



NEWSLETTER



ISSUE 1 - June - September 2020

WEBSITE LAUNCH

We are delighted to announce the launch of the brand new INOCA International website. The website received over 700 views in the first 24 hours and is receiving superb feedback from Professionals and Patients alike! We have also already added three new doctors to our 'Doctors Treating INOCA' list!



Prof. Juan Carlos Kozak (Spain)
[Click for details](#)



Prof. Noel Bailey (UK)
[Click for details](#)



Prof. John Bellotti
[Click for details](#)



Prof. Colin Berry
[Click for details](#)



Prof. Paolo Carosi
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Dr. Alina Cate
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Prof. Peter Collins
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Prof. Filippo Crea
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Dr. Ashley Davidson
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Prof. Thomas Lüscher
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Prof. Maria Marzilli
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Prof. Diwakar Parasi
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Dr. Rajan Sharma
[Click for details](#)



Dr. Rami De Siva
[Click for details](#)



Dr. Carolyn Webb
[Click for details](#)

MEDICAL ADVISORY BOARD

Our superb Medical Advisory Board comprises some of the leading experts in INOCA. Each member interacts with patients and is also genuinely passionate about raising awareness, furthering education and improving patient care. We are delighted and honoured to partner with these outstanding experts!

The website can be seen at

www.INOCAInternational.com

INOCA International also has a Facebook Information Page here -

www.facebook.com/groups/491395198372627

And a Twitter page here -

[@INOCAInternati](https://twitter.com/INOCAInternati)

MEETING OF MINDS



The date for the next Meeting of Minds has of course been put on hold during COVID, but the work continues. We are looking forward to yet another amazing Meeting of Minds when the time is right!

FUNDRAISING BALL

The date for the Fundraising Ball (organised by the Microvascular Angina Coronary Artery Spasm (Vasospastic) & CMVD Community in support of INOCA International), has also been put on hold during COVID. We also look forward to announcing this new date soon!

DID YOU KNOW...

Did you know that the advice regarding GTN spray is not to wait, but to administer the spray as soon as you start to feel symptoms? Did you also know that angina may not just be felt in your chest but can also be felt in other parts of your body like your jaw, arm upper stomach or upper back?

PATIENT PARTNERSHIP

Our Patient Partnership pdf contains information from 130 patients living with INOCA and is available for free download from the INOCA International website.



CAFE CONVERSATIONS

The INOCA CAFE is a virtual space where members can go to relax and chat. We will soon be launching our brand new 'CAFE CONVERSATIONS'. Once a month we will be hosting a members evening - this might be discussion around a research paper, a Trial or Study, hosting a guest speaker, or perhaps something completely different! If you would like to join us in the INOCA Cafe, please request this via our 'contact us' page at www.INOCAInternational.com



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 medical practitioner before trying any new medications or therapies and before changing any of your current routines.



'The Emperor has no clothes'

Professor Mario Marzilli, Pisa



"Many, many years ago lived an emperor, who thought so much of new clothes that he spent all his money in order to obtain them; his only ambition was to be always well dressed ...". This is how begins a tale written in 1837 by Christian Andersen. The story was about people that deny even the most obvious evidence and pretend not to see what is in front of their eyes just to follow the prevailing trend and for the fear to contradict the 'Emperor'.

Current Cardiology is reminiscent of that old tale, with a diffuse reluctance to accept:

- a.** Lack of prognostic benefit with a routine invasive strategy in patients with chronic ischemic syndromes.
- b.** Persistence of angina in a substantial fraction of patients after stenosis removal.
- c.** Low prevalence of obstructive coronary atherosclerotic lesions in patients with typical angina and/or documented myocardial ischemia.
- d.** High rate of peri- and post-procedural complications of PCI.

This evidence strongly challenges the 'stenocentric' conception of myocardial ischemia and explains why Guidelines recommended, since long ago, to consider revascularization only in patients with angina despite optimal medical therapy and why, more recently, they have officially acknowledged that myocardial ischemia is a complex, multifactorial, dynamic, life long condition. This new understanding of myocardial ischemia has prompted a change in name for this condition: from disease to syndrome.

This new, revolutionary conception offers both challenges and opportunities to Cardiologists and patients as well. Diagnostic, therapeutic, and prognostic processes have all to be reconsidered and redesigned. Detecting an atherosclerotic obstruction can no longer be accepted as a surrogate for diagnosing myocardial ischemia and absence of coronary obstructions should no longer be considered enough to rule out myocardial ischemia. Most recent epidemiologic reports suggest that the probability of a stenosis is lower than 30% in male patients with typical angina and even lower in female patients.

The obvious conclusion of these figures is that typical angina is associated in the majority of patients with non-obstructive mechanisms (INOCA) and that, even when an obstruction is present, other mechanisms may also be present, and be responsible for post-PCI angina. and symptoms of transient myocardial ischemia should be searched and documented for a definite diagnosis. The identification of the mechanism(s) responsible for ischemia in a specific patient is the second step in the management of a patient and is essential to plan a tailored treatment.

These conceptions are not really new. The role of functional mechanisms (vasospasm), the relevance of microvascular function /dysfunction, even the possibility that non-vascular mechanisms may precipitate myocardial ischemia have all been proposed decades ago. Unfortunately, the Cardiology community has reacted with scepticism or overt disbelief, but in the meantime the body of evidence supporting the multifactorial nature of myocardial ischemia has become overwhelming and can no longer be overlooked.

LIVING WITH INOCA

Living with an INOCA condition can be very challenging. Where traditional angina tends to come on as a result of exertion and is usually experienced in the day time, some INOCA conditions can be experienced without any exertion at all and can also come on during the night or in the early morning hours.

PACING. Being aware of the rate at which you do things and of your body's ability to cope with that rate of activity (and slowing down or spreading out your tasks over a longer time period where needed), can sometimes make a noticeable difference to how you can manage your symptoms. Pacing well can also mean you can sometimes achieve more.

KEEPING A DIARY. If you can keep a diary of your activities and symptoms, it can sometimes help to identify triggers and avoid some of the things which trigger or exacerbate the symptoms for you. There are many possible triggers, but coffee, smoking, cold, change of temperature, emotional upset, and excitement are just a few known triggers for INOCA.

MINDFULNESS AND MEDITATION can sometimes help with stress levels and can bring a sense of peace and with it, an increased ability to cope. There are many mindfulness techniques including Thai Chi and Yoga, but a simple quiet time of meditation can also be effective in reducing stress.

MEDICATIONS used for the treatment of INOCA conditions can differ from country to country and sometimes from doctor to doctor. There is currently no cure for CAS or CMVD, but in the care of a medical professional who has expertise in treating INOCA conditions, it is often possible to carefully adjust medications over time to reduce the frequency and severity of acute episodes.



The journey to diagnosis in INOCA conditions can be long and difficult and flare ups can happen for no apparent reason, even when on medication. Raising awareness and furthering education takes time, but people ARE listening. There are also dedicated medical professionals out there, working to bring about a better, clearer, more consistent understanding of INOCA, so don't give up! Together we can make a real difference as we work in partnership to influence change.



You can remove your name from the newsletter list at any time by using the 'Contact Us' page of the website.

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IN THE SPOTLIGHT

From Issue 2 onwards, we will be including a 'Spotlight' section which will focus on a particular topic with input from one of our experts. Issue 2's spotlight is on 'Living with a Chronic Condition'. If there is an area of interest you would like us to cover in a future issue, please get in touch via the 'contact us' page of the website.

QUOTE OF THE DAY



"For the patient, just knowing the cause of the chest pain is helpful, but for the doctor it is even more important. If, as a doctor, I know the cause, I can treat the patient more efficiently"

Professor Filippo Crea

DONATIONS



Funds raised on the GoFundMe page go towards covering the costs of the Meeting of Minds. They also cover other costs such as website hosting. (None of our team are paid). If you feel that INOCA International has helped you in any way, please consider making a small donation so we can continue to raise awareness and further education in INOCA