

Winter Newsletter



The International Study Group of Pediatric Pancreatitis: In search for a cuRE (INSPPIRE)

Winter | Issue 4 | December, 2021

Our Team: 26 Centers Worldwide- Meet Our Mid West Teams

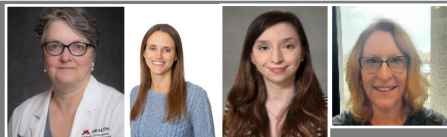
Consortium for the Study of Chronic Pediatric Pancreatitis and Diabetes and Pancreatic Cancer (CPDPC)

Identifying the cause and progression of acute recurrent and chronic pancreatitis and how it affects patients and their families. We are looking for treatment options for these children to improve their quality of life.

The INSPPIRE 2 study is recruiting children with acute recurrent and chronic pancreatitis from all corners of the United States, Canada, Israel, and Australia. In this newsletter, we are highlighting our sites in the Midwestern United States. Please see below for contact information.



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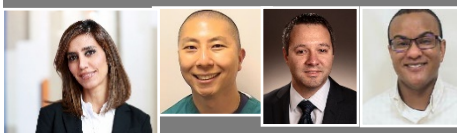
The Pancreas Programs at Mid West sites provide specialized care for children with pancreas disorders. We offer organized, coordinated and efficient means to find out if kids have pancreatitis and to treat them. We closely work with pain, endocrinology and surgery teams to provide the best of patient care.

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Pancreatitis and Pain

Q: Why is pain such a big problem in children with chronic pancreatitis?

A: Many nerve endings are present in the pancreas. When the pancreas is injured, many things can cause pain: increased pressure inside the ducts from blockages (drainage tubes), swelling, inflammation or cyst formation (as seen in burns) can all create pain. Importantly, over time, the nerves that carry pain signals to the brain get overly sensitized or get bigger (because they are used over and over). Sometimes these large nerves send a pain signal to the brain even when the pancreas does not look injured. Sometimes the nerves carry a pain signal from the pancreas, but the brain interprets it as coming from someplace else. For example, the child may experience the pain in the leg or head even though the real source is the pancreas; this is when the brain is confused by the upcoming pain signals.

Q: If my lipase is normal, is my pain real?

A: Absolutely. None of our current methods of looking at the pancreas (ultrasounds, computer tomography, or magnetic resonance imaging) can tell us if the pancreas is causing pain. Lipase levels can be normal in someone with chronic pancreatitis having a “flare” (worsening of disease). Pain should always be taken seriously in someone with chronic pancreatitis. It is important to remember that people with pancreas disease can experience pain related to other diseases, such as constipation, gastroesophageal reflux and other painful conditions.

Q: Sometimes my child hides his/her pain. What is the best way to tell if my child is in pain?

A: Children may be more afraid of going to the doctor than of their pain. This may be especially true if they feel they were not believed in the past when they complained. Think about what your child has been doing for the last day or two. Can they go to school and stay the whole day in class? Are they doing their usual after-school activities (playing a sport, playing with friends, chores)? Are they eating regular meals and sleeping well at night? If there has been a big change in these activities, your child may be having pain.

Q: What can I do to help my child manage pain?

A: The best thing you can do is plan for managing pain before the pain starts or gets worse. Your gastroenterologist may be able to refer you to a pain management program to create a pain plan. Some primary care doctors do this, too. The plan will usually include things your child can do now to learn how to relax during pain and a plan for the gastroenterologist or emergency room for when the pain is worse.

Many pain plans include:

1. Use of acetaminophen or a non-steroidal anti-inflammatory drug (for example, ibuprofen). This is a good option right when the pain starts, before it is too severe.
2. A “back-up plan” with a stronger pain medication for times acetaminophen or a non-steroidal anti-inflammatory drug do not produce relief.
3. Tips for when to call the doctor or go to the emergency room, for example, if your child is vomiting, or cannot eat or drink, cannot sleep because of pain, has a fever, or the pain is becoming worse rather than better.
4. A pain management plan for the emergency department, that tells them about your child’s condition and suggested medications to treat them. Be sure and carry a copy in your wallet just in case.
5. Activities your child can practice that will make them feel more in control when they have pain and be able to do more activities when they feel better. Some ideas include:
 - a. Physical therapy, stretching exercises
 - b. Cognitive behavioral therapy (“talk therapy”)
 - c. Aromatherapy or other integrative therapy
 - d. Evaluation and treatment for anxiety and depression, if appropriate

Watch your inbox!

Seattle Children’s and the University of Iowa invite you to complete a survey! We want to help youth reduce the impact of pain in their lives by learning more about pain, health, and medication use in youth with pancreatitis and their parents/families. **If you receive an email with the subject “Pediatric Pancreatitis Survey Study (INSPIRE-2)” or similar, please click the link to learn more about the study and participate.** Parents who complete the survey earn a \$15 Amazon.com gift card, and youth who complete the survey earn a \$10 Amazon.com gift card.

