

Minutes of the Eighth Meeting of the Cross Party Group on Inflammatory Bowel Disease (IBD)

Wednesday 22nd May 2019, 6-8pm

Committee Room 4, Scottish Parliament

1. Welcome and apologies

Pauline McNeill MSP welcomed everyone to the eighth meeting of the Cross Party Group on IBD. She gave a special welcome to Sarah Sleet, new Chief Executive of Crohn's & Colitis UK and to Colin Smyth MSP. She noted that Liam McArthur MSP would also be joining the meeting.

Apologies were received from:

Kirsty Gibson
Angus McLean
Gail Grant
Janice Taylor
Dr Daniel Gaya
Prof Angus Watson
Vikki Garrick
Seth Squires
Allan Boal
Dr Johnathan McDonald
Dr Graham Naismith
Prof David Wilson
Prof Ian Welsh OBE
Carolyn Duncan
Roisin Robertson
Elaine Smith MSP
Clare Adamson MSP
Miles Briggs MSP
Jamie Greene MSP

2. Minutes of 13th March AGM, actions and work plan

The minutes of the previous meeting (Wednesday 13 March) were approved as an accurate record.

Pauline explained that she was awaiting further contact from the Minister for Public Health, Sport and Wellbeing to discuss the topic of patients being copied into clinical letters, which was raised with him during the Members Business debate on 20th March

It was noted that the Chief Medical Officer's 'Personalising Realistic Medicine' report, published on 25 April, highlighted this as an example of good practice.

Dr Philip Gaskell stated that he had raised a question about this at the Health and Social Care Alliance Scotland annual conference. He was under the impression that the CMO could

only influence practice in this area.

3. 'Not Every Disability is Visible'

Andy McGuinness, Campaigns Manager, Crohn's & Colitis UK

Pauline welcomed the next speaker, Andy McGuinness from Crohn's & Colitis UK who is well known to the Cross Party Group, having been instrumental in setting it up in 2016.

Andy McGuinness gave an update on Crohn's & Colitis UK's 'Not Every Disability is Visible' campaign, which aims to tackle the stigma and discrimination that people with invisible conditions experience when trying to access accessible toilet facilities and raise awareness of Crohn's and Colitis.

Copies of Andy's slides will be circulated to members.

- The campaign has had success in achieving improved signage across nearly 2500 supermarkets, 16 major travel hubs and 250 retail areas.
- An impact survey conducted in 2018 with Crohn's and Colitis UK members showed the campaign had been very well received so far, and identified an appetite to go further, with high street restaurants and pub chains noted as an important target audience.
- Time has been spent developing a new brand identity for the campaign, with an accompanying microsite www.noteverydisabilityisvisible.org.uk
- High street restaurants and pub chains are the next target group for the campaign and following a comprehensive audit, the 15 largest chains were targeted, 3 of which were receptive straight away. 39,000 emails were later sent to the CEOs of the remaining 12 biggest companies. Positive discussions are ongoing with a number of these at present.
- Patient and public surveys were undertaken. With 2,000 respondents each, these resulted in a rich data set being established.
- A highly successful media campaign was launched, which resulted in 82 pieces of news coverage, 53 of these being in national press outlets
- The next stage of the campaign is to work closely with the target businesses to:
 - 1.install improved accessible toilet signage,
 - 2.train staff and raise awareness of the needs of people living with invisible conditions and
 - 3.promote their involvement in Crohn's and Colitis UK's campaign via communications channels.

Liam McArthur MSP entered the meeting at this point.

Andy then took questions from members. This signage is not used in all accessible toilets within the Scottish Parliament. Nancy Greig explained that she had invited the Parliament's Diversity and Inclusion Manager to the meeting and would follow up with her.

The question was asked whether the campaign has done any work to try to engage schools? This is potentially a big impact area with many children affected by a lack of accessible toilets or embarrassed or afraid to ask to be excused from class. Andy said that the signage had been installed in some London schools, but uptake had been sporadic.

Pauline McNeil MSP suggested this could be a topic that could be discussed at a future meeting.

Actions:

- **Circulate link to a BBC Radio Scotland programme where Edmund Murray was interviewed about the campaign- NG**
- **Set up meeting or call with the Diversity and Inclusion Manager- NG and ES**
- **Consider adding the schools issue to future work plan or working jointly with other CPGs on the issue.**

4. Peter's Journey with Crohn's

Peter Convery- Patient

Michelle Convery- Parent

Peter Convery shared his experience of living with Crohn's Disease and gave an insight into the particularly hard impact that it can have on young people. He spoke of how having to miss school had affected his ability to socialise with friends and how the experience of multiple hospital admissions had led to feelings of loneliness, depression and anxiety.

Peter spoke about how having an x-box during hospital admissions helped him. During 2nd and 3rd year he got help from tutors with Maths and English because he missed so much school. Music is an escape route for him, and he enjoys playing the guitar and bagpipes. Now he is 15 he is really looking forward to going to college and he will be on tour -next year with his pipe band in Holland, Belgium and Germany.

It took Peter and his family a period of 18 months (and seeing 4 different Paediatricians) to obtain an accurate diagnosis at the age of 7. For Peter, misdiagnosis was the key thing that he would like to see tackled, so that other young people would not have to go through the same difficult and protracted process that he did.

Michelle, Peter's mother echoed this message, adding that she felt that the length of time it had taken them to get a diagnosis was since people didn't think that a child of Peter's age could have the condition. She was clear that parental instinct needs to be listened to.

She described clinicians telling them that Peter's inflammatory markers were at one stage a cause for concern, but no one explained to them what this term meant or helped them understand it.

Michelle explained that they felt that they had a good relationship with Peter's care team at Wishaw General Hospital, particularly being able to contact the Gastro nurse via mobile phone. However, they did not feel like they benefitted from the same level of contact with staff at the Glasgow Children's Hospital.

Peter eventually asked to have surgery as biologic drugs were not working for him. Now he volunteers to take part in paediatric exams every year, in the hope that it might help improve care and treatment and ensure that other children will not have to go through the same experience that he did.

Michelle raised the issue of her 'fight' to apply for Disability Living Allowance (DLA). Every year their application is turned down and they have to take it to appeal, where the decision is then overturned.

Pauline stated that this would be a matter for the new Social Security Agency. It is important for the determination to be right the first time.

5. Paediatric IBD in Scotland: Solutions, Achievements, and Improvements **Professor Richard Russell, Consultant Paediatric Gastroenterologist and Honorary Professor, Glasgow Royal Hospital for Children**

Professor Russell gave an update on what has changed since paediatrics was last discussed at the Cross Party Group. Copies of his slides will be circulated.

Looking at the rich data set that is available to us, the number of new cases of paediatric IBD has steadily risen. The rate in Scotland looks to be higher than most places in England, but it must be noted that the same data set is not available to allow for reliable comparison. Rates in the North of Scotland are also slightly higher- this is a common theme with IBD and northern latitudes. There is an inverse relationship between rates of IBD and hours of sunshine, but vitamin D is only part of the puzzle as many other factors such as genetics play a part.

Where 10 years ago it might be realistic (in a Children's hospital such as Glasgow) to see 1 or 2 new cases per month, 1 or 2 new cases per week would now be the expected figure. It is becoming a much more common condition for a paediatrician to see. That said, across the whole of medicine (primary care for example) it is still a very uncommon condition for most people to see.

Scotland has one of the highest prevalence rates across the world. Based on a study undertaken in a comparable location (Canada), it is predicted that the figure will continue to rise in the future.

The number of paediatric patients on biologics medicines has increased dramatically in recent years. However, the cost of these medicines has decreased significantly due to the loss of these medicine's patents, allowing generic equivalents to be produced (biosimilars). Approximately £60,000 savings have been made in the Glasgow service due to the biosimilar switch.

Areas of progress include

- Regular IBD multi-disciplinary team clinics
- Telephone advice lines are now universal, and now phone and email clinics are being used more. It's recognised that these will not be an appropriate appointment for everything, but there are some types of information sharing (such as feeding back routine results) where this option is helpful
- Transition clinics. The aim is for transition clinics to be an organised process and to minimise disruption, but this is not uniform around Scotland.

No progress around

- The provision of young adult clinics for 16-24 year olds, recognising the specific needs of this age group
- The provision of a 24 hour advice service has still not been achieved in the South of Scotland.

One area where things have regressed is in access to timely endoscopy. This is a major issue that is delaying diagnosis and treatment. Dr Dagmar Kastner noted that there is a minimum of 8 weeks waiting time for routine endoscopy in the North of Scotland.

Prof Russell explained that ESPGHAN (the European Paediatric Gastroenterology, Hepatology and Nutrition) annual meeting was to be held in Scotland (5th-8th June) and the Cabinet Secretary for Health and Sport would be speaking at it on 6th June. She would also be introducing a young speaker with IBD.

Action: Put together a briefing for the Cabinet Secretary which Prof Russell will draw to her attention via the ESPGHAN office- NG and ES

6. North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN) Patient Satisfaction Questionnaire

Dr Dagmar Kastner, Consultant Paediatrician, Tayside Children's Hospital

Pauline then introduced Dr Dagmar Kastner who presented the results of a questionnaire carried out among parents and carers using paediatric gastro services in the North of Scotland. Copies of Dr Kastner's slides will be circulated.

The survey was developed in partnership with Crohn's & Colitis UK to ensure that it was accessible, and the purpose was to gather patient and family opinions on the services provided and if they felt they were well supported and able to make timely contact with clinicians. Almost 100 people took part and there was an overwhelmingly positive response in relation to staff and the service.

Suggestions for improvement included earlier diagnosis, greater availability of support within primary care settings, interventions to reduce patients having to travel long distances and more liaison with schools and the education sector.

Dr Kastner highlighted the issue that in NHS Tayside, faecal calprotectin testing is only routinely available for children, not adults.

She also noted that the doctors in the North of Scotland Network routinely copy all clinic letters to parents, and these are sometimes used for liaison with schools.

7. Discussion and actions

Pauline McNeil MSP thanked all the presenters, noted that the Members' Business Debate of March 20th was well attended by all parties, and tremendous contributions were made by MSPs. A response was still being awaited regarding an offer for a meeting from the Minister for Public Health, Joe Fitzpatrick MSP.

8. Date of next meeting

Wednesday 2nd October 6-8pm in Committee Room 4.

Attendance list:

Pauline McNeil MSP – Convener

Colin Smyth MSP

Liam Mc Arthur MSP

Edmund Murray

Prof Richard Russell

Dr Dagmar Kastner

Dr Philip Gaskell

Lis Bardell

Matthew Hilferty

Dr Ian Arnott

Paul Johnston

Christopher Doyle- the ALLIANCE

David Pratt – Scottish Government

Michelle Convery

Peter Convery

John Convery

Maddie Simpson

Nancy Greig- Crohn's & Colitis UK

Elaine Steven- Crohn's & Colitis UK

Sarah Sleet- Crohn's & Colitis UK

Andy McGuinness- Crohn's & Colitis UK