

Inflammatory Bowel Disease Center Clinic Visit Roadmap

For new patients

Resources

- Seattle Children's Hospital IBD website www.seattlechildrens.org/clinics-programs/gastroenterology-hepatology/
- Seattle Children's Hospital IBD group for updates. Email IBD@Seattlechildrens.org
- Crohn's and Colitis Foundation www.crohnscolitisfoundation.org
- Camp Oasis: Sleep-away camp specifically for children with IBD. Our medical team helps direct and support this camp.
- Our team will also share the latest in IBD research with you.

Our Mission

To partner with you and your family to provide a comprehensive care plan. To help you return to your previous normal state of health, and to help you and your family return to doing all of the things that you did before your inflammatory bowel disease (IBD) symptoms began.

Clinic visit schedule and what to expect

The Inflammatory Bowel Disease Center has locations in Seattle, Bellevue, South/Federal Way and Olympia.

Appointment	What will occur?
First visit	Discuss diagnosis of IBD, possible causes and therapies
Second visit - 1 to 2 months after first visit	Evaluate response to therapies
Third visit – 2 to 4 months after second visit then every 3 months thereafter	General care and check-in

It is very important to keep follow up visits even when you are doing well.

At each visit we will:

- Discuss how your child is doing, and how current therapies are working
- Ask questions about symptoms such as abdominal pain, stooling, appetite, energy level and overall well-being (and perform a physical exam)
- Send a detailed update to your primary care provider after each clinic visit
- Discuss blood tests

Tests that may be scheduled

- Blood and stool tests to check for inflammation
- Colonoscopy, upper endoscopy/flexible sigmoidoscopy, wireless capsule endoscopy
- Imaging: MRI, CT scan, upper GI study with small bowel follow-through, bone density scan

To Learn More

- A GI doctor is on-call 24 hours a day 7 days a week, and can help with concerns or emergencies
- Call the nurse line weekdays 8 a.m. to 5 p.m. 206-987-2521, option 4.0
- After hours: 206-987-2000 (ask for GI doctor on-call)

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

Team members to partner with you

The primary healthcare providers and clinical staff you will see include:

- **Medical Doctor (MD)** - the doctors who direct your child's care.
- **Advance Practice Care Provider (APP)** - includes advanced registered nurse practitioners (ARNPs) and physician assistants (PAs). Once your child is stable and doing well, you may have follow-up visits with our advanced practitioners who are specifically trained in IBD.
- **Registered Nurse (RN)** - a licensed nurse who provides and coordinates most of your IBD care and education. This is your main point of contact for communicating with the IBD team.
- **Registered Dietician (RD)** - works with you on a plan for nutritional health, growth and development. Provides guidance on what foods to eat and avoid since diet plays an important role in IBD.

Based on your child's needs, you may also see these team members:

- **Psychologist (PhD)** - a mental health provider skilled in the psychological impact of gastrointestinal diseases on children. IBD is a chronic illness that will require lifelong care and we hope to prevent added stress to the patient and the family. Questionnaires are used to help assess overall functioning.
- **Social Worker (MSW, LICSW)** - a skilled counselor who works with families to provide emotional support and get the resources they need. Assists you with barriers to treatment (such as medical costs, transportation and school), and help with other concerns with lifestyle adjustments with inflammatory bowel disease.
- **Child Life Specialist** - focuses on your child's emotional and developmental needs. Can create a coping plan you can use during a medical test or procedure and offers support during and after medical procedures.