

The Top Questions to Ask of Any Bowel Management Program

There is no “One Size Fits All” solution for children undergoing bowel management. Approaches to treatment and the associated outcomes vary widely according to the unique complexities of each child. Prior to deciding on a bowel management program there are several important questions to ask to better understand which will be the best fit with your child’s specific situation in mind.

To help our patient families make the most informed decision, we have compiled the top questions that we receive from families at the Center for Colorectal and Pelvic Reconstruction (CCPR), and to allow comparison of our Center to others across the country we have provided our answers to each question.

1. How often is the program held?

The CCPR at Nationwide Children’s Hospital in Columbus, Ohio, hosts our Bowel Management Bootcamp (BMB) 12-15 times per year, offering a one-week session each month and two sessions during several summer months. In the past four years the program has helped more than 1,700 children from all 50 states and 22 countries.

2. How much time will be spent at the hospital during the week of BMB?

The outpatient program runs from Wednesday through Thursday of the following week. In certain cases tests may be required, which are typically done a few days prior to the session’s start. The BMB features parent educational sessions, parent support groups and guided age-appropriate patient lessons with psychologists, social workers and child life specialists. Patients have three clinic visits during the week and daily contact with the team as their progress is monitored.

3. Who leads the BMB team?

Dr. Marc Levitt, Dr. Richard Wood, Dr. Karen Diefenbach and Dr. Alessandra Gasior run BMB in collaboration with nine Advance Practice Nurses (APNs) and nine Bachelor of Science (BS) trained nurses who provide continuity of care during BMB and for all long-term care needs.

4. What support is provided for patients and their families who are traveling from out of town?

The CCPR has two social workers dedicated to BMB, providing assistance in making travel arrangements and lodging. Arrangements can be made with the Ronald McDonald House (RMH) for a nominal donation. The Columbus RMH is the world’s largest and is conveniently located across the street from the hospital.

5. Is assistance offered for insurance approvals?

CCPR has an insurance authorization specialist who can provide tips for families to use when they work with their own insurance companies for preauthorization.



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6. How are questions or problems handled between appointments?

The majority of our patients come from out of state and out of country to receive care. For our established patients who cannot easily make the trip for a clinic visit, many times our team can help in a virtual way via email and phone communications. The CCPR's dedicated email for parents and patients — **CCPRonCall@NationwideChildrens.org** — is monitored seven days a week from 7 a.m. to 10 p.m. and urgent concerns after hours are handled via an answering service.

7. How are patients followed after the program is over?

Follow up visits after the completion of our one-week BMB are essential to finding a successful treatment plan. Our team connects with patients one month, three months and one year after completion of the program.

8. Does the program offer transition of care for adolescent and adult patients?

Our Center offers a Transition of Care Program. The program is led by Dr. Alessandra Gasior, the first surgeon in the world to have completed training in both pediatric and adult colorectal care. This dual training makes her uniquely qualified to help adolescents as they begin to explore how their care will be managed as an adult as well as adults seeking care.

9. What data demonstrates that the CCPR produces positive outcomes for BMB patients?

Evidence-based care is the foundation upon which we make decisions on how to treat our patients. In fact, the CCPR was the first Center in the world to publish long-term bowel management data. Some of the biggest accomplishments of our dedicated research team are:

- Development of a validated tool to measure outcomes and patient experience for bowel management patients, which allows for a better understanding of the challenges faced by patients and families. It is important to note that other centers reporting bowel management results have focused exclusively on continence. At the CCPR, we focus on how parents and patients tell us they are doing throughout the process of BMB and on an ongoing longer-term basis. We consider successful outcomes to be continence as well as how patients are living with their treatment plan. We are very focused on understanding the burdens the treatments place on the patient and their family.
- Previously published global research from other teams on bowel management results track success only at one week. Maintaining success at one year, and beyond, is much more difficult. Continence is defined as having less than one stool accident per week. Our data indicates that our patient population who are successful at bowel management are able to maintain continence at least a full year beyond BMB. And, we are always striving to improve our results.

At the CCPR the goal is not only for our patients to return home on a treatment plan that keeps them clean and in normal underpants, but also vital that we find a treatment that is easy to manage on an ongoing basis at home and will be effective months and years after the program. The ongoing research we conduct gives an understanding of long-term outcomes and enables us to provide longevity of care of each of our patients.

For more information visit [NationwideChildrens.org/CCPR](https://www.nationwidechildrens.org/CCPR) or call (614) 722-4086.



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