



Season's Greetings from all the team at INOCA INTERNATIONAL





A very warm welcome to the 2020 INOCA International Christmas Newsletter

2020 has perhaps been one of the most difficult years in recent times and many of those reading this newsletter will have had COVID-19 themselves or will know family members, friends or colleagues who have contracted the virus. Some have also lost family members and friends in varying circumstances, so we begin our Christmas Newsletter with a heartfelt tribute to all those who have passed away this year, to all those who have lost loved ones and to all those who been affected by the COVID 19 Pandemic.

Our thoughts are with you and for those who follow a faith, our prayers are with you too.

COVID-19

It seems almost impossible to find a positive from Covid-19 as I am sure most people reading this would agree. Covid-19 seems to be a sneaky virus. Those who develop it can suffer from a wide-range of symptoms from the very mild to the very severe often making it very difficult for medical professionals to figure out what is going on and to develop optimal treatment regimes

While many patients do make a full recovery, others sadly do not and can sometimes be left with longer term symptoms – a condition now referred to as Long Covid.

There are major challenges in dealing with a condition where little is known about it (something INOCA patients are also very familiar with) and the possibility of microvascular involvement in Covid-19 is now being considered, with a number of publications in scientific and medical journals proposing a possible link between Covid-19 and coronary microvascular dysfunction.

If there is any silver lining to the Covid-19 Pandemic, it is perhaps the possibility that it might somehow shine a brighter light on coronary microvascular dysfunction bringing it out from the fringes and into the mainstream.

Worldwide interest in COVID-19 could potentially result in a much greater awareness of INOCA conditions, encouraging further research and clinical trials, which might then also accelerate the development of effective treatment for the still difficult to treat and challenging conditions of INOCA.

VACCINES

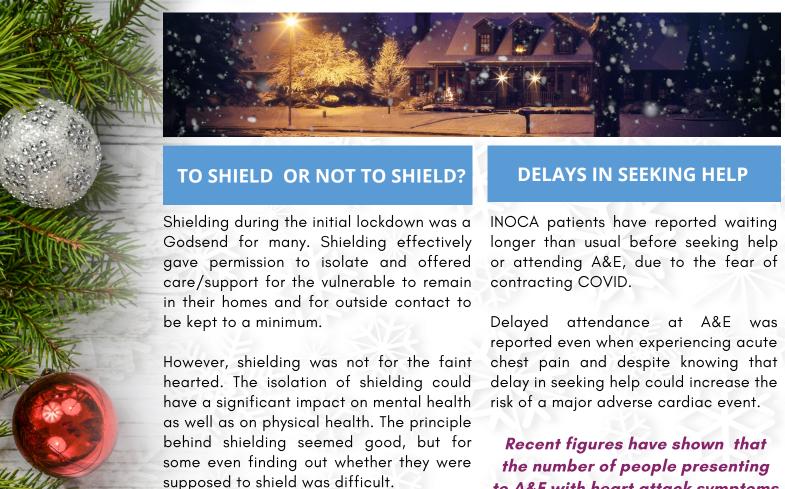
After many months there at last seems to be some light at the end of the tunnel. The UK say they are now on the cusp of an effective vaccine. At the time of writing there are three different vaccines at the point of being ready for regulatory approval, with even more in development.

It is claimed that the leading vaccines have efficacy of around 95% and 90% (subject to a specific dosing regime) and just today (2nd December), it has been announced that approval has now been given for one of the vaccines to be used in the UK from as early as next week.

This really is an extraordinary achievement. A process that would normally take many years has taken just 10 months – a worldwide collaboration of the finest scientific and medical minds on an epic scale to be acknowledged and applauded.

There is a saying 'Where there is a will there is a way' – a motto that also sits well with what INOCA International are trying to achieve – but to witness this level of commitment and expertise on a global scale is really very humbling.

Yes indeed, there is truly light at the end of the tunnel - and it is a light we very much welcome!



Some INOCA patients have reported being

recommended to shield by their GP or Consultant and were able to get letters to

support this, while others fell by the

wayside with, in many case, INOCA

patients being told they did not need to

from some of the medical profession that contracting COVID19 could indeed leave INOCA patients at increased risk

developing serious complications.

second

announced the advice seemed to be that shielding was no longer required. In the recent words of one of our INOCA

patient's care teams - 'I cannot help but wonder if anyone has told the Virus that?'

This way

That way

lockdown

the

When

to A&E with heart attack symptoms was down by around 50% compared to pre-Covid figures.

It will take some time for treatment centres to catch up on the backlog of appointments and surgeries that are an added consequence of COVID-19.



MENTAL HEALTH

The impact of COVID-19, of shielding and of late presentations to A&E may well have implications far into the future for patients and for our healthcare systems, affecting not just the physical well being of those waiting for surgeries and treatments, but also - and perhaps even to a greater degree - the mental health and well being of those who have shielded or self isolated and who have in some instances been without any human interaction for many months.



THE INOCA WELL-BEING ADVENT CALENDAR

After such a difficult year it is perhaps even more important than ever that we take care of our personal well being. One of the team at INOCA International has very kindly created this Well-Being Advent Calendar. We hope you like it as much as we do and we hope it will help YOU to take care of yourself better, during the busy Christmas holidays!

DAY 1 - ITS OK NOT TO BE OKAY

You know that wonderful advice you would give to a friend? Yes, that advice that says, don't be so hard on yourself. It's ok to not be ok? Well, you deserve that advice from yourself too! Be self-compassionate. If today is a day when all you can manage is having a shower, then so be it!

DAY 2 - FIND WHAT CALMS YOUR SOUL

For some people it could be going for a walk in nature, for others it could be listening to your favourite piece of music. Whatever it is, try and make time for it in your daily routine.

DAY 3 - TRY TO BE ACTIVE

I don't mean join a gym or even do strenuous exercise (although I must admit, I do enjoy a bit of Mr Motivator in the morning...even if it is just to see what he is wearing!) I mean things like don't take all your washing upstairs at once, take 3 or 4 trips throughout the day. Maybe go outside for a short walk around the block, or a potter in the garden.

DAY 4 - TRY TO GET ENOUGH SLEEP

This is such a simple thing to really help with your wellbeing. For many of us, lack of sleep can be a trigger for our angina to hit us with force. If you can't sleep during the night but can rest during the day, then do it. Take a nap. Listen to your body. It knows when it needs to rest. (We sometimes can't hear it through the noise of the modern world).



DAY 5 - TRY TO RELAX AND REDUCE STRESS

Yeah, right...that's easier said than done...Or is it? If you take a few minutes out of every day to just focus on your breathing. Trying to not listen to your thoughts that could be running round your head at 100 miles an hour, will really help!

DAY 6 - TRY TO EAT AT REGULAR INTERVALS

Feeding your body with nutrient rich fruits and vegetables. Honestly, I am not a chef by any stretch of the imagination. I can even burn beans on toast! Trying new things, getting creative and maybe just throwing everything in a pan, crossing your fingers and hoping for the best can sometimes make a tasty meal!

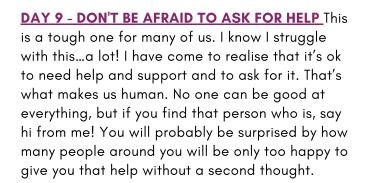
DAY 7 - STAY CONNECTED WITH OTHERS

I know this is a really tough one, especially at the moment. Remember with technology, you can see someone and interact too. Maybe write a letter, the old-fashioned ways still work! Who doesn't love to receive a card through the post. It shows someone is thinking of you!

DAY 8 - DON'T AIM FOR PERFECTION

Perfection rarely exists. I was always taught that 'practice makes perfect'. Let me tell you, as I cleaned up from my 5th attempt of making the perfect birthday cake for one of my son's. This is NOT always true! Did he mind that the hedgehog cake looked like road kill? Nope. He loved the fact that his mum had taken the time to make him a cake. (In my defence, it did taste yummy though!)





DAY 10 - ITS OK TO SAY NO

This is another one I struggle with too, as I'm sure many of you reading this will relate to. Did you know that I have never held a grudge, or fallen out with someone who was honest and said they couldn't do what I had asked? Ok there's a way of saying no nicely, but know your own limits. Remember, you need to make sure you are ok before you can help others.

DAY 11 - LET IT GO

Yes, I know most of you sang this tip, and if you didn't, look it up it's a good song. We all will have that one thing that keeps us awake at night. That thing that eats us up on the inside. If you ask yourself, who is that really hurting? The chances are it's you. Unfortunately, we can't change what has already happened. Many a time I wish we could. Forgiveness is a journey. It doesn't mean you've forgotten what has happened, it just means you have decided not to let it rob you of your future, as well as your past.

DAY 12 - FIND THINGS TO BE GRATEFUL FOR

Find things to be grateful for. This can be a tough one, but I find that writing a gratitude journal helps me get through the darkest of days. It doesn't have to be anything MAJOR – I once wrote that I was grateful for finding one more galaxy in a tub of celebrations! Try to hold on in the bad moments to the fact that whatever emotion you are experiencing, it will pass. No one is happy all the time, no one is sad all the time – even though it may feel like it some days/weeks/months. A gratitude journal helps you find the little rays of light and opens the way for them to shine brighter to illuminate your day





Look after yourself this Christmas - for you and for all your family



Christmas is a time for family and YOU are part of that family - so save some time for YOU!

COFFEE BREAK IDEAS FROM PATIENTS - PAGE 1

Wellbeing Wordsearch

There are 15 hidden words relating to wellbeing. (Answers will be given in the next newsletter) The first email received with all the correct answers gets a mention in the January Newsletter! Contact details can be found at www.INOCAInternational.com

Fancy a healthy alternative to alcoholic mulled wine?

(Recipe courtesy of Nutritional Therapist Shakela Shan - Thank You Shakela!)

Spiced Non-Alcoholic Mulled Wine Recipe - This warming drink

is perfect to share and enjoy over the festive season. The wonderful scent of cinnamon, cloves and star anise will fill your home with comforting aromatic spices. It is packed with anti-inflammatory properties and nourishing ingredients to support digestion and immune resilience over the winter months.

- Ingredients:
 150g pomegranate, blackberries and raspberries
- 250ml pure apple juice 250ml pure cranberry juice
- 1" piece of ginger root (grated)
- 2 cinnamon sticks
- 5 cloves
- 2 star anise
- 1 orange (sliced)
- 1 tablespoon of honey (optional)

- To a pan add all of the above ingredients (berries, fruit juice, spices, sliced oranges and
- Heat the mixture on a low heat for 15 minutes allowing the spices to gently infuse. Stir occasionally and try not to let it boil.
- Remove from the heat, strain into a glass or your favourite mug and serve hot...enjoy!

Adjust your recipe by adding your own variations- my favourites are sliced lemon, cranberries, black pepper, cardamom, nutmeg and lemon balm.

THE BRITISH HEART FOUNDATION has a superb recipe finder with lots of healthy eating ideas! You can search for meals by ingredient, dietary requirement, country of origin etc. Check it out! (just copy and paste the link below into your search bar).

https://www.bhf.org.uk/informationsupport/support/he althy-living/healthy-eating/recipe-finder

A POEM FROM ONE OF OUR MEMBERS

Phew what a year!

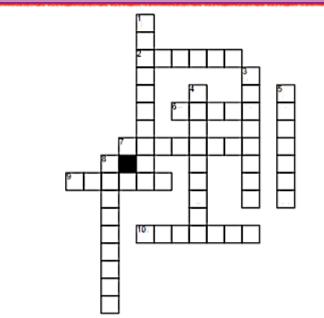
The waves this year have been rough and tough to ride, It's not been easy, always having to hide, The support of each other-should fill our hearts with pride, Praying for those who have lost and those that have died.

> Sometimes our resolve is put to the test, We really have tried to do our best, So have faith, believe, stay safe in your nest, It's in God's hands-let him do the rest.

Let the bells ring out loud and clear, We are going to face 2021 without fear, There is help and hope for those that seek, We may have to wait, but we won't grow weak.

The end of the rainbow is not far out of sight, So keep going and push on with all of your might, When you are in your bed in the dark of night, Remember that life is worth all of this fight.

FESTIVELY THEMED CROSSWORD ANYONE?



- 2. Fried potato pancakes eaten during Hanukkah
- 6. A Polish desert
- 7. Traditionally left for Santa
- 9. Christmas bird
- What is Bûche de Noël

- 1. What is Glühwein
- 3. Biscuits made with ground almonds
- 4. European Christmas dessert
- A sweet desert associated with Turkey
- 8. Traditional sauce served with dinner

COFFEE BREAK IDEAS FROM PATIENTS - PAGE 2

HOW MANY DIFFERENCES CAN YOU FIND IN THE TWO PHOTOGRAPHS BELOW?

(First correct entry received via the website contact email gets a mention in the next Newsletter!)





STEPS TO A

CALMER

HAPPIER

HEALTHIER

BOOK OF THE MONTH

The Stress Solution

by Dr. Rangan Chatterjee THE STRESS An excellent read. Very engaging and easy to SOLUTION follow. With INOCA Conditions, understanding and managing stress is extremely important. Dr. Chatterjee explains current research findings and how to incorporate easy changes into daily life in many easy and thoroughly enjoyable ways. (9/10 recommendation).

Do you have a family recipe, a fundraising story or a book recommendation you would like to share in the newsletter? You can send it to us via the 'contact us' link on the website at www.INOCAInternational.com

Please remember that nothing in any part of 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 own medical practitioner before trying any new medications or therapies and before changing any of your current routines or usual practices.

Just one of the fundraising stories sent in to us

My husband came home from walking the dog and held up a lost car key! Oh No! Someone was going to be really fed up.lt was also tipping it down with rain! I quickly posted on Facebook to alert the locals, but couldn't settle knowing someone somewhere was worried, soaking wet and facing huge difficulties in getting home, So off I went in an attempt to re unite the key with the owner. I checked all the places where a hikers car might be secreted. Success! It responded satisfyingly with the familiar beep beep and flashing lights. There was a number on the van but had forgotten my phone in the rush, so I asked a stranger if he could help. We managed to contact the owner - he was 5 miles away hunting for his key in the middle a torrential downpour! A rendezvous was arranged to re unite key and owner. As I prepared to drive off, he did that sneaky grandmother manoeuvre and shoved money through the window. I thanked him and said I wouldn't accept it for myself but would gratefully forward it on, in the spirit of Christmas kindness to the cause close to my heart - INOCA!

LOOKING BACK AT 2020

2020 has been a very challenging year, but INOCA International are delighted to report the following very positive achievements.

The brand new INOCA International Website

The brand new INOCA International Twitter page

with over 1,300 followers, many of them Cardiologists and medical professionals!

The launch of the INOCA CAFE

A space where patients and professionals come to relax and chat - not just about INOCA but also about other things too!

The INOCA Cafe is also the venue for our <u>Cafe Conversations</u>, where we welcome our guest speakers and hold our <u>Quiz Nights</u>.

The INOCA International Newsletter

A quarterly publication giving worldwide updates on INOCA and featuring a 'Spotlight' section for special guest articles and our regular 'Ask the GP' section.

The INOCA International Medical Advisory Board

Without doubt one of, if not THE most impressive Medical Advisory Board of any Patient led group, where each member is willing to help and wants the best possible care for INOCA patients around the world.

The addition of <u>3 more new pages to the INOCA International website</u> (all going live this month!)

'<u>Ask Our Experts</u>' - Our experts respond to your questions
'<u>Newsletter Archives</u>' instant access to past issues of the INOCA newsletter
<u>INOCA Insights</u> - the patient perspective, in live video format.

These are just a few of the wonderful things we have been able to achieve this year.

There are many other things which are in the pipeline and/or are under discussion – some of them very exciting indeed – and we look forward to bringing you more information on these just as soon as we can!

None of these amazing achievements would have been possible without the ongoing support and encouragement of our fellow patients, our superb Medical Advisory Board and the dedicated INOCA International team who continue to work behind the scenes for the benefit of INOCA patients worldwide.

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 education in INOCA conditions and each of us stand to benefit from this truly amazing, truly worthwhile and truly unique Patient Partnership.



We choose to look forward to 2021 with hope. Not just for a successful vaccine but also for renewed interest in research and understanding of all INOCA conditions.

2021 MEETING OF MINDS

We took the early decision to postpone the 2020 Meeting of Minds when news first broke about the COVID-19 Pandemic, but we are very much looking forward to bringing you details of the next INOCA International Meeting of Minds when the time is right.

TRIALLING OUR NEW ONLINE SELF-HELP GROUP

This month a small group of INOCA patients will be trialling a pilot scheme for an INOCA Self-Help group. If successful it is hoped we will be able to roll this out to INOCA patients in the New Year. If you are interested in the Self-Help Group please get in touch via the INOCA website at

www.INOCAInternational.com

FUNDRAISING

INOCA International do not fundraise, but we have many loyal and wonderful supporters who do! It is because of the generosity of our supporters and sponsors that we were able to fund the 2019 Meeting of Minds. As this year closes, we want to say a very special Thank You to all those who donated to 'A Heart With No Voice' - the INOCA patient fundraiser on the GoFundMe platform - and to thank each and every person who by their belief in us, made The Meeting of Minds possible.

SUMMER BALL

We also want to say a very special thank you to yet another very kind INOCA patient who spent many months organising a fabulous Fundraising Ball to be held in support of INOCA International. This too had to be postponed due to COVID, but I am delighted to report that the Fundraising Ball will also be re-arranged when the time is right. What a fantastic event for us all to look forward to!

We thought we would close this Special Edition Christmas Newsletter by sharing photos from just a few of the fantastic fundraising ideas from our superb INOCA International supporters! (Further details of these and of other fundraising events can be found on the INOCA Cafe)

Card Sales - Sponsored quiz nights - Equestrian Events - Clothes sales - Dinner Parties (pre-Covid) (Whether you donated a pound, a dollar or considerably more, your generosity made this happen!)



