



NEWSLETTER

Issue 5 - July to September 2021



Welcome to the
ANNIVERSARY EDITION
of the

INOCA International Newsletter

As always, our sincere thanks go to our Medical Advisory Board Members, our INOCA International Associates, to the healthcare professionals, patients, families, friends and so very many others, for the ongoing and very much appreciated help and support in producing our INOCA international newsletter.

INOCA INTERNATIONAL



Myocardial Ischaemia is a multifactorial, complex and dynamic syndrome. It can change quickly and can have multiple (and even changing) precipitating mechanisms. We currently know how to test for just a few of these mechanisms, but it is possible that there are many more mechanisms not yet discovered or not yet fully understood, so this is very much a developing and evolving area of medicine.

The lack of knowledge and understanding can be frustrating at times for patients and health care professionals alike. This is however also an extremely exciting time too, as we continue to face and overcome new frontiers in the many mechanisms of Myocardial Ischaemia. We are currently witnessing a growing interest and awareness in INOCA conditions and we very much look forward to encouraging and supporting this interest even further, in the months and years to come.

This year has been a particularly difficult one for so many and our hearts go out to all those who have lost loved ones and to those who are struggling with the long term effects of COVID-19. We are eternally indebted to our NHS and to our incredibly brave doctors, nurses and health care professionals around the world, who have held the hands of our loved ones when we could not and who have fought so tirelessly, even in the midst of extreme exhaustion and despair, for the dignity of every single patient in their care.

To INOCA International you are ALL heroes, so to each and every one of you we say -



"THANK YOU"

for being there for all of us and for all our loved ones too.





NEWSLETTER

1st Anniversary Edition



ISSUE 5 July - September 2021

INOCA WEBSITE

It has been a busy few months on the INOCA International website!

INOCA MATTERS This is where we share videos of interviews with specially invited guests. Since our last newsletter we have had the pleasure of interviewing 4 more amazing guests!



PROFESSOR
EVA PRESCOTT



PROFESSOR
MARIO MARZILLI



DR ALAIDE
CHIEFFO



DR TINA
PEERS

INOCA International are incredibly fortunate to have the involvement and support of our outstanding Medical Advisory Board, our INOCA Associates and additional Medical and Health Care Professionals around the world, who give their time freely to help raise awareness of INOCA conditions to help improve care for patients. So, the first Thank You of this Newsletter goes to all those Professionals around the world, who continue to help and support INOCA International and whose generous commitment and dedication make the work of INOCA International possible. Thank You!

All INOCA International videos can be viewed free of charge on our website at www.INOCAInternational.com

EUROPEAN HEART JOURNAL



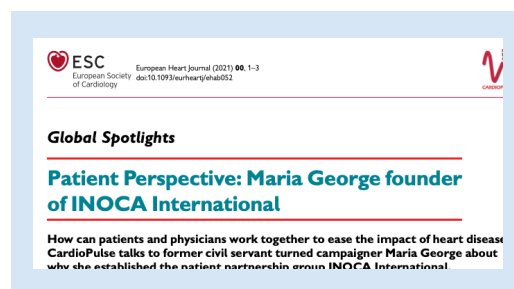
Raising Awareness, Furthering Education, Improving Patient Care

INOCA International were delighted to be invited for interview by The European Heart Journal - the flagship journal of The European Society of Cardiology.

It was such a great honour to have the interview published in this prestigious Journal and to have the INOCA International voice heard far and wide! This is just one example of how The European Society of Cardiology is leading the field and continuing their mission to reduce the burden of cardiovascular disease.

Our thanks go to all those involved in bringing this interview to publication, helping to raise awareness and further education of INOCA conditions. To read the interview please click on the link below (best viewed via the pdf option).

[Read the INOCA Interview with The European Heart Journal by clicking here](#)



CONNECT WITH US

www.INOCAInternational.com
(or use the QR Code above right)

For our Facebook Information Page
<https://www.facebook.com/groups/491395198372627>

We also have a Twitter page
<https://twitter.com/InocalInternatitl>

FEATURED ARTICLES

INOCA TRILOGY

Defining the Condition

THE (R)EVOLUTION OF CARDIOLOGY 2021

Professor Mario Marzilli

THE POWER OF PURPLE

Dr Ailsa Care

RESEARCH



Medical Advisory Board member Dr Ranil De Silva and his team at The Royal Brompton, London have been successful in applying for funding from The British Heart Foundation for a new study into a procedure it is hoped will help to improve symptoms for patients with CMVD. It is a significant achievement to be granted funding in amidst COVID-19. Congratulations to Dr DeSilva and to all the team at RBH!

N.B. Nothing in this newsletter should be considered in any way as advice or recommendation. All information contained in this newsletter is an opinion only and is shared here only in the hope that it is of interest to other patients and medical professionals. Always consult your own medical practitioner before trying any new medications or therapies and before changing any of your current routines.



THE INOCA TRILOGY

The 3 part series talking about INOCA conditions

Part 1 - 'DEFINING THE CONDITION'



INOCA stands for Ischaemia with Non Obstructed Coronary Arteries and encompasses a very important classification of heart diseases as approximately 50% of patients with symptoms of Ischaemia have clear coronary arteries. Ischaemia is caused by reduced blood flow to the heart and in the absence of obstructed coronary arteries it is important to understand why this happens. Some of these conditions can be interlinked and it is not uncommon for patients to suffer from more than one INOCA condition or to have other non-INOCA cardiac conditions also.



CORONARY MICROVASCULAR DISEASE

Microvascular diseases are chronic conditions caused by malfunction and/or abnormality of the coronary microvessels. The coronary microcirculation has a fundamental role in the regulation of coronary blood flow in response to cardiac oxygen requirements. Impairment of these can result in an increased risk of adverse cardiovascular clinical outcomes. It should be noted that there are a number of underlying mechanisms of Coronary Microvascular disease and distinguishing between these is vital to be able to offer the optimal management regime. This area of coronary pathophysiology is still far from being fully understood.

a) CORONARY MICROVASCULAR DYSFUNCTION

This is the abnormal dilation of the small blood vessels in the heart. Normally when there is an increased oxygen demand the micro-vessels in the heart expand to meet this need. However, in the case of Coronary Microvascular Dysfunction this does not happen as the vessels either do not expand at all, or do not expand sufficiently. This can be because the vessels are normal to begin with but are unable to expand as necessary or because the vessels are already expanded to begin with so cannot expand further when required. The heart is unable to meet the increased oxygen demand so symptoms of Microvascular Angina will be experienced when increased energy is needed e.g. for exercise, work, physical or mental stress etc.

The coronary microcirculation is responsible for adjusting myocardial blood flow to the myocardial cells energy needs, independently from arterial pressure. The coronary microcirculation not only modulates the volume of the coronary blood flow, it also modulates the distribution of coronary flow to the layers of the left ventricular wall, according to regional variation in energy needs.

Dysfunction of this key segment of the coronary vasculature may be global or regional, may be transient or persistent and may or may not be associated with structural changes occurring in microvessels, the heart wall and beyond.

Clinically microvascular dysfunction may manifest with inadequate vasodilation resulting in reduced coronary blood flow reserve, as inappropriate vasodilation, or as excess vasoconstriction and more.

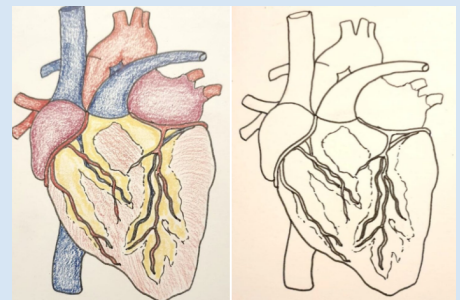
The regulation of myocardial perfusion and the matching of regional perfusion to regional contractile function can be both complex and fascinating!

b) CORONARY MICROVASCULAR SPASM

This is a functional abnormality where the micro-vessels go into spasm, causing reduced blood flow and oxygenation of the heart, which leads to symptoms of Microvascular Angina. This type of Coronary Microvascular Dysfunction can occur at any time & often occurs at rest. The symptoms can last for much longer than with traditional Coronary Artery Disease & are sometimes not relieved by rest.

c) HYPERSENSITIVE HEART SYNDROME

This is a condition where the neural messaging between the heart & the brain are impaired. This results in increased cardiac pain sensitivity which can contribute to determining the symptom severity experienced.



INOCA TRILOGY - Part 1 - continued

CORONARY ARTERY SPASM

Coronary Artery Spasm is a chronic condition where there is a sudden narrowing of a coronary artery which supplies blood and oxygen to the heart. When the larger arteries spasm this can result in cardiac ischaemia and angina. Spasms can occur in just one part of the vessel and are usually brief.

However, if the spasm lasts long enough, it can lead to a heart attack or arrhythmia. Microvascular Spasm, Coronary Artery Spasm can occur at any time, and can often occur at rest.

HEART FAILURE WITH PRESERVED EJECTION FRACTION

Heart Failure with Preserved Ejection Fraction (HFpEF) is a chronic condition which results when the heart pumps normally but is stiffer than it should be. This means that the heart is unable to supply blood to the body at a rate to compensate for its needs. It may be linked to Coronary Microvascular Disease but has very different symptoms. Symptoms of HFpEF are similar to those of traditional Chronic Heart Failure e.g. Fatigue, Weakness, Dyspnea, Fluid Retention etc. However, unlike traditional Chronic Heart Failure, in the case of HFpEF patients have a left ventricular ejection fraction that is not markedly abnormal. HFpEF is associated with the same adverse cardiac outcomes as traditional Chronic Heart Failure.

INOCA

Ischaemia **N**ot due to atherosclerotic
Obstructions of the **C**oronary **A**rteries

TAKOTSUBO SYNDROME

Takotsubo Syndrome is an acute condition. It is a sudden onset myocardial injury in which the left ventricle changes shape, enlarges and loses some of its function. It presents very much like a myocardial infarction (a traditional heart attack) and is a life-threatening medical emergency. There are a number of known underlying triggers for example, emotional stress, physical stress, underlying medical conditions, medications or procedures and neurological disorders. However, in a substantial number of cases there is no identifiable trigger.

For many patients this is a reversible condition where heart function returns to normal within weeks. However, others can be left with long term cardiac damage when the condition can become chronic with persistent symptoms. Although not common, some patients can also go on to suffer further Takotsubo events in the future.

MYOCARDIAL INFARCTION WITH NO OBSTRUCTED CORONARY ARTERIES

Often referred to as MINOCA, this is an acute condition which is a medical emergency. It is a sudden onset heart attack in which there is damage to the heart muscle. This happens in the case of MINOCA with clear coronary arteries. There can sometimes be serious structural causes, for example coronary thrombosis or embolism or spontaneous coronary artery dissection. MINOCA can also be caused by an INOCA condition (many of which are outlined above).

The above outlines just some of the most common INOCA Conditions as this is an area of Cardiology which is constantly being updated.

INOCA TRILOGY (Part 2)

The next part in our INOCA TRILOGY series will focus on the various diagnostic tests available for INOCA.

LIVE CHAT WITH DR TINA PEERS



INOCA International were delighted to welcome Dr Tina Peers to our INOCA Live Chat. Dr Peers treats patients with MCAS

Histamine Intolerance and Long Covid and has also been interviewed for the INOCA MATTERS series. The Live Chat with Dr Peers was very well attended with lots of discussion and lots of patient questions answered from the Live Chat too!

In the words of just one of the attendees 'This was such an amazing meeting and helped so much in explaining MCAS!'

Thank You Dr Peers!

PATIENT LIVE CHAT

Our next LIVE CHAT is with INOCA patient, Stephen Miller. Stephen has had INOCA for many years and will share first-hand some of the things which he has experienced. The meeting will take place on Tuesday 13th July at 7PM (GMT). If you would like to attend the Live Chat and Q&A session with Stephen, please contact us via the link below. Please share this widely with any friends, family and colleagues who may be interested in attending!

<https://www.inocainternational.com/contact-form/>

N.B. Nothing in this newsletter should be considered in any way as advice or recommendation. All information contained in this newsletter is an opinion only and is shared here only in the hope that it is of interest to other patients and medical professionals. Always consult your own medical practitioner before trying any new medications or therapies and before changing any of your current routines.



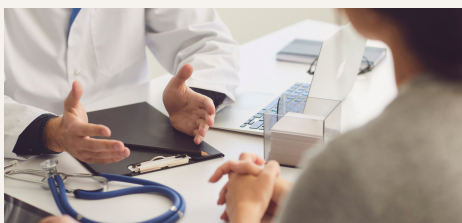
THE (R)EVOLUTION OF CARDIOLOGY 2021

Featured article from
Professor Mario Marzilli

Ischaemic Heart Disease (IHD) remains the leading cause of death in industrialised countries despite continued efforts and huge investments to reduce mortality and morbidities. This sober balance is, at least in part, due to a gap in knowledge.

Traditionally the approach to diagnosis and treatment of IHD has been dictated by the assumption that myocardial ischaemia is closely linked to coronary atherosclerotic obstructions. As a result, research and management have been focused on the identification and removal of these obstructions.

Technological advances have made both the visualisation of coronary stenosis and the performing of coronary recanalization, relatively easy. A number of invasive and non invasive techniques are available today to search for coronary obstructions and to accurately assess their location, severity, and nature. Once the obstruction has been diagnosed, removal is, in most cases, straightforward for the experienced interventional Cardiologists and represents an almost irresistible temptation. No surprise then if these diagnostic and therapeutic opportunities have fuelled great expectations in both doctors and patients alike.



Unfortunately, these expectations do not seem to have been confirmed by current scientific evidence as a number of prospective randomised large clinical trials have failed to prove a survival benefit in patients with chronic IHD undergoing coronary revascularization on top of medical therapy. The latest guidelines of the European Society of Cardiology offer a convincing explanation for these disappointing results: myocardial ischemia is not so closely linked to coronary atherosclerotic obstruction as traditionally thought, but may be precipitated by a number of mechanisms

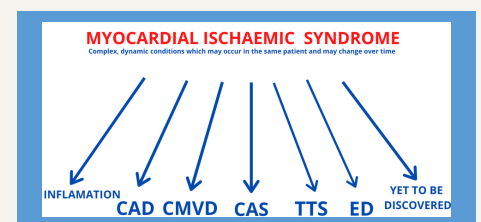
Based on this new understanding of the pathophysiology of myocardial ischemia the Guidelines recommend a change in terminology, proposing to refer to this condition as a "syndrome" and no longer as a "disease" .

According to Wikipedia a syndrome is "**a collection of symptoms and findings without necessarily tying them to a single identifiable pathogenesis**".

The Guidelines offer a list of possible pathogenetic mechanisms, including coronary stenosis, coronary vessel vasospasm and microvascular dysfunction. The Guidelines also go further, reporting that coronary atherosclerotic obstructions are present in only a minority of patients experiencing typical angina pectoris: 30% of male patients and 13% of female patients in the age range 50–59 years. The implication appears to be that in most patients angina is not associated with atherosclerotic obstructions.

This message demands dramatic changes in the management of chronic ischaemic syndromes. So far, diagnosis and treatment of chronic myocardial ischaemia were focused on assessing the presence of a stenosis and removing it. From now on, the focus should be in assessing the presence, extent and severity of myocardial ischemia and identifying which, among the many possible mechanisms, is the responsible one in that specific patient, but there are several obstacles which might potentially slow down the transfer of this new conception from Guideline to clinical practice.

There is an understandable reluctance in Doctors and in patients in admitting that a strategy proclaimed as effective and safe for decades may not be the best choice in their particular circumstances. But there is also a paucity of scientific data. In much of the research, studies and trials, angina patients have been dumped together with no consideration of the precipitating mechanisms. For instance, some evidence does exist on the superiority of Calcium Channel Blockers over β -blockers in the treatment of vasospastic angina, but the best treatment for microvascular angina has yet to be identified.



N.B. Nothing in this newsletter should be considered in any way as advice or recommendation. All information contained in this newsletter is an opinion only and is shared here only in the hope that it is of interest to other patients and medical professionals. Always consult your own medical practitioner before trying any new medications or therapies and before changing any of your current routines.



THE (R)EVOLUTION OF CARDIOLOGY 2021

Featured article from

Professor Mario Marzilli

(Continued)

Unfortunately, one of the major negative effects of the enthusiasm for percutaneous coronary revascularization has been the message, repeated in articles, congresses and webinars, that the problem of angina pectoris was a solved problem. This illusion has discouraged studies and research on new antianginal agents. In the last two decades, a number of new stents and new devices have been commercialised, but no new drug has been registered.

The Cardiological community has to face an incredible challenge: the list of the mechanisms that can possibly precipitate myocardial ischemia is far from being complete and, for each mechanism, the most appropriate diagnostic tools and the most effective treatment must be identified.

Once the simplistic dogma of the “hydraulic” conception of myocardial ischaemia is abandoned, an era of exciting opportunities will open up for Cardiologists and patients: the era of the tailored management of chronic myocardial ischemic syndromes.

To reach this goal intensive research will be needed to identify all the possible precipitating mechanisms, to find appropriate stressors to confirm their role and to test new or old drugs in homogeneous groups of angina patients. Time and huge resources will be needed.

The ESC Guidelines on chronic ischaemic syndromes were published shortly before the burst of the COVID pandemic that has disrupted the practice of Cardiology world wide. As soon as this tsunami is over, Cardiologists will have to concentrate on how to translate the new conception of myocardial ischaemia into appropriate diagnostic protocols and effective therapeutic choices.

One-to-one conversations with specially invited guests



Professor Marzilli has very kindly recorded a 2 part interview with INOCA International. Professor Marzilli’s interview will be uploaded to the INOCA MATTERS page of the INOCA International website at www.inocainternational.com/inoca-matters/



Advocating for yourself can be one of the most difficult things to do, especially if you are in pain or in a situation where there is a lack of understanding about your condition. It is important however, that in exactly those kinds of circumstances, patients are able to find a way to to explain their condition and their symptoms in as clear and calm a manner as possible. This can be very much easier said than done when a patient finds themselves in a stressful situation or in a place where they are being disbelieved or dismissed.

In our next Newsletter, one of the things we will be looking at are some of the different ways in which we can advocate for ourselves and some of the tools we can use to help us do this in the most effective way possible.

We often hear it said that those who shout loudest get their voices heard, but to hear a voice is one thing, to hear it, understand it, empathise with the problem and want to do everything possible to help, is another thing entirely!

COMMUNICATION

N.B. Nothing in this newsletter should be considered in any way as advice or recommendation. All information contained in this newsletter is an opinion only and is shared here only in the hope that it is of interest to other patients and medical professionals. Always consult your own medical practitioner before trying any new medications or therapies and before changing any of your current routines.



In her regular GP spot, Dr Ailsa Care talks to us about 'The Power of Purple'



It is common knowledge, and there is plenty of research evidence, for the health benefits associated with eating a varied 'rainbow' of vegetables and fruits.

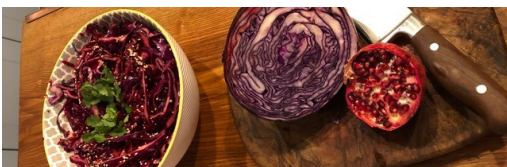
The different colours all contain a number of plant chemicals called phytonutrients that together support our ability to fight infections and cancer, support a healthy heart, liver, kidneys, brain, reduce inflammation and more.

A study in 2009 showed that 8 out of 10 people had a "phytonutrient gap" meaning they were not eating the full range of food colours resulting in implications for their health. Purple is one of the colours that is most often missing from our plates, particularly the savoury dishes.

Purple, blue and black colour pigments contain a group of phytonutrients like anthocyanins, resveratrol, chlorogenic acid which have anti-oxidant, anti-inflammatory and immune supporting benefits.

Some of the cardiovascular benefits are that these phytonutrients protect the inner lining of blood vessels from damage and relax vessel walls resulting in reduced pressure i.e they help to lower blood pressure.

Brain benefits are in part due to anthocyanins which cross the blood brain barrier to exert their benefits on brain cells. Blueberries and strawberries contain pigments which reduce inflammation and inhibit DNA damage resulting in reduced risk of cognitive decline and improved memory. Berries contain resveratrol and quercetin which are beneficial for the production of brain derived neurotrophic factor (BDNF) which is involved in the survival and maintenance of nerve cells.



Purple foods to consider:

- dark berries like blueberries, blackberries, purple grapes, cherries
- other fruits - plums, prunes, figs
- purple cabbage, purple broccoli, purple carrots, purple potatoes, purple sweet potatoes, purple cauliflower, beetroot, aubergine, black olives, purple fries cheese beans, radishes, purple kale
- black or purple rice

Tips for including more purple foods:

- keep a variety of frozen berries in the freezer for convenience to add to smoothies, make a healthy chia jam or fruit compote.
- add berries to a smoothie
- add berries to yoghurt and serve with porridge or pancakes
- try purple kale instead of green
- shred some purple cabbage into a salad
- add some grated beetroot to a salad
- make beetroot burgers
- substitute purple or black rice for white rice



Here are a couple of recipes to get you started. Please do let us know the ways you have found to include more purple power!

Purple Power Salad

Inspired by a recipe from The Medicinal Chef Dale Pinnock (Serves 2)

- 1/4 red cabbage, finely shredded or grated
- 1/2 red onion, finely chopped
- 1 large beetroot, grated
- 1/2 pomegranate deseeded
- 2 tbsp flax oil
(or hemp oil or extra virgin olive oil)
- 1 tsp honey
- 1 tsp balsamic vinegar
- 1 clove garlic
- 1 tsp toasted sesame seeds
- Sea salt and black pepper to taste
- Fresh herbs to garnish

Mix the shredded/grated/chopped vegetables in a large serving bowl.

Combine the dressing ingredients in a small bowl or blend together in a blender.

Pour over the salad and mix well.

Sprinkle with toasted sesame seeds and garnish with your choice of fresh herbs.

Purple Power Smoothie

The amounts and ingredients are not crucial, you can vary what goes in depending on the season and what you have available. I used:

- A handful of mixed berries
(can be fresh or frozen)
- A chopped fresh beetroot
- A chunk of purple cabbage
- 100ml coconut kefir (could also be natural yoghurt or dairy kefir)
- 250ml non-dairy milk
- 2 scoops of collagen powder

Simply whizz all the ingredients in your blender and it's ready to drink!

N.B. Nothing in this newsletter should be considered in any way as advice or recommendation. All information contained in this newsletter is an opinion only and is shared here only in the hope that it is of interest to other patients and medical professionals. Always consult your own medical practitioner before trying any new medications or therapies and before changing any of your current routines.

Donations and Fundraising

All funds raised by patients via the GoFundMe crowdsourcing page go towards covering the costs of the Meeting of Minds. They also cover other costs such as website hosting. Donations into the fund are managed entirely by GOFUNDME who keep a strict record of all monies paid into the fund, providing an independent audit trail of all monies received.

No member of the INOCA team, the INOCA International Medical Advisory Board or INOCA Associates are paid.

If you feel that INOCA International has helped you, please consider making a donation (which can be done anonymously if you prefer), so we can continue to help others and to raise awareness and further education in INOCA conditions worldwide.

<https://gofund.me/a03141bf>



Below is a photo from one of the recent patient fundraisers. This is Helen, who won first prize at the Easter Bonnet parade!



INOCA INSIGHTS

We are delighted to have been able to add a further 4 patient video stories to the INOCA INSIGHTS page on our website. We are sincerely grateful to Stephen, Cathy, Lisa and Lucy who all very kindly shared their stories to help understanding of INOCA conditions.



The next patient video in our INOCA INSIGHTS series is from Hazel. Hazel lives on the Island of Gibraltar and has had INOCA for around 10 years.

JUST FOR FUN

There are 14 words relating to INOCA hidden in the word search below.

Can you find them?

H	P	M	V	T	J	G	P	A	N	G	I	N	A	A
A	A	G	I	V	A	S	O	S	P	A	S	M	U	V
A	D	C	I	C	A	H	Z	K	H	B	Z	O	I	A
F	W	E	E	O	R	R	E	E	B	E	B	A	C	S
V	C	W	N	T	Y	O	T	G	Z	X	L	B	A	O
I	W	O	B	O	Y	S	V	E	F	F	O	O	N	D
E	S	Y	Z	G	S	L	T	A	R	H	O	W	G	I
I	C	C	Y	T	M	I	C	N	S	I	D	I	I	L
Y	N	F	H	C	U	T	N	H	M	C	E	B	O	A
U	D	O	J	A	A	W	A	E	O	S	U	S	G	T
Z	G	P	C	A	E	Y	Z	M	X	L	S	L	R	O
P	A	E	O	A	C	M	J	T	X	C	I	T	A	R
I	Y	T	U	G	Z	J	I	W	W	V	S	N	M	R
T	J	U	F	W	N	O	I	A	E	C	H	O	E	Z
W	J	T	J	D	Y	S	F	U	N	C	T	I	O	N

Did you know...

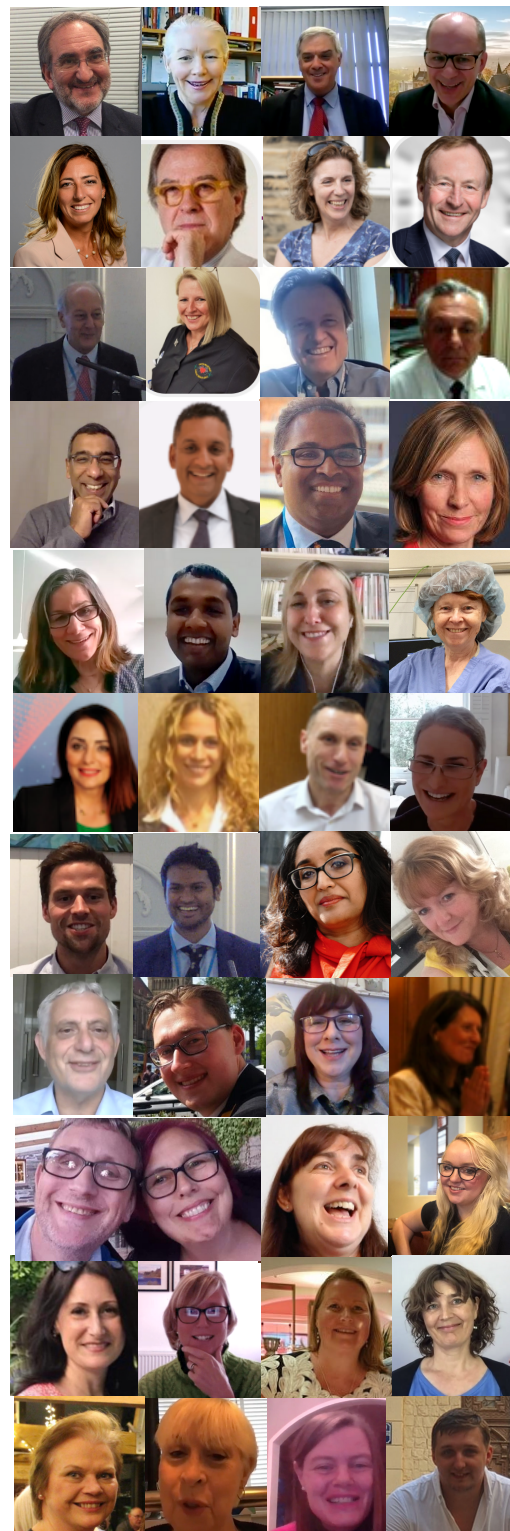
Your heart needs around 5 litres of blood every minute, beats around 100,000 times a day and around 35 million times a year? During an average lifetime, that's more than an amazing 2.5 billion times!

TAKE SPECIAL CARE OF YOUR BODY'S HARD WORKING ENGINE

WHAT A TEAM!

Here are just a few of the truly amazing people it has been our pleasure to work with during this past year. We are looking forward to working with you all further in the year ahead and to arranging our next INOCA International

MEETING OF MINDS!



WORKING TOGETHER, IMPROVING PATIENT CARE

The whole team at INOCA International were very sorry to hear of the recent death of

His Royal Highness Prince Philip

INOCA International wrote to offer our sincerest condolences to Her Majesty and to The Royal Family.

We know that like us, many of you were also very saddened to hear of Prince Phillip's death so we share with you the very kind responses received.

In Memory of HRH Prince Phillip.

