

# Worthing Area Fibro Group



April 2010 Issue 5 Written and Produced by Nichola Del Nivo, Simon Stuart and Kelly Thompson

## **Fibromyalgia Awareness Day is on the 12<sup>th</sup> May**

This month has been very busy and interesting. It is **Fibromyalgia Syndrome Awareness Day on the 12<sup>th</sup> May**. So I have decided to have a coffee morning at my home on the 12<sup>th</sup> May 10.30am to 12.30pm anyone that is interested to come along please get in touch with me; on 07796653477. You can bring a friend or carer or family member or all. As we need to raise much needed funds it will be donations at the door. I am hoping that sufferers that can't make it to the monthly meeting as well as can will be able to come along.



I have been looking for a local company to donate a printed running vest for Dave and some T shirts to sell for the group. I have had a yes back from

**[www.impresscdp.co.uk](http://www.impresscdp.co.uk)**  
147 Montague Street, Worthing  
**01903 218 189**

A big thanks from you to them.

So I went to see what they do and decide on what T Shirts to get. It was very interesting.

I have been given 12 T shirts, 6 will go to Dave to sell at the marathon and 6 will be on sale at our meeting for £5 each (Medium / Large available). If they go down well I will be looking for another company to donate. So if anyone knows a printing company for T Shirts, Mugs, Pens etc... please email me. I will send you a

letter and information about Fibro and our group for you to take when you go and ask for donations.



### **Helpful Information**

I am also looking for anyone that would like to help with getting items donated to us for our Christmas Raffle. I don't really like talking about Christmas at this time of the year but I have to look ahead. We will have a Xmas meal and the raffle will be pulled then. So please talk to me and I will give you an information pack to help you asking your local business's & shops for prizes. For an example: Butchers, if they say yes ask them for a voucher. Chemists, smaller items can be made up into a creative hamper. Electrical shops anything they want to donate. Veg & fruit shop, ask for a voucher. Hair and beauty voucher for cut and blow dry and massage or facial. News agency box of choc's. Toy shop, cuddly bear or a game, the list is endless.

Before you ask company's please ask me for a letter which explains who we are and that we are a charity. At the end of the day If we don't ask we don't get and

**If you have any messages for the newsletter please let Simon know either via email at [simon10pq@sky.com](mailto:simon10pq@sky.com) or 07806 808862 by the first Tuesday of the month, for the current months issue.**

# Useful information from last month.

I Once got a brand new bike from the bike shop in West Worthing, booze, toasters, a music centre, a lawn mower. You will be surprised at what people are happy to give. This of course means we need to sell our raffle tickets soon for everyone to get the opportunity to win a wonderful prize. I do hope you all can do your bit as it is all for you to get support and to bring a smile to your faces.

However as well as gifts for Christmas Raffle we are also looking for items for our weekly raffle; unwanted gifts, brick-a-brack etc. Many Thanks.

We were given some information from one of our members.

She has found a web-site that prints T Shirts with Fibromyalgia on, which we thought very useful. The link is:

[www.cafepress.co.uk](http://www.cafepress.co.uk)  
have a look.



Continued from last months  
Here is one condition that Fibromyalgia sufferers know all about.

## **IBS: Irritable Bowl Syndrome.**

There isn't a cure for IBS; however, it can be controlled through avoiding foods that you are intolerant to. Adding the right foods to help your digestive process will create a healthy and happy digestive system.

Symptoms of IBS include

- Abdominal pain, bloating and wind

- Diarrhoea or constipation, or episodes of both
- Nausea and vomiting
- Depression, anxiety and stress
- Backache, Tiredness, Headaches,
- Urinary or Gynaecological Symptoms.

IBS is not linked to life-threatening diseases and doesn't develop into bowel cancer. There are certain things that trigger attacks and so should be avoided, including stress, certain foods irregular mealtimes and in some cases, a lack of dietary fibre.

The whole length of the bowel is controlled by a nervous system, which carries signals back and forward between the gut and the brain, controlling factors such as how fast food is pushed through the intestines. Some experts believe this 'enteric' nervous system is faulty in people with IBS. The bowel responds with powerful contractions or spasms to stimuli that wouldn't bother other people. The gut normally responds to food by contracting, and one reason is the strength of the response seems to be linked to the amount of fat in the meal. So try to cut down on the fat in your diet. Avoid fat-rich food, such as dairy food, ensure your milk is skimmed or semi-skimmed, and cook with minimal fat by baking or steaming food rather than frying or roasting. Avoid large meals as they can trigger spasms. Instead, eat small amounts more often.

There is so much more that I could write about but I am limited to space.

IBS is a symptom of Fibromyalgia and if you avoid eating the foods that feed this condition your Fibromyalgia can feel a bit



# Fibromyalgia group, Surrey and Sussex

better. This is just one condition that is part of the syndrome. Start to get to know your body inside and out. Look into avoiding foods that are harmful to your digestive system and in turn your body, you will have one less thing to worry about and suffer with.



### Exercise:

Walking. Swimming. Yoga. Pilates. Biking. It has become increasingly advertised that to manage your Fibro one important factor is exercise.

This does not mean I expect you all to jump up and get to it. I of all people know and have been in the position where you think I am in to much pain to exercise. I have been in a wheel chair I have been so ill I couldn't get out of bed; just lifting my wrist was hard and painful. However Through a lot of soul searching and feeling desperate for more of a life I listened and was told and read everywhere exercises will help you to manage your Fibro. The penny dropped and of I went. Starting with gentle movements, Yoga was my main saviour. It was very gentle and I was amazed how quickly I could sit crossed legged, that was unheard of. Actually the last time I could do that was in my teens. I then went to a hydrotherapy pool for a long time, twice a week. Then I moved on to a gym. I needed a pool that was not too cold to swim and do my exercises in, the best part is the Jacuzzi, sauna & steam room. I have found I have more energy I am stronger, fitter, and I feel so much happier. Try not to wait to long start today. Become disciplined. Wake up knowing you have all the time to fit in exercise as your daily, do exercises in bed, swing round and do some more, stand up and walk back and forth before you wash and do your teeth. If you do this every day it will feel second nature. You have the afternoon while sitting in front of the TV lift your feet up and down, turn your ankles one way and the other. When you are in the shower or bath sing your arms, reach up and down, try and put your arm behind your back. Do these slowly, if you are unstable do these while



sitting down and have another person around you to encourage you?

I do hope you can try because it does work just give it a try.



**Fatigue** Can you "feed yourself more energy"?

Nutritional intervention may be a useful tool in the management of fibromyalgia. Many fibromyalgia sufferers report that global fatigue is one of the symptoms they find most difficult to deal with. With that in mind this article focuses on causes of fatigue and dietary

**Interventions** that may help boost your energy. Have you wondered why the diet that seems to give one person more energy does not work for everyone? There is no single cause of fatigue; hence there is not one universal way to boost energy levels. Tiredness & Exhaustion... When you have ME/CFS or FMS your fatigue can be overwhelming. But why? Find out why next in next months newsletter.



### Starting simple

**Thirst for life** Being well hydrated is one of the first strategies for tackling fatigue. Research has shown that moderate dehydration (approx 4%) can reduce Endurance by 15%<sup>1</sup>. Ideally an average adult should drink the amount of water your body needs which varies depending on the individual. Here are three aspects you need to consider:

- Your Weight
- Physical Activity
- Climate you Live in

For example the more you weigh the more you need to drink (If you weigh 120 pounds you should drink at least 60 ounces of water a day).

If you struggle with drinking water then you can add juice or eat some fruit whilst drinking this can be very refreshing.

**Hot Weather and exercise** can increase how



much water you need to stay well hydrated. Drink regularly, don't wait to feel thirsty. Feeling thirsty indicates you are *already* dehydrated!

**Discussion Time.** Last month we spoke about Food-Digestion-Swallowing difficulties. Digestion starts once you put food in your mouth, for you to prevent reflux, heart burn etc chew your food until it is pulped to a smooth consistency before swallowing. Each organ needs to take something from your food to help to keep your organs healthy. The stomach acids breaks it down further. If you eat fast food and foods with a lot of chemicals it blocks, burns, builds up, turn's cells to over produce and under produces anything in the body so to create an unbalanced diseased body. It has taken me most of my life to realize that one of the reasons for ill health & I believe a big % is what we put in our mouths is turning our bodies against it's self & creating ill health. These foods can create allergies, sores, bowl problems, thrush, cystitis and many more. Most sugar free produces has Aspartame in; this is a chemical that studies say can be cancer forming; it creates more pain in your muscles. Once I stopped eating foods and drinks with it in, the aggressive pain I experienced stopped.

**When hungry** try eating a celery stick, carrots, grapes, apple, all salads & fruits you will be surprised how nice it is and will satisfy your sweet craving, so you get 2 for 1 a healthier food for your Fibro and lose

**Channelopathies:** I did some research and found it very technical so I have briefly explained a part of it but please look up on Google punch in the name & you will find a lot of info on this condition. It is a disease involving dysfunction of an ion channel. This is a pore-forming protein that helps establish and control a small voltage gradient across the plasma membrane of all living cells. It is known that is involved in the ion channels for Potassium, sodium, chloride & calcium. There are also Channelopathies involving the acetylcholine which is a chemical transmitter substance released by certain nerve endings. Acidosis is a condition in which blood has an excess hydrogen ion concentration and a decreased PH. Each Channelopathies can play a role in a number of different diseases.



#### **Internet**

If you are on the internet you are able to download previous copies of the monthly newsletter (also more copies of this newsletter) via [www.fms-sas.co.uk](http://www.fms-sas.co.uk) and go to "meetings"



If you wish to join the Fibromyalgia Surrey and Sussex Group email which is send out weekly please send an email to [web-mistress@fms-sas.co.uk](mailto:web-mistress@fms-sas.co.uk)



Thank you for reading this months newsletter. I hope you get something from our news letters and they are beneficial

Our next meeting is **Tuesday 18th May 2010.** Look forward to seeing you then. Ferring Baptist Church, Greystoke Road, Ferring, West Sussex, BN12 5JL. Our group co-ordinator is Nichola Delnivo her email address is [youandme1@sky.com](mailto:youandme1@sky.com) or phone 07796653477. Pick up a full Brochure at our meetings.

Fibromyalgia Dvds and Pins can also be bought at the meetings and don't forget to look at the Library where books are only 50p per book/audio CD per month.

This month for the food competition the cake is **chocolate roulade and the prize for the best one is a full Reflexology treatment from "You and Me" holistic treatments.**

Please don't forget that mini treatments are available for £5 for 20 minutes please book a slot when you arrive so that you don't miss out!!