



# AMMF

THE CHOLANGIOCARCINOMA CHARITY

# News



## Fantastic Fundraisers

See pages 4 and 5

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- AMMF's Fantastic Fundraisers • AMMF out and about • and more...



Welcome to this edition of our occasional newsletter.

It's been two years since the last one – two incredibly busy years which have seen a phenomenal growth in the charity's activities in all directions.

In reviewing those years, successful would seem an odd word to use when we are concerned with such a devastating disease as cholangiocarcinoma, yet we have seen some success and improvement in almost every area – awareness, diagnosis, treatments. Still a hard road to travel – but the journey has begun.

AMMF has definitely broadened its outlook and its reach. We have more fundraisers and supporters than ever before, our Awareness Month is now firmly established and is helping us to reach all parts of the UK. We are supporting a variety of research projects, and the charity is rapidly becoming the cholangiocarcinoma 'go to' organisation, with requests for reviews and cooperation coming in from a wide variety of bodies.

AMMF is and, by its nature, will remain a niche charity. However, as we move into 2014, I believe it is safe to say it is now recognised as a force for good in the CC world, and is firmly established to continue the work towards its aims, which remain – to raise awareness, to encourage and support research and to provide information to those who need it.

Heartfelt gratitude goes out to all AMMF's amazing fundraisers and loyal supporters. Without you the charity could not exist – with you, we hope to achieve a far better future for those diagnosed with cholangiocarcinoma.

**Helen Morement**  
Founder & CEO

# A symbol of hope...

**"We need a symbol to encapsulate what AMMF is about!"**

This was a tall order, but after many brainstorming sessions working on refreshing the logo and creating a unique identity for AMMF, we had a selection of icons to test on some unsuspecting, but willing market research volunteers.

Our chosen icon is the one that received by far and away the best and most encouraging feedback: 'positive', 'uplifting', 'creates a sense of hope', were some of the comments, and were definitely the sentiments we really wanted to convey.

The icon was launched in February 2012 and was equally well received by our supporters:

**"I like it. Very simple. Positive, lively and effective."**  
*Jane Gyamfi-Sarkodie*

**"I really love the new icon, feels really positive."**  
*Louise Clayton*

**"Feels positive and energetic."**  
*Malcolm Robinson*

**"Love it!"**  
*Julia Wise*

**"Fantastic!"**  
*Sharon Solomon*

We had showed it to some CC medics, too, for their thoughts, and a couple actually said it put them in mind of bile ducts... so it seems it's all in the eye of the beholder!

We feel AMMF's very own icon works well, as we hoped it would, and is helping to cement the charity's individual identity.



# Our CC Family

At AMMF, we believe that, just like in any family, there is strength and comfort to be found in sharing experiences, and so a recent new addition to the website is "Our CC Family", an area which works like a family photo pinboard and is for anyone – patient, carer, friend, family member, supporter, fundraiser – whose life has been touched in any way by cholangiocarcinoma.

Our CC Family is a place where photos and messages can be shared. Each image on the main pages opens to a larger image, on its own separate page, and this is where the personal messages are. Those who are happy to share more, to chat or have email contact with others, have a contact symbol on their photo.

We wanted to show that it's real people who are affected by this disease – and give them a chance to share a little of their story. So, have a look, and become part of Our CC Family. We look forward to meeting you.

<http://www.ammf.org.uk/our-cc-family/>



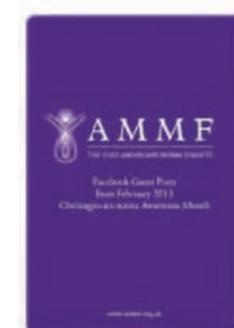
# Awareness Raising

Raising the awareness of cholangiocarcinoma, one of AMMF's core objectives, is increasingly being undertaken by AMMF's supporters, with the website and social media proving invaluable tools in the armoury, too.

## Cholangiocarcinoma Awareness Month

February, designated by AMMF as Cholangiocarcinoma Awareness Month, is now firmly on the annual calendar, and it was especially gratifying in 2013 to see several CC specialists recognising this and putting out articles to coincide with it.

Many thanks go out to our supporters brave enough to speak to local radio stations and the press during Awareness Month, and to AMMF's Sarah Eden who works tirelessly firing off press releases, and setting up interviews across the UK. And, of course, could there be anything more powerful to raise the awareness of cholangiocarcinoma than the incredible



personal stories that appeared as Guest Posts, one of the daily features during February on AMMF's active Facebook page.

February 2013's inspirational Guest Posts, collated and available on AMMF's website.

## Cholangiocarcinoma appears in Holby City...

In early March 2013, just after February's Awareness Month, Holby City's storyline included a patient with cholangiocarcinoma, which raised a fair bit of interest amongst us all at the time.

It was a one episode wonder (well, one and a half) with a situation that was verging on the improbable, and symptoms, path to diagnosis and MDT meetings that were certainly far removed from most people's experiences.

From AMMF's point of view, it was disappointing that the researchers neglected to research the facts more fully, because it would have been such a golden opportunity for awareness raising.

However, as commented by Professor Simon Taylor-Robinson of Imperial College London, "Medical dramas are rarely correct, but it is a step in the right direction!"

For a full report on the not altogether satisfactory feedback we received from the BBC, see the website – Latest News section or search for Holby City.



# Our Grants Portfolio

In line with one of our major objectives, to encourage and support specialised research into cholangiocarcinoma, AMMF is currently supporting CC research teams in a variety of areas: at the Institute of Hepatology, Imperial College London, and at the Cambridge Research Institute.

## The Institute of Hepatology (Foundation for Liver Research)

AMMF has 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."



Dr Salvatore Papa and his team.

## Imperial College London

Over many years AMMF has been involved with the CC research work at Imperial College London. The most recent grants given were:

- **£63,904** given over two years to fund the CC proteomics and genetics work of Research Fellow, Dr Abigail Zabron.
- **£2,000** for consumables on Dr Chris Wadworth's biliary imaging work.
- **£29,758** towards funding the work of Dr Simon Ralphs, who is collaborating with Thailand on the ongoing CC urinary biomarker work.

## Cambridge Research Institute

A grant of **£5,000** was given specifically to fund Dr Hayley Whitaker's work on the biomarker BI-101, a novel protein for diagnosing cholangiocarcinoma and monitoring response to treatment.



Dr Hayley Whitaker.

More information on the work of the research teams AMMF is helping to support can be found on our website: [www.ammf.org.uk/grants-for-research](http://www.ammf.org.uk/grants-for-research)

# The Thai connection

In June, AMMF's Helen Morement was invited to Imperial College to give a presentation on the work of the charity to a group of visiting Thai cholangiocarcinoma experts. Their visit was to finalise the setting up of a formal research collaboration between Khon Kaen University in Thailand and Imperial College London.

Thailand has the highest incidence of cholangiocarcinoma, and it is hoped that this collaboration will prove useful to both sides.

As a result of this presentation, Helen has now been invited to attend the 3 day international workshop being held in Khon Kaen, Thailand, in March 2014 to talk again about the work of AMMF. (This event is fully funded by the British Council.)



**Photo shows: Men – left to right:** 1. Prof Witoon Prasertcharoensuk, 2. Prof Paiboon Sithithaworn, 3. Prof Narong Kuntikeo, 4. Prof Weerachai Kosuwon, 5. Prof Pisake Lumbiganon, 6. Dr Simon Ralphs – Imperial, 7. Prof Simon Taylor-Robinson – Imperial, 8. Prof Ross Andrews – Imperial, 9. Dr Shahid Khan – Imperial  
**Ladies – left to right:** 1. Prof Sopit Wongkham, 2. Mrs Duangsamorn Chankwang, 3. Prof Nittaya Chamadol, 4. Helen Morement – AMMF, 5. Dr Abigail Zabron – Imperial (AMMF's Research Fellow)



## Out and about...



### Imperial College London research update, March 2013

AMMF and the Imperial Cholangiocarcinoma Research Team – l to r: AMMF Trustee Harry Corrigan, Professor Simon Taylor-Robinson, Dr Verena Horneffer van der Sluis, Dr Shahid Khan, AMMF's Helen Morement, Dr Chris Wadsworth, Dr Abigail Zabron, Dr Simon Ralphs, Dr Nimzing Ladep

### Aintree Hospital, Liverpool, June 2013

Aintree CC Patient Support Group launch. Below, back row, left to right, CNS Claire Burston, Mike, Michelle, Jim, AMMF's Helen Morement, Dr Clare Byrne. Front row, left to right, Beryl, Sylvia, Mary



Above: AMMF's Helen Morement with Professor Dan Palmer (l) and Mr Hassan Malik (r)

### Institute of Hepatology, London, research update, June 2013

Left to right: Dr Shilpa Chokshi, AMMF's Helen Morement, Dr Marco Briones-Orta, Gemma Choy (PhD student), Dr Salvatore Papa, Dr Wing-Kin Syn



### The Christie and The Paterson Institute, Manchester, May 2012

AMMF's Helen Morement and Liz Heywood with Professor Juan Valle



## AMMF's external activities

The charity is now becoming recognised nationally, both amongst the general public and within medical circles.

- AMMF was asked to participate in the complete revision of the "Guidelines for the Diagnosis and Treatment of Cholangiocarcinoma in the UK", which was undertaken by a group of leading specialists and published in the prestigious medical journal, GUT, in August 2012. The Guidelines now are available on AMMF's website.
- **Cancer Research UK** asked AMMF to review the new section for bile duct cancer on their patient information website, CancerHelp UK. An enormous task, as much of the prepared information had been taken from out of date sources. Over a year later the site is finally live and most of AMMF's comments (but not all!) have been acted on. AMMF's work is acknowledged on the site, and the charity is listed as a resource.
- AMMF was asked to submit information on its research spend to the **NCRI (National Cancer Research Institute)** who, working with Cancer52, have prepared an analysis of the research spend in the rarer cancers during 2012. This is the first report of its kind, and it is hoped it will provide a base line for the future. (Copies of the report, "Research into less common cancers", are available from AMMF.)



- As a member of the **NCRI 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 cholangiocarcinoma. 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.

- AMMF is an active member of **Cancer52** – the umbrella organization providing "the common voice for less common cancers". Through Cancer52, AMMF has a presence and a voice within every national cancer initiative, which is increasingly important, not least because of the rapidly changing face of the NHS.



- Early in 2013, AMMF was asked to become involved in the first stages of **The Saatchi Initiative**, now known as the **Saatchi Bill**. Despite various hurdles, the Bill has had its 2nd reading in Westminster and with the backing of Health Secretary, Jeremy Hunt, is now going forward to full consultation in early 2014. (More information on the Saatchi Bill can be found on AMMF's website.)

(For info – NCRI, The National Cancer Research Institute is a UK-wide partnership between the government, charity and industry which promotes co-operation in cancer research among the 22 member organisations for the benefit of patients, the public and the scientific community.)

## In Memory...

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

We have recently seen a marked increase in the amount 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 recognise 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.

**The following are the names of loved ones lost to cholangiocarcinoma over the last two years, and in whose memory AMMF has received donations...**



<u>Lisa Alam</u>	<u>Mary Foster</u>	<u>Peter Lamb</u>	<u>Steve Selwood</u>
<u>Charles Apps</u>	<u>Chris Goodfellow</u>	<u>Susan Maxwell-Keys</u>	<u>Kathleen Smith Falconer</u>
<u>Rosa Baldacchino</u>	<u>Brig Gorman</u>	<u>Derick McRobert</u>	<u>Linda Stanley</u>
<u>Anthony Ballard</u>	<u>Doris Gower</u>	<u>Stephen Miller</u>	<u>John Swail</u>
<u>Jacky Barrow</u>	<u>JJ Greene</u>	<u>Louise Nearney</u>	<u>Margaret Taylor</u>
<u>Barry Blackwell</u>	<u>David Grundy</u>	<u>Peter Odell</u>	<u>Michael Toms</u>
<u>Grant Blair</u>	<u>Douglas Harding</u>	<u>Bernard O'Neill</u>	<u>Colin Tong</u>
<u>Alan Bradburn</u>	<u>David Harris</u>	<u>Ron Palmer</u>	<u>Phyllis Tropia</u>
<u>Michael Chapman</u>	<u>Doug Harris</u>	<u>Nikki Petrie</u>	<u>Pauline Trotman</u>
<u>David Chumley</u>	<u>John Hepworth</u>	<u>Anna Philpott</u>	<u>Mary Tuttsell</u>
<u>Michael Cianchetta</u>	<u>David Hetherington</u>	<u>Jack Price</u>	<u>Marie Davine Weston</u>
<u>Chris Clark</u>	<u>Donal Hollywood</u>	<u>Derek Rankin</u>	<u>Jill White</u>
<u>James Daniels</u>	<u>Chris Jackson</u>	<u>Adam Reay</u>	<u>Susan Whitfield</u>
<u>Jonny Dunhill</u>	<u>Vera Jones</u>	<u>Rita Reynolds</u>	<u>Paul Wilkinson</u>
<u>Kelly Eastwood</u>	<u>Judi Kidd</u>	<u>Nigel Robinson</u>	<u>Melanie Wisbey</u>
<u>John Ferguson</u>	<u>Matti Kuorehjarvi</u>	<u>Patrick Secular</u>	<u>Susan Wise</u>



Barry Blackwell with his wife Sandi.



Susan Wise with her sister Julia (r).



Chris Jackson with his wife, Nicki.



Kelly Eastwood with her husband Jason and their children.

## 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 cancer arising in the liver. 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.

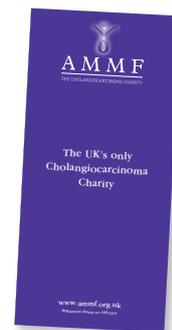
Over recent years an enormous and extremely worrying worldwide increase in CC's incidence has been noted. Latest figures show CC causes over 1800 deaths each year in the UK alone (CRUK 2009), and the incidence appears to be increasing across all age groups, including younger people. The cause of this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

## 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.

## Thank you for your support...

We are extremely grateful for each and every donation we receive – 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 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)

### Donations by cheque

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

**All cheques should be made 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.

*giftaid it*

### Donations by kind

Offers of help can be really valuable to the charity, anything from items for auction or raffle prizes to services such as printing, supplying sportswear, or volunteering. Please email us with your offer of help.



## Contact details

**AMMF** Ambrose Cottage Oxen End  
Little Bardfield Essex CM7 4PR UK  
T: **01371 811811** E: [info@ammf.org.uk](mailto:info@ammf.org.uk)  
W: [www.ammf.org.uk](http://www.ammf.org.uk)

## AMMF's Website

Details on all AMMF's events, past and future, plus latest news, helpful links and contacts, and a wealth of information on cholangiocarcinoma can be found on the website, [www.ammf.org.uk](http://www.ammf.org.uk)

## 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)