

Cross-Party Group on IBD

Wednesday 1st December 2021 @6pm VIRTUAL

Minute

Present

MSPs

Pauline McNeill MSP

Clare Adamson MSP

Invited guests

Jackie Glatter: Crohn`s & Colitis UK

Sarah Sleet: Crohn`s & Colitis UK

Pamela Smith Case Worker P. McNeill MSP

Non-MSP Group Members

Kirsty Gibson Dr Iain Chalmers

Amy Bednarz

Cher Antonia Khedim

Sandra Macrae

Edmund Murray

Seth Squires

Nancy Greig

Prof Richard Russell

Derek McEwan

Dr Dagmar Kastner

Allan Boal

Dr Ian Arnott

Denyse Aitken

Apologies

Dr Daniel Gaya
Rob Gowans

Agenda item 1: Welcome and Apologies

Pauline McNeill MSO welcomed everyone to the meeting and asked for approval to record the meeting for the purpose of minute taking
There were no objections

Pauline explained to the group that the meeting was taking place during Crohn`s and Colitis Awareness Week and that she had tabled a MOTION in support of the week that had been signed by 25 MSP`s [S6M-02300 | Scottish Parliament Website](#)

Agenda item 2: Notes from Meeting 29th September

Clare Adamson MSP joined the meeting at 7.20pm after which the minutes of the previous meeting were approved as a true record

Agenda item 3: Matters Arising

Actions from the previous meeting:

Pauline informed the group that letters had now been sent to Humza Yousaf, Cabinet Secretary for Health and Social Care and the Chief Executives of all Health Boards.

Agenda item 4: My family`s experience of Paediatric & Adult IBD

Services: Carrie Thomson

As Carrie could not attend the meeting Elaine Steven read Carrie`s account of her personal experience of having 2 sons with a diagnosis of Crohn`s disease, one diagnosed and treated in Paediatric services and the other in Adult Services.

For Carrie and her family having 2 sons with Crohn`s has been devastating and the difference in care between paediatric and adult services stark; the support from the paediatric service being excellent while the support has not been so helpful from the adult service.

Carrie wishes that there was some way that both the boys could have been treated with the same consultants in the same hospital and surroundings and commented that the differences in care from both these hospitals are huge and thinks that maybe

because the family got such great care with one son that they are struggling to understand why the care is so different for the other “it's like we're starting all over again”

Pauline thanked Elaine for presenting Carrie's story and commented on how important it is for the CPG to hear the patients' experience

Amy commented that her friend's daughter was diagnosed at 16 and went straight to adult services with her mother suggesting that some overlap between paediatric and adult services until around the age of 25 would offer a much better experience for young people

Kirsty commented that it was interesting to hear a parents perspective as her own parents have never discussed their experience of supporting Kirsty during her diagnosis and early years with IBD

Derek McEwan commented that Carrie's story highlights a number of challenges that families often speak to The Catherine McEwan Foundation about; the great paediatric care and the different experience with adult care. Derek added that transition and adolescent care is an issue that needs addressing as a community and by CPG

Pauline asked Elaine to thank Carrie for her story which had raised an important issue which the CPG would re-visit

Agenda item 5: IBD Paediatric Services in Scotland: Prof Richard Russell, Consultant Paediatric Gastroenterologist, The Royal Hospital for Children and Young People Edinburgh, Clinical Lead of Paediatric Gastroenterology, Hepatology and Nutrition services in the East of Scotland

In his presentation Dr Russell reflected on what has been achieved since the last presentation on paediatric services in Scotland to the CPG 4 years ago.

There are 2 new children's hospitals in both Glasgow and Edinburgh with paediatric services in Scotland run as 3 regional networks in the West, the North and the South East

There are good working relationships between the networks and good links with adult colleagues but different models of care in each network

Scotland has one of the highest incidences of childhood Crohn's disease and IBD in the world with a rapid rise being seen over time

Dr Russell commented that the difference in children and adolescent IBD was poorly recognised; investigations and treatment are broadly the same but the impact on children with a lifetime burden of disease was significant and that adolescents with

IBD as a group can bring challenges both for individuals and in meeting their care and support needs.

Dr Russell told the group that The National Blueprint had been the backbone for paediatric services and since its publication most of the recommendations within had been achieved:

All services have regular IBD clinics and MDT meetings

All services have Advice Lines

All services have Transition processes in place although these differ across the country

However, there remains a specific need for an in-between service to cater for the needs of young adults and to mitigate the harsh transition that some young people experience. Scotland could learn from models of care for 18-25 year olds available elsewhere.

Also to note that there is now a 24 hour on call advice service available across all the regional networks

Dr Russell went on to say that Scotland is known for its excellent model of paediatric IBD care with HCPs visiting from across Europe, Canada and Australia to view and understand the model.

Good models of Transition have been in place for a long time but not available to everyone as this is dependent on adult service provision in each locality.

Dr Russell informed the group that there was a significant burden of mental health issues for the adolescent group of patients which has worsened since the pandemic

There is little provision in adult services for psychological support but this could be available in a young adult service.

Dr Russell finished by reiterating that paediatric IBD is a serious condition with the biggest gap in provision being the need for a young adult service as a bridge between paediatric and adult services.

The group was further informed of an International Paediatric IBD Meeting taking place in Edinburgh in September 2022 with A Family Day on September 10th supported by The Catherine McEwan Foundation and Crohn's & Colitis UK

Pauline thanked Dr Russell for his excellent presentation and confirmed the intention for the CPG to re-visit this issue in a later meeting.

Derek McEwan commented that learning should be sought from the Barts and London model.

The group discussed the need for robust transition and young adult service provision with a particular emphasis on the need for both paediatric and adult services to be adequately resourced in order to fully support the process.

Dr Russell commented that a staff mapping exercise across all services in Scotland would help the understanding of the current situation and any gaps in provision

Seth Squires informed the group that the Modernising Patient Pathways Programme National IBD Steering Group will be undertaking a staff mapping exercise of adult services in 2022 and that Vikki Garrick had produced a report on IBD Nursing in Scotland a few years ago.

ACTION : A meeting to be arranged between Pauline McNeill, Dr Russell and Elaine Steven to discuss how the CPG can add pressure to the need for an IBD adolescent or young adult service

Agenda item 6: CPG Workplan 2022

The draft workplan was tabled.

Agenda item 7: Any other business

There was no other business

Pauline thanked everyone for attending and contributing to the discussion