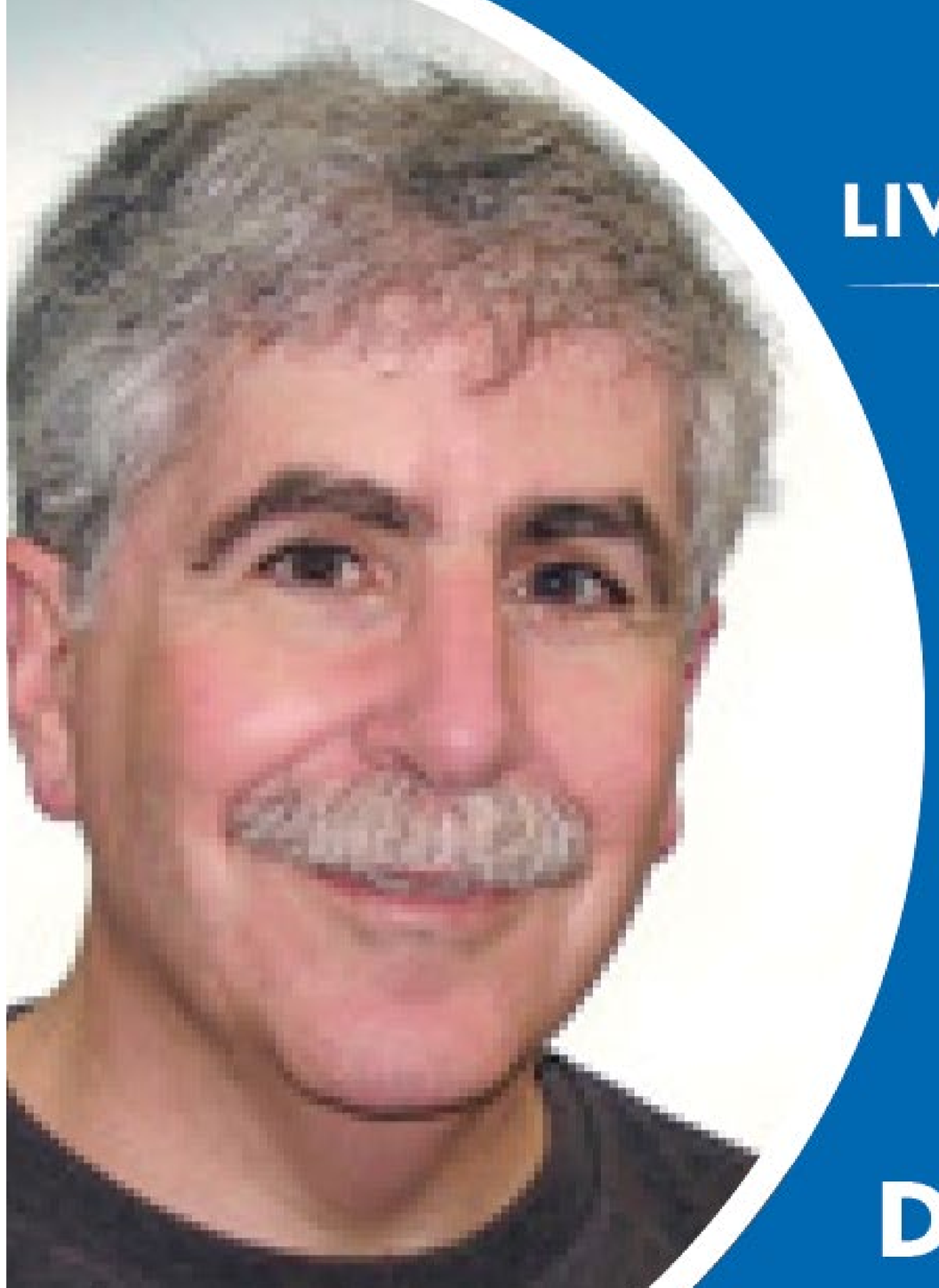


LIVING WITH IBD

Seminar & workshop

NAVIGATING YOUR HEALTH CARE SYSTEM

Behind the scenes of how the hospital gastro departments really work and what you need to know.

with

DR. RICHARD STEIN

RICHARD STEIN, MD

NEGOTIATING THE DHB

Making Sense of the System

ABOUT ME

- Been working in the NZ system for 14 years
- I have worked at five DHBs: Hutt Valley, Capital Coast, Wairarapa, Hawkes Bay, and Northlands
- Current member of the Hutt Valley District Health Board
- I review complaints about GI care for the Health and Disability Commissioner

DHB's: The good and the bad

WHAT IS GOOD ABOUT OUR SYSTEM

- **It is free.**
- **We generally have very competent doctors and nurses**
- **Our training programs are excellent**
- **There is a mandate for equity so that all people, no matter what their social or economic status or where they live, should play a role in their care. Note: this is the mandate, not necessarily the reality.**

BUT THERE ARE MANY PROBLEMS

THE PROBLEMS NUMBER 1: THERE IS NOT ENOUGH $

The DHBs are severely underfunded.

They all operate with a deficit each year of millions of dollars. There is strong pressure by the Ministry of Health to work within the confines of an inadequate budget.

Despite this, the Ministry expects the DHBs to meet its goals and provide excellent care.

THE PROBLEMS: NOT ENOUGH STAFF

New Zealand Society of Gastroenterology

A Critical Analysis of the Gastroenterology Specialist Workforce in New Zealand

Increases in the prevalence of bowel cancer, inflammatory bowel disease and Hepatitis C, together with the demands of the rollout of the National Bowel Screening Programme, are placing huge pressure on the capacity of GE specialists to deliver high quality, timely services to patients. Substantial numbers of patients nationwide are already enduring unacceptably long waiting times for gastroenterology follow ups. There are simply not enough GE specialists and not enough graduates coming through to meet current needs.

We have no gastroenterologist or IBD nurse in four of our DHBs! Tairawhiti, West Coast, Wairarapa, and Whanganui

Counties Manukau Health - Average waiting time by Services and Priority for 01 March 2020 to 28 February 2021

The table below provides approximate wait times in weeks according to the priority assigned to a referral by a clinician. This is measured from the date of referral receipt at CMDHB to the date of appointment. Services are not able to guarantee how long patients will have to wait in the future. Information is subject to change.

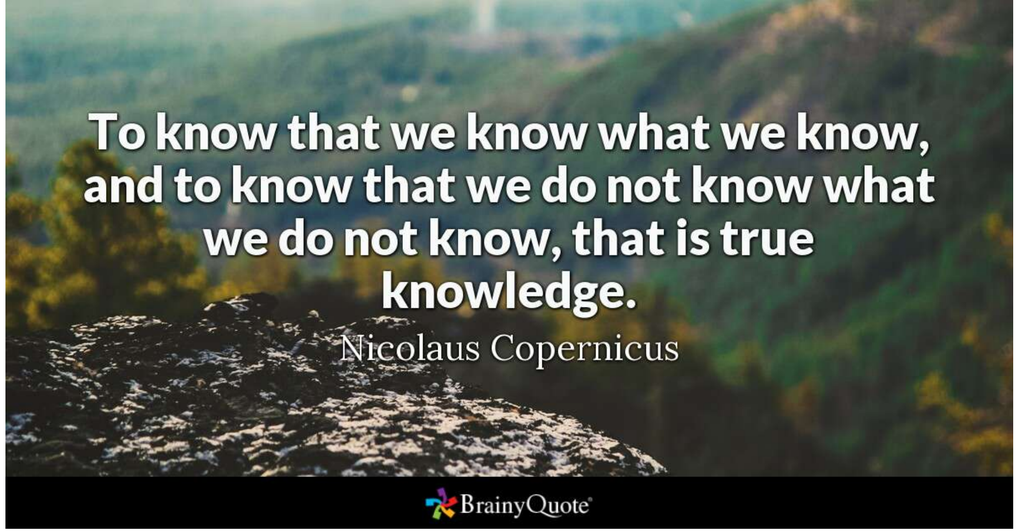
Disclaimer: The capture period for the table below was throughout multiple COVID-19 lockdowns. Therefore, the wait times are longer than may otherwise be expected under BAU circumstances.

	Average waiting time (weeks) by priority		
Speciality	**Urgent**	**Semi-Urgent**	**Routine**
Cardiology	4	11	15
Chronic Pain Service	3	7	12
Dermatology	6		17
Diabetes	5	8	
Endocrinology	4	12	13
Gastroenterology	2	12	13
General Medicine	4		10
General Surgery	2	11	18

THE PROBLEMS: DHBS REACT TO CRISES, RATHER THAN PLANNING AHEAD TO DELIVER QUALITY CARE

- **The look for more staff only when staff shortages are critical**
- **They will contract out colonoscopies to private providers when their long waiting times are found to be resulting in bad outcomes.**
- **They will revise how they care for people only when the current way of doing things results in unacceptable complications.**

WHAT WE KNOW:



- Most departments are understaffed.
- Doctors and nurses are often overworked
- Waiting lists for clinic appointments and colonoscopies are way too long (depending on the DHB) especially with the rollout of bowel cancer screening.
- Many doctors often refuse to be overbooked
- Most messages left with the receptionist never reach the doctor or IBD nurse
- Doctors usually will not take calls from patients or return calls
- The situation may get worse after Covid as doctors start taking heaps of accumulated holiday time

THE DHB'S ARE BEING DISESTABLISHED IN JULY 2022, BUT DON'T EXPECT ANYTHING TO CHANGE SOON! IN FACT, I EXPECT THINGS INITIALLY TO GET WORSE!

- **If anything changes, the system will only become more confusing.**
- **Gastroenterology services will likely be combined among different DHBs. This can be good for underserved areas.**
- **Specialty services will probably be very disorganized in the beginning.**
- **No one has any idea how HealthNZ will be organized.**

WHAT CAN WE DO? WE KNOW THAT IBD IS BEST MANAGED WHEN WE STAY ON TOP OF OUR SYMPTOMS, TREAT FLARES EARLY, AND AVOID COMPLICATIONS BEFORE THEY HAPPEN.

- **We need to be proactive and learn how best to get the care we need.**
- **We need to understand how the system works.**
- **We need to know what care we should be routinely receiving**
- **We need to speak up when our needs are not being met.**

FIRST WE NEED TO KNOW: WHO ARE THE PLAYERS?

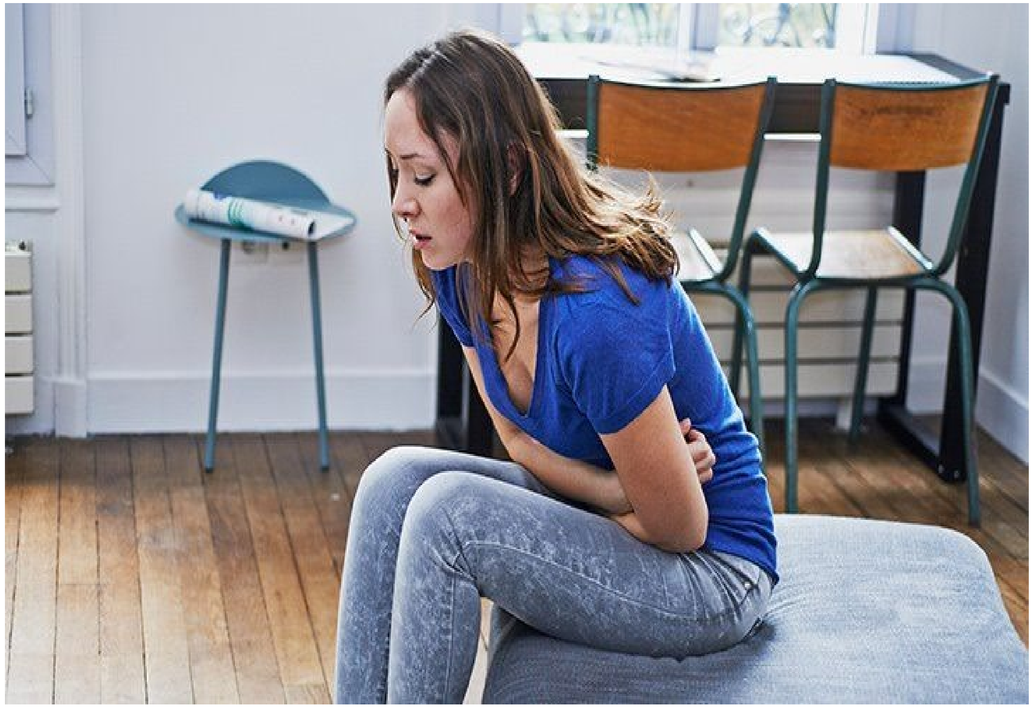
- **Consultant Gastroenterologists (Also called Consultants or Senior Medical Officers) These are fully trained gastroenterologists who have completed their specialty training and can practice independently without supervision. Generally three years as a house surgeon, followed by 3 years of specialty training in gastroenterology. Locums doctors are temporary SMO's who are filling in.**
- **GI Fellow. This is a fully trained gastroenterologist who has chosen to do an additional year to learn very advanced endoscopic procedures, get more experience, or do research.**
- **Registrars They are in their specialty training. Gastroenterology registrars can be in their first year, second year, or third year of training**
- **House Surgeons They are in their earlier years of training and are rotating through different specialties. Usually for two-three years**
- **IBD nurse is an RN who has special training or experience in treating people with IBD. Currently they cannot prescribe medications. They work under the supervision of a gastroenterologist.**
- **Endoscopy nurses assist doctors doing colonoscopy, gastroscopy, and other endoscopic procedures**
- **Scheduling clerks schedule your appointments and endoscopic procedures.**
- **Receptionists take phone calls, arrange appointments, and are often "gate-keepers".**

Getting an appointment

APPOINTMENTS

- If your GP sends a referral it is triaged: “urgent”, semi-urgent”, or “routine”
- You will get your first appointment (also called a “First Specialist Appointment” or “FSA”)
- You may be seen by a registrar who is working under the supervision of a Consultant. The degree of supervision varies.
- You will then be given a follow up appointment
- Ask when that follow up will be. Six months or a year may be fine if you are really stable.
- Ask if you will be seeing your consultant at the next appointment (or a registrar).
- Ask if and when you will be getting your next colonoscopy
- If you are moving, have your gastroenterologist directly refer you to a specialist in your new DHB and get an appointment arranged BEFORE you move. This is especially important if you are on infliximab.

HOW TO GET SEEN WHEN YOU ARE SICK



-Call the IBD nurse… this is your best option. Try and get an appointment when you ring or a definite plan of action and timeframe.

-Call the Consultant: Good luck. Operators will not ring consultants until it is from another MD.

-Go to your GP. GPs vary tremendously in their ability to treat IBD. Some are very good. Others do not have a clue.

-But you can ask your GP to call your consultant, or the consultant on-call. Many will do this if you ask. There is always a gastroenterologist on call and he/she is only a phone call away from your GP. Make sure there is a follow up plan.

-If you are really sick, go to the ED. Ask to see the GI on call (registrar of consultant). The ED doctor should at least agree to ring the GI on call doctor to discuss your situation. Remember, ED's are crowded. They are only interested in finding out who is really sick and needs to be admitted. Otherwise they want you in and out as soon as possible. The ED doctor is not interested in managing your IBD. They take care of emergent situations that can't wait. ED doctors do have an obligation to arrange a follow up plan, but, for the most part, they do not really care if that follow up is appropriate. Try to get them to arrange a follow up in the GI clinic, rather than with your GP.

-Some doctors enroll their patients in a programme with an app like IBDsmart.

GETTING YOUR SURVEILLANCE COLONOSCOPY

-Many people with ulcerative colitis and Crohn's colitis are at increased risk for bowel cancer.

-When should you get your first "surveillance colonoscopy"?

This baseline colonoscopy should be 8–10 years following a definitive diagnosis"

"You don't need a colonoscopy, but I'm sending you for one because, quite frankly, I don't like you."

WHO IS THAT PERSON DOING MY COLONOSCOPY?

- **Consultant (or SMO)**
- **Your colonoscopy may be done by a surgeon or a locums doctor (some of whom may not be very familiar with IBD). When you book, ask who will be doing it. Best to request it be done by your regular consultant**
- **Registrar acting independently**
- **Registrar working under supervision**
- **Nurse Endoscopist**

- **You should never be asked to sign a consent when you are in a vulnerable position (in a gown or in the procedure room)**

HOW ABOUT YOUR NEXT COLONOSCOPY AFTER YOUR BASELINE?

5 years if: Low risk:

-extensive but quiescent ulcerative colitis or

-extensive but quiescent Crohn's colitis or

-left-sided ulcerative colitis (but not proctitis alone) or Crohn's colitis of similar extent'

3 years if Intermediate Risk

-extensive ulcerative or Crohn's colitis with mild active inflammation that has been confirmed by biopsies

-if there are post-inflammatory polyps (pseudopolyps) or a

-family history of colorectal cancer in a first-degree relative aged 50 years or over.

1 year if High Risk

-extensive ulcerative or Crohn's colitis with moderate or severe active inflammation□

-primary sclerosing cholangitis (including after liver transplant) or

-colonic stricture in the past 5 years or

-any grade of dysplasia (pre-cancerous cells) in the past 5 years or family history of colorectal cancer in a first-degree relative aged under 50 years

COMPLAINTS

- **DHB’s take written complaints very seriously.**
- **Write your complaint down and send it to the manager or complaint person at the DHB.**
- **Tell them you have concerns for patient safety or your rights have been violated. Be respectful, but firm. Never use swear words. On the phone, don’t interrupt, but keep restating your concerns.**
- **Tell them you are asking for resolution, but, if necessary, you will file a complaint with the Health and Disability Commissioner (HDC).**

Your rights

In accordance with the Health & Disability Services Code of Consumer Rights, when you are receiving services from Hutt Valley DHB, you have the right to:

•Be treated with respect. This includes respect for your culture, values and beliefs, as well as your right to personal privacy

•Fair treatment. No one should discriminate against you, pressure you into doing something you do not want to do or take advantage of you in any way

•Services which are provided in a way that supports your dignity and independence

•Receive care that meets legal, ethical and professional standards. All those involved in your care will work together to provide quality and continuity of services

•Effective communication and to be listened to. Information should be given in a form,language and manner which you understand.

Full information:

•To have your condition explained to you and be told what your choices are as well as the possible benefits and risks

•To know the name, position and role of any staff involved with your care and

•To take part in decisions about your care and treatment (however, this may be difficult or impossible in emergencies).

Make your own decisions. You can:

•Say no or change your mind at any time

•Refuse treatment if you choose to (in special cases this right may be limited by law)

•Give written (or verbal in some instances)consent before any treatment, procedure or surgery is carried out and

•Give consent before involvement in any research or teaching session (research consent must be written) and you can withdraw from either at any time with out this affecting your care in any way.

Have one or more support persons of your choice present, except where safety may be compromised or another person's rights maybe unreasonably infringed by this.

Have all these rights apply when taking part in teaching and research situations.

Make a verbal or written complaint.

You can make a complaint by:

•Approaching the person caring for you.

•Approaching the manager of the service

•Contacting our feedback line (Phone 04566 6999 ext. 2613) or email feedback@huttvalleydhb.org.nz, or by writing to Feedback, Quality Team, Hutt Valley DHB,Private Bag 31907, Lower Hutt 5040.

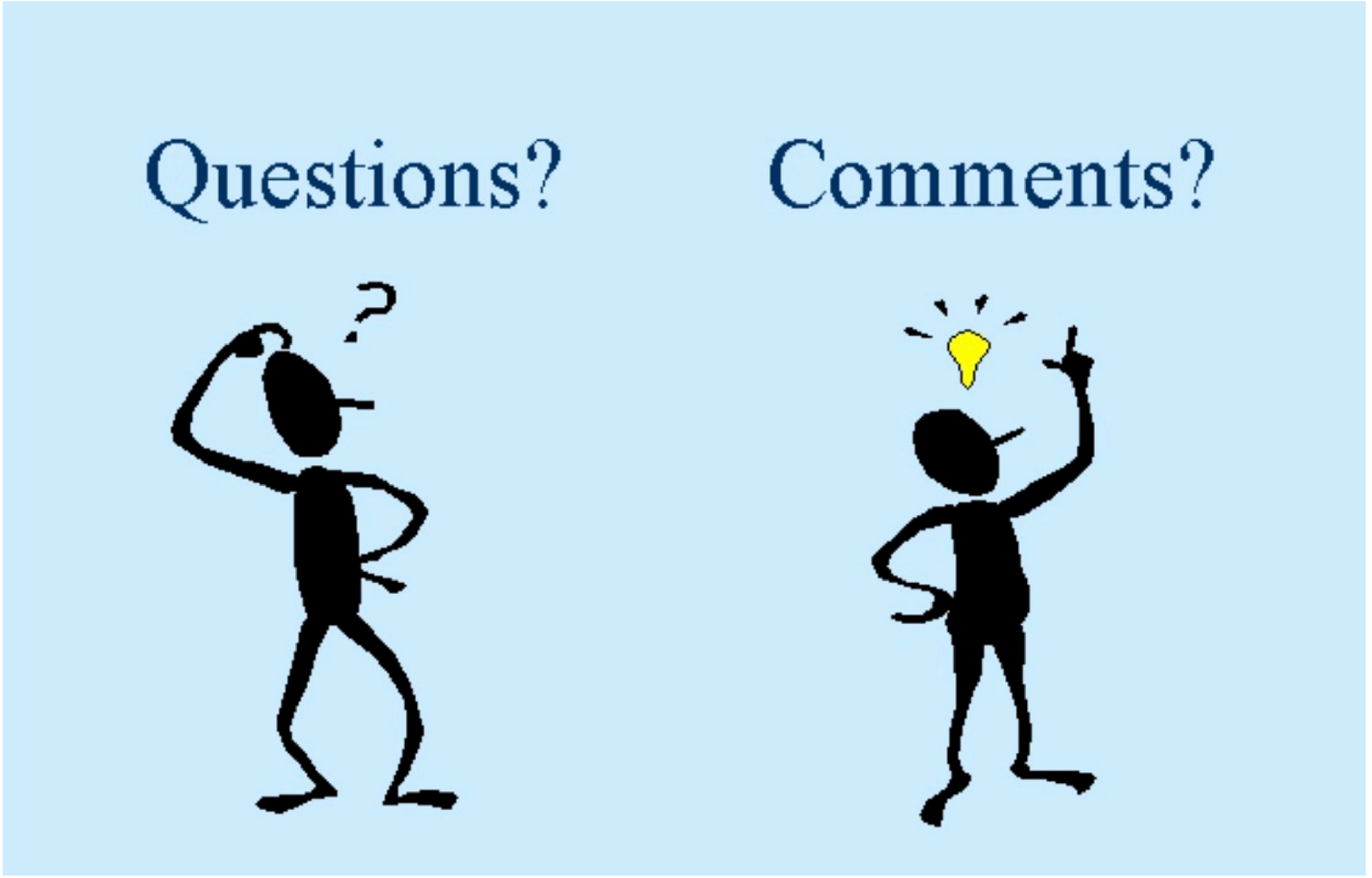
•See our compliments and concerns web page for more information.

•Contacting the Nationwide Health Disability Advocacy (Phone 04 570 0850). This service is independent of Hutt Valley DHB.

THINGS TO ASK FOR

- **Flu jab and pneumococcal vaccine**
- **Dietitian referral**
- **Periodic DEXA scans if you have been on steroids. Ask for Vit D/Calcium if you are started on steroids.**
- **When you leave, ask when your follow will be. Ask for a more frequent follow up if you do not think it is adequate**
- **If you think you are having a flare, ask for blood tests and a faecal calprotectin**
- **Ask about surveillance colonoscopy (when are you scheduled for your next exam).**
- **Education with the IBD nurse**
- **Mental health referral if you think you need one, even though these are difficult to arrange.**
- **A referral to a specialist if you think it may help (stoma specialist, rheumatologist)**
- **To change doctors: Talk to your IBD nurse. Then talk to the receptionist. Explain the problem. Then the Manager of the department. Then make a complaint.**

REMEMBER, EACH DHB IS A BIT DIFFERENT. BE PROACTIVE AND BE ASSERTIVE (BUT NOT AGGRESSIVE) TO GET THE CARE YOU NEED, CCNZ IS HERE TO HELP.



Richard Stein chair@crohnsandcolitis.org.nz