INSPPIRE-2

Winter Newsletter



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

| Winter | Issue 2 | February, 2021

Our Team: 27 Centers Worldwide- Meet Our Western 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 Western United States. Please see below for contact information.



University of Southern California Children's Hospital Los Angeles, CA





Site PI: Yuhua Zheng, MD, MS Associate Professor https://www.chla.org/pancreas-program

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University of California San Francisco Benioff Children's Hospital





Site PI: Emily Perito, MD
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Stanford University Lucille Packard Children's Hospital





Site PI: Zachary Sellers, MD, PhD Clinical Instructor

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The Pancreas Programs at our Western 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.

Cedars-Sinai Medical Center, CA





Site PI: Quin Lui, MD
website: www.cedars-sinal.org/
CRC: Eleanor Chang, Karen Hu

University of Colorado Children's Hospital Colorado





Site PI: Jacob Mark, MD

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University of Utah , Intermountain Primary Children's Hospital





Site PI: John F. Pohl, MD

Professor of Pediatrics

CRC: Carly Straley Phone: 801-213-3599

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. 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. 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 10-19 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.

Keep Yourself Well hydrated

Proper hydration is important in the health of all people, but especially for people with chronic pancreatitis. Although the exact reason is not known at this time, patients may have flares when they are dehydrated. Fluid needs can be met with any beverage that does not have caffeine or alcohol. Foods with high water content such as fruits, vegetables, and soups are also helpful in meeting fluid needs.

How much water do you need to drink a day?

1-3 years	35 OZ
4-8 years	40 OZ
9-13 years	50 OZ
14 years+	70 OZ



Veronique Morinville MD

Montreal Children's Hospital



What is Exocrine Pancreatic Insufficiency? (EPI)

The pancreas does two important things. The exocrine role is to break down food. This is done mostly by digestive proteins called pancreatic enzymes. The endocrine role includes making a hormone called insulin that helps the body take in and use sugar for energy. Exocrine pancreatic insufficiency (EPI) occurs when the pancreas does not make enough enzymes to break down food. EPI is caused by many things. When an acute pancreatitis (AP) attack occurs, the exocrine part of the pancreas is swollen and doesn't work well for a short while. When someone has chronic pancreatitis (CP), the exocrine pancreas is scarred and can even stop working forever. EPI can also be caused by other disorders such as cystic fibrosis and Shwachman-Diamond syndrome that people are born with.

How to know if you have EPI?

People with pancreas disease may have EPI without knowing. EPI may affect their health, absorbing vitamins in the intestines, thinning of bones, eye problems, and even problems with the nervous system. The doctor will monitor for signs of EPI and nutritional health and do tests to make sure these have not developed. There are many ways to test for EPI, but most are difficult. These are: collecting poops for 24-72hours or involve the patient to be put to sleep and a tube placed down the throat to collect fluid from the intestines. The easiest test is fecal elastase-1. The amount of elastase found in a stool sample can help decide if the pancreas is able to make enough enzymes. The stool sample can even be collected at home and stored in the freezer until it is taken to the lab. Collecting stool is easy, doesn't hurt and is important so your doctor can tell if your pancreas is working well.

How to treat EPI?

People with EPI may need to take special pills called pancreatic exocrine replacement therapy (PERT). PERT helps to break down food to provide nutrition, health and growth. PERT is taken with food and snacks. PERT helps with what the exocrine pancreas is unable to do.