Institute of Hepatology, and Imperial College London.

### University of Edinburgh

In June 2014, AMMF agreed a grant of £70,000 to be given over three years to support the work of Professor Stuart Forbes and his team on the macrophages that help to drive intra-hepatic cholangiocarcinoma, including the signals involved (Wnt and Notch).

### Cambridge Research Institute

In June 2014, AMMF agreed a further grant of £10,400, to be given over two years, to allow Dr Hayley Whitaker's BI-010 biomarker work to continue. This follows the initial grant of £5,000 given during 2012 and the promising interim reports received on this work.



Dr Whitaker (l) in the lab

### Institute of Hepatology

In 2013 AMMF agreed a grant of £34,800, to be given over three years to support the work of Dr Salvatore Papa at the Institute of Hepatology, "Understanding the Molecular basis for the development of intrahepatic cholangiocarcinoma." This work is achieving some exciting early results, and the second part of the grant was made during 2014.

### Imperial College London

In October 2014, AMMF approved a grant of £30,000 to help support the national cholangiocarcinoma bio-repository at Imperial College London. This funding will help to employ a technician who will log the samples in detail, and will also help to fund necessary equipment and consumables.





Our Amazing Fundraisers!

During 2014 we had an amazing number of people involved in fundraising for AMMF, and doing so in an equally amazing variety of ways.

From coffee mornings, football tournaments, fun days, running marathons, half marathons, 10ks and 5ks, cycling enormous distances, jumping out of planes, swimming, getting covered in mud and half drowned, being slightly electrocuted (yes really, just ask those who took part in the Tough Mudder events!) and climbing massive mountains, to head shaves, creating pet portraits, baking cakes, holding online auctions and losing weight – whatever you have done for us to raise sponsorship, we send our enormous thanks to each and every one of you.

These photos show just a few of AMMF’s wonderful, loyal fundraisers...



Out and about...

Cambridge Research Institute, April 2014 – research update

Left to right: Drs Hayley Whitaker, Jonathan Kay, Hayley Luxton and AMMF's Julie Morement and Helen Morement



University of Edinburgh – Scottish Centre for Regenerative Medicine, April 2014



AMMF visit to meet Professor Stuart Forbes and his team.  
Left to right: Professor Stephen Wigmore, Drs Rachel Guest & Luke Boulter, research scientists, Professor Stuart Forbes, AMMF's Helen Morement

Institute of Hepatology, London, September 2014 – research update

Left to right: AMMF's Nicki Jackson and Helen Morement, Professor Roger Williams, Dr Salvatore Papa, Gemma Choy (PhD student), Dr Shilpa Chokshi



House of Commons, Westminster, December 2014

AMMF attended the Cancer52 parliamentary event "The hidden majority – improving outcomes for people with rare and less common cancers..." Left to right: The 'AMMF reps' Helen Morement, Dr Chris Wadsworth, Julia Wise, Dr Shahid Khan, Dr John Bridgewater, Susan Robinson, Malcolm Robinson



AMMF's external activities

AMMF is now recognised nationally, amongst the general public and within medical circles.

- As a member of the **NCRI<sup>1</sup> Upper GI HPB subgroup**, AMMF has made valuable contacts with those at the forefront of CC research and treatments. This group is concerned with the development of various clinical trials, including those for CC. Through involvement with this group, AMMF is able to put forward the CC patient's point of view, and also to review information from the patient's perspective.

<sup>1</sup> The NCRI (The National Cancer Research Institute) is a UK-wide partnership between the government, charity and industry, which promotes cooperation in cancer research.

- AMMF is an active member of **Cancer52**, an alliance of some 80+ of the rarer and less common cancer organisations, which provides "the common voice for less common cancers". Through Cancer52, AMMF has a presence and a voice within every national cancer initiative.
- Currently, AMMF is working with Cancer52 and the **NCIN** (the National Cancer Intelligence Network) on a new project, the first of its kind, to produce detailed incidence and mortality statistics for individual rarer and less common cancers (this work is due to be published in the summer of 2015).



Helen Morement appointed to Cancer52 board

In March 2014 AMMF's Helen Morement was appointed a board director of the organization, Cancer52.

For several years, AMMF has been an active member of Cancer52<sup>1</sup> – the umbrella organization providing "the common voice for less common cancers", working together to address the inequalities that exist in policy, services and research.



After her appointment, Helen commented: "AMMF has always valued its membership of Cancer52. This alliance of 80+ organizations provides unparalleled access to the 'movers and shakers' amongst today's policy makers, service providers and researchers. There is strength in the number of its members, and in their diversity – all united by their wish to improve outcomes for patients with less common cancers. Being a member of Cancer52's board will enable me to work closer with this pioneering organisation in identifying priority challenges and opportunities, and in ensuring that the rarer cancers community is included in key current policy issues affecting those with cancer."

[www.cancer52.org.uk/](http://www.cancer52.org.uk/)

<sup>1</sup> Why the name Cancer52? When the organization was formed, 52% of UK cancer deaths were from the less common cancers (i.e. excluding the 'big four': bowel, breast, lung and prostate). That figure is now 54% (source: NCIN 2014).

In Memory...

AMMF is honoured to receive donations from families and friends in memory of loved ones lost to cholangiocarcinoma.

Once again we have seen an increase in the number of donations received in this way – many times these donations come from people who haven't been in touch with us before, so we know that AMMF is becoming far more widely recognized as the cholangiocarcinoma charity and, although we are profoundly grateful to receive these donations, it is with sadness that we recognize far too many people are still being diagnosed too late and, in many cases, are not getting to the experts in time, if at all...

Thank you to everyone who has donated in memory of a loved one. With your support, and in the memory of all those precious lives lost, we hope to work towards a better future for those diagnosed with cholangiocarcinoma.

*"There's Rosemary, that's for remembrance..."*  
*William Shakespeare*



The following are the names of loved ones lost to cholangiocarcinoma, and in whose memory AMMF received donations during 2014...

Jenny Allen	Susan Fairhurst	Tim O'Donoghue
Mary-Jane Ansell	John 'Jackie' Finlinson	Desmond O'Hanlon
Margaret Arnold	Nicholas Francis	Rita Orton
John Barton	Victoria Garrett	Pauline Pinfold
John Beaumont	James Gray	Nigel Pointon
Alan Bodimeade	Linda Gregory	Robert Prudames
Barbara Bragg	Dorothy Harber	Pauline Schwab
Steve Chambers	Mei Lin Hart	Carole Sheehan
Barry Chapman	Alan Kendall	Susan Sheppard
Richard Churchill	Helen Kennedy	Derek Slater
Gwendolen Collick	Christopher Knights	Sharon Solomon
Daphne Darbyshire	Diane Lathbury	Julie Stenning
Lizzie Dellow	Nora Leonard	Joanne Sutton-Reid
John 'Dai' Dixon	Olive May Lewis	David Taylor
Michael Dudley	Dilip Majithia	Sheila Vine
Hedley Easter	Mark Matthews	Alexander Walker
	Jenny Merry	Sophie Watts
	John Munns	Sonia Wheeler



## About AMMF

### The UK's only cholangiocarcinoma charity

After Alan Morement died from cholangiocarcinoma at the end of the year 2000, AMMF (The Alan Morement Memorial Fund) was set up and registered as a charity. AMMF is the UK's only dedicated cholangiocarcinoma (CC) charity.



Although cholangiocarcinoma (bile duct cancer) is considered a rare cancer, worldwide it is the second most common primary liver cancer. However, because it is so difficult to diagnose accurately and early, CC is often advanced by the time of diagnosis and so surgery, currently the only potential cure, is not an option. Only 5% will survive one year from a diagnosis of CC.

Over recent years an enormous and extremely worrying worldwide increase in CC's incidence has been noted. Latest figures show CC causes over 1800 deaths each year in the UK alone (CRUK 2009), and the incidence appears to be increasing across all age groups, including younger people. The cause of this ongoing increase is unknown and much research is desperately needed.

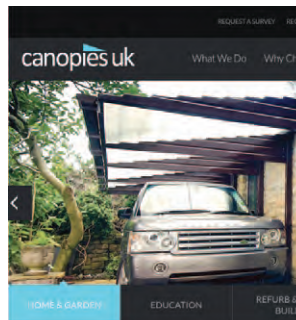
AMMF is dedicated to raising awareness, providing information and supporting research into the causes of CC, better diagnostic tests and more effective treatments for this devastating disease.

## Canopies UK choose AMMF

In May 2014, we were delighted to learn that Canopies UK, the UK's leading designer, manufacturer and installer of outdoor canopies, had chosen AMMF as their charity to support.

Sales Director, Jason Eastwood, who lost his wife, Kelly, to cholangiocarcinoma in 2011, said "We've been discussing supporting a charity for some time, and I'm glad to say it was a unanimous decision – we would like to support AMMF."

We are very grateful to Jason, and to everyone at Canopies UK for this ongoing support.



[www.canopiesuk.co.uk](http://www.canopiesuk.co.uk)

## Thank you for your support...

Each and every donation we receive is important to us – put simply, without your help AMMF could not continue its work. If you would like to donate to AMMF, this can be done in a variety of ways:

### Online giving

Donate on-line with a credit or debit card via [www.justgiving.com/ammf/Donate](http://www.justgiving.com/ammf/Donate). Donations made in this way can be one off, or regular, eg monthly.



### Donations by cheque

Please send your donation to:  
AMMF, Ambrose Cottage, Oxen End,  
Little Bardfield, Essex CM7 4PR.

**Please make cheques payable to 'AMMF'.**

Please remember, if you are a UK taxpayer AMMF can claim an additional 25p for every £1 you donate through Gift Aid. Donations made via the Justgiving site will automatically attract Gift Aid if the UK

taxpayer box is ticked. For other forms of donation (cheque or cash), please download a Gift Aid form from AMMF's website, or contact us on: tel: 01371 811811, email: [info@ammf.org.uk](mailto:info@ammf.org.uk)



*giftaid it*

## In Appreciation

AMMF would like to express its gratitude to those companies who have supported the charity over many years and continue to do so, in a variety of practical ways. Two in particular stand out:



**Swallowmax Ltd**, fantastic print specialists who take charity support seriously and who, for many years now, have featured AMMF in the charity section of their website. They generously supply the printing of the charity's literature without fee, and huge thanks go to Phil Pearson and Rob Beaton, directors at Swallowmax, for their unstinting practical help. [www.swallowmax.co.uk](http://www.swallowmax.co.uk)

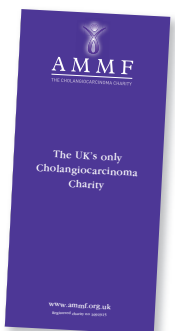


**Gane Jackson Scott LLP**, an experienced firm of accountants with an excellent reputation, have been AMMF's accountants and advisers since the charity's inception in 2002. They give advice on the charity's financial matters throughout the year, and prepare the charity's annual accounts for submission to the Charity Commission, totally without fee. Their help is invaluable, and many thanks especially go to Graham O'Malley and John Best. [www.ganejackson.co.uk](http://www.ganejackson.co.uk)

## AMMF's brochure

AMMF's brochure has recently been updated and is available in two versions – a printed version and a download version available from the website.

This 6-page brochure contains information on AMMF and its aims, and provides details on cholangiocarcinoma in an easy to understand way. Everyone can use the brochure to raise the awareness of cholangiocarcinoma and of AMMF – make sure you have some when you have a fundraising event, take them to the hospital for your CNS, doctors and consultants, and definitely drop one or two in at your GP's surgery.



If you would like some copies, just email [info@ammf.org.uk](mailto:info@ammf.org.uk) with how many you would like and your postal address, and we'll get them sent off to you.

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