Pancreatitis Supporters Network Information Pack

Please Note: The information contain in this pack is not necessarily the opinion of The Pancreatitis Supporter Network and no change in medical routine should be undertaken without prior consultation with your GP or Specialist.

Information Pack complied by

The Pancreatitis Supporters Network

PO Box 8938

Birmingham

B13 9FW

Telephone 07914421541

Email: psn@pancreatitis.org.uk

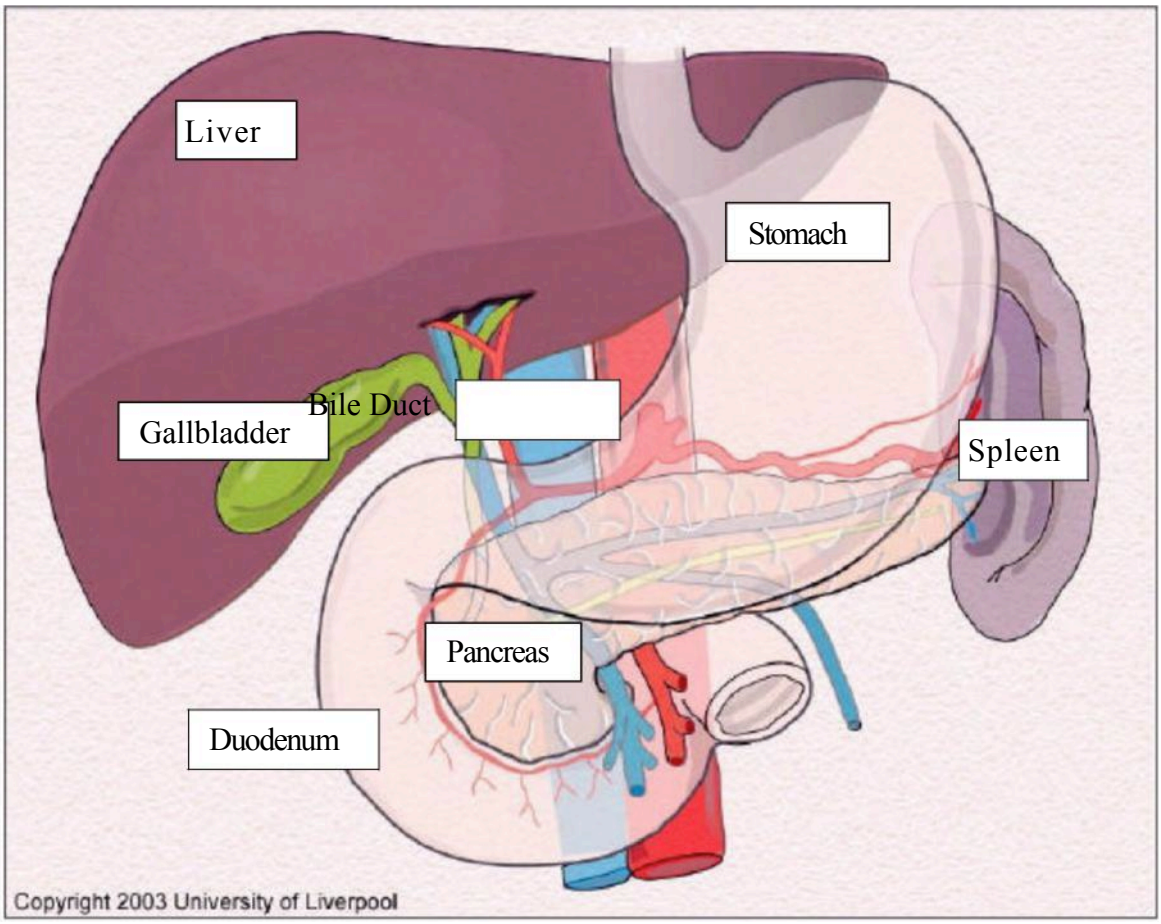
Website: www.pancreatitis.org.uk

We are a registered charity (Number 102447) and as such have our costs to cover, we would appreciate a contribution of £2 for this information and this can be in the form of stamps, postal order, Cheque or cash (taped between cards to disguise the same). However, telephone and email advice is free, (just leave your message and number and we will call you back), as is the use of our Pancreatic Pen Pals List and Discussion Board.

You have received this Pack from the Pancreatitis Supporters Network. You may have either Acute Chronic or Cancer of the Pancreas. You may have a partner with the condition or have a friend or general interest in the same. More specific information on these three versions can be downloaded from the Downloads Section of our website, along with Recipe Books as well.

WHAT IS THE PANCREAS?

The pancreas is a solid gland measuring 20-25cm in length, 4-6cm in width and 3-4cm in depth. It is firmly attached in the back of the abdominal cavity behind the stomach. The pancreas is divided into 5 parts - the head, the uncinate process, the neck, the body and the tail. The head of the gland is closely attached to the duodenum which is the first part of the small intestine into which the stomach empties liquids and partially digested food. The head of the gland is situated just to the right of the midline of the abdomen and below the right rib-cage.



The digestion of fat is very special.

Fat needs to be dispersed before the pancreatic enzymes can properly break it down. This dispersion of fats is made by bile acids which are present in bile produced by the liver and stored in the gall bladder. Bile acids act in exactly the same way as detergents which are used to wash up greasy dishes. Therefore, both bile acids and pancreatic enzymes are needed for fat digestion. This is why the main pancreatic duct and the main bile duct join up together so that pancreatic juice and bile can be emptied together. If there are not enough pancreatic enzymes, fat is not digested and the stools (bowel motions) become pale and greasy. These greasy stools may become difficult to flush away from the toilet and may give off a strong offensive smell. Doctors call this ***steatorrhoea,*** which is a way of saying fatty stool.

For the same reason if the main bile duct becomes blocked, then the bile cannot get into the duodenum, fat cannot be properly digested and the stools are again pale in colour. Because the bile made by the liver cannot go into the bowel it goes into the blood and out through the kidneys into the urine. This results in the eyes and skin becoming yellow and is known as yellow jaundice. As the bile is in the urine this now becomes dark in colour. Because the flow of bile is blocked (or obstructed), doctors call this condition obstructive jaundice. As the bile duct goes through the head of the pancreas yellow jaundice can be caused by disease of the pancreas (such as pancreatitis or cancer.

Tests for Pancreatitis

Your doctor may need to do some tests to find out more about your particular problem. Perhaps you've already undergone one or more of them. The next section describes what these tests are, how and why they are done, and how they can help your doctor to treat your problem.

ULTRASONOGRAPHYOR ULTRASOUND (US) SCAN. This is a simple, painless and relatively quick investigation which can be used to obtain a "picture' of the inside of the abdomen.

NEEDLE BIOPSY OR CYTOLOGY v USING ULTRASOUND OR CT SCAN. Occasionally a small piece of tissue from the pancreas needs to be taken to help make a diagnosis. There are many ways that this can be done especially using an ultrasound scan or a CT scan to tell the doctor where to pass the needle. These procedures are always done in the X-ray department and require additional informed, written consent.

ENDOLUMINAL ULTRASOUND (EUS) This is a special investigation for taking ultrasound pictures of the pancreas, pancreatic and bile ducts and surrounding tissue such as blood vessels. The pictures are taken by a special probe inserted into the stomach and duodenum.

ERCP is rather a mouthful: endoscopic retrograde cholangio-pancreatography! As with EUS it involves inserting a flexible telescope or endoscope (also called a duodenoscope) into the mouth. This is passed down the gullet and into the stomach and then into the duodenum opposite the opening of the bile duct and pancreatic duct.

Is ERCP safe?: ERCP is safe with no complications in about 95% of cases. There are occasionally complications from ERCP however, the most common of which are abdominal pain, acute pancreatitis, biliary infection and bleeding.

For these reasons, an ERCP must be:

- **Performed by a specialist.**
- **Performed for a good reason.**

(NOTE from a Conference I attended of the Pancreatic Society of Great Britain and Ireland it was confirmed the statistics to be: An ERCP can cause an attack of pancreatitis in 1% of healthy people with a 1% death rate. However, for someone who has pancreatitis the first figure rises to a 90% chance of an attack but no one would give me the corresponding death rate but I took this to be similarly high! Hence why a Specialist and for a good reason)!

MAGNETIC RESONACE IMAGING (MRI) An MRI scan is similar to a CT scan but uses magnetic resonance to image the pancreas instead of X-rays.

PTHC Sometimes it is not possible to approach the bile duct or to enter the bile duct using ERCP. In this situation it may be necessary to insert a very fine needle into the bile duct by going first through the skin on the right side and then finding a branch of the main bile duct in the liver. Therefore the full name of this procedure is percutaneous transhepatic cholangiography and is always performed in the X-ray department.

Is PTHC safe?: PTHC is safe with no complications in about 95% of cases. There are occasionally complications from PTHC however, the most common of which are abdominal pain, biliary infection, bleeding and a bile collection or abscess. In most cases, the complications improve. Occasionally the complication is serious and death may result in a very small proportion of cases.

PET Scan This is a special scan performed in the Nuclear Medicine Department and is sometimes performed in certain centres if there is uncertainty as to the diagnosis. In other words this is performed if the doctors are not sure if you have chronic pancreatitis or a small pancreatic cancer. The full term for a PET scan is Positron Emission Tomography.

SPECIAL TESTS FOR PANCREATIC FUNCTION IN CHRONIC PANCREATITIS

TESTS FOR DIABETES

The urine can be tested for sugar using a simple technique of dipping a special strip of paper into a sample. Depending on the amount of sugar, it changes colour (normally there is no sugar in the urine). Urine testing is often used as a screening test.

More precise tests involve measuring the actual glucose level in the blood by taking a blood sample from an arm vein. The blood glucose level can also be measured using another special paper strip dipped into a drop of blood obtained by pricking the pulp end of a fingertip.

TESTS FOR PANCREATIC ENZYME PRODUCTION.

These tests are not as accurate as determining blood glucose levels because many factors are

involved in the digestion of food by pancreatic enzymes. Few patients actually require such a test since the clinical outcome is the most important factor. This means that if a patient has greasy stools and is losing weight, then pancreatic enzyme supplements (tablets or capsules) are required. The number of tablets or capsules will be increased by the doctor, or the patient will be instructed by the doctor to do so until the symptoms disappear. *(See info later on concerning doseage)*. Nevertheless, confirmatory tests are usually required. **None of these tests is ideal and different institutions use different tests**.

The precise details of these are not required but may include the following:

Faecal Elastase Test Elastase is one of the enzymes produced by the pancreas to digest protein. There is always a small extra amount produced which means that it can be measured in the stool. The extra amount of elastase produced is related to the amount of normal pancreatic function. The faecal elastase

PLT or Pancreato-Lauryl Test A standard meal is taken following an overnight fast along with a test "food" (with PLT). One or more blood tests or a urine test is then made to see if the test "food" has been digested (by the pancreatic enzymes) and then absorbed.

Triolein breath test This is a more specific test for fat digestion and absorption and is fairly simple to perform. Triolein is a fat which contains a minute trace of radioactive carbon. The amount of fat metabolised is determined by taking a simple breath test at a fixed time following ingestion of a small amount of triolein.

Faecal fat test This is an excellent way of determining fat digestion but involves collecting stools for 1-3 days. As you can imagine this is not popular with either patients or the laboratory staff who have to make the measurement. (At the same time pancreatic enzymes present in the stool can also be measured.)

Secretin test This is performed in only a few very specialist pancreas units and is very accurate (like the faecal fat test).

How can I modify my diet and daily activities to help treat Pancreatitis? Answer submitted by The Pancreatic Society of Great Britain and Ireland.

The single most important change that any sufferer from chronic pancreatitis can make is to stop drinking alcohol. Even if your pancreatitis is not directly caused by alcohol, it is likely that drinking alcohol will harm the pancreas because it stimulates the production of a thick, sticky pancreatic juice which tends to clog the pancreatic ducts. This adds to the drainage already taking place in the pancreas. It is probably also helpful to stop smoking, because smoking stresses the body's natural defence mechanisms against inflammation and may contribute to the damage occurring in the pancreas. A well balanced diet is probably helpful. You need not restrict fatty food and in fact an adequate intake of fat may help to prevent weight loss. If you have access to a dietician, you should ask for advice on how to maintain an intake of 100 grams of fat and 100 grams of protein each day. If this diet causes symptoms such as diarrhoea or looseness of stools it is better to begin or increase the dose of pancreatic enzyme supplements rather than to cut down the amount you are eating.

Can vitamin supplements help? There is some evidence that antioxidants help to protect against inflammation in a wide variety of diseases. There are many vitamin preparations with added antioxidants available from chemists and Health Food shops. These preparations will certainly do no harm, and some patients find their pain is less severe or less frequent when they are taking them. Look out for formulations which contain vitamin C,

ANTIOXIDANT THERAPY FOR PANCREATITIS - BIO ANTOX INFORMATION SUMMARY

February 1995 *(edited due to lack of space. Full article in Archives on The Pancreatitis Supporters Network website).*
Bio Antox. This preparation allows substantial reduction in daily tablet intake by combining the essential amino acid methionine, antioxidant vitamins and trace element selenium. Detailed background evidence, to support the use of antioxidants in pancreatitis, is given in the summary which follows. It is stressed that treatment should be part and parcel of a shared care protocol, so that blood antioxidant and free radical marker profiles can be checked at intervals to ensure compliance and adequacy of dosage.

PROPRIETARY NAME: BIO ANTOX.

MANUFACTURER: Pharm Nord and distributed by Pharma Nord (UK) Ltd. Spital Hall, Mitford, Morpeth NE16 3PN

PRESENTATION	Tablets (150 in a box) typically containing:
selenium (organic)	75 ug
methionine	400 mg
beta carotene	3 mg
vitamin C	150 mg
vitamin E	47 ug

LICENSED INDICATIONS: None

CURRENT STATUS:

Pharma Nord have given Pancreato Biliary Consultants an undertaking that Bio-Antox, the formulation of which is based entirely on the work of the Manchester group, will not be available "over the counter". The same company markets a range of food supplements, one of which is called Bio Antioxidant, but this should not be confused with Bio Antox. Both contain micronutrients and vitamins but the formulations of each markedly differ.

DEVELOPMENT OF ANTIOXIDANT THERAPY

Background: There is increasing evidence that habitually poor diets render body organs vulnerable to oxidative stress, and hence tissue injury, when free radical load exceeds antioxidant defence capability. In general terms this load may derive from such dissimilar sources as ultraviolet light, substance abuse (for example alcohol or cigarettes), and, above all, environmental pollutants. The notion that antioxidant supplementation might be protective to a population by increasing its defence against pro oxidant factors, is gaining ground, as witnessed by a plethora of studies in the field of atherosclerosis. The therapeutic corollary was exploited by the Manchester group almost a decade ago and has been validated by placebo controlled trials, while sporadic reports from other groups are beginning to offer independent endorsement of this treatment.

QUESTIONS TO BE ANSWERED

Q: What need is met by this therapy?

A: Treatment of patients with chronic or recurrent acute pancreatitis

Q: What happens now?

A: Patients are treated with anal-gesics, or may go on to near-total pan-createctomy resulting in malabsorption and diabetes.

Q: Is quality improved?

A: Yes - patients on this treatment do not have pain.

Q: What does the treatment cost?

A: Less than 15 pounds per month per patient.

Q: Can cost savings be made?
A: Yes - though not quantified, the cost of treatment with antioxidants is likely to be much less than present treatments.

Advice to Health Authorities and GP‟s Will increase quality and effective-ness. May result in reduced costs. Worth considering in specification.

*(**WARNING**: Do not self dose with these ingredients as without proper monitoring some of these ingredients are POISONOUS! We no longer have a group supporting this treatment but if they set up another helpline in the future we will include it here).*

TRANS FATTY ACIDS

First, a little about trans fat. I would like to climb up on the soapbox, but I'll save that for another time. Trans Fatty Acid's (TFA's) main use is to extend the shelf life of a product. Foods containing trans-fat have a much longer shelf life because it doesn't spoil. It's secondary purpose is to change a liquid oil into a solid. This is why shortening is white and solid, but pure corn oil is a liquid. The following list contains the most common foods containing TFA's. It is by no means complete. It will identify some of the obvious foods to watch out for.

Trans Fat List:
Margarine, vegetable shortening , pastries, peanut butter, French fries (except those made at home from fresh potato's, fried in pure vegetable oil), most fast food, most cookies (Internet cookies are OK), most frozen dinners (low fat included), most snack foods, most cakes
(prepared and boxed, I would . like to give the Dough Boy an extra hard poke in the belly), most potato chips, most crackers, most restaurant food (because it is usually prepared with shortening), some candies, some ice creams, some pizza (depends on ingredients used), most vending machine foods.

TFA Free Foods:
All fat free foods, Meats, Eggs, Milk, Fruits, Vegetables, Fish, Most candy, Soft drinks, Coffee, Tea, Vegetable oil, Chocolate, Grilled foods, Most cheeses, Yogurt, Most breads, No fat mayonnaise, Ketchup's, Mustard.

Specific TFA Free Foods:
Krusteze brand cake and muffin mix, Certain Pringles Potato chips, Smart Balance spread (new and patented for not containing TFA‟s, and for being able to help balance fat metabolism), Kraft or Henry's no fat salad dressing, These specifics were included because in these food categories it's hard to find any products that are TFA free. If anyone finds more please let me know and I'll add them to the list. If the theory holds and the condition of the pancreas improves, small amounts of other natural fats, such as monounsaturated, polyunsaturated, and saturated, may be beneficial. Some research indicates that a balanced fat diet is very important to the overall health of an individual.

A Final Thought:
Human evolution has been taking place for some 4 or 5 million years. During that long span our digestive systems slowly adapted to the foods that were consumed. Now we have been introduced to hydrogenated oils. It is killing or making sick those who cannot adapt to it. Given a few thousand years we won't have to worry about hydrogenated oil because those not able to adapt to it will be gone.

PANCREATIC ENZYME SUPPLEMENTS

(We are often asked how many enzymes should we be taking, I hope the below article, from Liverpool University Hospital"s Web site will help).

There are many preparations available. These preparations differ considerably in their effectiveness of action. The better preparations consist of capsules containing scores of small granules. The enzyme preparations can also be divided into two types depending upon their strength of action: regular and high dose. The capsules need to be taken during each meal and with any snack.

Requirements vary enormously from patient to patient: **typically 20-30 high-dose capsules per day** are required but this can be lower or much higher. The requirements vary greatly from patient to patient partly because of the different level of secretion by any functioning pancreas and partly because there are still some enzymes secreted by the salivary glands, tongue stomach and small intestines but which also varies greatly from person-to-person.

In a few cases of children and adults with cystic fibrosis, a serious problem with the large bowel (colon) has been reported. This condition is called fibrosing colonopathy and causes narrowing of the bowel. It seems to be related to the use of a particular acid-resistant coating of the enzyme preparations (called methacrylic copolymer). The problem does not arise with preparations without this covering. The latter preparations are therefore recommended. The ingredients are always listed on the pack leaflet or label.

Once patients are accustomed to taking enzyme supplements, they are usually allowed to adjust the number they take them-selves to suit their own individual needs.

AN ANSWER TO PANCREATIC PAIN?

Written by William D Broadfoot FISTC, MCIM [Heavily edited by the Editor!] The author is a Fellow of the Institute of Scientific and Technical Communicators and is also a Chartered Consultant who is working alongside two Bristol based doctors (AJR MacDonald and TW Coates) to help them introduce a new method of pain relief known as Transcutanous Spinal Elec-troanalgesia (TSE for short)

The X-Pain machine is fundamentally different to the well-established "TENS" machine and indeed has more in common with the surgical technique known as Spinal Cord (Dorsal Column) Stimulation which has been practiced since 1967 to provide sufferers of acute pain with measure of relief. Over a 28 year period there has been no indication of any possible side effects related to the transmission of electricity to this area.

In a major scientific breakthrough it was discovered that when injury was caused to any part of the body, spinal cord interneurones (nerve cells) exhibit a dramatic behavioural change which is manifest by the production of c-FOS protein. Once spinal cord interneurones have been triggered by news of an injury it would appear that these nerve cells can subsequently remain active for decades - and certainly long after the injured part has healed completely. As a result - and for reasons which remain obscure - spinal cord interneurones continue to send warning messages to the brain which results in millions of people suffering completely unnecessary pain for much of their lives.

Since electricity was first generated and harnessed for use; its pain relieving properties have been noted and applied. Transcutanous Electrical Nerve Stimulation (TENS) devices use electrical stimulation to excite AB [Editors note: the B here is the Greek symbol] fibres in the area where pain is experienced. They are arguably the modern equivalent of applying a hot water bottle or ice pack (or healers hands) to the apparent seat of the pain. All these methods have an indirect effect on the mechanism of the spinal cord interneurones. *However they have to be applied to the correct place [My italics, Editor],* and therefore considerable skill is required by the practitioner. When pain is felt in the elbow, for example, the tender region which requires treatment may well be in the neck. If the patient has two elbows in trouble and a knee as well, several regions require simultaneous treatment *[rather like acupuncture: Editor]*. The only way to do this was to aim for the spinal cord itself. The key to success, the two Bristol doctors discovered, was to determine the precise intensity, frequency and pulse width of electrical input to the spinal area which would cause the spinal cord interneurones to become dormant. To achieve this they placed two electrodes at the top and base of the spine.

Obviously, electrical energy takes the most direct route and will therefore flow parallel to the spine. The electrical energy which reaches the spinal cord is minute in terms of duration so there is no stimulation of the peripheral nerves in the area - in other words, no localized pain. The doctors then developed a simple portable pulse generator which the patient adjusts until a slight warming sensation is felt. There is no discomfort. One patient who was treated by doctors using this device suffered recurring spasms of pain for over 40 years since being struck in the stomach by a rifle butt during the Korean War. Other patients using the X-Pain device have experienced almost immediate relief where the original cause of the injury has long healed or is 'on the mend'. This is particularly true of neck and back sufferers who have sufferers an injury to their spine sometime previously. The same is true to people who suffer from painful limbs, stress aches, migraines, headaches, postoperative pains, arthritis, menstrual pains, and 'modern living' complaints such as repetitive stress injury and M.E. The X-Pain method of pain relief is not an anesthetic. It will not provide

relief for patients suffering from any pain generating condition. Equally, it will not hide the symptoms of heart attacks, or angina, or where there is inflammation to any organ brought about by disease. Such pains are ongoing and the signals will continue to be sent to the brain regardless of any TSE treatment. People who have a medical condition which requires the use of a Pacemaker or other implanted electrical stimulator would not use the TSE method - nor should pregnant women, without first seeking medical advice. The closest competitor to the TSE method is the widely practiced method of the "TENS" machine. TSE offers five distinct advantages when compared to this form of treatment:-

a) TSE provides longer lasting relief from pain (possibly even permanent relief in some cases).

b) The pain relieving benefits do not diminish the more you use the TSE machine.

c) TSE takes less time to use

d) TSE provides simultaneous relief of pain across the entire body rather than one place.

e) TSE does not require anatomical knowledge to site the electrodes correctly.

In summary, TSE would appear to represent a major advance in pain therapy. (Editor in this article refers to The Pancreatitis Supporters Network.

Acticare TSE

Dr Alex Macdonald co-inventor of TSE

Available from: http://www.acticare.com (When produced)

Article refers to the original ENM/X-Pain Device now refined with more features and called Acticare

Question to our Patron – Prof Mike Larvin on the relationship between alcoholism and Pancreatitis

Q: By the way has there ever been any statistics on the causes of pancreatitis?

A: The only 'survey' I have heard of was by Manchester Royal Infirmary for their Bioantox treatment and they could only find 20% alcohol related.

Q: The Digestive Diseases Foundation is quoting 70-80% as the cause in Acute attacks. Is this true?

A: No-one really has good data. Almost everyone who develops it used to drink some alcohol so it is an easy assumption that this was the cause (as you and your wife know)! My own suspicion is that rich western style food, maybe social alcohol and possibly stress (oxidant and mental) all contribute to gradually knackering the pancreas. Add in a little genetic predisposition (this is becoming a hot topic) and it explains why some get it but most don't - despite the same risk factors. Undoubtedly some patients also have a mechanical element - sphincter dysfunction, gallstones recurrently passing by etc.

Q: What do you conclude from this long list?

A: Well just that we don't really know. What you read depends on location and social mix of the patients concerned. US, Germany and Scandinavia have a big proportion of alcohol related disease (notice that I avoid the term 'alcoholic' Pancreatitis' as most alcohol related disease occurs in social drinkers).

(I think this is a very important point to get across to a lot of the medical profession who automatically class us as being alcoholics! – Editor)

Question to Mike Larvin on Pregnancy and Pancreatitis plus Cystic Fibrosis (CF)

Q. My reason for writing, is that my Niece has been trying for a long time to have a child.. and no results. She is wondering if the combination of a CF gene and the Pancreas condition prevents her from becoming pregnant? She is too upset to search this information on her own (she also suffers from depression), so she has asked for my help. Please provide as much medical information, or sources, on this topic (asit relates to preventing pregnancy) as possible. **(Left Anon by Editor)**

A. Poor nutrition can occur if enzyme replacement is not given/taken for either condition, so infertility can be a result of that. I can't really add much here as I am not an expert in non pancreatic elements of CF. She should also consider that it is best to have depression treated fully before aiming for pregnancy maybe, but there is no alternative to seeing her GP with a view to a specialist consultation at her local CF clinic - they will know what to advise. Even though she is only a carrier (you need two genes to develop CF but we know some carriers do have problems pancreatic and otherwise, it is unfortunately not as exact a science as we would like. I would encourage the lady to make sure her niece seeks a professional CF opinion unless her GP can help with this.

Forms of Pancreatitis

(As taken from University Hospital Website, Liverpool)

I think this is a marvellous description of all the forms of Pancreatitis and for those of you who do not have web access I thought it would be useful!

NARROWING OF THE PANCREATIC DUCT.

There are many different reasons why the pancreatic duct becomes narrowed. For this reason, it is important not only to show that the pancreatic duct is narrow but also the cause for this. Surgery is often required to deal with pancreatic duct narrowing.

PANCREATITIS DIVISUM

The pancreas develops as two separate buds from the intestinal tube during embryological development of the foetus in the womb. These buds each have a separate pancreatic duct. The two buds eventually combine together before birth to form a solid single organ. When this occurs, the separate pancreatic ducts also combine. In about 10% of healthy individuals, the pancreatic tissue combines but the two pancreatic ducts remain divided and they empty separately into the duodenum. This situation is called pancreas divisum because the pancreatic ducts remain divided.

Pancreas divisum is not harmful in the vast majority of cases. Very occasionally one of the ducts becomes narrowed and this can eventually lead to chronic pancreatitis.

The treatment involves enlarging the narrowed pancreatic duct opening and can occasionally be done by endoscopic sphincterotomy (see above). An open surgical operation can also be performed that involves opening the duodenum and is called trans-duodenal sphincteroplasty.

The operation may involve enlarging both the biliary and pancreatic sphincters (see above) and is therefore called a double sphincteroplasty. If the pancreatic duct is very distended then this can be drained into a piece of bowel and the operation is called a Roux-en-Y lateral pancreato-jejunostomy. If the head of the pancreas is damaged by the pancreatitis sometimes it may be necessary to remove a part of the pancreas (Beger‟s operation).

AUTOIMMUNE PANCREATITIS

This is a rare condition that causes chronic pancreatitis. The actual cause of the condition is not known. In the pancreas of this condition there are many cells of the type that make antibodies and other cells involved with immunity. This is why it is called autoimmune pancreatitis. The diagnosis is extremely difficult to make. There is often obstructive jaundice and a swelling in the head of the pancreas. It is therefore not surprising that it is often confused with a tumour in the head of the pancreas. In fact the correct diagnosis is usually only made after major surgery to remove the head of the pancreas (Kausch-Whipple operation). The condition will respond to a course of steroids and pancreas enzyme supplements.

IDIOPATHIC

This is a loosely applied term used by doctors to mean “the cause is specific to an individual person” – in other words the cause is not known for certain. Many patients initially diagnosed as ”idiopathic‟ turn out to have a known cause – such as autoimmune pancreatitis or hereditary pancreatiti

The pancreatitis can begin in children or young adults and is referred to as juvenile-onset idiopathic pancreatitis. Alternatively it may first begin in older adults and is referred to as late-onset idiopathic pancreatitis. There may be a genetic basis to the pancreatitis. This often involves an alteration to a gene called SPINK-1 or an alteration to a gene called the cystic fibrosis gene, which is also called the CFTR gene. Inheritance in pancreatitis is explained in more detail below.

DOES CHRONIC PANCREATITIS RUN IN FAMILIES?
In general, the answer is NO as it is mainly due to alcohol. Nevertheless alcohol is not the problem in one in three patients and in these cases there may be a genetic basis for the pancreatitis. Therefore, although it is quite rare, it is possible for pancreatitis to run in families and falls into two types: hereditary pancreatitis and some forms of idiopathic pancreatitis.

INHERITED PANCREATITIS
Inherited pancreatitis happens because they have an altered gene which predisposes to pancreatitis.

What are genes?
Each person has exactly the same number of genes as every other person. The total number of genes is 30,000. Genes are in the nucleus of each cell of the body. Genes are like the blueprints in a factory. These blueprints (or genes) enable the cell to make proteins which then organise the two other types of basic molecule (carbohydrates and fats) to create particular types of cell and hence the different organs (such as liver, arms and legs and so on).

In the cells of different organs only some of the 30,000 genes in the nucleus are selected for use. This number varies from 6,000 to 10,000 genes in any particular cell. The different combination of genes used as blueprints for making proteins is how the human body can be organised in such a complicated way (compared to a simple worm that has only 900 genes).

Genes are always in pairs, so that one set comes from the mother and one set comes from the father. There are tiny variations in each gene. These tiny variations are essential to make every person an individual. Occasionally a tiny variation in a gene can give rise to a disease condition. An alteration in a gene that gives rise to a disease is often referred to as a mutation (this is a Latin word that simply means "changed"). Patients and their families with inherited pancreatitis require the care of a specialist surgeon, paediatrician or gastroenterologist and genetic counselling.

Hereditary Pancreatitis
In this type of inherited pancreatitis there is a tiny variation in the cationic trypsinogen gene. The trypsinogen gene provides the blueprint to make a protein called trypsinogen. Trypsinogen is not active in any way and itself is quite harmless. During a meal trypsinogen is secreted into the main pancreatic duct and then into the duodenum. Trypsinogen is then made very active by the removal of a protective cap at one end of the molecule. Once this cap has been removed it is now called trypsin, which is also an enzyme and is now very active. As mentioned above trypsin is also an enzyme and is used to digest the proteins in foods such as meat.

What happens in hereditary pancreatitis is that the protective cap of trypsinogen is removed in the pancreas. This unfortunately results in active trypsin in the pancreas. This activation occurs before it has had a chance to be secreted into the duodenum. This activated trypsin then begins to attack other proteins actually within the pancreas and causes acute pancreatitis.

The gene is officially called the PRSS1 gene and the two commonest alterations (or gene mutations) are called R122H and N29I. There are however 20 or so different mutations that have been discovered. Affected individuals tend to develop pancreatitis as children, adolescents or young adults. There may be other members of the family with sugar diabetes. Not all members of the family will be affected in the same way.

On average only half the individuals will carry the altered gene. The altered gene can be passed on by either the father or the mother and only one altered gene needs to be passed on to cause pancreatitis. The technical term for this kind of inherited disease is autosomal dominant. ("Autosomal" refers to the fact that is not linked to the sex genes and "dominant" means that the altered gene is stronger than the normal gene).This means that half the children of an affected parent will have the gene passed on to them. Even then, some members of the family (about 20%) with the altered gene will not be affected at all. We call this 80% penetrance because the disease will only "penetrate" into 80% of people with altered gene.

The presence of the gene can be tested for by a single blood test. Genetic counselling is required before any tests can be performed. Some families with hereditary pancreatitis have a normal set of PRSSI genes. This means that another gene is affected and scientists are trying to find out which one this is.

Idiopathic Pancreatitis
Up to half of all patients with idiopathic pancreatitis (see above) have inherited one of two other altered genes that can trigger pancreatitis. One is called SPINK-1 and the other is called CFTR.

In order to protect the pancreas against accidental conversion of trypsinogen to trypsin, humans have been equipped with a safety mechanism called SPINK-1. This is a special enzyme that destroys any active trypsin in the pancreas and hence stops pancreatitis from occurring. Unfortunately some individuals have an alteration in SPINK-1 called the N34S mutation, which destroys the safety mechanism.

About one in fifty people have the N34S mutation but less than 1% of these people ever get acute pancreatitis. In other words this altered gene has less than 1% penetrance, or very low penetrance. This means that there is some other reason as well for the pancreatitis. This means that even though the N34S mutation was inherited from either the mother or the father, the parents are usually not affected. Also this means that the disease is very unlikely to be passed on to the children even though there is a fifty-fifty chance that the N34S mutation will be passed on to them.

Some patients have an alteration in the gene that causes cystic fibrosis, known as the CFTR gene. This gene provides the blueprint that makes a protein also called CFTR. This protein regulates the passage (or conductance) of small molecules through the outer surface (or membrane) of the cell. An alteration in both genes (the one from the mother and the one from the father) causes the disease called cystic fibrosis. For all of these reasons the full name of the gene is the cystic fibrosis transmembrane conductance regulator gene.

One in 20 of the normal population has a CFTR gene mutation but only a tiny handful has idiopathic pancreatitis. Individuals with cystic fibrosis disease have both of the CFTR genes altered. People with idiopathic pancreatitis only have one CFTR gene mutation (either from the mother or from the father). This type of genetic disease is therefore called autosomal recessive. We do not understand why some people with only one CFTR gene mutation develop pancreatitis. Scientists are trying to find out why this happens.

In these rare forms of pancreatitis, the symptoms begin as acute pancreatitis and usually progress to chronic pancreatitis. This also applies to a number of other causes of acute pancreatitis but gallstones never cause chronic pancreatitis.

Thank you to Sue Ballard

Sue has set up a **Facebook page** for the Network and please feel free to **'like'** us and get involved with posting on the site!

There are links to other resources, separate to ourselves. This is new and will no doubt change as you give your thoughts and ideas so, get involved, it will only be as good as you all make it!

Here is the horrendously long link to it for your browser:

https://www.facebook.com/pages/Pancreatitis-Supporters-Network/320147184684604

USEFUL ORGANISATIONS

Pancreatic Society of Great Britain and Ireland This is a professional organisation of specialist doctors involved in the care of patients with pancreatic disease. The Society is allied to the European Pancreatic Club and the International Association of Pancreatology.
Write to: Mr Ross Carter, Secretary, Pancreatic Society of Great Britain and Ireland, Consultant Surgeon, Glasgow Royal Infirmary, 84 Castle Street, Glasgow, G4 0SF.
Tel: 0141 211 5129 Fax: 0141 211 4991 email rcarter@clinmed.gla.ac.uk

Pancreas Research Fund Specifically supports basic and clinical research of all diseases of the pancreas.
Write to: Professor JP Neoptolemos, Department of Surgery, Royal Liverpool University Hospital, Daulby Street, Liverpool, L69 3QA. Tel: 0151 706 4175
email j.p.neoptolemos@liv.ac.uk website http://www.liv.ac.uk/surgery/about.html

Digestive Disorders Foundation Supports research into digestive diseases.
Write to: 3, St Andrew‟s Place, London, NW1 4LB. Tel : 0207 486 0341
Website http://www.digestivedisorders.org.uk

EUROPAC European Register for Familial Pancreas Cancer and Hereditary Pancreatitis. The principal register in Europe providing advice and research in inherited pancreatic disorders.
Write to: EUROPAC Co-ordinator, Department of Surgery, Royal Liverpool University Hospital, Daulby Street, Liverpool, L69 3QA.
Email europac@liv.ac.uk **website** http://www.liv.ac.uk/surgery/europac.html

Pancreatitis Supporters Network The only worldwide registered charity working for the patient. This is a support group which has members throughout the UK. The Network provides information and support to patients with pancreatitis and their relatives. This is a registered charity.

Write to: Mr. Jim Armour, Chairman, The Pancreatitis Supporters Network, PO Box 8938, Birmingham, B13 9FW.

Tel: **07914421541** email psn@pancreatitis.ord.uk website http://www.pancreatitis.org,uk

MRI Pancreatitis Support Group Provides support and advice to patients with pancreatitis in the Manchester region.
Write to: MRI Pancreatitis Support Group, Pancreato-biliary administrator, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL.

Benefits Help

Although we will do what we can to help over the telephone it is often more appropriate for you to get a LOCAL help center to assist you in filling in the forms when claiming for Disability Living Allowance or Attendance Allowance etc. We can give general hints and tips on how to claim these, and other benefits but nothing beats having someone sit beside you while you fill one of these forms in. The following are the Head Offices of a number of Organisations who should be able to help and if you call them they should be able to give you a local branch to where you live:

AdviceUK 12th Floor, New London Bridge House, 25 London Bridge Road, London SE1 9ST
Tel: 020 7407 4070 Email: general@adviceuk.org.uk Web Site: www.adviceuk.org.uk

AdviceUK can provide details of your local advice agency.

Age Concern, Freepost (SWB30375), Ashburton, Devon TQ13 7ZZ
Tel: 0800 00 99 66 Web Site: www.ageconcern.org.uk

Age Concern can provide you with details of a local Age Concern Branch.

Citizens' Advice, Myddelton House. 115-123 Pentonville Road. London N1 9LZ
Tel: 020 7833 2181 Web Site: www.citizensadvice.org.uk

Citizens' Advice can provide details of local Citizens' Advice Bureau

DIAL UK, Park Lodge, St Catherine's Hospital, Tickhell Road, Balby, Doncaster DN4 8QN
Tel/Textphone:01302 310123 Email: enquiries@dialuk.org.uk Web Site: www.dialuk.org.uk

DIAL is a national network of disability information and advice services. They can provide a list of local DIAL groups in England and Wales.

Law Centres Foundation, Duchess House, 18-19 Warren Street, London W1T 5LR
Tel: 020 7387 8570 Email: info@lawcentres.org.uk

The Law Centres Federation can provide a list of local law centres in England and Wales.

Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA
Tel: 020 7247 8776 (textphone also available) Fax: 020 7247 8765
Email: office@dial.pipex.com Web Site: www.disabilityalliance.org

Rights Advice Line: 020 7247 8763 (textphone available).
This Organisation produces a variety of publications on specifically how to claim a benefit. It is worth while buying a copy of the one relating to the benefit you are trying to claim as these show the language and format needed for a successful claim. ALWAYS be prepared to APPEAL or even the next stage TRIBUNAL. At each of these stages get a copy of what basis you were turned down on in the first place.

Specialist Pancreatic Centres

Find your specialist and get your GP to do a letter of referral. Your GP cannot refuse to do this under Choose and Book and The Patients Charter. Both of which can be found in the LINKS tab. Some will do a one off private consultation for about £150 BUT you MUST specify at your initial consultation that you want all tests and treatment under the NHS.

Aberdeen
Aberdeen Royal Infirmary Foresterhill Aberdeen AB24 2ZN

Barts and the London
St Bartholomew's Hospital West Smithfield London Greater London EC1A 7BE

Belfast Health and Social Care Trust
Trust Headquarters, A Floor Belfast City Hospital Lisburn Road Belfast BT9 7AB

Birmingham
Queen Elizabeth Hospital Birmingham Mindelsohn Way Edgbaston Birmingham B15 2WB
Note: I also know of a Paul Wilson at Heartlands Hospital, Bordesley Green East, Bordesley Green Birmingham. This is my Specialist.

Blackburn
Royal Blackburn Hospital, Haslingden Road Blackburn Lancashire BB2 3HH

Bristol Royal Infirmary
Marlborough Street Bristol Avon BS2 8HW

Cambridge
Addenbrooke's Hospital Hills Road Cambridge Cambridgeshire CB2 0QQ

Cardiff
St David's Hospital Cowbridge Road East Canton Cardiff CF11 9XB

Cork
Mercy University Hospital Grenville Place Cork Ireland

Coventry
University Hospital Clifford Bridge Road Coventry West Midlands CV2 2DX

Derby
Royal Derby Hospital Uttoxeter Road Derby Derbyshire DE22 3NE

Dublin
St Vincent's University Hospital Elm Park Dublin 4

Dundee
Ninewells Hospital Dundee DD1 9SY

Edinburgh
51 Little France Crescent Old Dalkeith Road Edinburgh EH16 4SA

Glasgow
Glasgow Royal Infirmary 84 Castle Street Glasgow G4 0SF

Guilford
Frimley Park Hospital NHS Foundation Trust Portsmouth Road Frimley Surrey GU16 7UJ

Hammersmith Hospital Du Cane Road London Greater London W12 0HS

Hull Royal Infirmary Anlaby Road Hull East Yorkshire HU3 2JZ

Kings College Hospital
Denmark Hill London SE5 9RS

Leeds General Infirmary Great George Street Leeds West Yorkshire LS1 3EX

Leicester Royal Infirmary
Infirmary Square Leicester Leicestershire LE1 5WW

Liverpool
The Royal Liverpool University Hospital Prescot Street Liverpool Merseyside L7 8XP

Luton
Luton and Dunstable Hospital The L&D Hospital NHS Foundation Trust Lewsey Road Luton Bedfordshire LU4 0DZ

Manchester Royal Infirmary
Oxford Road Manchester Greater Manchester M13 9WL

Marsden
The Royal Marsden Hospital Fulham Road London Greater London SW3 6JJ

Newcastle
Freeman Hospital Freeman Road High Heaton Newcastle upon Tyne Tyne and Wear NE7 7DN

North Manchester General
Delaunays Road Crumpsall Manchester Greater Manchester M8 5RB

Nottingham University Hospitals
NHS Trust – City Campus Nottingham City Hospital Hucknall Road Nottingham Nottinghamshire NG5 1PB

Oxford
John Radcliffe Hospital Headley Way Headington Oxford Oxfordshire OX3 9DU

Plymouth Hospitals NHS Trust
Derriford Road Crownhill Plymouth Devon PL6 8DH

Royal Free
The Royal London Hospital Whitechapel Road London Greater London E1 1BB

Royal London
Whitechapel Road London E1 1BB

Sheffield
Royal Hallamshire Hospital Glossop Road Sheffield S10 2JF

Southampton General Hospital
Tremona Road Southampton Hampshire SO16 6YD

Stoke
Royal Infirmary Princes Road Stoke on Trent ST4 7LN

Swansea
Morriston Hospital West Glamorgan SA6 6NL

UCL
University College London Gower Street London WC1E 6BT

Please reply to: Mr Jeremy J French, Department of HPB Surgery, Freeman Hospital, Newcastle, NE7 7DN
Tel: 00 44 191 2231525/ 00 44 191 2448750
Fax: 00 44 191 223 1191
e-mail: jeremy.french@nuth.nhs.uk24

Extract from Choose and Book – NHS – UK only

What is Choose and Book?

Choose and Book is a service that lets you choose your hospital or clinic and book your first appointment.

When you and your GP agree that you need an appointment, you can choose which hospital or clinic you go to. You will also be able to choose the date and time of your appointment.

What does Choose and Book mean for me?

As well as giving you a choice of hospital, date and time for your appointment, Choose and Book will also give you the ability to:

- plan and manage your appointments around any existing appointments, if you are currently undergoing treatment;
- fit your treatment in with your other commitments, at home and at work;
- choose appointments that fit with your carer's schedule; and
- check the status of your referral and change or cancel your appointments easily over the phone or on the internet.

How does Choose and Book work?

When you and your GP agree that you need an appointment with a specialist, Choose and Book shows your GP which hospitals or clinics are available for your treatment. Your GP discusses with you the clinically appropriate options that are available for treating your medical condition.

If you know where and when you would like to be seen, you may be able to book your appointment before you leave the practice. You will be given confirmation of the place, date and time of your appointment.

You may want more time to consider your choices. If so, you can take the Appointment Request letter away with you and book your appointment later. Your Appointment Request letter lists your unique booking reference number, your NHS number and a list of hospital or clinic options for you to choose from. Your GP practice will also give you a password with your Appointment Request letter.

You can then decide how you wish to book your appointment; via the telephone, using the national number on the letter or via the internet. Please note that whilst the vast majority of appointments can be booked this way, in some cases you will need to telephone your chosen hospital directly to make your appointment. This is because the hospital appointments system does not link to Choose and Book.

Can I book all my appointments through Choose and Book?

When you and your GP agree that you need an appointment with a specialist, you can book your first hospital or clinic appointment using Choose and Book. Any follow up appointments, are arranged by the hospital themselves.

The benefits of Choose and Book:

- You can choose any hospital in England funded by the NHS (this includes NHS hospitals and some independent hospitals). More information about hospitals is available on the NHS Choices website;

- You can choose the date and time of your appointment;

- You experience greater convenience and certainty. With Choose and Book, the choice is yours; and

- There is a reduced risk that correspondence gets lost in the post as most of the communication is done via computers.

For more information please go to their website:

http://www.chooseandbook.nhs.uk/patients/whatiscab

Extract from The Patients Charter – NHS – UK Only
Patients and the public – your rights and NHS pledges to you

Everyone who uses the NHS should understand what legal rights they have. For this reason, important legal rights are summarised in this Constitution and explained in more detail in the Handbook to the NHS Constitution, which also explains what you can do if you think you have not received what is rightfully yours. This summary does not alter your legal rights.

The Constitution also contains pledges that the NHS is committed to achieve. Pledges go above and beyond legal rights. This means that pledges are not legally binding but rep Access to health services: You have the right to receive NHS services free of charge, apart from certain limited exceptions sanctioned by Parliament.

You have the right to access NHS services. You will not be refused access on unreasonable grounds.

You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary, and in the case of public health services commissioned by local authorities, to take steps to improve the health of the local community.

You have the right, in certain circumstances, to go to other European Economic Area countries or Switzerland for treatment which would be available to you through your NHS commissioner.

You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.

You have the right to access certain services commissioned by NHS bodies within maximum waiting times, or for the NHS to take all reasonable steps to offer you a range of suitable alternative providers if this is not possible. The waiting times are described in the Handbook to the NHS Constitution.

The NHS also commits:

- to provide convenient, easy access to services within the waiting times set out in the Handbook to the NHS Constitution (pledge);
- to make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered (pledge); and
- _to make the transition as smooth as possible when you are referred between services, and to put you, your family and carers at the centre of decisions that affect you or them (pledge).

Quality of care and environment:

You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality.

You have the right to expect NHS bodies to monitor, and make efforts to improve continuously, the

The NHS also commits:

- to ensure that services are provided in a clean and safe environment that is fit for purpose, based on national best practice (pledge);
- to identify and share best practice in quality of care and treatments (pledge); and
- _that if you are admitted to hospital, you will not have to share sleeping accommodation with patients of the opposite sex, except where appropriate, in line with details set out in the Handbook to the NHS Constitution (pledge).

Nationally approved treatments, drugs and programmes:
You have the right to drugs and treatments that have been recommended by NICE[1] for use in the NHS, if your doctor says they are clinically appropriate for you.

You have the right to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your doctor feel would be right for you, they will explain that decision to you.

- **You have the right** to receive the vaccinations that the Joint Committee on Vaccination and Immunisation recommends that you should receive under an NHS-provided national immunisation programme.

  If you are detained in hospital or on supervised community treatment under the Mental Health Act 1983 different rules may apply to treatment for your mental disorder. These rules will be explained to you at the time. They may mean that you can be given treatment for your mental disorder even though you do not consent.

  You have the right to express a preference for using a particular doctor within your GP practice, and for the practice to try to comply.

  You have the right to make choices about the services commissioned by NHS bodies and to information to support these choices. The options available to you will develop over time and depend on your individual needs. Details are set out in the Handbook to the NHS Constitution.

  The NHS also commits:
  to inform you about the healthcare services available to you, locally and nationally (pledge); and to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the range and quality of clinical services where there is robust and accurate information available (pledge).

  Involvement in your healthcare and in the NHS:
  You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers.

  You have the right to be involved, directly or through representatives, in the planning of

The NHS also commits:
to provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services (pledge);

to work in partnership with you, your family, carers and representatives (pledge);

to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one (pledge); and

to encourage and welcome feedback on your health and care experiences and use this to improve services (pledge).

Complaint and redress:
You have the right to have any complaint you make about NHS services acknowledged within three working days and to have it properly investigated.

You have the right to discuss the manner in which the complaint is to be handled, and to know the period within which the investigation is likely to be completed and the response sent.

You have the right to be kept informed of progress and to know the outcome of any investigation into your complaint, including an explanation of the conclusions and confirmation that any action needed in consequence of the complaint has been taken or is proposed to be taken.

You have the right to take your complaint to the independent Parliamentary and Health Service Ombudsman or Local Government Ombudsman, if you are not satisfied with the way your complaint has been dealt with by the NHS.

You have the right to make a claim for judicial review if you think you have been directly affected by an unlawful act or decision of an NHS body or local authority.

You have the right to compensation where you have been harmed by negligent treatment.

The NHS also commits:
to ensure that you are treated with courtesy and you receive appropriate support throughout the handling of a complaint; and that the fact that you have complained will not adversely affect your future treatment (pledge);

to ensure that when mistakes happen or if you are harmed while receiving health care you receive an appropriate explanation and apology, delivered with sensitivity and recognition of the trauma you have experienced, and know that lessons will be learned to help avoid a similar incident occurring again (pledge); and
to ensure that the organisation learns lessons from complaints and claims and uses these to improve NHS services (pledge).

How you can help the Network financially

Your donations will help us to continue our work at the Network by allowing us to collect the tax paid on your donations, which until last April we were unable to do. It is ONLY for those members who are resident in the UK and STILL paying tax, this includes tax on savings. To clarify that statement: Your donation must be made out of UK Taxed Income, and/or Capital Gains Tax at least equal to the tax that the Charity reclaims on your declarations in the tax year (currently 28p for each £1 you give).

Please complete the Sections below:

I would like the Charity (The Pancreatitis Supporters Network) to treat all donations I have made since April 6th 2000 and all other donations I make from the date of this declaration and until I notify you otherwise as Gift Aid Donations.

Details of Donor:

Name……

Address……

……

……

..... Post Code.....……..

Date ..... Signed…….....

Please return to:

Membership Secretary, The Pancreatitis Supporters Network, PO Box 8938, Birmingham B13 9FW

You can also help the Network Financially by creating a fundraising page for free on

mycharitypage.com and also **justgiving.com** for free to promote any fundraising event you might like to organise for us. These sites will automatically collect the Gift Aid for us AND will accept Credit and Debit cards.

Use the Text Code **PSNB13** followd by your donation in round £1's to donate via your mobile phone.

THE PANCREATITIS SUPPORTERS NETWORK MEMBERSHIP FORM

Title……Forename ..... Surname……

Address……...

……

……

..... Post Code ……...

Date……Signed ……

Date of Birth……. Telephone……

Email……..

Payment Method: CHEQUE POSTAL ORDER STANDING ORDER (PLEASE RING)

Brief Medical History (Continue overleaf if needed)

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(NOTE: All information used in accordance with the terms of the Data Protection Act)
Please return the completed form to:
Membership Secretary, The Pancreatitis Supporters Network, PO Box 8938, Birmingham B13 9FW

Membership runs from April - April: Individual £7.50 Family £10.00

STANDING ORDER MANDATE

To .....Bank

Address

	BANK	BRANCH TITLE (NOT ADDRESS)	SORTING CODE NO.
Please Pay	**UNITY TRUST BANK PLC**	**BIRMINGHAM**	**08 - 60 - 01**

	BENEFICIARY NAME	ACCOUNT NUMBER & TYPE
For the credit of	**THE PANCREATITIS SUPPORTERS NETWORK**	**5 4 0 0 0 7 9 7 0 0**

	AMOUNT IN FIGURES	AMOUNT IN WORDS
The sum of	£.....	

	DATE AND AMOUNT OF FIRST PAYMENT	DUE DATE AND FREQUENCY
Commencing	**1ST APRIL or**	and thereafter every **1ST APRIL - YEARLY**
Commencing	***Now**(Please ring) £ ..... (starting amount)	

	DATE AND AMOUNT OF LAST PAYMENT
*Until	**UNTIL FURTHER NOTICE** £

*Until you receive further notice from me/us in writing.

Quoting the reference **PSN MEMBERSHIP FEE** and debit my/our account accordingly

Please cancel any previous standing order or direct debit in favour of the beneficiary named above under this reference.

SPECIAL INSTRUCTIONS .....

ACCOUNT TO BE DEBITED	**ACCOUNT NUMBER**
(Your account name details here)	(Your account number here)

Signature(s) ..... Date.....

The Bank will not undertake to : (i) make any reference to Value Added Tax or other indeterminate element.
(ii) advise payer's address to beneficiary.
(iii) advise beneficiary of inability to pay.
(iv) request beneficiary's banker to advise beneficiary or receipt.

* Delete if not applicable

If the amounts of the periodic payments vary they should be incorporated in a schedule overleaf. SO154 (3/90)

NSTRUCTIONS FOR THE COMPLETION OF ABOVE FORM

PLEASE FILL IN: **YOUR BANK'S NAME AND ADDRESS** WHERE IT SAYS TO..... BANK
YOUR MEMBERSHIP FEE (EITHER £7.50 0R £10 IN FIGURES AND WORDS)
YOUR ACCOUNT NAME WHERE IT SAYS ACCOUNT TO BE DEBITED **YOUR ACCOUNT NUMBER** WHERE IT SAYS ACCOUNT NUMBER
SIGN THE FORM WHERE IT SAYS SIGNATURE(S)
DATE THE FORM WHERE IT SAYS DATE

PLEASE RETURN THE WHOLE FORM TO: Your personal bank to undertake the instructions. There is enough information herein for you to set payment up online as well

Note: With Standing Orders I cannot request any money from your account and you can stop this at any time by writing to your