



# PEARL



The Pancreas Education and Research Letter

## Alcohol and Pancreatitis: Is Alcohol the Complete Story?

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Heavy alcohol use is reported to be the most common cause of chronic pancreatitis ("scarring" of the pancreas), with about 70% of chronic pancreatitis believed to be caused by alcohol use. Heavy alcohol use is also the second most common cause of acute pancreatitis ("inflammation" of the pancreas) in Western countries. Most patients with alcohol-associated pancreatitis report drinking large quantities of alcohol (more than 5-6 drinks/day\* for 5 years or more). More than 90% of these patients are also heavy smokers. In fact, we now know that smoking by itself is a risk factor for pancreatitis and can lead to progression of the disease.

Over the years, many questions about the association of alcohol and pancreatitis have continued to puzzle physicians. These questions include:

- Why do only a small proportion of individuals (less than 5%) who drink alcohol heavily ever develop pancreatitis?
- Why do some individuals who drink heavily develop pancreatitis, while others develop liver disease or heart disease, etc.?
- Do smaller amounts of alcohol use put a person at risk to develop pancreatitis?

The team of researchers and physicians at the University of Pittsburgh is trying to understand what factors lead to pancreatitis. The data collected in the NAPS-2 study in over 1,000 patients with recurrent acute and/or chronic pancreatitis and over 600 controls from the top 20 pancreatic care centers around the country will allow us to begin to understand some of these very important questions. A preliminary

analysis of the NAPS-2 data indicates that the proportion of individuals with chronic pancreatitis due to heavy alcohol use may be much lower than what has been previously believed and that the majority of individuals with pancreatitis are NOT alcoholics. Researchers now think there are other factors in addition to alcohol (i.e. smoking, diet, race, genetic factors, etc.) that may cause an individual to develop pancreatitis. The differences in these other factors are believed to determine why some people develop pancreatitis after years of heavy alcohol use, while other people do not. Knowing the mechanisms involved will also help in designing strategies for prevention and treatment of all types of pancreatitis in the future. ○

*Chronic pancreatitis should not be thought of as a self-inflicted disease, but more like rheumatoid arthritis, inflammatory bowel disease (IBD), chronic back pain, or other common disorders.*

### References:

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\*One drink of alcohol is equal to 12 oz. of beer or wine cooler, 5 oz. of wine, or 1.5 oz. 80-proof hard liquor.

See related article "Changing the Face of Chronic Pancreatitis Patients" on page 3

On the Internet:  
[www.pancreas.org](http://www.pancreas.org)

Toll-Free Phone:  
1-888-PITT-DNA  
(1-888-748-8362)

### What is a Gene?

**G**enes are the instructions that determine how we grow, develop, and how our bodies function. They are made of DNA and carry information about many qualities or traits that make you who you are: light or dark hair, eye color, height, and even how you smile or laugh.

Each cell in the human body contains about 30,000 different genes. As a human (or any living thing) grows, genes are turned on or off so that a cell can become a brain cell, a skin cell, or a heart cell – in fact all of the different parts and organs of the body.

Each gene has a special job to do. It acts as the instructions or blueprints for making proteins. Proteins are the building blocks for everything in your body such as bones, muscle, teeth, hair, and blood.

Genes are found on chromosomes, which are long threads of coiled DNA that act as packages for the genes. There are thousands of genes in one chromosome.

Chromosomes come in pairs, so you have two copies of each gene. Each of your parents passed along one of the chromosomes in each pair to make up the chromosomes you have. Half of your chromosomes and genes come from your mother and half are from your father.

Sometimes a change in a gene, called a mutation, can change how a gene works. The protein the gene makes does not work properly when this happens and can cause something in the body to not work properly as well. Mutations can cause a change in a trait. For example, some people have mutations that cause deafness; others have mutations that cause them to be short or tall. Mutations in three different genes are known to cause an increased risk of developing pancreatitis. These mutations can be passed down through families. Depending on the gene, sometimes having a mutation in one copy of a gene is enough to cause a trait. When this happens, a parent with a trait (like eye color or deafness) has a 50% chance of passing the trait on to each child. Other genes require a mutation in both copies of the gene before a trait appears. When this happens, both parents (who do not have the trait) must have a mutation in the same gene and both pass it on to a child in order for the trait to appear. Taking a careful family history can provide geneticists (people who study genes) with clues about how different traits are passed down in a particular family. ○

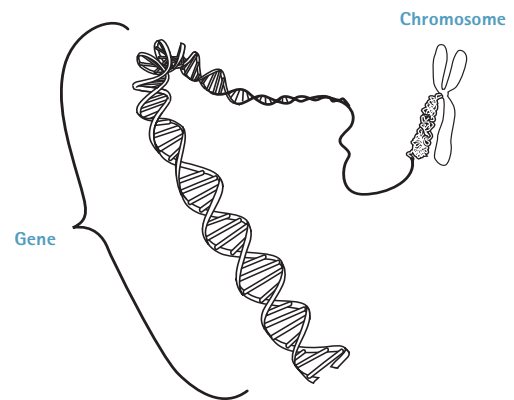


Figure from [www.genome.gov](http://www.genome.gov) with permission.

### Research on Pancreatic Cancer: Moving Ahead

**W**e would like to thank the many individuals who have come forward to help support our pancreatic cancer research program. We have experienced a large surge in support since the discovery of the first gene associated with familial pancreatic cancer this past December. Advances in understanding pancreatic cancer require the strong support of many individuals and families.

We are still seeking individuals to participate in a study of familial pancreatic cancer who either:

- Have had at least two family members diagnosed with pancreatic cancer, or

- Have themselves been diagnosed with pancreatic cancer and have had at least one relative who has been diagnosed with pancreatic cancer

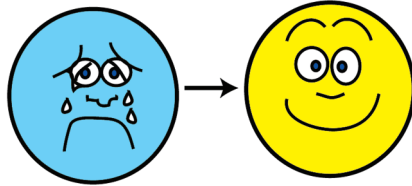
Participation includes completing a questionnaire and providing a blood sample. If you are interested in participating, please call our toll-free number **1-888-PITT-DNA**. Additionally, we are now collecting blood samples from individuals who previously participated in our familial pancreatic cancer registry. If you previously participated but did not provide a blood sample and are willing to provide one now, please call our toll-free phone number **1-888-PITT-DNA** for additional information. ○

# Changing the Face of Chronic Pancreatitis Patients

by David C. Whitcomb, MD, PhD

The article on page 1 titled "Alcohol and Pancreatitis: Is Alcohol the Complete Story?" highlights a shocking finding: the majority of 1,000 consecutive patients enrolled in the 20-center North American Pancreatitis Study 2 (NAPS2) were NOT alcoholics! This finding flies in the face of decades of dogma, where physicians and health care workers were taught that 70-90% of chronic pancreatitis was due to alcoholism. It was thought that this problem was due to the patients' self-destructive lifestyle. Chronic pancreatitis was generally considered a disease of derelicts and drunkards.

However, these statistics, based largely from studies outside of the United States, do not appear to be true. Instead, most people with chronic pancreatitis seem to have a complex combination of genetic changes and other factors that cause the pancreas to be easily injured and scarred. Therefore, chronic pancreatitis should not be thought of as a self-inflicted disease, but more like rheumatoid arthritis,



inflammatory bowel disease (IBD), chronic back pain, or other common disorders.

We believe that it is time to **change the face of chronic pancreatitis patients** in two ways. *First*, we want to change the image that comes into the mind of physicians and other health care workers when they diagnose or care for a person with chronic pancreatitis. In the majority of cases, an individual with pancreatitis should be viewed as a victim who is suffering with a disease that they developed through no fault of their own.

*Secondly*, we want to change the face of the individuals who suffer from the pain and disability of chronic pancreatitis. The pain is real, and not due to "drug-seeking behavior." We want to find new and effective treatments, and even a cure, so that the face of each individual patient changes from agony to relief.

To this end, we are asking for the help of patients, families, and friends to do whatever they can to help. Spread the news and help change the face of pancreatitis patients. ○

## Ideas For Your Next Medical Visit

Navigating the medical system and obtaining the medical care that you need can be challenging for anyone. When you have a rare condition, like hereditary pancreatitis, it can be even harder due to a general lack of knowledge about the disorder. The following suggestions can make getting the care you need easier.

- ✓ Keep a summary of your medical history, including medications, with you at all times. This can help emergency room physicians or new physicians understand your medical history quickly and efficiently.
- ✓ Carry a letter from your primary gastroenterologist explaining your diagnosis, the treatment for an acute attack of pancreatitis, and containing your gastroenterologist's contact information to help prevent emergency room physicians from suspecting that you are "drug seeking."
- ✓ Keep a copy of all of your medical records. You can then simply make a copy when you see a new physician, rather than trying to gather records from multiple physicians and hospitals.
- ✓ If you do not live near a major medical center with experience in treating pancreatic disorders, do not hesitate to interview physicians and ask them if they are willing to coordinate your care with a pancreatic specialist located further away. It is very important to find a physician that is willing to learn about hereditary pancreatitis and work with you and other physicians treating you, since most physicians will not be familiar with hereditary pancreatitis initially.
- ✓ Be persistent. It is important to realize that you have to be your own advocate in the medical system. Do not be afraid to ask questions and/or voice your concerns, then follow through until you feel your questions and concerns are addressed. ○



## Ask Dr. Whitcomb

*I am the first person in my family to develop pancreatic cancer. Is pancreatic cancer an inheritable disease? Do my children need to worry about their risk of developing pancreatic cancer?*

**Answer:** Only a small percentage of pancreatic cancer is due to inherited gene mutations. About 90–95% of pancreatic cancer is considered "sporadic," meaning that only one individual in the family has developed pancreatic cancer. The remaining 5–10% of pancreatic cancer occurs in families that have a higher risk of developing cancer due to an inherited gene mutation. Individuals who have had one first degree relative (parents, siblings, children) with pancreatic cancer have about double the risk of developing pancreatic cancer when compared to someone who has not had any relatives with pancreatic cancer (2.6% vs. 1.3% lifetime risk). This risk increases if you smoke cigarettes, if more than one relative has been diagnosed with pancreatic cancer, if there is clustering of certain types of cancer in the family (e.g. pancreatic

cancer and melanoma or breast and ovarian cancer), or if the family has a known genetic mutation. You and/or your family members may want to speak with your physician about being referred to a genetic counselor or a center specializing in cancer genetics to speak about possible genetic testing if:

- You have been diagnosed with any cancer at an early age (younger than age 50)
- There are two or more close relatives (parents, grandparents, aunts/uncles, children) on the same side of the family with the same or related types of cancer
- You or a relative have had more than one primary cancer or more than one type of cancer
- You or a relative has had a rare cancer

Genetic counseling and testing can save lives by identifying individuals with a high risk of developing cancer and helping them obtain appropriate cancer screening in order to detect cancer at an early, treatable stage.

If you have any questions for Dr. Whitcomb about the pancreas or management of pancreatic diseases, please e-mail the newsletter at [askpearl@pitt.edu](mailto:askpearl@pitt.edu). We want to share the answers to your questions in each **PEARL** publication to help educate everyone about pancreatic disease. ○



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