

# **Minutes of the Tenth Meeting and AGM of the Cross Party Group on Inflammatory Bowel Disease (IBD)**

**Wednesday 22<sup>nd</sup> February 2020, 6-8pm**

**Committee Room 6 the Scottish Parliament**

## **1. Welcome and apologies**

Pauline McNeil MSP welcomed everyone to the meeting and it was agreed to hold the formal AGM business at the start of the meeting.

In Attendance:

Pauline McNeill MSP  
Liam McArthur MSP  
Dr Ian Arnott  
Dr Dagmar Kastner  
Dr Alaa Jalall  
Elaine Steven  
Nancy Greig  
David Pratt  
Edmund Murray  
Amy Bednarz  
Matthew Hilfirty

Apologies were received from:

Clare Adamson MSP  
Neil Findlay MSP  
Prof David Wilson  
Dr Dan Gaya  
Kirsty Gibson  
Paul Johnson  
Angus McLean  
Gail Grant  
Janice Taylor  
Carolyn Duncan  
Rachel Hayward  
Roisin Robertson  
Dr Ian Arnott  
Lis Bardell

## **2. Election of office bearers for 2020**

All previous office bearers were unanimously re-elected. Pauline McNeill MSP as Convener, Clare Adamson as Deputy Convener and Dr Ian Arnott as non- MSP Deputy Convener.

Crohn's & Colitis UK will continue to provide secretariat support.

A draft Annual Return will be circulated to members to provide any amendments.

### **3. Minutes of 2<sup>nd</sup> October 2019 and actions**

The minutes were agreed and accepted by all present.

### **4. Update from Meeting with The Minister for Public Health Sport and Wellbeing, 18th December 2019**

Pauline updated members on this meeting with Joe Fitzpatrick MSP, Deputy Minister for Public Health. The meeting had been attended by Pauline and Elaine Steven from Crohn's and Colitis UK. It covered:

- The new IBD Standards and uptake of the Benchmarking Tool in Scottish IBD services.
- Increasing prevalence of IBD in Scotland.
- Knowledge of IBD, including paediatric IBD among GPs.
- The need for Ministers to understand the seriousness of IBD and to commit to action to improve the provision of services.

Elaine noted that it had been a positive meeting and that a number of actions will be taken forward. The Clinical Priorities Unit will liaise with the Education directorate and with Crohn's & Colitis UK to explore how information about IBD materials could be made IBD available to schools.

It was highlighted that resources for schools and higher and further education institutions already exist (produced by Crohn's & Colitis UK) and it would simply be a case of signposting to them.

Pauline said that she was really pleased with the meeting outcomes and will follow up with a letter to the Minister about signposting to resources.

During the meeting Elaine had also discussed inviting representatives from the Scottish Access Collaborative and re-inviting Jeff Ace, Chair of the NHS Chief Executives Group to a future Cross Party Group meeting to hear about the results of the IBD UK Benchmarking tools (possibly the September meeting).

David Pratt noted that it would be prudent to engage with the Scottish Access Collaborative ASAP with a choice of two dates to ensure one of them would be suitable. The work plan could then be adjusted accordingly.

Joe Fitzpatrick also suggested that consideration should be given as to how the patient voice could be included in the SAC Gastro work

Pauline is still keen for either the Minister for Public Health or the Cabinet Secretary for Health and Sport to attend a future meeting of the Cross Party Group in person.

### **5. Discussion- topics for 2020 work plan**

A draft work plan for the next three meetings in 2020 had been tabled. Pauline invited members to comment and suggest other topics that they would wish the group to cover.

Edmund suggested a celebration of the work of the Cross Party Group and its achievements over the last three years. Pauline agreed this would be a good idea. This could be an exhibition stand or a reception in a committee room. Pauline pointed to the awareness raising activities taking place in Parliament that day around Monica Lennon's Private Members Bill on period poverty and free period products as a good example of this sort of activity.

**Action: All to consider a celebration event/ activity around Crohn's and Colitis Awareness Week in December (Wed 2<sup>nd</sup> December) and requirements in terms of a room, equipment and resources.**

Dr Dagmar Kastner raised the issue of patients being copied into their clinic letters as an important tool for self-management. In her experience the practice is becoming more common, particularly when clinicians have come from a hospital in England where this already seems to be the norm. Letters copying in parents can be useful for liaison with schools and can include advice for schools about the nature of the child's condition and reasonable adjustments around access to toilets, time off for appointments, extra time in exams etc.

David Pratt highlighted the recent report from the Royal College of Physicians (RCP) which suggests clinicians should copy patients into letters. This is an issue which has also been discussed as part of the NHS Lothian community IBD service improvement project.

Amy Bednarz said she would like to see clinic letters including links to further information from Crohn's & Colitis UK. This would also be a useful way of signposting teachers to information (if parents choose to discuss the clinic letter with their child's school).

Dr Kastner said that at Ninewells Hospital they have a pack for families with Crohn's & Colitis UK and CICRA leaflets. They can also ask a nurse to go into schools to speak to staff. It was suggested that sometimes information may only go to a guidance teacher and does not filter through to all other subject teachers in secondary school.

Elaine reminded the group that giving out and signposting to information is part of self-management, as is the care planning process.

Dagmar asked patients present whether they prefer a clinic letter to be addressed to them directly. All agreed with this. Dagmar called for a 'Once for Scotland' approach to clinic letters.

Pauline explained that her niece had been asked to leave a college course and it would have been helpful to have had a letter explaining her needs. She noted that this matter was relevant to many other Cross Party Groups – the definition of a cross-cutting issue. She suggested putting a call out to other health-related Cross-Party Groups to hold a joint meeting around the recommendations from the RCP's

report, with a focus on support for self-management. David also suggested inviting the Scottish Access Collaborative to this meeting as they are working with the Royal Colleges on patient pathways.

**Action: Elaine and Pauline to explore possibility of an additional meeting or making one of the scheduled meetings on this topic, gauging interest from other relevant Cross Party Groups, the RCP and SAC.**

## **6. Patient Experience of Diagnosis and Faecal Calprotectin testing- Amy Bednarz**

Amy introduced herself. She has pancolitis and was diagnosed 27 years ago. She still has her entire large intestine. She explained that she was going to talk about faecal calprotectin (FC) testing. FC is a protein biomarker that is increased when there is increased inflammation in a person's stool sample.

About 3 months ago Amy had a flare and was tested for FC levels. She was also asked to produce a sample to test for infection. Her FC levels are normally tested every 6 months while she is on the drug Vedolizumab. These levels had been decreasing since she started this treatment, until the time of this flare-up.

Amy went to the ward where she has infusions for a sample kit. She chose to go to the ward as it was slightly closer than her GP surgery.

In advance of this talk, Amy had asked the ward and her GP for demonstration kits to show members what patients are given to collect a stool sample.

With the help of Edmund and some yoghurt to represent loose stool, Amy demonstrated the difference between the kit provided by the hospital which included plastic gloves and a tinfoil tray and the GP's kit which was only a small plastic tube with a plastic scoop. Everyone was invited to imagine the difficulties of collecting a sample without the gloves and tray.

Amy's results showed elevated FC levels - 6 months it was previously 146 micrograms per gram, but now it was 992. 200 or below is considered normal for her. This confirmed Amy was having a flare-up and her treatment was adjusted.

There was some discussion over whether patients need to fill a whole tube with the sample. Dr Kastner tells her patients to provide half a tube, so she is pleased when they manage to provide a third!

Amy called for changes to the process of collecting stool samples, i.e.

1. Give a better kit - and have it already at home. Allow patients to keep a spare kit so they can immediately provide a sample when they suspect they are flaring.
2. Give clearer communication of timing a delivery of a sample and an indication of how much they need

3. It is less gruesome than a colonoscopy but it can still be difficult to collect liquid stool when you are unwell.

Amy explained that previously when the FC test was not available her years ago her diagnosis took weeks. She had time off work, a cancelled holiday and still finds it emotionally draining to talk about.

At the time, she didn't have a colonoscopy, just an x-ray and blood tests. She had no psychological help to process what had happened and feels this would have helped.

IBD has had a huge impact on Amy's life. It affects her physically, restricts her diet and she has lost career opportunities, friends and family (though lack of understanding). Amy recognises that she may be too good at hiding how bad things are because she is in denial. She lives in fear of her next flare.

She believes that the availability of an FC test all those years ago might have made a difference. Testing would have confirmed inflammation earlier and treatment could have started earlier. FC testing would have also confirmed inflammation earlier during subsequent hospital stays.

She has come to realise that IBD is a progressive condition. Treatments can slow it down and catching the flares early may help reduce the damage to the gut lining. Delays to treatment and to diagnosis, bring more and lasting damage. Amy hopes that wider access to FC testing can make things slightly easier for patients in future.

Edmund shared his experience of delays in diagnosis. He was repeatedly tested for bacterial infections because he had been abroad. It was agreed that his GP may have been "out of touch" in terms of not considering IBD. Pauline said this reinforced how important it is to raise awareness in Primary Care.

## **7. Discussion- The availability of Faecal Calprotectin Testing in Primary Care across Scotland, Dr Dagmar Kastner, Paediatric Consultant NHS Tayside, Clinical Lead NOSPGHANN**

Dr Kastner is a paediatrician with a specialist interest in gastroenterology. She is Clinical Lead for the North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN) which covers a wide area.

The main points covered by Dr Kastner's slides were:

- FC is a protein that occurs in neutrophil white cells, in IBD neutrophils are increased in the lining of the bowel (mucosa)
- Calprotectin in the stool is raised in IBD and other bowel conditions but not in irritable bowel syndrome (IBS)
- It can be raised in bowel infection and in people taking aspirin, ibuprofen or other similar drugs (NSAIDs)

- Normal levels in children are higher (up to 200 ug/g- micrograms per gram) than in adults (up to 50 ug/g)
- It is useful in distinguishing between IBD and IBS and indicating whether someone is having a flare or IBS-type symptoms.
- If FC is normal and (in adults together with a normal FIT test to assess for bowel cancer) much fewer endoscopies or white cell scans need to be carried out.
- It can lead to step down in medication if levels are normal or near normal.

In the Adult GI Service in Tayside:

- There are more than 3000 patients with IBD
- There is no access to FC for adult patients, FIT is used instead but less reliable in assessing for bowel inflammation
- If FC had been available, 19 white cell scans could have been avoided in 7 months and 63 colonoscopies/flexible sigmoidoscopies in 2 months.

In the Paediatric GI Service in Tayside:

- There are 39 patients with IBD and these children have access to FC in secondary care.
- Results takes 3 weeks as sample is sent to Glasgow
- Sample can be repeated after 4 months if required
- Paediatrician can ask GP when screening referral to do Calprotectin before the patient is seen in clinic
- Over a 1-year period, 210 tests were done in Tayside in children costing £6300.

Cost and availability of FC testing:

- FC tests cost £30 per test when sent to Glasgow, £15 if in-house testing was available
- Adult colonoscopy costs around £517 each and the cost is higher for children who need an anaesthetic.
- FC testing is available in all other Scottish health boards except Tayside
- The IBD UK Standards, BSG guideline and IBD flare card for patients and primary care all recommend use of FC testing.

Pauline thanked Dr Kastner for her presentation and suggested that an MSP from Tayside could ask a parliamentary question about the availability of FC testing in NHS Tayside.

Elaine asked if a GP in Tayside can order an FC test. Dr Kastner explained that patients from North East Fife who are covered by Ninewells can get FC testing in Primary Care. NHS Fife has its own lab. However, NHS Tayside patients cannot.

It was noted that because FC decreases time to diagnosis it would create huge saving for Primary Care.

**Action: Pauline to raise this issue with colleagues from Tayside.**

**8. Any other business**

None.

**9. Date of next meeting- Wednesday 13th May 2020.**

DRAFT