Individual Highlights:

- Introduction  
- On the web  
- Dan’s Poem  
- Eating info  
- Strike out  
- Volunteer

Upcoming Events!

- Strike out Pancreatic Disease  
  September 13  
  Madison Bowl  
  4761 Madison Rd.  
  Cincinnati, OH 45227  
  More details inside!

Ohio Chapter NPF is here!

As of April 9, 2014, the Ohio Chapter National Pancreas Foundation was born.

Our purpose is simple. We are here to support the National Pancreas Foundation. The National Pancreas Foundation (NPF) provides hope for those suffering from pancreatitis and pancreatic cancer through funding, cutting edge research, advocating for new and better therapies, and providing support and education for patients, caregivers and health care professionals. We will do this with different events during the year, including fund raisers, educational events and health events.

"Strike out Pancreatic Disease – There’s no time to spare," is our big event this year. See page 6.

Donations can be made on the NPF website, pancreasfoundation.org

Why fund Pancreatic Cancer and Pancreatitis?

- Pancreatic cancer has the highest mortality rate of all major cancers. 94% of pancreatic cancer patients will die within five years of diagnosis – only 6% will survive more than five years. 74% of patients die within the first year of diagnosis.
- Pancreatic cancer is the 4th leading cause of cancer-related death in the United States. By 2030 it is expected to be the #1 cause.
- Pancreatic cancer is one of the few cancers for which survival has not improved substantially over nearly 40 years.
- Pancreatic cancer is a leading cause of cancer death, largely because there are no detection tools to diagnose the disease in its early stages when surgical removal of the tumor is still possible.
- Pancreatic cancer may cause only vague symptoms that could indicate many different conditions within the abdomen or gastrointestinal tract. Symptoms include pain (usually abdominal or back pain), weight loss, jaundice (yellowing of the skin and eyes), loss of appetite, nausea, changes in stool and diabetes.
- People with chronic pancreatitis may also have an increased risk of developing pancreatic cancer.
- Chronic Pancreatitis has no good treatment.
- A small number of cases of chronic pancreatitis appear to be due to an inherited gene mutation. People with this inherited form of chronic pancreatitis seem to have a high lifetime risk for developing pancreatic cancer (about 40% to 75%).

We ask that you spread the word about our chapter. If you need any information or pamphlets to hand out, please contact us. Join us on Facebook:

https://www.facebook.com/groups/OhioNPF/

Share our Facebook page with your friends.

Follow us on Twitter @OhioChapterNPF
Introducing Maisam Abu-El-Haija, MD, Chapter Medical Director

Maisam Abu-El-Haija, MD, is a gastroenterologist who has clinical and translational research interests in pancreatic disease. Her main research focus is on the clinical presentations of pancreatitis, different management trends, and outcomes of pediatric pancreatitis. As part of the pancreatic center at Cincinnati Children’s Hospital, Dr. Abu-El-Haija is the Principal Investigator of the database and registry for pediatric pancreatitis. This patient cohort will help determine the epidemiology and potential etiologic factors for pancreatitis in children. They hope to study complications and outcomes of therapeutic interventions for pancreatitis, and to be able to implement effective therapies with favorable outcomes in the future. Their long term goal is to find effective therapies for pancreatitis.

Dr. Abu-El-Haija’s mission stems from realizing that pancreatic disease affects personal health, pain, and emotional well-being. This is a tough disease that requires physicians to step in to help their patients beat it! Pancreatic disease is painful, and not realizing that may lead to mismanagement. Pancreatic disease can affect any age group, including infants, and not knowing this may lead to misdiagnosis.

As the medical director of the NPF Ohio Chapter, Dr. Abu-El-Haija is very enthusiastic about raising awareness in the community and providing support to all the families who need it.

Dr. Abu-El-Haija completed her medical degree at Jordan University of Science and Technology.

Meet your state chair: Dan Spracklen

I welcome the chance to introduce myself, Daniel Spracklen (Dan). I am a native of Ohio, living in the Marion, Ohio, area all my life. I have been married to my wife, Karen, for over 26 years now. We have 5 kids, 4 grandchildren and 3 great grandchildren. I have spent the last 32 years as a firefighter/EMT and Hazmat technician.

I had my first acute pancreatitis attack in August, 2012. I had a second attack in February, 2013, and spent our 25th wedding anniversary in the hospital. After not getting any pain relief, more tests were done and, in June, 2013, I was diagnosed with Hereditary Pancreatitis.

I, like many of you, have constant pain. I like to describe it as a roller coaster that never stops, with all the ups and downs. The last year, plus, has greatly changed my life. I struggle at my job as a firefighter. Even daily chores around the house are hard. Eating and physical exertion are my main issues that cause pain. I have asked many times, “Why me?”

But, I looked at the situation and decided to do some good. I have been helping people at my job for all these years; why change now? So, I have taken on the challenge of helping in the form of advocating and spreading hope for people who suffer from pancreatic issues. I have used, and have heard, the word frustration many times when talking to people. Even in talking to Dr. Abu-El-Haija the first time, she used the word frustration in not being able to do more for her patients. I want to help change that frustration for physicians and patients.

On page 4, I have included a poem I wrote one night when I was in pain and couldn’t sleep.
Important web sites

The National Pancreas Foundation has a wealth of information on their website:

http://pancreasfoundation.org

Another useful site:

http://pancreas.org

This Facebook page is open to anyone—patients, family, health, general interest. It will be the best place to keep up on events for the Ohio Chapter:

www.facebook.com/groups/OhioNPF/

Introduction continued

On the personal and family level, Dr. Abu-El-Haija is married to Dr. Dughman, who is a supportive and loving husband and an Interventional Cardiologist in Middletown, Ohio. He is a great supporter of the mission of fighting pancreatic disease. They both value family and health! They have two boys, ages three and one. During the little free time she has, Dr. Abu-El-Haija enjoys cooking, making healthy recipes, music and traveling.

I feel it really expresses how a lot of people fighting pancreatitis feel at times. I have no claims to being a writer, but I think my mom and grandmother would be proud.

I have lots of enthusiasm starting the Ohio Chapter of the NPF. I look forward to the challenges, and my wish is to bring everyone some hope to beat their disease. It will not be an easy fight, but we can do it. I welcome comments, questions, advice or whatever. If you have any words of wisdom, please contact me:

danocnpf@outlook.com

“Our Chapter is only as strong as the people who serve it.”

Thank You!

Just a quick thank you to Dr. Maisam Haija, Linda Parsons and Renee Maul for their help on this newsletter.
Dan’s Poem written by Dan Spracklen

This is dedicated to everyone who suffers with Pancreatitis.
8/24/13

I wonder in my head, will I ever be normal again?

My tired body feels like crap.
I feel like I’m caught in a big trap.

The Doctors, they try to help
Using expensive drugs that make you yelp

I wonder do they really know,
The stabbing squeezing pain I have below?

I sit and wonder, what happened to my life, will the Doctor say I need to go under the knife?

Blood work is done, they schedule more tests
MRI, CT and EUS

Find a reason, the pancreas is so mean, Mine is caused by a mutated gene

Hospitals we know them so well
For some it’s just a living hell.

A trip to the ER, it’s up in the air
Will the Doctor and nurse really care?

Wondering, when’s the next attack?
No way I’m eating that Big Mac

Others who suffer know what I mean
Facebook keeps us together on a fancy machine

All around the world our language the same
Pancreatitis sucks, is the name of our game

We talk about Doctors, meds and poop
Supporting each other if you get in the loop

Eating food causes much stress
And coming out, a big mess

A low fat diet they tell us to eat
Gluten free, if you’re allergic to wheat

Men and women, young and old
Pancreatitis so cruel, so cold

It’s 3 am and I’m wide awake
Doesn’t this pain ever take a break?

I’m doubled over holding my gut
The inflammation, such a pain in the butt.

Pain so bad I want to cry

Some say pot helps, if I would get high
I’m so tired my body needs rest
I’m sick of pancreatitis, it’s such a big pest

O yes, I know I’m very bitter
My pancreas stole all my glitter

My dreams they are so grand,
Now being stolen by this rebellious gland

I feel lost with no direction
My normal life has lost connection

Co-workers, they don’t realize
Can’t they see the pain in my eyes?

Family members, some are quick to criticize
I guess it is not easy for them to realize

Outside I smile hiding the pain
And say hi to my neighbor Jane

The pain and anguish that I feel
Tell me, why the hell can’t I heal?

I can give up, or fight with all my might
No way I’ll give up, it wouldn’t be right

Men and women, young and old
Pancreatitis so cruel so cold.

I feel lost with no direction
My normal life has lost connection.

Pancreatitis so cruel so cold.

__________

I feel lost with no direction
My normal life has lost connection.

Dan’s Poem written by Dan Spracklen

This is dedicated to everyone who suffers with Pancreatitis.
8/24/13

I wonder in my head, will I ever be normal again?

My tired body feels like crap.
I feel like I’m caught in a big trap.

The Doctors, they try to help
Using expensive drugs that make you yelp

I wonder do they really know,
The stabbing squeezing pain I have below?

I sit and wonder, what happened to my life, will the Doctor say I need to go under the knife?

Blood work is done, they schedule more tests
MRI, CT and EUS

Find a reason, the pancreas is so mean, Mine is caused by a mutated gene

Hospitals we know them so well
For some it’s just a living hell.

A trip to the ER, it’s up in the air
Will the Doctor and nurse really care?

Wondering, when’s the next attack?
No way I’m eating that Big Mac

Others who suffer know what I mean
Facebook keeps us together on a fancy machine

All around the world our language the same
Pancreatitis sucks, is the name of our game

We talk about Doctors, meds and poop
Supporting each other if you get in the loop

Eating food causes much stress
And coming out, a big mess

A low fat diet they tell us to eat
Gluten free, if you’re allergic to wheat

Men and women, young and old
Pancreatitis so cruel, so cold

It’s 3 am and I’m wide awake
Doesn’t this pain ever take a break?

I’m doubled over holding my gut
The inflammation, such a pain in the butt.

Pain so bad I want to cry

Some say pot helps, if I would get high
I’m so tired my body needs rest
I’m sick of pancreatitis, it’s such a big pest

O yes, I know I’m very bitter
My pancreas stole all my glitter

My dreams they are so grand,
Now being stolen by this rebellious gland

I feel lost with no direction
My normal life has lost connection

Co-workers, they don’t realize
Can’t they see the pain in my eyes?

Family members, some are quick to criticize
I guess it is not easy for them to realize

Outside I smile hiding the pain
And say hi to my neighbor Jane

The pain and anguish that I feel
Tell me, why the hell can’t I heal?

I can give up, or fight with all my might
No way I’ll give up, it wouldn’t be right

Men and women, young and old
Pancreatitis so cruel so cold.

I feel lost with no direction
My normal life has lost connection.

Pancreatitis so cruel so cold.
**Eating out – Maybe not as hard as you think.**

Fact Sheet - Dining Out

Going out to dinner is often thought to be a problem. Actually, most restaurants are more than willing to accommodate special requests.

When ordering in a restaurant, request a very low-fat meal and explain to the server that there is a medical reason for the request. Let the server know that your food must contain a very small amount of oil and no cheese or cream. Most restaurants will steam fish and vegetables or grill a piece of chicken. Many restaurants are happy to take on the challenge and will produce a truly delicious meal for you.

- Choose a restaurant that you know can accommodate your special requests. Call ahead if you are not sure.
- Choose low-fat appetizers like clear soup, steamed clams, shrimp cocktail or fruit cup.
- For your tossed salad, ask for vinegar or fresh lemon.
- Choose seafood, chicken or pasta. Do not order fried foods and dishes with creamy sauces. Make a special request to use no oil or just a minimal amount.
- Request that your entree be baked or broiled without butter.
- Lemon juice, wine or very small amounts of oil are other options to have the entree cooked with if you so desire.
- For dessert, choose fresh fruit, sorbet, frozen yogurt or gelatin without whipped cream.
- Do not eat all of these courses at one sitting. You are much better off eating small portions several times a day, so limit the amount that you order when you are dining out.
- For airlines, you can call ahead and request a low-fat meal if your airline is serving food.

Lemon juice, wine or very small amounts of oil are other options to have the entree cooked with if you so desire. For dessert, choose fresh fruit, sorbet, frozen yogurt or gelatin without whipped cream.

This fact sheet is provided courtesy of the National Pancreas Foundation.

---

**Fruits and Vegetables help protect.**

Fruit and vegetables help protect against common pancreatic diseases, Auckland University researchers say.

The biggest risks come from smoking, obesity and heavy drinking.

A team led by Dr. Max Petrov and Professor John Windsor, from the Department of Surgery, reviewed and analysed 51 studies, involving more than three million people and nearly 11,000 patients with pancreatic disorders.

Tobacco use was found to be the single most important risk factor in developing pancreatic diseases, increasing the risk by 87% compared to people who never smoked.

Smoking and heavy drinking had bigger effects on the risk of acute pancreatitis and chronic pancreatitis than on pancreatic cancer.

Vegetable and fruit consumption provided the greatest protection against pancreatic diseases, Petrov said. Vegetable consumption had a stronger association with protection against acute pancreatitis, and fruit consumption with protection against pancreatic cancer.

Most of the studies used in the review came from the United States, Scandinavia and Japan. No quality population-based study came from New Zealand, due to a lack of national linkage of health data, Petrov said.

"There is a strong need to invest in a health data linkage system in New Zealand, if risk and protective factors for diseases of the pancreas [and other organs] in New Zealanders are to be unveiled," he said.

Pancreatic cancer was predicted to become the leading cause of cancer deaths by 2050.

The pancreas is part of the digestive system, producing hormones including insulin, while also helping the body absorb nutrients, break down carbohydrates, proteins and other compounds.
Join the OCNPF, the National Pancreas Foundation, and our national sponsor, Aptalis Pharmaceuticals, on Saturday, September 13th, for an afternoon of bowling for a great cause.

12:00pm – 3:00pm
Madison Bowl
4761 Madison Rd.
Cincinnati Ohio 45227

We will have food, raffle items, and three hours of bowling for a great cause! Plus, we’ll have “red pin challenges,” and a host of other on site games to help raise money for a cure.

We’ll have teams spread out across all lanes, with each team “bowling for research dollars”. If you want to participate but don’t have a team, we will find you one.

Meet your state chair and medical director. Help us raise money, so we can help fund research! Come out and join us for a great time.

Volunteers and Information Needed!

Our chapter is only as strong as the people who serve it. It is my goal to grow our chapter, and to do this, we need help. The old saying, “There is no I in team,” is not any different here. We are a team. We will need help for future events for fund raising, educational events and to pass out information. I have a goal in future to attend many health events to spread the word. To do this, we need people who are able to attend these, hand out information and talk to people about it. If we can build a good core of people from all over the state, we can accomplish so much.

So please, think about taking some time to help fight for our goals. As we continue to grow, our goal is to continue to spread awareness for pancreas diseases. We can do this by attending different health events around the state. If you know of a health event in your area that would be a good fit for the OCNPF to attend, please contact us. The earlier we find out about an event and we get the information, the more probable we can get things lined up to attend. We may not be able to do all the events, but as we grow, hopefully, we can do many of them.