

The Pancreatitis Supporters Network

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Welcome and INSURANCE!

Welcome to the July/August Edition of the Pancreatitis Supporters Network Newsletter. In this edition we are going to look at some personal insights into Alternative medicines, Trans Fat, Benefits and also the big question for us all **INSURANCE!**

Straight away then into the most important subject for a lot of us - **INSURANCE!**

I am sure all of you with Pancreatitis have found it hard to gain any sort of Life or Holiday insurance and with this in mind we have been trawling through possible solutions. One we heard about for HOLIDAY insurance was through membership of the AA (Automobile Association). We assume the same will be available for those of you with RAC membership (Royal Automobile Club) but advise that YOU check first.

We have been in long correspondence with a Company called

G F Baskeyfield & Company and they can offer various insurance BUT only in the UK for ALL the areas.

They can help with outside the UK but as yet they can only offer SIMPLE LIFE ASSURANCE facilities and only for certain European countries.

They are looking into NON UNDERWRITING LIFE ASSURANCE for those of us in the UK and should be able to offer a full range - with this exception.

Contact Information:

Please contact the following and NOT US:

Mr Paul E Robinson
G F Baskeyfield & Company
Insurance and Mortgage Brokers
Tudor House
53 Chestergate
Macclesfield
Cheshire
SK11 6DG

Telephone (01625) 610022
Fax (01625) 619826

Quoting either us (The Pancreatitis Supporters Network) or reference PER.AJF

Finally, let me know if there are any other Companies you have had

success with getting insurance with so that we can hope in future Newsletters.

Members Questions

A question from Valerie Morris concerning Partial Pancreatectomys or Pancreatic Surgery in the past.

How do you find your physical capabilities? Can you do any Sport, Housework, or Physical work of any kind without pain? Or is it a case of a little in moderation?

Valerie goes on to say that although she has been told her Pancreas is 'burning out' she is physically very limited before the old pain kicks in.

Also Valerie says that she takes 60 Nutrizym a day - and they don't always help. Is so many unusual? Her Pharmacist worries that she is overdosing on them!

Any comments from the rest of you on these Questions? I will print them in the next Newsletter. While you are answering Valerie's questions are there any you could be asking yourself? Or even an article you could write? We can get anything typed ready for the Newsletter so you do not have to type your submission.

Problems getting Bioantox in Yougoslavia!

From the start may I first state we DO NOT advise anyone trying this without medical supervision and it is not a method of self treatment we would advise. For that reason we have not printed the dosages.

I first met Zeljiko on the Internet and he was trying to get on the Bioantox treatment. But due to the problems he has - smuggling in supplies from Hungary - he has had to come up with his own formula! At the moment he is taking Methionine from Hungary, Beta-Carotene from Ontario, Vitamin E from New York, Vitamin C from Connecticut and Selenium from Connecticut. He says himself he does not know how well the components correspond to

Bioantox but this is all he can get. His main problems are each of the pills are in different units and he has no conversion chart and that the costs are horrendous!

I have printed this anecdote for the rest of us - especially in the UK - who have the benefits of a National Health Service and access to various forms of treatment free of charge.

For further information about Bioantox call Margaret O'Brien of the Manchester Support Group for those taking Bioantox on 01475 873859.

To finish in Zeljiko's own words:

It seems to be working, believe it or not. Haven't started with Selenium,

but methionine seems to give results. I think I've put on a pound in ten days, and reduced the amount of enzymes. The rest of it are just vitamins basically Holy Water.

All the best to the Network and all its members,

Zeljiko

ALTERNATIVE MEDICINE

Member Endorses Alternative Medicine Man

Mrs Terry Townson has passed on her 'diet' from Dr A W Payne and alternative medicine practitioner. She comments that improvement takes about 4 months and she no longer takes enzymes.

Her 'diet' is as follows:

No White Flour, Sugar, Alcohol, Animal Fat, Salt and Coffee.

She can eat - Wholemeal Flour, Honey, a Little Cheese, Milk (skimmed), Fruit, Eggs, Vegetables, Rice (wholemeal), and Pasta (Wholemeal), Meat, Fish, Sunflower Seeds and Dried Fruit to nibble.

Again, of course, we do not recommend any change in diet or treatment but if you want to follow this up with your general practitioner or specialist the addresses are as follows:

Prof. Dr.med. A W Payne

Prof. Of Medicine

Dr. Of Homeopathy

Practitioner in Alternative, Herbal and Manual Medicines.

Two addresses, one in the UK and one in Germany. First the UK one:

Longdogs House
Longdogs Lane
Ottery St Mary
Devon
EX11 1HS
Telephone 01408 812128

And the German Address:

Ulmestrasse 58
26725 Emden
W. Germany

Telephone 04921/56180.

Trans Fats - One Pancreatic Sufferers Opinion.

My story begins 17 years ago. I was 25 years old. For the next 12 years I suffered with frequent bowel movement. During those years I wondered why I had diarrhoea so often. One night in the winter of 1993 my stomach began hurting.

The next day my condition hadn't improved so I went to the hospital. I was so weak that I called an ambulance but they wouldn't pick me up. They said it was not enough of an emergency. The emergency room doctor asked me a few questions and poked around on my very sore stomach. Before any tests were run he said he was 90% sure I had gall bladder disease. I was admitted for 4 or 5 days, during which several tests were run. Because of my condition and blood count, I was put on I.V. feeding and given Demerol shots.

The doctors could not figure out what was wrong with me, so after 4 or 5 days I was released. For the next several months I suffered with 3 or 4 less severe attacks. The pain with these attacks was bad enough to cause vomiting and dizziness. That fall, I had an attack bad enough to put me in the hospital. I still could not be diagnosed.

In the fall of the next year I had another attack, but this time it was considerably more severe. I was working at the time. That day I had lunch at a major fast food restaurant. I ate a half cooked burger with French fries. As soon as I got back to work, I went to the rest room with diarrhoea. Within 15 minutes the pain began. I left work a half hour later. The pain was so severe this time I wasn't sure I'd make it to the hospital without passing out.

Once at the hospital, a blood test revealed amylase in my blood. My

triglyceride levels were sky high. The mystery was over, I was diagnosed as having Acute Pancreatitis. This time I spent over a week and a half in the hospital. Before being released from the hospital I saw a dietician. I was put on a very low fat, low sugar diet. To control the triglycerides I was prescribed Lopid (generic Gemfibrozil) 300 milligrams twice daily.

The next 3 years were fairly uneventful. As long as I took the Lopid and stuck to the diet, I did pretty well. A few times I thought I was close to having an attack. Occasionally I would get diarrhoea and have minor pain, and mild nausea, but nothing severe enough to send me to the hospital. I would simply take an extra dose or two of Lopid and eat no fat at all for a few days. The Lopid would quell the diarrhoea and other symptoms. Because of the Lopid I was screened regularly for proper liver function. During this period my triglyceride level remained relatively low.

One evening, about a year ago I was watching the evening news. The story was about a medical study conducted in Great Britain. The participants in the study consisted of 500 nurses. The study's duration spanned 15 years. The nurses were broken into groups. One group was asked to eat foods containing mainly monounsaturated fat. Another group polyunsaturated fat, another saturated fat, another trans fat. Trans fat is found in foods containing partially hydrogenated vegetable oil. The results of the study intrigued me. The study participants eating the trans fat had, by far, the highest rate of heart disease. Their rate was much higher than the group eating the evil

saturated fat. I can't remember the name of the study. If anyone reading saw the report and remembers the name of the study, I would appreciate it if you'd drop me an e-mail (*Write to me and I will pass on your comments - Editor*).

At the time of seeing the story I was very bored with my diet. That evening I decided to eliminate trans fat from my diet. After abstaining from the trans fat I didn't have a bowel movement during the next 4 days. I was very aware of the regulating effect Lopid had on my diarrhoea. I had to make a very difficult choice. I had to either resume eating trans fat or stop taking the Lopid. I didn't want to stop taking the Lopid because I feared another Pancreatitis attack. Within a couple days my bowels became regular.

As time passed I found I no longer was having any symptoms of the disease. No pain, no diarrhoea, no nausea, no dizziness. Furthermore my bowels remained perfect. One very good bowel movement a day. I hadn't enjoyed such regularity for 17 years. Soon I was feeling 20 years younger. (It is a side effect of being regular.) I couldn't help but wonder if the trans fat was related to the Pancreatitis attacks I'd suffered.? I slowly began increasing the amount of natural fat in my diet. For the remainder of this document, when I use the term natural fat, I'm referring to all types of fat *except* trans fat. As I increased the amount of natural fat in my diet, I didn't experienced any of the telltale signs of an attack. I began slowly increasing the amount of sugar in my diet. I felt I was on the verge of making a major discovery. I needed to test its validity. I dramatically increased the amount of sugar and natural fat in my diet. I increased it to the point of abuse. I gained 25 pounds of weight but still had no symptoms of the disease. I have not taken the

medication or followed a low fat diet for about a year.

I am very hopeful that it is gone forever and not simply in remission. With this mysterious, goofy, hellish disease who can be sure? Before proceeding *I must warn you about trying this for yourself. You know the risks. Pancreatitis is a life threatening disease. Each attack does more damage to the pancreas. My doctor told me the last attack did much damage to my pancreas (At this point we must EMPHASISE NO ONE undertakes this diet without discussion with their GP, Specialist or dietician. We will NOT ACCEPT any responsibility for this diet. This does not necessarily form the opinion of The Pancreatitis Supporters Network - Editor)*. He also said that sometime in my life I will probably develop Diabetes.

If you are taking medication, continue taking it. Follow the wise

old saying "If something ain't broke, don't try to fix it." Those of you who have diabetes should not increase your sugar intake, but it is safe to abstain from eating foods containing trans fat (*We cannot offer an opinion on the validity of this statement - Editor*).

Pancreatitis has many different root causes. I doubt a trans fat free diet will be 100% effective for everyone, but maybe it will help some. There is one thing I am sure of: Abstaining from trans fat will not hurt you (*We cannot offer an opinion on the validity of this statement - Editor*). It is important that you completely abstain from it. Not too long ago I went to a chicken joint and they had rotisserie chicken on the menu. I ate two pieces. By sundown I was on the toilet and was suffering from mild abdominal pain. I couldn't figure out what had gone wrong. I called the restaurant the next

morning and found out the chicken was basted with margarine on the rotisserie. I have found that as little as 1 gram may loosen the bowel.

What can you expect during and after the first week of abstinence? If you have chronic diarrhoea, it should be gone in 3 or 4 days. If the complete abstinence from trans fat does not produce noticeable positive effects within a week, abstaining may not benefit you. However, you will probably reduce your risk for a heart attack!. It is not easy to identify foods containing trans fat. You must look at the ingredients. Look for partially hydrogenated vegetable oil. For at least the first week do not eat out. I have assembled a list of foods containing, and for foods not containing trans fat. If you would like the list just let me know, I'll gladly e-mail it to you (*We have copies of this information if you would like to present this to your*

FINAL COMMENTS

Snippets

If you are on Incapacity Benefit or Statutory Sick Pay in the United Kingdom READ THIS!

In October 1998 pilot studies will be run offering those who are on Incapacity Benefit or Statutory Sick Pay for at least 28 weeks the chance to meet a Personal Adviser. The Advisor will give help and guidance in the following areas:

Helping you find a job, Assisting those currently employed to stay in work, including the self employed and enabling carers to combine their responsibilities with work. This will include those of you on Incapacity Benefit, Carers receiving Invalid Care Allowance and those who are under threat of losing work through illness.

The pilot areas are Bolton, Lancashire, Eastern Valleys of Wales, South Downes, Sandwell and Bristol East and Bath. It will be delivered by the Employment Services. For more information write to:

**Barrie McGregor,
CRS Team, Room 3S25,**

Quarry House, Leeds LS2 7UA.

It would appear that Zeljko may not have pancreatitis after all! Though it is still to be seen what he has got! This is not the first time we have heard this. Indeed we had one member discover after 15 years that she did not have Pancreatitis. All this goes to show how important it is that we all see a specialist in this field!

Again a big thank you to Wendy Coady and the Southampton Women's Darts Team along with all the other Organisations and personal donations which help us out each year. We are SEVERELY down on funds this year and as usual a worrying time for us here at the Network.

Finally, next Newsletter out in March/April time of next year and apologies if this arrives late but we have been inundated with calls since appearing in two Women's Magazines - Woman's Own and Family Circle. We are also sending this one via land rather than Air mail to save postage costs.