



Welcome to the WoSPGHaN Newsletter

The newsletter is intended to keep you updated on what is going on within the network. We will let you know about:

- New developments
- The work being undertaken by the subgroups
- Forthcoming events, including education and family days
- Feedback from previous events

WoSPGHaN are at the moment without a lead clinician.

The WoSPGHaN MCN members from RHSC, Yorkhill have now moved to the new South Glasgow University Hospital campus where the new children's hospital is.

The specialist nurses contact numbers are:

Jenny Cowieson, Liver CNS—0141 451 5757

Vicky Garrick/Lee Curtis IBD CNS—0141 451 5759

Christina McGuckin, Parenteral Nutrition CNS—0141 451 5758

Michelle Brooks, Complex EN CNS—0141 451 5761

Avril Smith, Gastrostomy CNS—0141 451 5756

Jenna Tarr, Stoma CNS— TBC

Karen Sinclair, Nurse Educator—07534 919 342



Editorial Group

**News from your area?
Please contact the
Editorial Team to let us put
it into print.**

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Some new Faces—

Since our last edition of the newsletter there have been a number of changes within the network, with a few new faces taking up post. (See our section on What's new!)

What's New!

New faces in the network:

Alison Buchanan is the new gastro nurse in Lanarkshire taking over from Morag Alexander who has moved into Community Children's Nursing.

Helen Lowther will be the new clinical psychologist for WoSPGHaN. Helen joined the Paediatric Psychology team at Yorkhill in October 2014, having moved over from Edinburgh. She has joined the Gastroenterology team as their Psychologist, and is looking forward to inputting into the service, including an IBD new diagnosis group for adolescents.

Lisa Richmond has taken up post as the new IBD nurse; half of the post will be taken up with research.

Moving on are:

Dr Paraic McGrogan our lead clinician for the first 4 years of the network has moved onto pastures new, taking up a new role in Doha, Qatar where a new children's hospital is planned.

Janie Donnan Clinical Psychologist is changing her role and will not be involved with WoSPGHaN. We wish her all the best in her new role.

Events

Families Fun Day Out

The network organised a fun family day out for children with liver or PN conditions. The children and their families had a fun time at Valley Park in south Lanarkshire to enjoy their Winter Wonderland. This is the 3rd year we've organised this event for the families. The day included fun in the soft play area and we took over the function suite upstairs in the café where we had 6 students from Clydebank College who volunteered their time to come along and do face painting. We also had Christmas crafts for the families to create their own decorations and cards. It was a very successful day out for the families, apart from the power cut that closed Santa's grotto and put some of the lighting out in the hall. Santa arrived on his train to the park and took the children and families on a trip round the park, then the children had a chance to speak to Santa and were given a gift before leaving. All in all a good time was had by all. Below are some of the photographs taken.



Derek McEwan of the Catherine McEwan Foundation kindly donated a voucher to take primary school age children to the Wonder World softplay at Kinning Park, in Glasgow on Sunday, 24 May 2015. The day included lunch for the children and 2 hours play. The event was an opportunity to allow children of primary school age from across the West of Scotland to come together to meet with children their own age with IBD and to have some fun. Dr Richard Russell, Consultant Gastroenterologist took the opportunity to introduce Lisa Richmond the new IBD Research Nurse/Nurse Specialist who started that week at the children's hospital. The families were also given information on the New Royal Hospital for Sick Children as well as an educational update on IBD, especially how it effects younger children.

Holly Ennis from the Genetic Environmental Microbial (GEM) Project took the time to give the families an insight to the project and what would be involved should they decide to take part. Holly gave the families the opportunity to discuss the GEM Project with her throughout the day.

For more information on the GEM Project, please contact Holly Ennis via gem@ed.ac.uk or visit the project's website – www.gemproject.ca

A PATIENT'S PERSPECTIVE—Why are we not aware? by David Macleod

“When you’re walking down the street how many people have a medical disorder? It is only when you see someone in a wheel chair or using crutches that you think they have a medical problem, what if there were people who lived everyday lives just like the rest of us but were hiding something?

There are over 260,000 people across the UK living with Crohn’s and Inflammatory Bowel disease (IBD), people who have this condition keep it quiet due to how it affects them.

Crohn’s or IBD usually starts in some people at the age of 12-18, for people who get it this can be a very stressful and tiring time. When Crohn’s or IBD starts to affect you physically the most common symptoms are swollen and sore intestines. Having to deal with this on a daily basis is exhausting, and this isn’t a kind of exhaustion that goes away by a good night sleep, it’s just there all the time, but people just get on with it.

Ulcerative colitis (UC), Crohn’s or IBD can affect anyone, one person who is affected by it is Scotland and former Manchester united player Darren Fletcher. Darren Fletcher who suffered from UC now tries to raise money for Crohn’s and Colitis UK , Darren knows how hard the disease can be , it was also made harder by the need for constant training he had to do to peruse his Football career.

Darren says:

“I’ve come through it and back to playing professional football”

It shows that not all cases of Crohn’s in the UK are always as bad as it sounds. But why in this day has no one heard of the disease? It’s not only 5 people who have it , its hundreds of thousands of people who have it and with such influential people like Darren Fletcher and ex England rugby captain Lewis Moody MBE and still no one knows about it.

The reason members of the public are not aware of this disease is because people who have it don’t want to publicise it, would you?

Victoria Garrick and Lee Curtis are IBD nurses at Yorkhill Children’s hospital in Glasgow, they gave me this quote because they know what it is like to deal with children and young people who suffer with Crohn’s or IBD :

“We know IBD is an unpredictable condition. The symptoms give you belly ache, diarrhea, nausea and can make you feel really rotten (you know this already!). They can also make you feel really tired and it can be difficult to concentrate - all of this is hard when you're at school and working through exams. When you are growing up, I think it's really difficult to go through all of the usual changes (puberty etc...) never mind having all of the additional problems of IBD.

So - if people were more aware of what it felt like, I think they would be more sympathetic especially with teenagers. It's an invisible condition - that's what makes it difficult”

There should be more awareness of this disease because lots of people are affected and need help, even if it was sitting listening or someone who has had the disease for years helping someone who has just been diagnosed with it. Its better getting help from someone who knows what it’s like instead of sitting in an office listening to a doctor who has no personal experience of what the disease is like to live with.

The thing with Crohn’s and Colitis is that there is no cure for it just yet , there is research going on to find a cure but for now there are only limited options of what to do , there are only a few types of immune suppressant medications they can give before there are no more options. If these medications don’t work for you there is only one option left which is surgery to get a colostomy, this operation is a very stressful and emotional time and I wish it on no one because I know what it’s like to have all this done and I know what is like when it gets really bad but there is always hope, we just need help to raise funds and awareness!

You always see cancer research reaching out to people by raising awareness on TV, but think - have you ever heard or even seen a Crohn’s and Colitis UK advert on TV, or even raising awareness in the street? No that’s because we need people who will do this for us so that more and more people know what struggles we go through on a daily basis.”

Network Sub-groups continue to take forward objectives from the workplan.

Education

The network annual education event will take place on Monday, 31 August 2015 in the Education Centre at Forth Valley Royal Hospital, Larbert. Details of the programme for the day will be available on the website www.wospghan.scot.nhs.uk

IBD

A study involving Crohns patients on exclusive enteral nutrition started at the end of 2014. This study is being run by Claire Clarke and each DGH has reported that it is going well with patient volunteers.

Transition Guideline

There is a new Transition Guideline, this has been ratified by the Steering Group and will be available on the network website.

Enteral Nutrition

The EN sub-group has developed a new pathway for hospital discharge of a child or young person on enteral nutrition via a nasogastric tube (NGT). This will be completed by the discharging nurse and dietitian. Copies of this pathway will be available on the WoSPGHaN website once ratified by the steering group.

A Jejunal training pack is being developed by Michelle Brooks, EN Nurse Specialist & Karen Sinclair, Network Nurse Educator. The format of these training and competency documents is the same as the EN training pack for staff and will be put on the MCN website following ratification at the next steering group meeting. A Jejunal information leaflet for parents/carers is presently being developed and will be produced later this year.

Upcoming events

Patients

The patient experience questionnaire will be carried out at clinics in the District General Hospitals over 2015. The parent/carer or patient will be asked to complete the questionnaire after they've seen the doctor. The questionnaire will be completed on iPads. The results will help inform the network on improvements that can be made, if required.

This has already been piloted in Glasgow, and the report is available on WoSPGHaN website.

There is a family day organised in the ground floor lecture room of the Laboratory block at the New South Glasgow University Hospital. This will be on Saturday, 29 August 2015. There will be an element of education for parents/carers and activities for children organised by members of the network.

The network will continue to support family events and we will be looking at organising some events over the next year. Keep your eyes open for our fliers.

Professionals

WoSPGHaN Annual Education Day

31 August, 2015 in the Education Suite at Forth Valley Royal Hospital, Larbert

This is a multi-disciplinary day and is open to all professionals, both in hospital and community setting who see patients with gastroenterological problems. Please make colleagues with an interest aware of this event. Contact Karen Sinclair, WoSPGHaN Nurse Educator for more information karen.sinclair@ggc.scot.nhs.uk

IBD

- UK IBD Audit regional workshop is taking place on 18 September 2015. The workshop will be held at the Grand Central Hotel between 9.30am – 3pm. For info : <https://www.eventbrite.co.uk/e/uk-ibd-audit-workshop-all-scotland-tickets-17029447536>
- Dr Falk - 25th September 2015 - “**IBD but not as we know it**” Grand Central, Glasgow
- Dan Turner from Jerusalem will be speaking at the European Crohns and Colitis organisation on 25th November 2015

Contact Richard Russell for more information on any of these events. richardrussell@nhs.net