

NEWSLETTER

JANUARY TO APRIL 2023 (Issue 11 - Page 1)

The 2023 Meeting Of Minds!

As many of you know, we were hoping to hold our return Meeting of Minds in 2020, but covid struck. We had to make the difficult decision to postpone the meeting until a later date, as the health and wellbeing of patients guests and speakers was of paramount importance to us all.

After the amazing success of our first meeting, our wonderful venue, The Dorchester, very generously offered to host the INOCA International Meeting of Minds for a second time.

We are delighted to announce that the 2023 Meeting of Minds will take place at The Dorchester in London, UK, on 30th August 2023.

It is a great pleasure to be hosted for the second time by this incredible venue and to be able to hold this very special Meeting in such truly prestigious surroundings!

If you would like to be considered for a place at The 2023 Meeting of Minds, please get in touch by email at mom23@inocainternational.com as soon as possible. This is an invitation only event with limited places available.

For anyone not able to attend on the day, no one will need to miss out as we will be taking lots of photos to share with you all and will again be recording the meeting presentations uploading these to the website as soon as possible after the meeting. As always, all our video presentations are available to view free of charge on the INOCA International website. You can see some of the amazing photos and videos from our last Meeting of Minds on the two links below www.INOCAInternational.com/gallery https://inocainternational.com/video-

presentations-from-the-meeting-of-minds



Funding for this project was made possible in part by a grant from the World Heart Federation (The views expressed in written materials or publications do not necessarily reflect the official policies of World Heart Federation)

World Heart Federation Best Video Campaign Award

INOCA International is incredibly proud to have been voted "Best Video Campaign" in the 2023 World Heart Federation Awards!

"THANK YOU" to each and every one of those who took the time to be part of our video campaigns to raise awareness in INOCA and Thank You also to The World Heart Federation for this amazing award!

www.INOCAInternational.com https://world-heart-federation.org/.../world-heart.../2-23



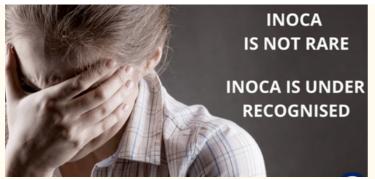
INOCA International Heart Month Series



In February Heart Month, NOCA International created and shared bitesize information slides to support the important work of raising awareness of these often overlooked and misdiagnosed conditions.

28 days and 28 slides of data brought together in collaboration with Professor Martha Gulati, one of our esteemed Medical Advisory Board members. Thank you Professor Gulati! As always, your your ongoing support is very much appreciated – this was a very insightful poster series!

March Messages - hearing from INOCA patients



In March we shared our specially created March Messages. This was a series of posters sharing patient feedback on their experiences, thoughts about their care and the various aspects of their own individual INOCA journey.

We are sharing just a few of these images and the very powerful messages that accompanied them here, but please do check out our Social Media Platforms for more!













Twitter - https://twitter.com/lnocalnternatil
Website - www.INOCAlnternational.com

Facebook - <u>www.facebook.com/groups/491395198372627</u>
Online Support- <u>www.facebook.com/groups/287960691855039</u>

World Heart Federation 2023 Angina Awareness Campaign

Did you see the 2023 Angina Awareness Campaign from the World Heart Federation? If you haven't seen it yet you can view it on the link below –

https://world-heart-federation.org/use-heart-to-act-now-on-angina/

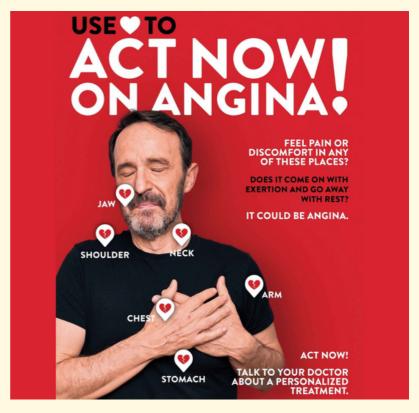
'The Angina Awareness Campaign is a worldwide campaign to improve disease awareness, facilitate timely detection of angina patients, and implement optimal angina management'

INOCA patient Mehmet was chosen to be featured on the one of the World Heart Federation videos. Mehmet suffers from Prinzmetal Angina (also known as Coronary Artery Spasm/vasospasm) and like many other patients with angina from INOCA conditions, Mehmet had found it very difficult to find a doctor who recognised and understood his condition.

INOCA was once thought to be a condition which mainly affected females but this is not the case, as men can and do get INOCA too!

You can hear Mehmet talking about his moving story here https://youtu.be/lm7AhgXs920





If you would like to know more about INOCA conditions, or think you might be suffering from an INOCA condition please visit the INOCA International website to find out more about the conditions. www.INOCAInternational.com

You can also keep in touch with the latest updates via our social media platforms – $\underline{\text{Twitter}}$ – $\underline{\text{elNOCAInternatil}}$ and on our online information page at

Facebook - https://www.facebook.com/groups/491395198372627

There is also an excellent online patient support group we link to where you can find support from other INOCA patients from around the world - https://www.facebook.com/groups/287960691855039

Look out for Spanish Translation of the INOCA website!

After many months work we are very pleased to announce that we are hoping to launch the dedicated Spanish translation option on our website very soon!

Our sincere thanks go to Teresa VALENCIA, President of Asociación Nacional de Addison y otras enfermedades endocrinas for her incredible translation skills and for the time and patience she has so generously given in translating the website for us.

This important work will allow us to raise awareness even further afield and will help Spanish speaking populations around the world to find out more about INOCA conditions.



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.

There is still time to register your voice!

As you may recall from our previous Newsletter, we are proud to be involved in TWO international surveys.



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 You already know that things are not always straightforward. your voice is just not being heard?

Each patient can present with very different symptoms and

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 for angina patients and one designed for doctors who treat angina.

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

International Survey on Patients' Needs and Expectations

Links to Patient Survey on Angina

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



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

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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 doctors AND from patients, 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!

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







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

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

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U.S. Microvascular Network

The U.S. Microvascular Network have been working on an excellent project which includes a clinic locator map for the U.S. This project has now been launched so we are delighted to share it. The MVN map is also searchable so you can use it to look for a clinic near you. You can also see the contact details of the clinics and also the tests available at that facility!

The Microvascular Network also has an MVN Newsletter which has just launched, so we have included a link to that here too – enjoy!

https://drive.google.com/.../100JjxcP0H5wquY9yrsbt33.../view

MVN NEWSLETTER

VOLUME 1 | ISSUE 1 | JANUARY 2023



Welcome back INOCA live chats!



We are delighted to bring back a popular feature that was set up for use during COVID.

People have been asking for a safe space in which to chat and socialise with fellow INOCA patients. We heard the call, we listened and we acted!

We hold regular INOCA live chats on a monthly basis in The INOCA Cafe on Facebook. Each chat has a theme which can be something patients have requested more information on, or could be a general chat /social time.

So far the INOCA chats have been very well received and we are all looking forward to the next one! Keep a look out on our social media platforms for more information!

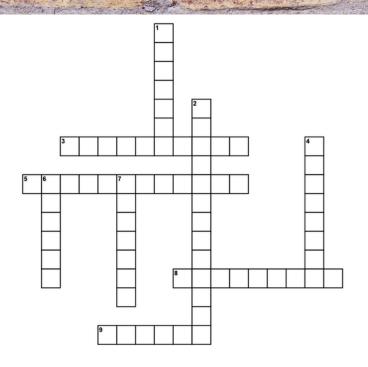
Easter zoom party was a HUGE success!

Huge thanks to Helen Parsons for organising and hosting the Easter Zoom Party which raised £86 for INOCA International. The quiz was fun from start to finish and everyone left the zoom party with a smile on their face – just what we all needed! Congratulations to Chris George on winning the raffle and a big thank you to all those who attended, who bought raffle tickets and who continue to support INOCA International so generously.

The patient GoFundMe page has already raised just over £10,000 of the £15,000 target - a huge achievement so far! All of the money raised goes to help towards the costs of the Meeting of Minds and the essential costs (like website hosting) that enable us to continue to raise awareness, so please do continue to support these events if you possibly can, as the more we raise, the more we can do! You can make your donation here - gofundme.com/f/larjharm00



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- [3] Which famous hotel is the meeting taking place at?
- [5] The sensation of your heart beating differently
- [8] What day of the week does the 2023 Meeting of Minds
- [9] In which city will the Meeting Of Minds take place?

- [1] Extreme tiredness
- [2] What is the name of the spray or under the tongue tablets patients may take to help ease angina symptoms?
 [4] What does the 'l' in INOCA stand for?
- [6] What month is the 2023 Meeting of Minds taking place? [7] what is the term used for something that sets of angina symptoms?



Take a moment to relax by trying out our Newsletter Crossword. All the questions are based on information from within this month's newsletter, so nothing too taxing and a great fit for a short relaxing tea/coffee break!





This month's wordsearch is related to the heart and again is a nice relaxing way to pass a short much needed tea/coffee/lunch break. Maybe you could challenge a friend or work colleague to see who can find the words first - Enjoy!

18.6m deaths every year from CVD

of all deaths are from CVD

https://world-heart-federation.org

temperature cold symptoms

coronary artery angina

stress echocardiogram exertion

If you are able to help support INOCA International by making a donation to the patient GoFundMe page you can do this here www.gofundme.com/f/lqrjhqrm00

Patients have already raised an amazing £10,000 of the £15,000 target with every penny raised helping to raise awareness!