

What is MMIHS?

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Megacystis Microcolon Intestinal Hypoperistalsis Syndrome (MMIHS, Berdon Syndrome) is an extremely rare disorder that affects the bladder and gastrointestinal tract. Kidney complications (secondary to bladder complications) are also common.



"MMIHS means I have a large bladder and my intestines did not work."
Sarah Marshall, Age 19

"MMIHS to me means having to be stronger and braver than any other time in my life. It has also shown me extraordinary support and compassion from family, friends and strangers that I never imagined possible."

Sarah, mother of daughter with MMIHS

"It means you can't eat, that a central line gives you your food."
Grace, age 9



Education and awareness of MMIHS is critical as proper diagnosis and treatment can significantly impact the prognosis for each individual.

Please visit our website to learn more and join the effort!

For more information
www.mmihs.org
please visit:

The creation of this brochure is dedicated to all those who have been touched by this rare syndrome. May our efforts contribute to making the future a place that is as extraordinary as each of you.



MMIHS



MEGACYSTIS

an unusually enlarged bladder

MICROCOLON

a small colon



INTESTINAL HYPERPERISTALSIS

abnormally sluggish intestinal muscular contractions



SYNDROME

a condition characterized by a set of associated symptoms



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What does MMIHS look like?

Although not all MMIHS patients require the same "accessories" these are some of the most common ones.

An ostomy helps rid the body of waste.

This is an example of an ostomy.

Mark, Age 4

The feeding tube can deliver food and medication directly into the stomach and/or intestinal tract and is able to drain contents as well.

This is an example of a feeding/drainage tube.

The central line is used to draw blood and administer nutrients and antibiotics into the blood stream. It must be kept VERY clean to prevent infection!

This is an example of a central line.

Everly, Age 1

Treatment

As unique as the syndrome is, so are it's patients. Although the symptoms are usually similar, the severity of the syndrome can be different for each patient and can even fluctuate amongst the patients themselves.

Bladder & Kidney Treatment

Most patients with MMIHS have a bladder that is unable to empty on its own either at all, or as regularly as it should.

- Therefore, many patients empty their bladder using a technique called catheterization.
- A tube, called a catheter, is inserted into their bladder via the urethra to drain the urine from the bladder.
- This process is done multiple times a day to prevent stress on the bladder and the kidneys.



Displaced intestines, lesions, and decreased intestinal motility and nutrient absorption are among the most common symptoms of MMIHS patients.

- Although some of these symptoms can be corrected with surgery the inability to properly digest food is the most complicated symptom to manage.
- Most MMIHS patients have a feeding tube and ostomy to provide their body with as much food as it can manage and a central line that delivers additional nutrients in the form of TPN (total parenteral nutrition).



What you should know about MMIHS

From MMIHS Families

- MMIHS is a serious and life threatening syndrome. This condition is ongoing with medical care and monitoring and just because someone who has the syndrome "looks healthy" it doesn't mean they are.
- There is currently no cure for MMIHS and the condition doesn't "get fixed." Some people with MMIHS have life saving multi organ transplants but it doesn't mean things will be magically all better or that they're fixed. In some ways a transplant is trading one set of problems for another.
- People with MMIHS don't always respond the same way to the normal cold, flu, etc. A simple cold or virus can result in ER visits, lots of poking and testing, and possibly a 2-4 day hospital stay if not longer. That's why it's extremely important that families try to prevent exposure to common illnesses.



- Most families would ask that you do not come around when you know that you are sick and that you make sure to wash/sanitize your hands frequently when you are around.
- Families with MMIHS tend to be extra thankful for the "normal days" and activities. These things are not guaranteed and they treasure these times very much.