

Fall Newsletter



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

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**Dr. Aliye Uc, Primary Investigator
University of Iowa**

Our Team: 27 Centers Worldwide

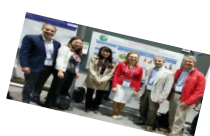
- Cedars-Sinai Medical Center, Beverly Hills CA
- Children's Hospital Los Angeles, CA
- University of California San Francisco
- Stanford University, CA
- University of Colorado Denver
- Emory University, Atlanta GA
- University of Iowa Stead Family Children's Hospital, Iowa City IA
- Riley Children's Hospital, Indianapolis IN
- Ochsner Hospital for Children, New Orleans LA
- Johns Hopkins, Baltimore, MD
- Children's Hospital Boston, MA
- Massachusetts General Hospital, Boston
- University of Minnesota Medical Center, Minneapolis MN
- Washington University, St. Louis MO
- Cincinnati Children's Hospital Medical Center, OH
- Nationwide Children's Hospital, Columbus OH
- The Children's Hospital of Philadelphia, PA
- Children's Hospital of Pittsburgh, PA
- Children's Health/UT Southwestern, Dallas TX
- Texas Children's Hospital, Houston TX
- Baylor- San Antonio, TX
- Primary Children's Hospital, Salt Lake City UT
- Medical College of Wisconsin, Milwaukee WI
- Sydney Children's Hospital, Randwick, Australia
- Montreal Children's Hospital, Canada
- The Hospital for Sick Children (SickKids), Toronto, Canada
- Hadassah University Hospital, Jerusalem, Israel



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

Identifying the cause, progression, effect on patients and their families, and looking at treatment options for children with acute and chronic pancreatitis.

The INSPPIRE 2 study is recruiting children with acute recurrent and chronic pancreatitis from a variety of geographic locations: all corners of the United States and other countries including Canada, Israel, and Australia. We think that children living in different areas of the world, from different backgrounds, may have different reasons to have pancreatitis, and we want to understand what these are. This is why it is so important to get children and teenagers from many different places involved!



I am a study subject!

What do I need to know and do?

As a research participant it is very important for you to see your GI physician at least every year. You should do this even if you are not sick or having problems. At this visit you will be asked to complete certain tests to make sure you are healthy. You will complete your questionnaires to stay in the study. Please make your appointments as suggested by your provider to assure you stay in good health.

If you have any questions, please don't hesitate to contact the research coordinator at your center or the PI.

- Your research coordinator is:
- Phone number:
- Your PI:
- Phone:



INSPPIRE-2 includes children from all over!

Watch your inbox!!

The University of Iowa is doing a survey! The survey is to tell us how pancreatitis affects you, your family, and others in your family who have pancreatitis. You are the experts when it comes to pancreatitis. We want you to tell us on what issues you would like us to focus our research. To take part you must be 10 years old or older. If you are less than 18 years old, your parents must allow you to take part in the study. Your parents and your brothers and sisters who are older than 9 years may also take part in the study. This will help us to learn how pancreatitis affects your family also. Thank you for completing this survey. **If you receive an email, please click the link to learn more about the study and take part in it.**

Web-MAP CP Study

Do you have chronic pain?

Seattle Children's is doing a study looking at pain management in children with pancreatitis between the ages of 10-18 years. If you are interested in taking part in this study to help find ways to deal with your pain please contact : palermolab@seattlechildrens.org or call the research staff at 253-987-6105 or toll free 1-855-932-6272.

Easy Mac and Cheese-Low Fat

Ingredients

US | METRIC

SERVINGS:

- 3 1/2 cups skim milk
- 1/2 cup vegetable broth
- 3 cups whole wheat elbow macaroni
- 2 1/2 cups low fat shredded cheddar cheese
- 1/2 cup part skim shredded mozzarella cheese (low-fat)
- 1/4 teaspoon kosher salt
- 2 tablespoons fat free cream cheese

Cook the macaroni per the directions on the container. Mix together all other ingredients on stove until warm. Add the cooked macaroni stirring carefully till covered in the mixture and serve.



Aliye Uc MD

What is Pancreatitis?

Pancreatitis is when your immune system responds to injury of the pancreas. The pancreas can be injured by an infection, trauma, virus, or medication. People who have pancreatitis often have belly pain. Signs and symptoms, lab tests and imaging studies can help medical teams find out if you have pancreatitis.

There are three types of pancreatitis:

Acute pancreatitis or AP is when the pancreas is injured but returns to normal after a short time. It occurs in 1:10,000 children. AP may be caused by gallstones, medications, an overwhelming or generalized illness, viruses, trauma, or metabolic diseases. Sometimes the cause is unknown. Children will report sudden onset of belly pain. They may not feel like eating, they may feel sick to their stomach or throw up. Rarely, AP may be severe and affect the heart, lungs, or kidneys.

Acute recurrent pancreatitis or ARP is when there are many attacks of acute pancreatitis and the pancreas gets better each time. ARP occurs in 15-35% of children with AP. It is mostly caused by genes or the way the pancreas developed or formed in mother's womb. ARP may turn into chronic pancreatitis.

Chronic pancreatitis or CP is when the pancreas is scarred. Attacks of pancreatitis may still happen. CP is seen in about 2 in 100,000 children. It is mostly caused by genes or how pancreas developed or formed in mother's womb. The pancreas may stop working in people with CP. If pancreas stops making proteins (called pancreatic enzymes) to break down food, it is called exocrine pancreatic insufficiency. When this happens, children will have to take pancreatic enzymes. The pancreas may stop making insulin, which controls how much glucose is in the blood. When this happens, it is called diabetes, children will have to take insulin.

How to Manage Pancreatitis?

Children with signs of AP need to be checked to make sure they receive enough fluid and they are able to control their pain. They need to be watched for signs of other problems such as issues with kidney, heart and lungs if pancreatitis is severe. They may be seen in emergency room or stay in the hospital. The pancreas recovers after children receive fluid for hydration, nutrition, and medications for pain control.

All children with ARP and CP need to be checked to find out what caused pancreatitis. Some pancreatitis may respond to specific treatments. For example, pancreatitis caused by celiac disease is treated by changing the diet to gluten free diet. An endoscopy can be done to open a blocked duct in the pancreas if that caused pancreatitis. If gallstones were the cause of pancreatitis, surgery will be needed to remove the gallbladder. Long-term care is needed to watch for dietary needs, measure vitamin levels and check for chronic pain, diabetes and pancreatic insufficiency.