

# Autumn 2024 Issue 18



**Stoma Support Group Working with St Mark's the National Bowel Hospital, CMH.**  
Incorporated with St Mark's Hospital Foundation Charity Registration No: 1140930

## *Dear Friends,*

As the daylight hours start to reduce and the night time starts to become longer and in some cases colder, Unfortunately the energy costs rise again. Please take care and keep as warm as you can.

While I was away on my break, I received a number of calls from people who needed help, of which hopefully I was able to point them in the right direction. However, one call I received, I was not able to make much headway before coming back. The disturbing call I had was reminiscent of a repeat of what was then the PCT, (Primary Care Trust), who was in charge of handing out monies to the NHS and kept a watchful eye on prescriptions. They in their wisdom did not understand the need for our appliances for the stomas we had and decided to cut by half what we needed. We invited them along to our coffee morning to explain the reasoning why such amounts were needed. We also had a stoma care nurse there to explain, this of course did not at the time make much difference and it took many meetings at board level for them to understand and make the change.

Since then, we have had the CCG, which was run by the GP's to run everything, after a few years they in turn blotted their copy books. We now have a new controlling group ICB (Integrated Care Board), I have written to them and I quote **"Thank you for your email. The Medicines Optimisation Team is currently developing a stoma prescribing guideline for prescribers in primary care, in collaboration with St Marks' stoma nurses. We hope this will help alleviate the issues you have described."**

**Regarding the cases you have highlighted, if there are particular GP practices in question, please share this information so we can liaise with them to further explore."**

Let us see if they are good at their word, although as at the present moment I am not sure who in the stoma care department they are talking to as there is nobody in charge as all of the lead nurses have left. I have also invited Atisha Sharma, lead pharmacist, to one of our coffee mornings so that we can express why our needs are so important to us so that we may have a quality of life.

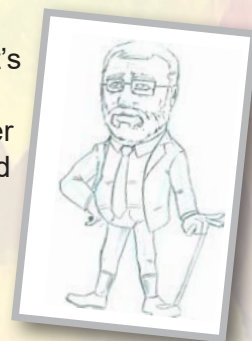
Congratulations are in order for Barry, our illustrious chair, as he has now set up a What's Up App, I think that's what it's called, for you all to be in touch.

I will try and get back down to up dating our web-site as soon as I can, but with a number of hospital appointments here there and everywhere, which are time consuming and hopefully not too many of them.

See you all at one of the coffee mornings,

Kind Regards

*Bob*



# **CARING WITH COMPASSION: The core values of a great carer:**

Caring for others is one of the most rewarding yet challenging professions.

In my years of using the hospitals as a patient, since before the time of the National Health Service and since the beginning of NHS, I have noticed a lot of changes in how the caring side has and is being portrayed now.

To be a good carer certain values and qualities are essential: respect, empathy, reliability, kindness, confidentiality, experience, and proper training.

However, the foundation of excellent care lies in understanding and practicing the 6 C's of caregiving: Care, Compassion, Competence, Communication, Courage, and Commitment. These principles ensure that clients receive the highest standard of care every day, regardless of the changes in the healthcare landscape.

## **CARE**

The goal is to provide the right care for each individual at every stage of their life. Carers and Nurses deliver care that improves the health and well-being of the entire community and underpins the commitment to treat each person with the utmost dedication, aiming for the best possible outcomes.

## **COMPASSION**

Compassion is not important; it is essential for delivering high quality care. It involves empathising with the individuals, respecting them, and treating them with dignity.

This empathy extends to colleagues and the broader community, fostering an environment where everyone is treated with respect, regardless of their background.

## **COMPETENCE**

Competence is about having the necessary knowledge and expertise to deliver effective care.

## **COMMUNICATION**

Communication is arguably the most vital of all of the 6C's. Effective communication builds strong, trusting relationships not only with the clients but with colleagues and other professionals involved in care. Good communication ensures that the care provided is co-ordinated and comprehensive. It involves more than just talking; it requires active listening, validating concerns and truly understanding the needs and preferences of those receiving care.



## COURAGE

Courage in caregiving means supporting individuals, especially in difficult or challenging situations. Address and raise concerns when necessary, ensuring that the care provided is safe and appropriate. That they also advocate for their clients, protect their wellbeing and are not afraid to speak up when something is not right.

## COMMITMENT

Commitment is the cornerstone of caring, dedication to improving the care and experiences of client.

These principles ensure that clients receive respectful, empathetic and reliable care. By focusing on these core values, carers can provide high-quality care that improves the health and wellbeing of individuals and communities. Whether a nurse working in a hospital or a carer working in the community, the quality of care should remain the same: dedication to caring for others with compassion and competence.

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**salts**  
HEALTHCARE

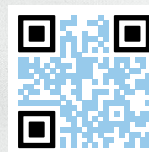
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## REGISTRATION FORM

Full Name: Mr /Mrs/ Ms.....

Address: .....

Post Code .....

Home telephone: .....

E/Mail:..... Mobile: .....

Date of Birth:.....

Please tick all that is relevant to you:

- ☐ Yes, please enrol me with immediate effect. My cheque of £5 (payable to St Marks Foundation (Ac /101)
- ☐ I am considering surgery.
- ☐ I had surgery in (year).....
- ☐ I have a friend /relative with a stoma and would like to introduce them.
- ☐ I am a stoma nurse / other professional interest.

My medical condition is/was:

- ☐ Ulcerative colitis ☐ Crohn's Disease (CD)
- ☐ Cancer ☐ Polyposis
- ☐ Other please state .....

Type of stoma:

- ☐ Colostomy ☐ Ileostomy ☐ Jejunostomy
- ☐ Urostomy
- ☐ Mitrofanoff ☐ Internal Pouch

My surgeon was/is.....

My surgery was at:.....

- ☐ Planned ☐ Emergency

Declaration: I am happy for these details to be recorded on the Inside Out data base and to talk to other members about my experiences in the hope it will help them.

SIGNED: ..... DATE:.....

Send to [secretary@iossg.org.uk](mailto:secretary@iossg.org.uk)



## CROHN'S:

While I was away in Portugal this item came up on the news and I thought that it may be of interest to some of you

### U.S. Army and Portuguese researchers. The result: a “revolutionary” discovery to prevent Crohn’s disease

28 August, 2024 - 18:44 • Lara Castro

International research with Portuguese origin took seven years and culminated in a discovery that “opens doors for the prediction and prevention of Crohn’s disease”.

In Portugal, **about 25 thousand people are diagnosed with Crohn’s disease** - an inflammatory bowel disease that, once diagnosed, **lasts a lifetime**. Characterized by being a highly “debilitating and disabling” disease, it mainly affects young people of working age. Common symptoms are diarrhoea, abdominal pain, fatigue, weight loss, among others.

In recent years, in Portugal and around the world, there has been a **growing incidence of this pathology that still has no cure**.

An **international investigation with Portuguese origin** has discovered an alteration in the blood that **may predict who will develop Crohn’s disease years before its development**.

To **Renascença**, Salomé Pinho, researcher and coordinator of the study, explains that “the transformative character” of the discovery was “the ability to identify a molecular change in the blood - a biomarker - that can predict who will develop Crohn’s disease years before its development and diagnosis”.

The researcher believes that the discovery **“can have a transformative impact on medicine and the clinical and therapeutic management of these patients”**.

Since 2017, this team from the Institute for Research and Innovation in Health of the University of Porto (i3S), in collaboration with the US Department of Defense, has studied for the first time what happens in the transition from health to disease.

To do this, **the team had access to the blood of the US Army soldiers**, at a pre-clinical stage, that is, before the existence of the disease was known.

Since these soldiers are monitored clinically every year, with blood tests, **they were able to access thousands of serums - a constituent of blood - up to six years before diagnosis**, four years before, two years before diagnosis.

These samples **allowed the team to “identify a molecular change in an antibody”**, explains Salomé Pinho. This alteration in the blood was only verified

in individuals who years later developed Crohn's disease.

"What we identified was a glycoform, that is, these antibodies are usually modified, they are decorated with sugars, it is not conventional sugar, they are chemically more complex sugars and, therefore, we found that individuals who developed Crohn's disease years later had an alteration in the composition of these sugars", he explained.

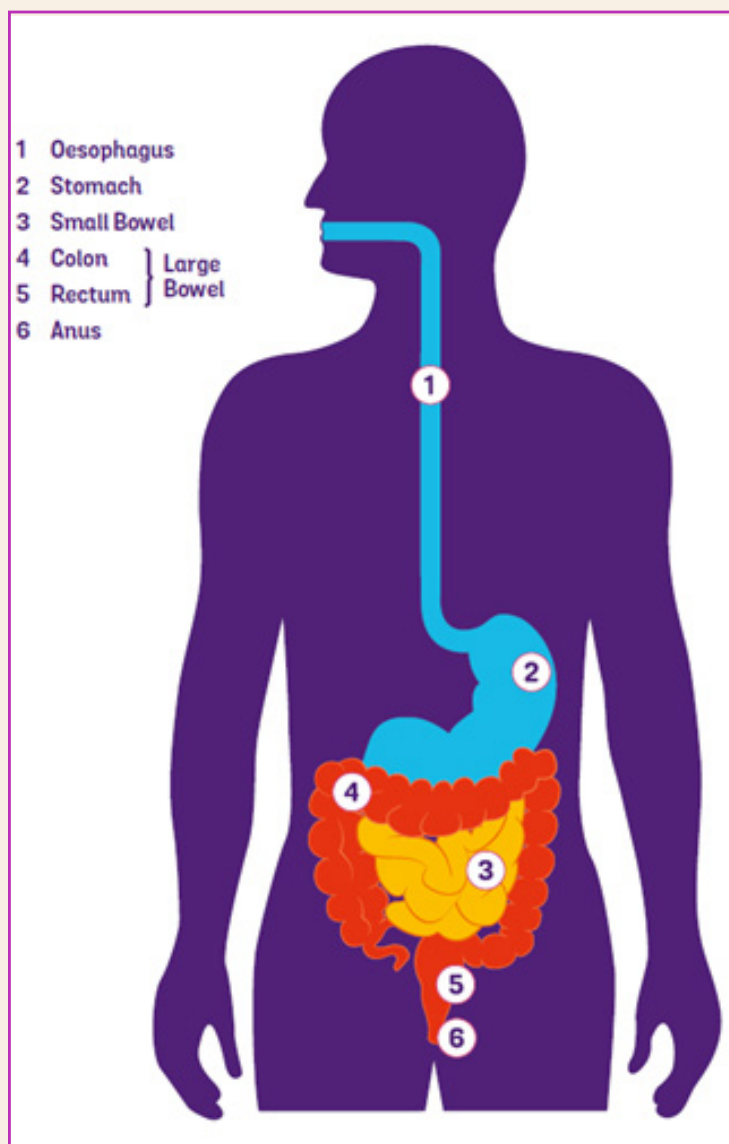
This glycoform can be detected through a blood sample. The researcher believes that the discovery "will be revolutionary for the prediction and prevention of Crohn's disease".

"If we can predict and stratify the risk of those who will develop Crohn's disease years before it develops, we can prevent and we can try to intercept what is one of the factors that lead to the ignition of the inflammatory process," he added.

**The next step is to understand the real causes that lead to this molecular change**, and then try to block the assembly of this inflammatory process that is still happening almost a decade before the diagnosis.

Within the scope of the **European project Glycan Trigger**, also led by Salomé Pinho, and based on these findings **a clinical trial will start in 2025 with patients with Crohn's Disease who have surgically removed part of the intestine.**

The objective is to try to intervene in these patients in order to **"prevent the restart of the inflammatory process"**, the recurrence of the disease, something common in patients with Crohn's. The recruitment of patients will begin at Hospital da Luz de Lisboa.



**Hi Everyone,**

sorry I was not able to make the last coffee morning as I was away with my good lady, hope you are all keeping well. We are trying to keep in touch with you via WhatsApp.

For those of you who do not have an iPhone, you can download it on the analogue phones, in your search in the mobile put what's app and it should come up for you to download. I have got most of your mobile numbers, but if you haven't yet joined us let me know and I will include you.

This way we can all keep in touch with each other. I know we still are having trouble with the Zoom connection, plus we have a new Id and Pass code for the next 12 months. Please contact me on What's App or via Email [barcap23@outlook.com](mailto:barcap23@outlook.com)

I hope those of you who use Zoom will find the connection better this year. I am hoping to arrange another lunch at Hatch End in October, so if you're interested please let me know, and then I can arrange a day that is suitable for everyone interested.

Look forward in to seeing you all again soon.

Kind Regards

*Barry Caplan* (Chair)



## **SECURE START**

### **Secure Start Advisors**

0800 376 1310

Mon – Fri 08:30am – 17:00pm

### **Secure Start Weekend on-call nurse line**

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Sat – Sun & Bank Holidays

09:00am – 13:30pm

### **Join our community:**

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\*CeraPlus skin barriers contain the Remois technology of Alcare Co., Ltd.



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**CHARITY NUMBER 1140930**

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Account name: St Marks Hospital Foundation

Account number 00085102                      Sort code 40 - 52 - 40

NB: When completed this form should be returned to:

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Room ENT-25, St Mark's Hospital,  
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|   | Code   | Qty    | Starter hole | Seal diameter |
|---|--------|--------|--------------|---------------|
|  | 071-20 | 30/box | 20 mm        | 45 mm         |
|   | 071-30 |        | 30 mm        | 57.5 mm       |
|   | 071-40 |        | 40 mm        | 70 mm         |

|   | Code   | Qty    | Starter hole | Seal diameter |
|---|--------|--------|--------------|---------------|
|  | 072-48 | 10/box | 18 mm        | 48 mm         |
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# COFFEE MORNINGS



## Coffee Mornings 2024

| DATE                       | VENUE        | COMPANY         | SPEAKER             |
|----------------------------|--------------|-----------------|---------------------|
|                            | Summer       | Holidays        |                     |
| September 4 <sup>th</sup>  | Masonic Hall | Salts           | Shelly Rust/ Janice |
| September 18 <sup>th</sup> | Masonic Hall | B Braun         | Tony Clare          |
| October 2 <sup>nd</sup>    | Masonic Hall | Dansac          | Jules Plumb         |
| October 16 <sup>th</sup>   | Masonic Hall | Clinimed        | Paul Fox            |
| October 30 <sup>th</sup>   | Masonic Hall | Oakmed          | Andrea Thomas       |
| November 13 <sup>th</sup>  | Masonic Hall | Hollister       | Laura Savage        |
| November 27 <sup>th</sup>  | Masonic Hall | Suportx         | Maria Manousi       |
| December 11 <sup>th</sup>  | Masonic Hall | Christmas Party | AGM                 |

Zoom meeting for those of you are unable to be with us in our coffee morning in person. Once you have established contact it will ask you for a meeting ID Number email: [barcap23@outlook.com](mailto:barcap23@outlook.com) and it will be forward on to you, to establish full contact and join in.

Everyone is welcome to come along to our meetings which are on every other Wednesday at the Masonic Hall, Northwick Circle, Harrow HA3 0EL. **10:00am till mid-day**

## Coffee Mornings 2025

| DATE                      | VENUE        | COMPANY | SPEAKER   |
|---------------------------|--------------|---------|-----------|
| 8 <sup>th</sup> January   | Masonic Hall | TBA     |           |
| 15 <sup>th</sup> January  | "            | CUI     | Emly      |
| 29 <sup>th</sup> January  | "            | TBA     |           |
| 12tg February             | "            | Salts   | Shelly    |
| 26 <sup>th</sup> February | "            | TBA     |           |
| 12 <sup>th</sup> March    | "            | Ostique | Stephaney |
|                           |              |         |           |

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## Useful Contacts:

|                               |  |
|-------------------------------|--|
| Stoma Care<br>(answer phone)  | 02084532196  |
| Stoma Care<br>(generic Email) | <a href="mailto:LNWH-tr.stomacare@nhs.net">LNWH-tr.stomacare@nhs.net</a> |
| Pouch Care<br>(answer phone)  | 02084532099  |
| Gladstone Ward<br>CMH         | 02084532027  |

|  |  |
|--|--|
| Chair: Barry Caplan                            | <a href="mailto:barcap23@outlook.com">barcap23@outlook.com</a>         |
| Vice Chair/Secretary:<br>Diane Owen            | <a href="mailto:diane_owen@hotmail.co.uk">diane_owen@hotmail.co.uk</a> |
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| President/Co-Founder:<br>Bob Azevedo E Gilbert | <a href="mailto:bob@iossg.org.uk">bob@iossg.org.uk</a><br>07777667367  |

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Sat – Sun & Bank Holidays 09:00am to 13:30pm **0800 592 202**. You can enrol at any time  
either by using those numbers or [www.securestart.co.uk](http://www.securestart.co.uk)