



Introducing the brand new INOCA INTERNATIONAL WEBSITE!

Welcome to the INOCA International website

(Also incorporating ANOCA and NOCAD)



Advisory Board



Patients



Professionals



Meetings

The results from the INOCA Patient Survey are published in The International Journal of Cardiology!

We are delighted to begin our Autumn newsletter by sharing the fantastic news that our brand new INOCA International website has now launched! If you haven't visited our new website yet, please click on the link to take a look for yourself. We hope you too will be delighted with our new and improved website!

www.INOCAInternational.com

The new website is full of information for patients and professionals alike including INOCA conditions summary sheets, videos, podcasts, interviews with experts, patient stories, downloads and much more. There is also a dedicated page for downloads too!

"It's FANTASTIC, so user friendly and interactive too. I didn't think it could be improved, but this has blown me away!"

Bringing a website like this together has, as you can imagine, taken many months of planning and hard work behind the scenes and our very talented web designer Alex, is the person responsible for bringing this vision to life. We are sure you will agree that he has done an amazing job!

In addition to Alex there were also a number of other amazing individuals who very kindly contributed their ideas, time and energy into making the new website the very best it could be for both patients and professionals alike and it gives us great pleasure to offer our very special thanks to Janis, Charmaine, Lisa and Chris who each contributed so much. Great team, great effort and a truly outstanding result.

"Thank You"
to everyone involved

Website Feedback

Wow! A great update to the website

Wonderful site and resource for the patient and professional community

I have just spent some time surfing this wonderful website Congratulations

You should all be proud of such a professional place, where INOCA patients and potential ones can source useful information and data.

This is a fabulously laid out, informative and wonderful website.

Well done to all involved

Your website looks great!



What is INOCA?



Doctors treating INOCA



Living Life With INOCA

The pictures in this newsletter's headers are taken from the pages on our new INOCA International website!

International INOCA Patient Survey

INOCA International were delighted to see the e-poster presentation from Professor Martha Gulati on the International INOCA Patient Survey at the ESC Congress last month. The results were received with great interest and sparked a great deal of interest on our Social Media platforms too!

As many of our readers will already know, for many years INOCA has often been viewed as an odd/unusual/different kind of angina and has often also been treated with a lack of understanding and disbelief.

Many patients report finding themselves in an endless loop of being in pain and seeking help, only to be told there is nothing wrong or that the symptoms they are experiencing are all in their head or are due to anxiety. When nothing shows up on routine testing, patients are often sent home without diagnosis or treatment.

Thanks to the very many years of diligence, tenacity and determination by pioneers in the field, interest in INOCA has continued. With growing evidence, understanding of INOCA conditions and their impact on quality of life has improved for some, but for many there is still a long way to go.

In the lead up to the INOCA International Meeting of Minds, an informal survey was carried out with 130 volunteer INOCA patients, looking at the problems and difficulties of Living with INOCA conditions and the findings were presented in a 12 poster display at the Meeting of Minds.



International Journal of
CARDIOLOGY

FULL LENGTH ARTICLE | ARTICLES IN PRESS

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

Martha Gulati • Najah Khan • Maria George • Colin Berry • Alaide Chieffo • Paolo G. Camici • Filippo Crea • Juan-Carlos Kaski • Mario Marzilli • C. Noel Bairey Merz • Show less

Open Access • Published: September 23, 2022 • DOI: <https://doi.org/10.1016/j.ijcard.2022.09.047>

Click on the link to read the full survey results in the open access publication featured in The International Journal of Cardiology
[www.internationaljournalofcardiology.com/article/S0167-5273\(22\)01396-1/fulltext](http://www.internationaljournalofcardiology.com/article/S0167-5273(22)01396-1/fulltext)

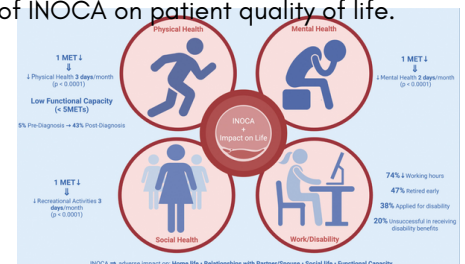
Prof Martha Gulati suggested re-doing the survey in a more formal setting to allow for full documentation and publication of the survey's findings and INOCA International were of course both delighted and honoured to work in collaboration with Professor Martha Gulati and Professor C. Noel Bairey Merz on this fantastic project.

The results again showed a significant impact on quality of life for INOCA patients with 40.4% of respondents experiencing INOCA symptoms for at least 1 to 5 years, and almost half experiencing symptoms for anywhere between 1 and 10 years before the diagnosis of INOCA was made.

Almost 70% of respondents (69.4%) were discharged from A&E without any treatment and 77.8% of respondents were told their symptoms were not cardiac.

Approx 3/4 of respondents had to reduce their working hours or stop work completely and almost half of respondents (47.5%) retired early, with over a third (38.4%) applying for disability

We will be featuring a more detailed discussion about the survey results in our next newsletter and on our Social Media platforms. In the meantime, please click on the link above to see the publication of our results and the significant impact of INOCA on patient quality of life.



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.



Patient Stories



Videos



Podcasts

RECENT PROJECTS

At INOCA International we have a truly inspiring and dedicated Medical Advisory Board with all of its members giving their time and expertise very generously to help improve understanding, recognition, diagnosis and treatment in INOCA.

It has been a very busy few months for both our Medical Advisory Board and our Management Team members. Below are just a few of the amazing projects our superb teams have been involved with.

PODCASTS



Our INOCA International Podcast series is now live. So far, we have launched the first 4 Podcasts in the series. These include interviews with leading experts in INOCA Conditions, including Prof Juan-Carlos Kaski and Prof Colin Berry.

In our podcasts you will find helpful information about INOCA conditions explained in a very straightforward manner. The podcasts are all around 20 minutes long and are available on all the usual platforms so you will find us where ever you normally listen to your podcasts. You can also subscribe to make sure you don't miss any new releases and can listen at a time that is convenient for you.

Our next podcast is due to be released soon and is an episode recorded with Professor Colin Berry which is specifically directed at medical professionals.

As always, everyone is welcome to listen to all of our podcasts whether patients or professionals. We would simply ask that listeners please be mindful of the fact that the language and terminology in this particular podcast may be a little more technical than is usual for our podcasts, given the audience it is specifically directed to.

In my case, it was an eight-year journey from sudden onset of symptoms, which were fairly catastrophic, to receiving a definitive diagnosis and an optimal treatment plan. During this time, I saw 15 different doctors, had 22 sets of tests and tried 18 different medications.

I really hope that sharing my story in such a prestigious publication will allow fellow INOCA sufferers to realise that they are not alone, that there is hope, that there are experts in treating INOCA conditions out there, if they can only find them.

Perhaps even more importantly, I hope that sharing my story helps to improve awareness of these conditions and also of the testing and treatments available, among medical professionals too so that awareness of and testing for INOCA conditions is the standard approach for patients with cardiac symptoms without obstructed coronary arteries.

I was delighted that alongside my article was a second publication providing an expert commentary on my article - "Shortcomings in Managing Patients With Ischemia With Non-Obstructed Coronary Arteries" by Rosanna Travella and John F. Beltrame, thereby allowing both the patient and professional viewpoint too"

Both of these articles are linked below - www.ahajournals.org/doi/10.1161/CIRCO.UTCOMES.121.008745

www.ahajournals.org/doi/10.1161/CIRCO.UTCOMES.122.008746



PATIENT ARTICLE



INOCA patient Lucy Flanagan was invited to write an article about her INOCA journey for The Circulation Cardiovascular Outcomes and Quality Journal. We asked Lucy to tell us in her own words, how it felt to tell her story.

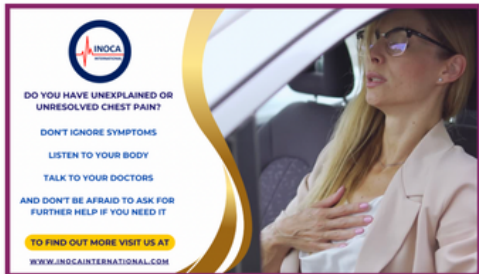
"I was very honoured to have my article 'My Journey with Ischaemia and Non-Obstructed Coronary Arteries' published in this very well respected Journal. It was an emotional and humbling experience to be able to share my story and really underlined for me not just what I have gone through as an INOCA patient, but also how similar my experience is to that of so many others living with INOCA conditions. too.



RAISING AWARENESS

At INOCA International we strive to maximise awareness and have launched a series of very short video clips to help us do this. These videos are all around a minute long and have been designed to provide vital information regarding INOCA conditions in a simple, short, straightforward and accessible manner to the maximum amount of people.

The video clips can all be seen on our Facebook page and Twitter feed where they can be liked, shared and retweeted to an even wider audience!



Click on the links to watch the videos

- <https://youtu.be/Q87ekmFHRsY>
- <https://youtu.be/Ti9lrS5FvOw>
- <https://youtu.be/rh3AlvmJ55c>



Our INOCA International promotional video has now been watched over 10,000 times on our Twitter platform alone! We continue to be overwhelmed by the incredible support we receive on our Social Media platforms and very much appreciate all the amazing help and support we receive in raising awareness!



<https://youtu.be/y2h0UXBH7zE>

MINOCA

We recently launched the fourth in our INOCA Conditions Summary Sheets. This one is called '**Let's Talk About MINOCA**'. MINOCA stands for Myocardial Infarction (a heart attack) with non obstructed Coronary Arteries. The summary sheet discusses triggers, symptoms, possible self help options and much more. You can read or download the MINOCA Summary Sheet via the downloads page on our website. There is also an Easy Read option available for anyone who might prefer a more visual learning experience. (All our Summary sheets are written with the input of at least one of our Medical Advisory Board members).



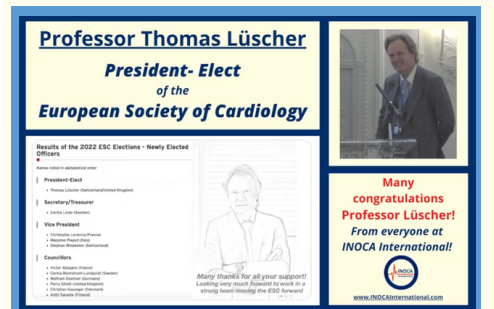
CONGRATULATIONS!

INOCA International are delighted to offer our sincerest congratulations to two of our Medical Advisory Board Members on receiving two very prestigious appointments!

Professor Thomas Lüscher is now President Elect of the European Society of Cardiology and Professor Martha Gulati has been appointed President of the American Society for Preventive Cardiology.

At INOCA International we are always very humbled by the level of dedication and hard work of our Medical Advisory Board members and by the outstanding work being done by each and every Board member. We happen to think you are all pretty amazing - and we are more than sure that very many others think so too!

Congratulations



www.INOCAInternational.com



Information From Our Experts



Ask Our Experts



Articles

Responding to requests from patients for an article on Thyroid Health

Let's Talk About Thyroid Health

Dr Ailsa Care



Do you feel tired all the time, low in mood, struggle to lose weight despite not having a great appetite, feel cold, have dry skin and hair loss? If so then you may have issues with your thyroid gland.

The thyroid is a gland which is shaped like a butterfly and sits over the lower part of your trachea (windpipe). It is responsible for regulating metabolism including energy production and temperature regulation as well as affecting the balance of other hormones

The most common reason for an underactive thyroid is an autoimmune condition called Hashimotos thyroiditis. This means that your body's immune system is attacking your thyroid gland impairing its ability to produce thyroid hormones. In the early stages of Hashimotos you may initially have positive thyroid antibodies and normal levels of thyroid hormones or sometimes even high levels.

As more thyroid tissue is destroyed it is unable to keep up with demands and the levels of thyroid hormones drop and TSH (thyroid stimulating hormone) rises as the brain senses the low thyroid hormones and tries to push the thyroid to produce more.

Another reason for an underactive thyroid is if there are not enough of the right nutrients required to make the thyroid hormones and /or convert the hormones to their more active form.

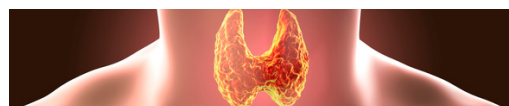
Essential nutrients for the thyroid include:
*selenium, Iodine, Magnesium, Zinc, Tyrosine, Vitamin A, Vitamin D, Vitamin E Vitamin B complex, Vitamin C and Iron.

Factors that inhibit thyroid function include Stress, Trauma - physical or emotional. Halogens - fluoride, chlorine, bromine compete with iodine for receptor sites.

Toxins - pesticides, heavy metals eg mercury, cadmium and lead. Medications - lithium, amiodarone, combined contraceptive pill, proton pump inhibitors, steroids (e.g prednisolone).

If you are taking any of these medications regularly please don't stop taking them but speak to your doctor about checking your thyroid function.

Gut dysbiosis - an imbalance in the microbes in your gut. Infections - viruses, bacteria, parasites. (Especially EBV Epstein Barr Virus which causes glandular fever) and Autoimmunity eg coeliac disease.



There can be a genetic predisposition to develop autoimmunity but it is other factors from our environment which cause those genes to be switched on - these factors include dietary triggers such as dairy, soy, eggs, gluten and other modern grains like corn, Gut dysbiosis, SIBO, hypochlorhydria, stress and exposure to environmental toxins.

Dr Alessio Fasano describes the autoimmune triad which includes genetic susceptibility, intestinal hyperpermeability and environmental triggers (stress, poor sleep, food reactions/allergies, toxic exposures, infections, nutrient deficiencies)



In intestinal hyperpermeability, commonly referred to as "leaky gut", the usual tightly regulated intestinal lining is disrupted and allows the passage of complex food proteins (the product of inadequately digested food) or microbes from the gut into the blood stream to circulate. These complex food proteins and microbes are recognised by the immune system as foreign and an attack is mounted. This is of course an appropriate response but the problem comes when these complex food proteins or the microbes look like tissue elsewhere in the body. The result of this is a process called molecular mimicry in which the immune system mistakes self tissue for food or microbes it has already reacted against and mounts an attack against that self tissue.



THYROID HEALTH continued

For example, it has been shown that gluten proteins look very much like thyroid tissue, so many patients with Hashimotos find it beneficial to exclude all gluten from their diet and we find over time that the levels of thyroid antibodies fall.

It makes sense, therefore, to reduce the chance of developing autoimmunity and also in established autoimmune disease, to ensure we are digesting our food as thoroughly as possible. (See Newsletter Issue 8 for tips to support digestion).

Look after your gut microbiome by feeding the 'good bacteria' with plenty of whole foods, fruits and vegetables containing fibre. You can even add some fermented foods like natural live yoghurt, kefir, sauerkraut, kimchi or take a quality probiotic. I liken the population of microbes in our guts to the human population in a city. You want the majority to be working hard, living in harmony, each having a beneficial role in the community and the criminals to be a minority. The more good microbes, the more the bad microbes are crowded out, keeping the "crime rate" low.



Stress - this can not only be psychological but also physiological due to toxic exposure, infections, hormonal imbalance etc. (See Newsletter Issue 6 for information on the vagus nerve and how we can support it which helps us manage stress).



Consider what you consume in terms of what you eat - processed food provides fewer nutrients, contains potential toxins and is harder for us to digest than whole foods. Also consider what you listen to or watch (TV, radio, films, conversations). Many people are watching or listening to less news as they find it increases their anxiety levels which especially late in the evening can cause disturbed sleep.

Sleep - getting a good nights sleep is essential to good health. It is a time when we complete digestion of food we have eaten, we process emotions, consolidate memories, process toxins and make repairs.

Toxins - every day we are exposed to so many potential toxins in the air that we breathe, water we drink, food we eat, products we apply to our skin and clean our environment with. This is not meant to scare you but more to prompt an awareness and gradual change to less toxic, more natural products. The UK based Pesticide Action Network produces a list of the most and least pesticide contaminated fruits and vegetables (in the USA Environmental Working Group) so we can concentrate on eating organic for the most contaminated and so reduce our exposure.

Start reading product labels and as you replace personal care products look for those without parabens and phthalates which have been implicated in autoimmunity and shown to disrupt thyroid function.

Iodine - deficiency of this essential nutrient for thyroid function is relatively common. The thyroid hormones T4 and T3 consist of a tyrosine molecule with either 4 or 3 molecules of iodine attached. However, it is a delicate balance and too much iodine can also be a problem for thyroid health. Dietary sources of iodine include seafood, seaweed, milk, eggs.

Support your immune system to fight infections by making sure your vitamin D levels are optimal (either your GP can check this or fingerpick tests are available privately through companies like Mediceck and Thriva in the UK). Optimal levels of vitamin D are 70-150 nmol/l.



You may find this information a little overwhelming. If you do, consider taking it one step at a time and look at just one thing that you can easily change and start there. Also you may wish to seek some guidance from a health professional such as a nutritional therapist or functional medicine practitioner.

I always like to recommend a book to provide more in depth information for those interested. My recommendation this time is Slow Butterfly by Dr Amy Gajjar. This book very gently takes the reader through each area which affects thyroid function. Remember we can't do it all at once, it is about gradually putting in place multiple small changes which shift us towards improved health.

COFFEE TIME THOUGHTS

DID YOU KNOW...

According to the latest figures from The World Heart Federation



Cardiovascular Disease (CVD) is the leading cause of death in women worldwide



Women with CVD continue to be under-diagnosed and under treated due to misconceptions and lack of awareness among both patients and doctors



Young women are more likely to die following a heart attack than young men.



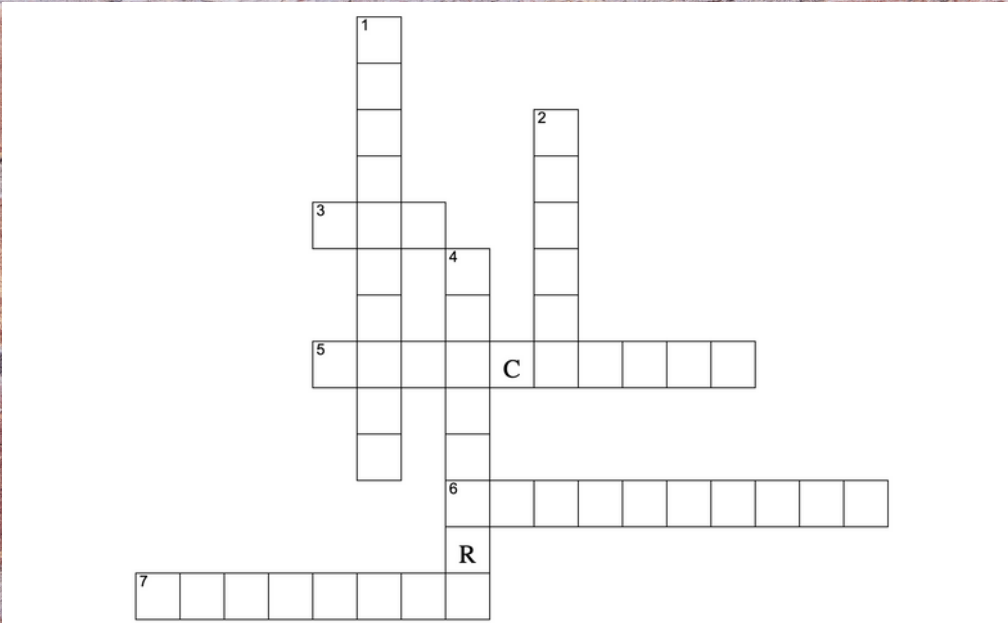
Cardiovascular disease is responsible for 35% of deaths in women each year - this is more than ALL CANCERS COMBINED!

35%



Search for words relating to thyroid

There are 14 words to find!



Across:

- 3. taken for short acting relief of Angina
- 5. something you are prescribed to help with symptoms
- 6. extreme fatigue
- 7. Things you experience with your condition

Down:

- 1. not able to breathe
- 2. pain often felt in the chest
- 4. Things that can set off your symptoms

Her Majesty Queen Elizabeth II



The beginning of September marked the passing of
Her Majesty Queen Elizabeth II
after 70 years as Monarch

We offer our condolences to the Royal Family
and echo the words heard so often in recent weeks

"Thank You Ma'am"
for your many years of devoted service