

A Very Happy New Year!

from everyone at

INOCA INTERNATIONAL



Professor Juan-Carlos Kaski



Professor C. Noel Bairey Merz



Professor John Beltram



Professor Colin Berry



Dr Chiara Bucciarelli-Ducci



Professor Paolo Camio



Dr Ailsa Care



Professor Peter Collins



Professor Filippo Crea



Cardiac Nurse Consultant Ashley

Davidson



Professor Martha Gulati



Professor Thomas Lüscher



Professor Mario Marzilli



Professor Divaka Perera



Dr Rajan Sharma



Professor Hiroaki Shimokawa



Dr Ranil De Silva



Dr Carolyn Webb

2023

A very warm welcome to our first 2023 INOCA International Newsletter!

What an incredibly busy year 2022 was! From the launching of our brand new website, to the re-branding of our Social Media platforms, the creation of numerous free downloads on our website, to our INOCA podcasts and so very much more!

We begin our 2023 New Year's newsletter with a heartfelt thank you to all our Medical Advisory Board and Management Team members who so very generously contribute to our many projects throughout the year, because without each of you and the generous support you give, none of our amazing work would be possible!

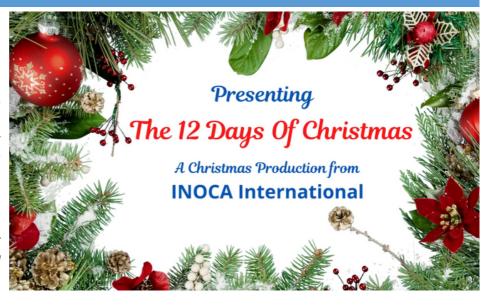
Did you see the specially recorded videos for our INOCA International 12 Days of Christmas?

We were delighted to end 2022 with the launch of our INOCA International 12 Days of Christmas – 12 daily posts following the INOCA patient journey – all sung just a little bit differently!

We so enjoyed bringing this together and very much hope it brought a deeper sense of understanding to some of the most commonly asked and important questions about INOCA – and also brought a few smiles to faces too!

If you haven't seen the video series yet, you can catch up on them all on the links opposite. (Remember to look out for our special guest appearances along the way and maybe keep an eye on the singer's daily outfit too!)

A huge Thank you goes to all the patients, doctors, Medical Advisory Board and Management Team members who so very kindly took time out of very busy schedules in the lead up to Christmas, to contribute to our 2022 Christmas Messages.



inocainternational.com/our-2022-christmas-video-messages

Twitter - https://twitter.com/InocaInternati1
Facebook -www.facebook.com/groups/491395198372627
Website - www.INOCAInternational.com









Announcing a Brand New project for 2023!

We start off the New Year with some very exciting news!

Not one, but two International surveys - one for patients and one for doctors too!



Management of angina – help us understand patients' needs & expectations!

An international survey to better understand how angina and its management affects patients' lives and what patients expect from doctors

As an angina patient, have you ever felt that you are not being listened to or that your voice is just not being heard?

In Patient forums around the world we often hear that projects should involve both doctors and patients and should be designed in a way that the voices of both are clearly heard and have equal importance. This exciting new project offers exactly this and more!

In early 2022 INOCA International were invited to join **Translational Medicine Academy** to work with them on bringing together a brand new international angina project.

This new project forms part of a worldwide program designed to better understand how angina and its management affects the lives of patients. The project also looks at the existing levels of communication between patient and doctor and at how both of these important areas might perhaps be improved.

As part of this global project, we are delighted to announce the launch of not one, but two carefully designed surveys - one designed specifically for angina patients and one designed specifically for doctors who treat angina.

The patient survey is available in English, Portugese, French, Spanish, Arabic, Hindi, Tamil and Malayalam.

It takes just around 10-15 minutes to complete each of the surveys so we hope that as many doctors and patients as possible will take the time to participate and to help improve understanding and care for angina patients around the world.

Working with TMA on this project continues to be a pleasure and we very much look forward to the insight the results of these surveys will bring!







Management of Angina - understanding the educational needs of healthcare professionals

An international survey to understand how angina & its management affects patients' lives & what patients expect from you

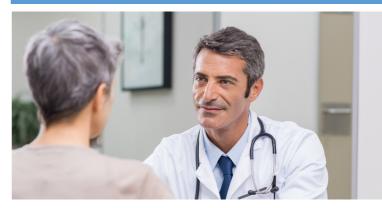
As a doctor treating angina you already know that things are not always straightforward. Each patient can present with very different symptoms and respond very differently to medication and treatment options. Add to this, the variations of presentation in different areas of the world and the often misunderstood and under-diagnosed forms of angina such as INOCA, and the task of the doctor in treating angina can be even more difficult still.

It is often the case that surveys capture the feedback either from patients OR from doctors, but seldom, if ever, is feedback made possible from BOTH doctor AND patient, giving the opportunity of a comprehensive review of both the patient AND doctor experiences and perspectives – until now!

As with the patient survey, the doctor survey will take only around 10-15 minutes to complete, so please take the time to participate, to have your voice heard and to be part of our patient and doctor worldwide conversations on angina!

We ask all our Newsletter readers to please share the surveys with as many patients and doctors as possible so that all voices can be heard!

Come take our surveys and be a part of the worldwide conversation on Angina care!



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 is it 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.

You can access these amazing new surveys on the links below!

International Survey on Patients' Needs and Expectations

Links to Patient Survey on Angina

PACT-ANGINA patient survey - English: https://medsurveys.questionpro.com/t/ATYSFZueOa

PACT-ANGINA patient survey - Portuguese: https://medsurveys.questionpro.com/t/ATYSFZwSFQ

PACT-ANGINA patient survey - Spanish: https://medsurveys.questionpro.com/t/ATYSFZwRGS

PACT-ANGINA patient survey - French: https://medsurveys.questionpro.com/t/ATYSFZwRpq

PACT-ANGINA patient survey - Arabic: https://medsurveys.questionpro.com/t/ATYSFZwFK3

PACT-ANGINA patient survey - Hindi: https://medsurveys.questionpro.com/t/ATYSFZwQtq

PACT-ANGINA patient survey - Tamil: https://medsurveys.questionpro.com/t/ATYSFZwQls

PACT-ANGINA patient survey - Malayalam: https://medsurveys.questionpro.com/t/ATYSFZwFyb

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International Survey on Educational Needs of Healthcare Professionals

Links to Doctor Survey on Angina

PACT-ANGINA healthcare professional survey - English: https://medsurveys.questionpro.com/t/ATYSFZwYLI

PACT-ANGINA healthcare professional survey - Spanish: https://medsurveys.questionpro.com/t/ATYSFZwWgg

PACT-ANGINA healthcare professional survey - Portuguese: https://medsurveys.questionpro.com/t/ATYSFZwWXT

Are you a Doctor treating Angina?

Take our survey to tell us what you need!

The information from these surveys will be used to develop a patient-centered educational program designed by angina experts and patient representatives

The surveys are fully anonymous - no personal data will be collected

Are you an Angina patient?

Take our survey to tell us about your needs and expectations!



LOOKING BACK AT 2022

Sharing just a few of the incredible achievements of the last year

Medical Advisory Board Members

We were delighted to welcome Professor Martha Gulati & Professor Hiroaki Shimokawa to our Medical Advisory Board in 2022. The Professors bring a wealth of INOCA knowledge, experience and expertise to our Advisory Board and very much complement our global reach!





INOCA International Patient Survey

INOCA International were honoured to work in collaboration with **Professor Martha Gulati and Professor C. Noel Bairey Merz** on this fantastic project and we were delighted to see the results of this survey published in the International Journal of Cardiology.

Ischemia with no obstructive coronary artery disease (INOCA): A patient self-report quality of life survey from INOCA International.

The results of the survey were also presented at the **ESC Congress** by Professor Martha Gulati. The results from the survey were described as 'sobering', yet in many ways the results were unsurprising to experts in the field and to INOCA patients themselves.

You can see the full article via the following link. www.internationaljournalofcardiology.com/article/S0167-5273(22)01396-1





INOCA International Podcasts

We launched our podcast series in July Of 2022 and began the series with Professor Juan-Carlos Kaski and Professor Colin Berry.

Our podcasts are made up of easy to digest information available at the most convenient time for you. Whether on your way to work, enjoying a coffee break, sitting on the train, or doing the housework. You can simply choose the episode you want to listen to, tune in and off you go!

We have already aired 5 podcasts providing valuable information from top experts in INOCA conditions and our next podcast airing soon is with **Professor Thomas Lüscher**







You can listen to our INOCA podcasts here https://inocainternational.com/podcasts



World Heart Federation

In 2022, INOCA International became an Associate Member of the World Heart Federation. We are truly honoured to be working with this amazing organisation!

INOCA International had the privilege of working with WHF on their 2022 global campaign to raise awareness of Angina with an INOCA patient being featured in their WHF angina campaign video.

We very much look forward to the many wonderful thing we might achieve together in the future, working in partnership with this superb organisation!

The New INOCA Website

The launch of our brand new website was one of the highlights of 2022.

After many months of work our new look website was released in September and the feedback has been outstanding! The following is just one example of the many lovely comments we received.

"It's FANTASTIC, so user friendly and so interactive too. I didn't think it could be improved, but this has blown me away!" If you haven't visited our new website yet, please click on this link to take a look! www.INOCAInternational.com











Our new website is full of information for both patients and professionals including our INOCA condition summary sheets, videos, podcasts, interviews with experts, patient stories, downloads and much more. There is also an interactive page specifically designed for patients. The page is divided into 8 sections and focuses on one highlighted section at a time. Our current focussed section is on Resting and Pacing, which as you can see in the image below, is highlighted in green on the page.



On this page, INOCA patients from around the world are invited to share the things they themselves found helpful on their own journey. If you are an INOCA patient you may initially feel that you have nothing to share, but it is important to remember that knowledge shared from those who have themselves experienced the journey, can often feel like a lifeline for other INOCA patients who are perhaps newly diagnosed or who might be seeking a diagnosis.



Click on the link to see our brand new Patient Interactive page!

www.inocainternational.com/livinglife-with-inoca

You can also submit your comments, photographs, ideas and suggestions on the current topic by emailing us at LivinglifewithINOCA@Inocainternational.com

SOCIAL MEDIA

We continue to be very active on our Social Media platforms and have a very active following on Twitter and Facebook. Social Media is so very valuable for getting the INOCA message to patients and doctors around the world and our amazing Facebook and Twitter family help us to do this on a daily basis!

So a huge shout-out here to all our amazing Twitter and Facebook followers!



https://twitter.com/Inocalnternatil

GTN SUMMARY SHEET

In response to patient requests for a no nonsense, easy to understand summary sheet on how and when to take fast acting nitrates, we created the next in our series of summary sheets. This is slightly different to our previous sheets, as this includes a hints and tips section from other patients too. There is, as always, an easy read version available too, for anyone who might prefer a more visual reading format. You can view and download all our summary sheets here - www.inocainternational.com/downloads

We have also produced a very short video clip on the use of GTN which may also be of interest –

https://youtube.com/shorts/fVqIATD cg_Q

Please note that nothing in any of our summary sheets should be considered in any way as any form of medical advice or recommendation. These documents are simply summary sheets written in an easy to understand, nontechnical language about using fast acting GTN and include a collection of hints and tips shared by INOCA patients in the hope of helping other INOCA patients.

As with any medication, only take GTN if it has been prescribed for you by your doctor as not all medications are suitable for everyone. Please remember that it is also very important you read the information leaflet that is included with your GTN fast acting medication. This contains important information about precautions, possible side effects and more. You can also ask your Doctor, Pharmacist, or care team if you need more information.

ACKNOWLEDGEMENTS

These are just a few of the things we were able to achieve in 2022.

Please remember as always, that none of these amazing achievements would have been possible without the ongoing support and encouragement of our fellow patients, our followers, our superb Medical Advisory Board and the INOCA International management team who continue to work tirelessly behind the scenes for the benefit of INOCA patients everywhere.

At INOCA International, we as patients have the unique opportunity to learn from world leading experts in the field of INOCA and to have them stand alongside us in our joint and concerted efforts to raise awareness and further global understanding in INOCA. INOCA patients and doctors around the world stand to benefit from this truly amazing, truly worthwhile and truly unique Patient Partnership.

LOOKING FORWARD TO 2023



LOOKING TO THE FUTURE WITH HOPE!

Many of our Christmas and New Year messages have expressed very clearly the need for continued understanding, patience and kindness amidst all the things that have been happening in the world in the last 12 months and we very much echo each of those heartfelt messages. If you have not seen the messages or would like to see them again, you can do so on the link below.

https://inocainternational.com /our-2022-christmas-videomessages

IMPROVING CARE FOR ANGINA PATIENTS

Launching today in our Newsletter and also on our Social Media platforms are two brand new angina questionnaires created with worldwide collaboration and with the aim of improving and unifying global understanding and care for patients with angina.

INOCA International were invited to be involved in the creation of these questionnaires and we are very much looking forward to seeing the results!

With almost 4,000 followers on Twitter and Facebook alone and over 60,000 visitors to our website, we are hoping for a great response from all our very supportive Twitter and Facebook families

You can read more about this exciting new project on pages 3 and 4 of this newsletter - please come join us and be a part of this important research!

READY FOR A 2023 MEETING OF MINDS?

We took an early decision to postpone the Meeting of Minds when news first broke about the COVID-19 Pandemic. After 3 years of COVID and extended vulnerability isolation for many, we are now looking forward to bringing you details of the next INOCA International Meeting of Minds and are already in discussions regarding possible dates!

Please make sure you are following us on our Social Media platforms and are also signed up to our INOCA Newsletter so you don't miss any of our upcoming news and updates!

You can see details of our previous Meeting of Minds here -

https://inocainternational.com/meetings

You can also sign up to our quarterly Newsletter on our website here -

www.INOCAInternational.com





OUTSTANDING PATIENT FUNDRAISING EFFORTS!

At INOCA International we do not have a donate button on our website as we do not feel this is appropriate given the extreme hardships currently being faced by so very many people around the world.

INOCA International do not fundraise, but we have some wonderful supporters who do! It is because of the amazing generosity of so many supporters and so many generous donations, that we were able to fund the 2019 Meeting of Minds and were also able to live-stream the meeting presentations around the world. We were also able to produce 16 videos of the meeting presentations that can all be viewed free of charge on our website.

Now that we are planning our next Meeting of Minds, we would simply ask that if you are in a position to be able to make a contribution, however small, your donation would be very much appreciated. The more money raised, the bigger the meeting we hope to be able to have! (You can also donate anonymously if you prefer).

The patients GoFundMe page has already raised more than £9,000 of its £15,000 target - a truly amazing achievement! Not far to go now to reach their target, so if you can help them do this, that would be fantastic! https://www.gofundme.com/f/lqrjhgrm00

£9,534 raised of £15,000 goal

Professor Hiroaki Shimokawa

INOCA International are delighted to welcome Professor Hiroaki Shimokawa to our Medical Advisory Board. Professor Shimokawa brings a wealth of knowledge and expertise in INOCA conditions. He has also made significant contributions to the understanding of INOCA conditions over the last 4 decades and is considered a pioneer in this area of cardiac research.

Professor Shimokawa graduated from Kyshu University in 1979 and obtained his MD & PHD Degrees from the same university. He moved to the USA in 1985 where he studied endothelial functions at Mayo Clinic and following a very successful career path, is currently Vice Dean of Graduate School, at the International University of Health and Welfare and also serves as a visiting professor at Tokohu University.

Professor Shimokawa's main research areas include coronary artery spasm, microvascular dysfunction, endothelial functions, epidemiological studies and development of non-invasive advanced therapies. He has also led advances in non-invasive options for treatment of coronary vasospastic disorders.

Professor Shimokawa has most recently been researching the use of low intensity pulsed ultrasound (LIPUS). LIPUS is a non invasive and painless treatment which could potentially be used in the treatment of INOCA conditions and also in myocardial infarction, heart failure and even dementia. Professor Shimokawa is currently undertaking a double-blind, placebo-controlled trial in collaboration with 10 university hospitals in Japan and we very much look forward to hearing the outcome of the trial.

As Professor Shimokawa said "What you can see is not everything, and rather, what you cannot see may be more important than what you can see"

We recently had the opportunity to interview Professor Shimokawa. It is an interview well worth seeing and covers many areas key to INOCA conditions including the prevalence of INOCA, how Japan is at the forefront of diagnosing INOCA conditions, non-invasive treatments and current research.

Professor Shimokawa's mentor - Dr Takeshita was a huge influence in his life. He kindly and continuously supported him, teaching him the importance of continuing with research even under difficult circumstances.

Unfortunately, Dr Takeshita died of cancer in 2009 at the age of 69. However, as Professor Shimokawa said in his interview, Dr Takeshita's DNA lives on in his heart and in the hearts of all the many students he taught.

Professor Shimokawa is continuing the legacy of being a good mentor for young researchers and in encouraging and supporting them to continue their research work even in the most difficult of circumstances.





You can watch our video interview with Professor Shimokawa on the INOCA International website on this link -

https://inocainternational.com/interviews-with-experts/



You can also see further information on Professor Shimokawa including links to some of his many published articles and research papers on the INOCA International website via Professor Shimokawa's Personal Profile page:

https://inocainternational.com/professor-shimokawa



Immune Resilience for the Winter Dr Ailsa Care

One thing the COVID19 pandemic has done for us is to expose a number of things about our current model of healthcare:

- The costs of being unhealthy, both in monetary terms for society but also in terms of unnecessary suffering and death.
- We have been using a reactive disease care system which often treats symptoms rather than addressing the root cause.
- It seems there is a need for a radical transformation in WHAT healthcare is and in HOW we deliver it. Perhaps now is the time for Functional and Lifestyle Medicine to become more mainstream!

It has been amazing to see how quickly communities came together to support the most vulnerable people showing how important being part of a supportive community like INOCA International is.

Never before has it been so important to build IMMUNE RESILIENCE in the population. Covid has been just one infection and there are many more out there to potentially infect us. It makes sense to provide our bodies with what they need to combat infections as it would be difficult to vaccinate against all of them.

To develop immune resilience we need a whole person approach which empowers and equips people to take charge of their physical and mental well being so that they can be the best version of themselves and this is where Functional and Lifestyle Medicine can sometimes tick the boxes. Our emphasis is on healing rather than cure (as our bodies inherently know how to heal) and this approach addresses not only the clinical side but also the physical, emotional and spiritual too. There is no one 'magic bullet' but there is often a combination of personalised interventions that can help to shift a person gradually from the disease end of the health -> disease continuum towards health. Resilience = the ability to adapt successfully to stress and adversity.



Immune resilience = the body's ability to deal with a biological pathogen successfully without resulting in chronic infection or inflammation.

We need to have both immune tolerance and immune resilience.

With immune tolerance you don't have food intolerances, chemical sensitivities or autoimmune diseases.

When tolerance is lost the immune system becomes hyper vigilant and can mistakenly reacts to foods, chemicals and even self tissue. Loss of tolerance suggests immune resilience is already impaired but it also further impairs immune resilience.

It is so important that our immune system is balanced so that it recognises infections and tissue damage appropriately and is able to clear waste from this efficiently and without triggering the immune system to react to self tissue.

Remember, with a viral infection the disease is not the virus. The disease is how an individual's immune system responds to the virus. We cannot change the virus but we can change how our immune system responds. The most important factors as you will see below, are lifestyle and environmental factors.

Factors which disrupt immune resilience and tolerance include -

Nutrient and fibre poor,
processed food diet
Poor blood sugar regulation
Sedentary lifestyle
Poor sleep
Stress

Several of these are Issues I have written about in previous newsletters so do go back and review them for some 'top tips'!

Factors which support immune resilience and tolerance include:

<u>Microbiome diversity</u> - look after the healthy bacteria in your gut. They love fibre and vegetables, probiotic foods like sauerkraut, kimchi, kefir or even a daily probiotic capsule can be helpful

<u>Nutrient dense, brightly coloured foods</u> remember 'Food is Medicine', so try and 'eat the rainbow' of fruit and vegetables

<u>Balanced blood sugars</u> - cut back on obvious refined sugars, add protein and healthy fats, eat complex carbohydrates that release their sugars over a longer time

Regular exercise - it doesn't matter what sort of exercise it is as long as you move regularly. Start where you are and gradually increase. If you have problems with fatigue it is important that you exercise at a level that you can repeat every day without feeling increased fatigue or pain.

Adequate hydration - drink enough water to make your urine a pale yellow colour (2 litres of water a day is suggested).

Good sleep - 7-9 hours.

Stress management, breathing exercises mindfulness, meditation, and vagus nerve exercises can all be helpful too.



IMMUNE RESILIENCE

(continued)

Supplements to consider to support immune health include:

 $\underline{\text{Vitamin D}}$ - we make this naturally in the summer months when our skin is exposed to sunlight. A deficiency of vitamin D is a risk for people who don't spend much time outside, maybe don't tolerate the sun very well or who cover their skin.

The NHS recommends that we should all take a vitamin D supplement through the winter months from September/October through to March/April

<u>Vitamin C</u> - we know our requirements for vitamin C increase massively when our immune systems are actively fighting an infection. As humans we are unable to make our own vitamin C and rely on getting it from our diet, so it can be useful to increase your intake of vitamin C at the first sign of illness.

<u>Zinc</u> - This is important for immune support and our requirements increase if we are fighting an infection. Take it with or after food to minimise the risk of it causing any nausea.

Beta-glucans - from foods such as oats, barley, mushrooms

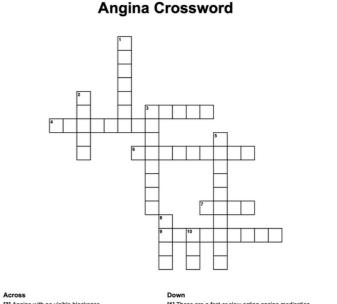
Other nutrients such as vitamins A, E, B complex, essential fatty acids, selenium, magnesium can be taken if needed as a supplement

If you are taking any medications please speak to your pharmacist before starting any supplements as they may interact with your medications.

Making such healthy changes can seem overwhelming at first. Perhaps start by picking an 'easy win', something you feel can be put in place without too much difficulty. Lots of small changes add up over time to make a huge difference in how you feel! Always try to be kind to yourself, listen to your body and rest when you need to. Enlist the help of those around you to share the burden of preparations (and of any clearing up!)



OUR QUARTERLY COFFEE TIME CROSSWORD



AND SO INTO 2023

As we leave 2022 behind and head into a New Year, we remember the difficult times we have faced and we celebrate all the blessings we have received. We mourn those we have lost and we welcome those who have joined our circle. We consider the things we might have done differently and perhaps promise ourselves that we will aim to do better.

For all of our good intentions we can still sometimes find ourselves ending the year with a few regrets. But in life, just as in INOCA, every day is a new day and a new opportunity to do better, to try harder and to make a difference. It may sometimes seem that making a difference in our own life just isn't enough to change the world, but if we are all determined to do better and to try harder, then changing the world is exactly what it is possible to do.

INOCA conditions are better recognised, better understood and better managed than ever before, but this is still not the case for many. There are many new things on the horizon for 2023 which we very much hope will improve care for INOCA patients. INOCA International are determined to continue supporting those working in INOCA research, to continue raising awareness for both patients and doctors, and to continue helping to achieve a clearer, better, global understanding of INOCA.

From all of us, to all of you, we wish you

"A Very Happy New Year!"

Wishing you all a happy, healthy and prosperous New Year!



from everyone at INOCA International

www.INOCAInternational.com