



# NEWSLETTER

## Autumn 2025



### INOCA INTERNATIONAL GOES GLOBAL AT ESC!



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**WELCOME TO THE AUTUMN 2025 NEWSLETTER** - What an extraordinary season! From our featured presence at ESC Congress (with 33,000+ attendees), to launching 10 professional education videos on the NHS Learning Hub, to expanding translations into Czech and Bulgarian - INOCA International's global impact continues to grow!

**IN THIS ISSUE:** -

- ESC Congress 2025 Highlights
- NHS Partnership Launch
- Patient Voice: Rebecca's Story
- International Translations Expanding
- World Heart and World Adherence Day

We hope you enjoy reading the Autumn 2025 INOCA Newsletter and Thank you for being part of this journey!

**Share this newsletter with your Cardiologist!**

INOCA International hit the ground running at the ESC Congress in Madrid this August - and what a phenomenal response we had! Not only did we have a fabulous booth in the ESC Exhibition hall for the 4 full days of Congress, we were also able to speak to people who can make a profound difference to patient care worldwide. Such an honour and privilege to be hosted at this truly outstanding event! We also have to thank our Medical Advisory Board members for their outstanding support, as always, and for giving up their valuable time during their already packed ESC schedules, to spend time with us on the INOCA International Booth. Also to Chris and Naomi who together helped to man the booth and host the Meeting Room with our Founder Maria - True commitment from all and selfless partnership at its highest level!

The booth was incredibly busy, and the valued discussions, insights, suggestions, ideas, collaborations and partnerships

were so much more than we could ever have imagined. So a very sincere thank you to all those who spent time with us at our booth at ESC. It was GREAT to see you all and we cannot wait to move forward with the plans we all discussed!

But it didn't end there. We were also delighted to have our 2025 INOCA International Meeting of Minds hosted on site by ESC and World of Cardiology Congress too! What an genuine honour and what a great opportunity!

If you haven't seen the photos from the 2025 Meeting of Minds and from the INOCA Booth yet, you can see them on the link below.

**Photo Gallery:**

<https://inocainternational.com/2025-inoca-international-meeting-at-esc/>

**VideoClip:**

<https://youtu.be/yyuirQVlu4c>

## PHOTOS FROM ESC

Here are just a few of the many superb photographs very kindly taken by Chris and Naomi at our 2025 INOCA International Meeting of Minds and at our 4 day Booth in the ESC Exhibition Hall. Aren't they fantastic?



You can see lots more of our fantastic photos from our meeting at ESC via the link below -

<https://inocainternational.com/meetings/>



You can see more fantastic photos from our 4 day booth in the exhibition hall at ESC via the link below -

<https://inocainternational.com/meetings/>

## ADVOCACY

## THE PATIENT VOICE



There were three separate patient presentations given at our 2025 Meeting and the slide pictured above was one of the most poignant. This presentation shared the views of a number of patients from the online support group INOCA International links to and their words were often stark. In many ways their words sadly reflected how many INOCA patients are often left feeling when they are repeatedly disbelieved, dismissed and sometimes also disrespected.

The meeting room fell quiet during all 3 of the patient presentations with all eyes on the screen, the attention was absolute.

Professors, Clinicians, Doctors, Nurses, Researchers, Academics, Pharmacists, Pharma, Industry and more - all listening intently to the heartfelt message of INOCA patients for better knowledge, understanding and care.

If as an INOCA patient you imagined that attendees at ESC would not listen, I can absolutely assure you all that every eye in the room was on the screen, every face set deep in thought and the ear of every person was tuned in, not just to listen to - but to really to hear - the patient voice.



If you are struggling with symptoms or would like to share your experience with others who understand, you are not alone on this journey. The online support group we link to can be found here

<https://www.facebook.com/groups/287960691855039>

Huge thanks go to all 10 patients from the online support group who so very kindly contributed their video messages to be included in the 3 patient voice presentations at ESC.

Look out for video presentations from the meeting also coming to the INOCA International website soon!



## TRANSLATIONS

After conversations at our ESC Booth with Prague Cardiologist Dr Petr Kala, work began almost immediately on translating our INOCA international Summary Information sheets into Czech. The translations have all now been completed and can be download free of charge on our website.

We would like to thank **Dr Petr Kala** for his very kind collaboration in translating all 9 of our INOCA Summary Sheets!

The INOCA Summary sheets on Microvascular Angina have also just been translated into Bulgarian too and are now in the process of being distributed in doctors offices and clinics across Bulgaria!

We would like to thank **Ms Parvoleta Petrova** for her very kind collaboration in translating this INOCA information.

<https://inocainternational.com/downloads/>

**Download resources  
in your language!**



# The NHS Learning Hub

## Now Hosts 10 INOCA International Video Modules!

<p><b>Professor Juan-Carlos Kaski</b> Introduction to INOCA</p> 	<p><b>Doctor Ranil de Silva</b> Medical Management in INOCA</p> 	<h3>INOCA and ANOCA - Diagnosis and Management</h3> <p>Add to my bookmarks</p> 	
<p><b>Professor Colin Berry</b> Pathophysiology of INOCA Unpacking the Mechanisms</p> 	<p><b>Doctor Ailsa Care</b> Non Pharmacological Management of INOCA</p> 		
<p><b>Doctor Rajan Sharma</b> Clinical Presentation and Diagnosis of INOCA</p> 	<p><b>Professor Martha Gulati</b> PROGNOSIS</p> 	<p>SCAN THE QR CODE FOR THE SIGN IN PAGE OF THE NHS LEARNING HUB!</p>  	
<p><b>Professor Divaka Perera</b> Diagnostic Testing in INOCA</p> 	<p><b>Professor Colin Berry</b> INOCA in the Emergency Care Setting</p> 		<h2>INOCA and ANOCA</h2> <h3>Diagnosis and Management</h3>
<p><b>Dr Chiara Bucciarelli Ducci</b> The use of CMR in the diagnosis of INOCA ©2019 - Corvita 1009</p> 	<p><b>Maria George</b> THE INOCA PATIENT PERSPECTIVE</p> 		<p><a href="http://www.INOCAInternational.com">www.INOCAInternational.com</a></p>

## DID YOU KNOW?

That there are now 10 brand new INOCA videos hosted on the UK NHS Learning Hub all about the Diagnosis and Management of INOCA?

INOCA International have been working quietly behind the scenes with the NHS and are now delighted to launch a whole series of 10 specially recorded videos, all created with our INOCA International Medical Advisory Board members for the Health Care Professional Audience, and all with a view to helping improve recognition understanding and care for INOCA patients.

This provides such an amazing opportunity for medical professionals on the front line of caregiving to learn about these often missed and misdiagnosed conditions.

Please share this news with as many health care professionals as possible so that vital stations of care like GP surgeries, Hospital Clinics, Nurses Stations, Medical Students, Emergency Departments and more, will have access to this valuable information on INOCA and ANOCA

## INOCA and ANOCA Diagnosis and Management

If you have an NHS email address and haven't viewed the videos yet, please take a look on the NHS learning hub and please make sure that all your team and colleagues know about this new resource too!

Thank you so much to all our amazing Medical Advisory Board members who took the time to record these videos and thank you also to the superb team at NHS Learning Hub who were absolute fantastic to work with throughout!

<https://learninghub.nhs.uk/>



**Tag a healthcare professional who should see the NHS videos!**

# INOCA 2025 MEETING IN LONDON

INOCA International was delighted to participate in the INOCA 2025 London Meeting hosted by INOCA International Medical Advisory Board member **Professor Divaka Perera** and his team, and organised by **Millbrook Medical Conferences**.

Our 2 presentations at the meeting centred around What Patients Might Want From a UK Microvascular Network and Living with an Invisible Heart Condition - and shared a specially created montage of video clips from patients living with INOCA conditions.

A particular highlight of the meeting was the live cases where procedures and investigations in the Cath lab were live streamed into the meeting room where attendees had the opportunity to comment, offer advice and suggestions and ask questions in real time - truly, interaction and professional collaboration at its best!

The programme for the 2 day meeting was packed full and included discussion sessions throughout. We have included just a few of the many photos from the meeting below which we hope will give you a taste of this collaborative, informative and exciting meeting!

You can see more photos from the meeting on our website here - <https://inocainternational.com/meetings/>



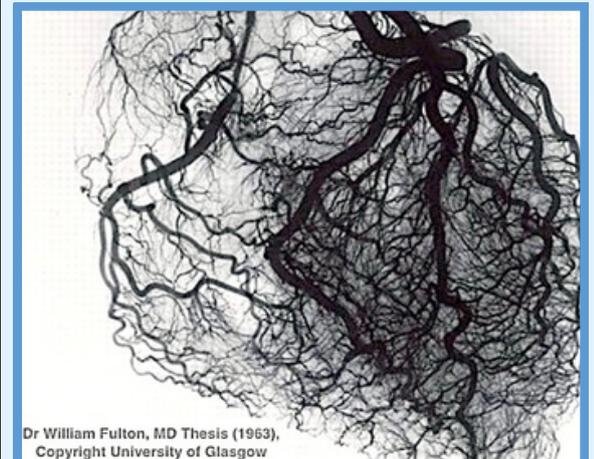
## IS INOCA REALLY A HEART CONDITION?

People living with one or more INOCA conditions can often endure a relentless combination of symptoms: life limiting fatigue, chest pain triggered even by mild stress - whether physical or psychological - a disheartening inability to concentrate, and many more symptoms. INOCA can be a life-altering disability.

But despite the very real suffering, far too many patients are still being told that their condition is "benign" or, worse, that their symptoms are all in their head.

INOCA International is fighting to raise awareness among practitioners and patients alike. The organisation's message is unequivocal: INOCA is caused by coronary physiological problems, such as coronary microvascular dysfunction, Coronary Artery Spasm (also known as vasospasm) and Takotsubo.

**This is not a debate:** INOCA is heart disease and dismissing it is denying care.



Dr William Fulton, MD Thesis (1963),  
Copyright University of Glasgow

# INOCA



**ITS TIME TO  
EXPAND THE  
DEFINITION OF  
HEART DISEASE**

**INOCA IS HEART DISEASE**

# INOCA IS HEART DISEASE - FULL STOP!

*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.*

# Invisible on Routine Tests: Devastating in Real Life

(A patient perspective from the online Support Group)

<https://www.facebook.com/groups/287960691855039>

The gravity of this title is remarkably profound. I invite you to imagine the following scenario. Imagine that you have the breadth of symptoms a heart condition elicits and you approach the health sector to seek assistance. But the standardised tests available all report unsubstantial results and you are discharged with no further action, instead perhaps attributing your symptoms to anxiety. You go home with all of the same symptoms you went to the hospital with, to suffer in isolation. Unheard, unbelievably, untreated.

Allow me to expand on personal experience whereby conventional cardiac assessments did not indicate a cardiac illness.

I had extensive blood work done (including troponin levels) on multiple occasions and all came back as 'normal'. My BP was also taken on many occasions with no serious findings. Countless electrocardiograms were also performed that did not detect any irregularities and several 24-hour ECG monitorings, an echocardiogram, chest x-rays, and a CT scan with contrast - all concluded no evidence of a heart condition

I was wheelchair bound. I had to move my upstairs bedroom to my downstairs living room as I could not manage a single flight of stairs. I could barely breathe when talking. My severe palpitations made me think my heart could explode. I could not eat and had to survive on protein shakes. I couldn't lie down horizontally at all and had to sleep sitting up. I felt like my chest was crushed under the weight of a lorry. Yet I was discharged with no further action. Time and time again.

As all of the mainstream investigative tests reported 'normal' findings, it was concluded that anxiety was the cause of my symptoms.

***"I thought I was going to die at home..."***

I knew I needed help but help wasn't coming. I thought I was going to die at home.

The outcome of only adhering to and abiding by routine tests can be detrimental to patients welfare and to their quality of life. Discharging patients from cardiology services denies people access to individualised treatment plans and to life-changing medications.

The population of people with ischaemic conditions will continue to be underdiagnosed and underrepresented, and this can also perpetuate limitations in awareness of INOCA disorders. If routine tests don't flag anomalies, patients are essentially disconnected from professionals and left at risk in communities. The terrifying physical symptoms persist and the raw emotional toll is stingingly impactful.

Undiagnosed patients may be left feeling lost and confused, still seeking the answers they desperately need to access the support and the pharmacological input that can modify their quality of life. Discharged patients can become marginalised and yet their suffering continues.

The cost and time demanded from healthcare institutions often increases with undiagnosed patients repeatedly attending emergency services, GP surgeries, and seeking referrals to other departments as the quest for answers continues.

What's really needed?

Greater understanding and awareness of INOCA conditions within the whole of the healthcare industry, GPs, paramedics, emergency departments, cardiology teams



Policies and procedures requiring that microvascular conditions are on professionals' radar. We need to move away from stigmatisations that imply heart disease can only interfere with large arteries.

Imperatively, health care professionals must retain a curious and open-minded approach to patients and their presentations. If symptoms persevere, investigative action must persevere too.

Enhanced flexibility ensures that medical practitioners don't feel uncomfortable extending tests beyond the norm if they could be beneficial; remaining explorative instead of discharging cases that seem obscure will serve those with INOCA.

So will greater networking and peer support where professionals ask questions and seek advice from others in the field when test results and symptoms aren't completely adding up.

continued...



## REBECCA'S STORY

(continued)

There also needs to be shared trust between patients and professionals; professionals also need to be cautious when referring to symptoms as anxiety.

Pathways for diagnosticians need to be more sophisticated and extend to ensure that regular steps in the investigative process factor in INOCA conditions.

Guidance from advisory bodies needs to be inclusive of INOCA pathology and be committed to issuing relevant recommendations that inform direct practice effectively. Ultimately, we need awareness that heart conditions can be present even if tests seemingly contradict this.

Lastly, we need physicians to trust patients with an open mind AND an open heart.



## World Heart Day

29th September 2025

**Did you celebrate World Heart Day this year?**

World Heart Day isn't just about one day. It stands as a reminder to take our heart health seriously throughout the year and to make decisions that could help us live healthier lives – for ourselves, and also for all those we love and who love us too.

The World Heart Federation is calling for us to sign the petition to call for better treatment TODAY and to stop needless deaths.

If you haven't already done this, please sign the World Heart Federation petition today and let's get our voices heard!

<https://world-heart-federation.org/sign-our-petition>

An infographic with a red background. At the top, it says "Did You Know?" in white. Below that, in yellow text, it says "That out of 194 countries, only 16 have a stand alone cardiovascular plan?". At the bottom, there is a white box with a red outline containing a stylized red heart and a person's silhouette. To the right of this box, it says "LET'S CHANGE THAT!" in white, followed by "FOR YOU and for all those you love and who love you too!" in white. Below that, it says "Sign the petition for change at" and "www.world-heart-federation.org/sign-our-petition" in small white text. There is also a small speaker icon.

## World Adherence Day

27th March 2026

A red rectangular graphic with a white sunburst icon on the left. To the right of the icon, it says "WORLD ADHERENCE DAY" in white, with "27 MARCH" in a white box below it. At the bottom, it says "#DONTMISSAMOMENT" in white.

World Adherence Day was launched by The World Heart Federation in 2025 to highlight how adherence can reduce long-term mortality risk and improve health outcomes. World Adherence Day aims to encourage patients to stay committed to their full healthcare plans and is not just about taking medication.

WHF partnered with leading institutions and organisations (including INOCA International) to create an annual campaign and a global call to action to ensure patients stay on track with life-saving medicines and healthier lifestyles.

Across the globe, adherence rates are often at dangerously low levels. In high-income countries, it is estimated that over 50% of patients with chronic conditions do not follow their prescribed treatments and rates are said to be even lower in lower-income nations.

Save the Date for the **2026 World Adherence Day on 27<sup>th</sup> March** and join the new WHF campaign to improve global adherence and health!

## ADHERENCE

Have you seen the brand new publication on adherence?

A small image of a Springer article cover. The title is "Therapeutic Adherence in Cardiovascular Diseases: Insights from the Patient and Physician—A Narrative Review". Below the title, it says "Review | Open Access | Published 04 November 2022". At the bottom, it says "Download PDF" and "Maria George, Inese Maurino &amp; Alitta E. Schutte MD".

**"...many physicians are unaware of the challenges being faced by individual patients..."**

<https://link.springer.com/article/10.1007/s12325-025-03413-2>

**OPEN ACCESS ARTICLE**

[www.INOCAInternational.com](http://www.INOCAInternational.com)

INOCA International were delighted to be asked as co-author on this brand new paper on ADHERENCE. If you haven't read it yet please do as it brings together both the doctor and patient perspectives on adherence and clearly illustrates many of the reasons why patients might not be following recommended treatment plans as prescribed – and many of these reasons are not intentional!

A huge thank you to fellow authors Dr Alta Schutte and Ms Inese Maurino for being such a great pleasure to partner with on this and to Servier for generously supporting this free access publication.

You can view this publication here – <https://link.springer.com/article/10.1007/s12325-025-03413-2>

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# The Heartbreak of 'Clear' When a Normal Angiogram Still Means Persistent Pain

## Have you had a clear angiogram?

Getting this news can sometimes be a devastating reality felt by thousands of INOCA patients: angina, shortness of breath, heart palpitations, hot flashes and more – yet, every conventional heart test, including the crucial angiogram, can often be reported as 'negative'. For these individuals, the journey ahead is often one of confusion, dismissal, and ongoing suffering.

This diagnostic gap is the reality for so many patients suffering from INOCA (Ischemia with Non-Obstructive Coronary Arteries); a variety of cardiac conditions under the umbrella of Myocardial Ischaemic Syndromes; and can include coronary microvascular dysfunction (CMD), Coronary Artery Spasm (also known as Vasospastic Angina (VSA), MINOCA and Takotsubo.

INOCA International is fighting to close this knowledge gap. We are actively raising awareness among patients and practitioners that a "clear" test should not be considered the end of the line, but a signal to dig deeper in identifying INOCA conditions.

Raising global awareness can be a difficult challenge, but advocacy is an essential part of getting this message across.

Our website has many resources for patients and medical health professionals including videos, information sheets, a symptoms tracker, medical alert cards and much more and has a very full page of free downloads too, some in different languages!

The number of people accessing the information on our website has risen steadily each year – from 10,000 in 2020, to over 50,000 this year to date and over 180,000 in total so far!

If you ever wondered how many people and how many countries our website reaches and how it impacts patients' lives, just take a look at the amazing statistics and patient quote below!

### WHEN DEDICATED VOLUNTEERS AND WORLD-CLASS MEDICAL EXPERTS WORK TOGETHER, AMAZING THINGS HAPPEN!

*"INOCA International gave me hope when I felt completely dismissed. Their resources helped me get proper diagnosis and care."*

180,000+  
INOCA International  
website views



170 out of 193  
Countries Reached  
88%



54 Language  
Groups



5,000+  
Online Support  
Group Members



# INOCA - NOT JUST A FEMALE PROBLEM

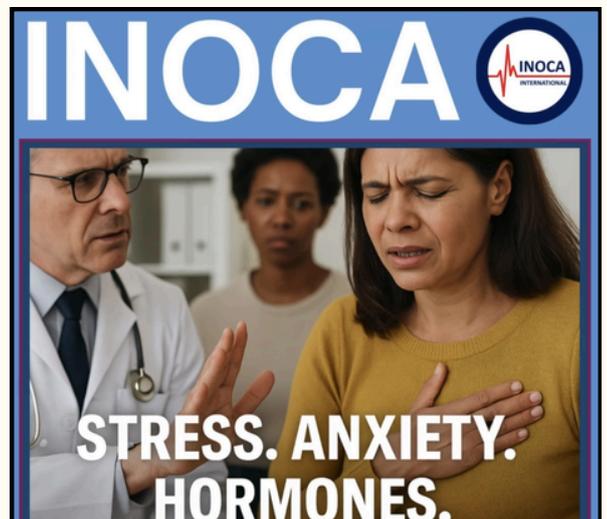
**CONSTANT FATIGUE.  
CHEST PAIN.  
SHORTNESS OF BREATH.**



From a young athlete, a fit and healthy mother, to an older man, INOCA can affect anyone, yet, it is still often overwhelmingly viewed as a woman's condition. The WISE study showed that the gender divide in INOCA is not as marked as had been previously thought, so it is important to remember that men can get INOCA too!

INOCA International continues to undertake the critical and important work to root out bias in growing INOCA research and care. The goal is clear: That we don't repeat the cause of the decades-long struggle for equity that the women's heart health community has fought to overcome in other cardiac conditions. Some may reasonably argue that we are already there but the overarching message is still the same.

Ending this bias in Heart Health Care is essential to saving lives, regardless of gender – and you can help! (see next page for how)



[www.INOCAInternational.com](http://www.INOCAInternational.com)

# HOW YOU CAN HELP!

**Join Our Community** and connect with over 5,000 patients worldwide -  
<https://www.facebook.com/groups/287960691855039>

**Join our INOCA Facebook page** and follow us on our social media platforms -  
<https://www.facebook.com/groups/491395198372627>

**Share this newsletter**, tag healthcare professionals in posts and use **#INOCA**

**Support Our Work** and find out more about partnership opportunities  
[contact@inocainternational.com](mailto:contact@inocainternational.com)

**Subscribe to our quarterly INOCA Newsletter** - and share it with a family member or friend!

**Because together - we are changing the reality for INOCA patients worldwide**

## THANK YOU!

At INOCA International we are constantly working behind the scenes on projects, studies and trials and attending global conferences and meetings to help raise awareness of the INOCA patient journey. However, our work is only made possible because of the truly extraordinary collaboration and support we receive.

OUR SINCERE GRATITUDE GOES TO:

☀️ **Our Medical Advisory Board** - Thank you for volunteering your world-class expertise, time, and dedication - and special thanks too, to all who participated at ESC Congress Meeting and Booth and in our NHS videos!

☀️ **Our Funders** - World Heart Federation, Translational Medicine Academy, Medical Education Global Solutions, and all the patients and professionals who so very kindly raise funds, make donations and volunteer their time to support our mission.

### ☀️ **Our Recent Project Partners** -

- The UK NHS
- ESC Congress
- World Heart Federation
- Dr Petr Kala
- Ms Parvoleta Petrova
- Servier
- Professor Alta Schutte
- Ms Inese Maurina

and to all those currently working with us on projects yet to be announced!

☀️ **Our Volunteers** - From translations, to this newsletter, to social media, to event support and to so much more, patient or professional, your generous contributions make everything possible!

☀️ **Healthcare Professionals** - Thank you to every doctor, nurse, researcher, and clinician who is working to improve INOCA awareness and care.

☀️ **Our Patient Community** 5,000+ strong and growing - your voices, your stories, your experiences and your support, inspire everything we do.

☀️ **Rebecca** - Thank you for bravely sharing your story in our newsletter!

☀️ **Families & Supporters** - Thank you for supporting our volunteers while they gift their time to serve others.

To everyone who contributes, supports, believes, and participates -

T H A N K

Y O U

This, as with everything else we do here at INOCA International, is a collaborative achievement with the generosity of so very many others.

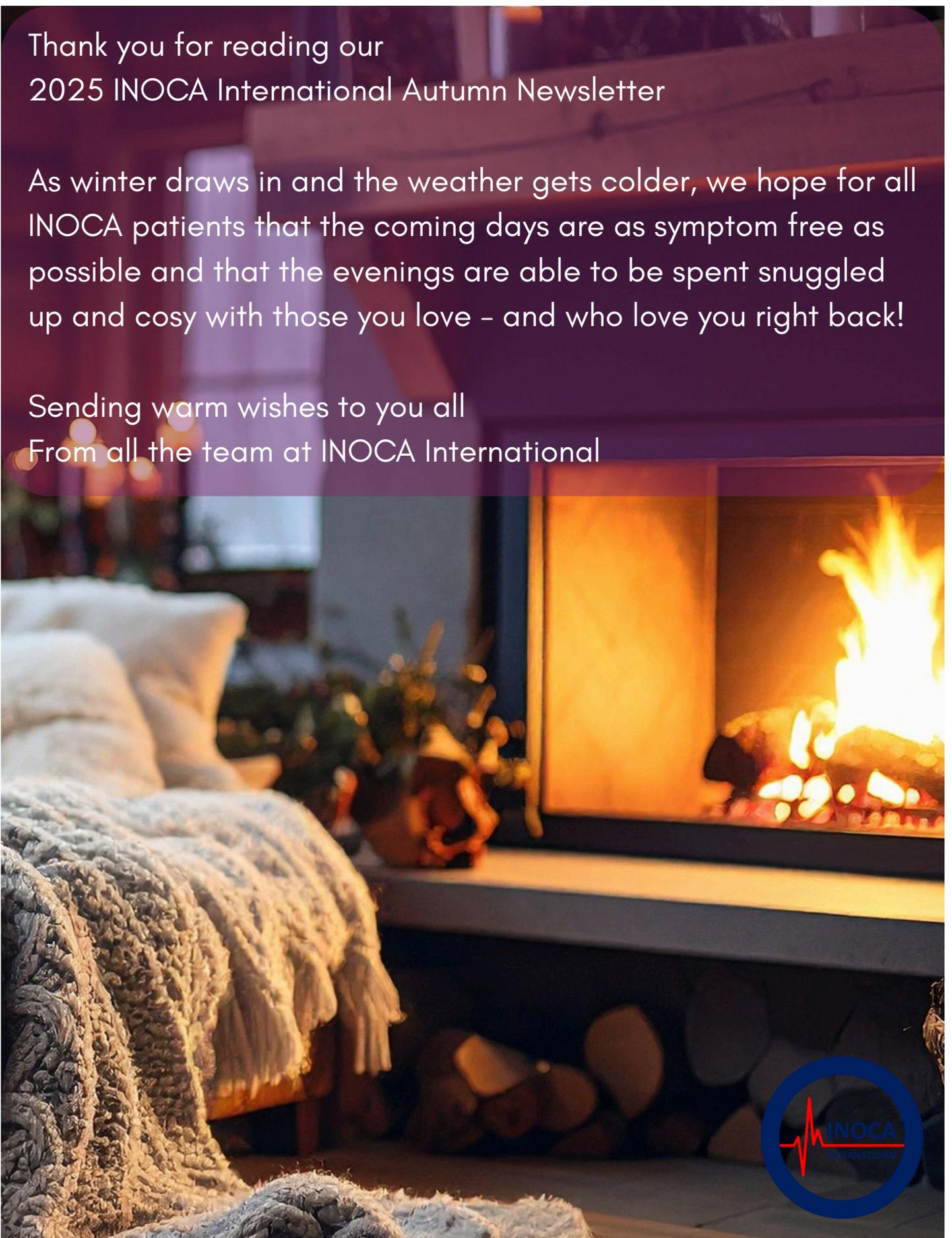
### **NEXT NEWSLETTER: WINTER 2025/26**

Until then, you can stay connected [via our website](http://www.INOCAInternational.com) at [www.INOCAInternational.com](http://www.INOCAInternational.com)  
[Via our social media platforms](#) (QR codes on front cover)  
[Via email](mailto:contact@inocainternational.com)  
[contact@inocainternational.com](mailto:contact@inocainternational.com)

Thank you for reading our  
2025 INOCA International Autumn Newsletter

As winter draws in and the weather gets colder, we hope for all INOCA patients that the coming days are as symptom free as possible and that the evenings are able to be spent snuggled up and cosy with those you love – and who love you right back!

Sending warm wishes to you all  
From all the team at INOCA International



[www.INOCAInternational.com](http://www.INOCAInternational.com)

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