

SUCCESSFUL FIBROMYALGIA CONFERENCE PLAN A REUNION IN 2011

By Jeanne Hambleton ©

The first ever fibromyalgia conference with a pamper weekend in the SE of England, Bracklesham Bay, last weekend (April 23/26 2010) kept it promises as a memorable weekend with eminent speakers, workshops, a range of therapies and some great evening entertainment. So successful was the event that a reunion date for the next event was fixed on the spot for another conference in 2011 on April 8/11. With this first event a sell out, bookings will be accepted on first come first booked.

The Fibro Fillies Race Night had folks shouting for their horse to win and the message that came back means we had to do it again. On Saturday the Folly Pogs Ball and fancy dress competition with great support from the fibromites saw the Nuns from the Order of Discontent (the Irish lasses) amusing the audience. Sunday evening featured the charity auction with paintings, Elvis' shirt, a valuable wine collection and jewellery, all donated by visitors, raising money for research. Partners enjoyed deep-sea fishing with good catches, played golf, and some enjoyed the workshops, while the fibromites listened to 12 keynote speakers over two days. The climax on Sunday afternoon was Question Time with 4 doctors on stage.

Perhaps one of the many 'best' things to come out of the Fibromyalgia Conference & Pamper Weekend, under the umbrella of FMA UK, was an announcement from Professor John Davies from Guy's Hospital and the FM Clinics, who sadly was unable to be with us, and Professor Ernest Choy, Kings College Hospital, who was so well received the delegates want him back next time.

The announcement said, "We are pleased to announce a new NHS Fibromyalgia collaboration under the King's Health Partners (Guys, Tommy's and Kings NHS Hospitals). Heading this new initiative is Professor Davies and Professor Choy, who share a common objective of creating an integral clinical and research programme to advance the understanding and management of patients with Fibromyalgia.

Professor John E. Davies is Consultant Rheumatologist at Guy's and Professor Ernest Choy is Clinical Reader in Rheumatology at KCL and Director of the Kings Musculoskeletal Clinical Trials Unit."

The delegates received the news with cheers and expressed relief that further progress was being made in the recognition of our invisible disability - fibromyalgia.

A DATE FOR THE DIARY

In view of the enthusiasm of delegates to come back and meet the people they met this time, the 2011 event on April 8/11 2011 will be reunion with all they liked and some new speakers. All fibromites will be welcome to the residential weekend. There will be staged payments to help those on benefits to spread the cost.

Other on site activities included fun workshops including Maryse Boules's sound therapy, Karen Henderson sharing her Bath Hospital experience following a one month stay; Gemma Kingsman from Consultaid who talked about Finding the Funds for Groups; and hygienist Jane Russell who talked about teeth and health. Giselle and Ian Smith from the DWP spoke about the benefit system. Sunday saw two informal 'Meet the Doctor' sessions with Dr. Robert Lister and Dr. Ray Perrin. The weekend included Pilates, Tai chi, yoga with a free pamper taster day, with a shopping experience and fibromites arts and crafts. One to one pamper therapy sessions ran over two days at conference discount.

SPEAKERS PRESENTATION SUMMARIES

The following summaries are reported by fibromites who attended the conference and helped to provide information for this article. My grateful thanks to the following note takers as it was impossible for me to sit in and listen to any of the speakers due to other conference commitments.

Group Leader of West York's FM SG Denise Rhodes wrote the following reports

Denise wrote, "Overall, the information from the speakers was delivered with humour, sympathy and great authority. The passion with which much of the subject matter was disseminated demonstrated a level of caring far and above what I expected and definitely above the experience level of many of the GPs and consultants reported to me on the helpline and by colleagues in my group. All speakers made themselves available after their presentations and showed great interest in questions asked and gave detailed responses.

Report by Leanne Daniels from Horndean FM SG with thanks for her commitment and help during the weekend

Dr Ernest Choy MD, FRCP is Consultant Rheumatologist at King's College Hospital and Director of the Sir Alfred Baring Jarrod Clinical Trials Unit in the Academic Department of Rheumatology, King's College London. He is also Director of Research and Development at King's College Hospital in London.

Discussing the new advances in the pathophysiological management of fibromyalgia Professor Choy said it was hard to investigate pain with doctors feeling there is nothing they can identify to reach a diagnosis. Many controversies have been removed by trying not to label patients. He said MRI scans show the structure of the subject but not how the organ or tissue was functioning. Brain functions can be seen and the magnetic properties in the brain are changed by the blood flow. Since the MRI uses magnets the brain functioning can now be seen.

Brain scans have even shown a reaction when red-hot chilli peppers are placed on the skin, with pain registered in certain areas of the brain. Pain results from a pain response and activates areas of the brain. The scan is useful as a tool to see how pain is perceived in FMS using pressure applied to the thumbnails, a sensation for pain against the pressure, can be detected. When this is applied to someone with FMS the signal to the brain can be identified to see if it correlates to the pain felt. So the pain is not just in your head.

In normals increased pressure eventually results in pain. In someone with FMS pain is triggered in the brain much sooner. This confirms the patient was not lying.

Professor Choy confirmed there are areas in the brain where normals and those with FMS show differences. Those with FMS were found to have less activity in regions of the brain than normals.

FMS patients react differently to normals, as their brain inhibitor is not working. They do not respond well to morphine. The brain produces its own morphine-type drugs. As the inhibitor does not work the natural drug produced by the brain is also reduced.

Sleep is very important and there is a link between sleep quality and pain. Good sleep reduces pain to manageable levels but it may not go away. Researchers are working towards identifying the relevant pathways and how to clear them. The focus is now on research to improve sleep,

Aims in the treatment of FMS include reducing pain, improving functions, better quality of life, and allowing patients to self manage. It has been identified that FMS is a complex and hereditary condition and not everyone with fibromyalgia is the same.

Three sub groups within FMS have been identified and this is significant enough to show that blanket or individually tailored treatment would be needed. In trials random meds are given and there have been similar observations about 3 sub groups. Drugs trialed in the USA revealed similar results with sub groups in different pathways. Some patients have more sleep disturbances, mood changes or depression. Depression can lead to poor sleep patterns and hinders the ability to cope. Researchers are trying to develop treatments suitable for each individual pathway for patients. To date there is not one magic cure but with these small steps forward it is hoped that one day there may be one drug to help all fibromites.

Dr Choy said they were trying to educate doctors on what FMS actually is, and explain to the patients' relatives more about the pain they cannot see.

Exercise may hurt but if you do not exercise you lose muscle tone, which can make fatigue worse. It is important to push on doing gradually more each day. Best time to exercise is in the evening followed by a warm bath and bed to enhance sleep quality.

Dr Choy confirmed medical guidelines could be sent to GPs on request to FMA UK - <http://www.fibromyalgia-associationuk.org/general-articles-highlights-208/271-medical-pack.html>

Report by Leanne Daniels from Horndean FM SG

Dr Peter Fisher Chirr, MB, FRCP, From is Clinical Director and Director of Research at the Royal London Homoeopathic Hospital, London, Physician to HM Queen Elizabeth II and chaired the World Health Organization's working group on homeopathy, whose report is due for publication soon.

Talking about fibromyalgia and homeopathy he described this as treatment of like with like. It is different from herbal medicines and is often confused with this. Homeopathic treatment is for the person not the disease. One of the conditions treated may be a bee sting with pain, swellings, relieved by cold and worse from pressure. The preparation to cure the condition would be one part of the mother tincture, and maybe 99 parts of water.

Dr Fisher reported that at the last survey in 1998 8% of the population was using homeopathic remedies with 470,000 users nationwide. This related particularly to the chronically ill. The growth in users is between 12% and 13% annually.

Clinical research on Rhus Toxicoderdron for FMS using double blinds with placebos and homeopathic pills showed 25% of FMS patients responded to treatment in just over a month. Tender Points cannot be reduced but these will respond and get worse if these points feel the condition is getting worse. Overall people did better taking the pills than those on the placebo treatment.

Dr Fisher felt a condition with normal care and homeopathic treatment would work better offering a broader package of treatment than just normal care. He said people went to the Royal Homeopathic Hospital for treatment because other treatments did not work, or gave unwanted side effects, with the majority of patients responding well and improving.

The advantage of using homeopathic treatments was you could do it yourself, based on a small number of typical symptoms, it treats the person and not the disease. There are a limited number of homeopathic remedies, compared to many medications available, but you can do it yourself and it does not need a practitioner. It also has low dilution content compared to high dilution with meds.

Dr Fisher spoke of the symptoms homeopathic remedies could help and the treatments used. Homeopathic treatment was available on the NHS but it was not easy to get. These treatments seem to work for fibromyalgia. With Choose & Book you can advise your GP you wish to be referred to the Royal Homeopathic Hospital in Great Ormond Street, London, or do it yourself on the Internet.

Group Leader of West York's FM SG Denise Rhodes wrote the following report

Professor B K Puri MA (Can tab), PhD, MB, Chirr, BSc (Hones) MathCAD, MRCPsych, DipStat, PG Cert Maths, MMath, is at Hammersmith Hospital and Imperial College London, he has carried out pioneering research work and is a world-leading neuroscience and biochemistry expert.

Professor Basant Puri asked is Fibromyalgia associated with changes in brain anatomy? Previous studies show no grey matter reduction in normal healthy patients and fibromyalgia sufferers. This is in contrast to patients with psychiatric conditions. His very recent study tested FMS sufferers against a healthy control group and identified loss of grey matter in relation to fatigue.

His tests were carried out using very sophisticated MRI scanners at a higher level than normally used 1.5T(Teslas) Teslas are measures of magnetic strength. His tests were carried out using 3T and a totally unbiased research method called VBM approach.

His conclusions are that there is degeneration in grey matter in areas of the brain as a result of visual stimulus overload, and problems of coordinating motor and visual tasks, along with problems with sequenced complicated actions.

Group Leader of West York's FM SG Denise Rhodes wrote the following report

Dr Cathy Price MB BCH, DCH, FRCA, FFPMRCA is a Consultant in Pain Management, Southampton University Hospital NHS Trust and a member of the British Pain Society who has an interest in fibromyalgia said there was a need to focus on patient needs rather than on conditions.

She said pain services offers a multi-disciplinary team approach, which includes psychologists, doctors, physiotherapists, occupational therapists, pharmacists, nurses, acupuncturists and job advisors in order to improve the quality of life. Dr Price said 70% of patients at discharge report positive results as against 30% who feel that it has been of little or no benefit.

Dos and Don'ts for FM -

- Do promote balance in activities
- Manage depression
- Discuss pros and cons of therapies, treatments, and strategies.
- Don't use opioids
- Use Pain Toolkit booklet

Useful sources for FM information:

HYPERLINK "http://www.patient" <http://www.patient.co.uk> and /healthyFM.htm

HYPERLINK "http://www.18weeks" www.18weeks website dept of health – pain

Dr. Price is the clinical lead for the National Pain Audit and argues that getting information into GP surgeries, hospitals and pharmacies is vital, so anything we can do to promote FM in this way will help us all.

She emphasised how important pacing is and how it is difficult to achieve – it may take months and help is so limited. Southampton has dropped organised courses such as 6 weeks on hydrotherapy etcetera, in favour of a cafeteria approach where individuals can take bits of

services according to their individual needs. She referred fibromites to ICAS an independent body who will support patients to fight their corner. She also referred us to PALS who are also very helpful.

A question was asked regarding whether the very high number of GPs who are either non-believers, or non-supporters will reduce as further training, younger doctors come into the system. She said that more training and awareness is having an effect, often via e learning – online. She also said that Dr Liam Donaldson, the Chief Medical Officer, is promoting greater awareness of the condition.

Report by Leanne Daniels from Horndean FM SG

Dr Ian H Treasaden MB BS LRCP MRCS FRCPsych LLM Head of Forensic Neurosciences, Lipid Neuroscience Group, Imperial College, London. Dr Treasaden discussed mood disorders associated with FM and the management of nutrition. He spoke about normal and abnormal depression and FMS and mood disorders. He said Charles Darwin had fibromyalgia. He wrote books about species after years of travels and would suffer a fibro flare when defending his theories.

He believed the causes included hyper excitability of the nervous system, brain functions, and altered brain waves that deal with pain. Management would include a mixture of drugs and non-drug treatments plus antidepressants. On the non-medicines he included walking and exercise, hydrotherapy, CBT (cognitive behaviour therapy) that challenges negative attitudes to symptoms, plus a multi-disciplinary approach, which is rare to find.

On mood disorders he said depression causes could be more than a low mood. Periodic low moods can improve over time without treatment. Grief can be confused with depression. The Doctor spoke about Bipolar, which had replaced the manic depressant illness.

Depression symptoms included low mood, no feelings or tears, loss of interest, socially withdrawn and no interest in hobbies or work. In severe cases that can include suicidal thoughts, low self esteem, helplessness and pessimistic, loss of appetite or even weight gain, constipation, lack of sex drive, impotence, poor sleep and paranoid. Those with FMS and depression often have headaches, worry about their symptoms and are delusional. Management can include counselling, self help, CBT, exercise and antidepressants for 6-9 months. Omega 3 is good for depression, elevating your mood and reducing anxiety. His recommendations included medication to help sleep, exercises, brain exercises and nutritional management.

Report by Leanne Daniels from Horndean FM SG

Dr Nick Avery MB BS LRCP MRCS MFHom from the Natural Practice at Winchester & Eastbourne helps patients within the Health Service benefit from complementary techniques for IBS, CFS, Eczema, Allergies, Asthma and Migraine, using homeopathy for the emotional component of the illness.

Fibromyalgia is a very common condition that is poorly served by conventional medicine. In his experience, the key features are extreme fatigue, muscle pain and emotional disturbance. Interestingly the emotional aspect is the reason why patients suffer – otherwise the illness would just be interesting! Anti-depressants do not deal with this – they can help elevate mood in some patients but they do not address specific emotions. Similarly fixing the underlying fatigue state cannot be helped by drugs, which are mainly designed to block symptoms rather than create energy. Many patients that Dr Avery treats suffer from underlying mitochondrial failure. Mitochondria are present in most cells of the body and this is where the ATP cycle occurs, providing the energy needed for all cellular functions. A blood test has now been

developed which can identify which of the two underlying possible problems is causing the low energy state. There is a lack of raw materials to make the necessary ingredients involved in the process and some kind of block in the circuit usually from a chemical / drug or other toxic substance. The only way to treat these abnormalities is to correct the underlying nutritional problem – there is either an absorption problem or nutrients are lost – or to use some kind of ‘detox’ technique. Neither of these treatment modalities is available from conventional practitioners – despite the fact that the condition has an underlying demonstrable biochemical explanation. The Doctor showed a scientific approach to the condition, sorting out problems with absorption, retention of nutrition and the use of a variety of treatment modalities designed to improve energy levels, pain and emotional disturbance. Much of the talk is based on 15 years’ experience of helping patients who suffer from fibromyalgia – many of whom (but not all) have done very well. He intends to concentrate on what can actually be done in the light of our current understanding.

Report by Leanne Daniels Horndean FM SG.

Dr Robert Lister BSc PhD FBS C Biol. is a Director of Phyla Ltd, a health care consultancy and Director of Cubic Ltd, which develop innovative medical electronic devices. He is Chairman of the Institute of Brain Chemistry and Human Nutrition at London Metropolitan University. **Linda Horncastle** Dip COT SROT, Group Leader South Bucks FM SG, due to FM stopped work. Thanks to the Alpha-Stim she has returned to work as an Occupational Therapist.

Dr Lister spoke of a pilot study relating to chemical imbalances, which showed a 60% improvement with microcurrent stimulation, but he felt something else was going on in the brain. Many people suggested the pains were a figment of the imagination and various drugs were needed to treat the condition. He felt there as ‘faulty wiring’ on the malfunctioning connections to the nervous system although imbalances may be able to fixed there was evidence that brain stimulation can modify the signals.

Dr Lister spoke about the influences we feel and the chemical receivers. But when the muscle or bone is injured the body sets up an electrical current. Electricity can affect the brain. Some elements may be faulty and disconnected but this can be changed by introducing the microcurrent. By changing the electrical status this can alter the way we behave. People with psychological disorders had purely behavioural problems and these could be improved by talking. The brain is made up of a lot of active centres and neuroscientists were using deep brain stimulations for diseases such as Parkinsons. He made reference to CES Cranial Electric Stimulation, which produced a similar effect to deep brain stimulation at a cost of £250. Stimulation can provide relaxation in some parts of the brain and stimulation in others. It can block pain, reduce anxiety, increase positive effects and alleviate insomnia. The stimulation can also change the concentration of chemicals, releasing more so the energy levels are increased,

Studies in the USA have helped pain, anxiety, stress, muscle tension and insomnia. In recent trials based on 500 patients the majority received between up to 99% relief of symptoms and headaches. There were moderate improvements on trials involving 2,500 patients in RSD, FMS, myofascial pain and migraines.

Introducing Linda and told her story. He said she had FMS for 20 years, stopped working but was now walking again thanks to the microcurrent. Dr Lister confirmed microcurrents had been used in the USA for 29 years and were safe and claimed 90% success rate. At a lower power than TENS machines the effect is cumulative where the TENS stops when you turn it off. The machines use probes and sticks.

Linda’s group had tried the microcurrent machines and reported improvements in 3 weeks. While it is not a magic cure it should be used most days and then mobility improves and fibro fog disappears. There are no side effects except perhaps some tingling.

Report by Clare Palmer ANOM

Dr Raymond Perrin DO PhD, Hon. Senior Lecturer, School of Public Health and Clinical Sciences, UCLAN, Registered Osteopath and Specialist in CFS. He spent 16 years researching medical and scientific evidence while treating CFS/ME/ Fibromyalgia patients with of the Perrin Technique.

Dr Perrin explained his treatment, based on manual drainage of toxins from the central nervous system, could relieve many of the symptoms of fibromyalgia. Some doctors treat fibromyalgia (FMS) and chronic fatigue syndrome (CFS) separately, while others think they are actually the same thing – or at least, variations of the same condition. According to the Arthritis Foundation, research shows that 50 to 70 percent of people with one diagnosis also fit the criteria for the other.

Raymond Perrin's earlier research at the University of Salford in conjunction with the University of Manchester, coupled with the hundreds of successful clinical case studies and the latest findings in neurophysiology, has provided strong evidence that CFS involves a disturbance of the drainage of toxins from the brain and muscles? These poisons often enter body in the form of viruses, bacteria and other microbes, parasitic infection or due to environmental toxins such as pesticides. Yeasts, bacteria, viruses, parasites, pesticides and heavy metals have all been implicated in cases on Fibromyalgia.

Osteopath and bioscientist Ray Perrin, who has developed this treatment technique over the past twenty years, showed how simple measures can bring relief to the patient and explained the possible patho-physiological pathways that lead to this terribly debilitating disease. The basis of this condition being a toxic overload of the brain and spine affecting the sympathetic nervous system, can over stimulate the peripheral nerves leading to pain and muscle spasms etc.

Dr Perrin stressed that although The Perrin Technique has brought much relief to many, it is not a cure-all treatment. In cases of fibromyalgia it should be used in conjunction with other therapies such as acupuncture and hypnotherapy. Supplements of vitamins and minerals, omega 3 and 6 fatty acids and pacing are all important in the overall therapy. His best-selling book *The Perrin Technique*, Hammersmith Press, London, 2007, sold out with a conference discount and is available from most good book supplies.

Report by Leanne Daniels from Horndean FM SG with thanks for her commitment and help during the weekend.

Andrea Barr MRSS (T) is a Shiatsu teacher/Complementary Pain Specialist, interested in FM, and has lectured in Switzerland, Austria and UK. She runs Pilgrim Hospital Boston Pain Clinic, Lincs. Talking about the logical empowerment approach to pain managements, she looked at the physical symptoms of FMS.

People who eat carbohydrates may suffer from an intolerance of this substance that can also lead to many of the symptoms associated with fibromyalgia she said recommending that oats and rye should be retained but most carbohydrates should be removed from the diet.

Andrea Barr referred to emotional symptoms including questioning yourself, the pressure of time, being self critical if doing nothing, feeling stressed, concerned with details and a low level depression.

The Autonomic nervous system - or fight and flight feelings - often resulted in difficulty expressing feeling, feeling under threat, while our bodies undergo a series of dramatic changes in blood flow, digestive tract, and the muscles. Signs of flight or fight syndrome are

poor sleep with an inability to shut down, tight shoulders/neck, digestive upsets, regular headaches. The fight or flight feelings can stem from childhood, long term trauma, too much activity and no calmness, and undetected stress.

Referring to rest, digest and repair Andrea Barr said the heart rate drops, blood pressure falls, respiration slows and deepens. Blood flow is re-established, the immune and lymphatic systems are supported, and you feel relaxed, calm and refreshed if you slept well.

Summarising she said the body can only repair itself during rest and digest. During fight or flight the rest does nothing for the body. Traumas and triggers can put a patient in a fight or flight condition. She described how the brain reacted during this sensation.

Resources to encourage better sleep included EFT, thought field therapy, cognitive behaviour therapy, yoga, medication and breathing, Shiatsu and cranial treatments. For more help email andrea_barr@hotmail.com or ring 01522 521 817.

Group Leader of West York's FM SG Denise Rhodes wrote the following report

Dr Nina Bailey BSc, PhD is a nutritional scientist working in dietary health and nutritional intervention in disease, with emphasis on the role of fatty acids in fibromyalgia, depression and ME. She has a DVD, which explains how to manage IBS that at least 50% of FM/CFS/Depressives/chronic headache sufferers experience.

Basically her argument is that there is no perfect dietary cure but findings show that red meat, particularly if seared/charred/barbequed produce carbonation. That produces ammonia, which leads to inflammation in the gut and is extremely bad for IBS just as many sweeteners are, such as xylotomy and sorbitol. Also insoluble fibers such as whole-wheat grains, bran, unpeeled fruit, salad greens, fried foods are in question. An expansion of this is on the **www.drninabailey.com site**. Dr Bailey said information is available on her websites www.igennus-hn.com, www.drninabailey.com and from ninabailey@aoum.org.

Group Leader of West York's FM SG Denise Rhodes wrote the following report

Dr Mageb Agour MB, BS, MRCPsych recently presented his latest research findings into sleep disorders in this area at a major international medical conference in Italy in September 2009, looked at objective sleep management.

The gold standard test is

- In a laboratory where subject is wired up to record all body functions.
- A device that looks like a watch, strapped to the wrist and used in one's own home. This is programmed to record movement and defines when/when not asleep
- There are 5 stages of sleep with normally 3 – 4 cycles per night.
- The longer we sleep the more we dream. But dream is only achieved in stage 5 (REM)
- Stage 1 light sleep/dozing low eye movement, often slightly aware and easily aroused
- Stage 2 eye movement stops, slower brainwaves
- Stage 3 Delta waves deeper stage
- Stage 4 No eye movement or muscle activity
- Stage 5 REM breathing increases, rapid eye-movement - muscles paralyzed

Babies spend 50% of sleep time in REM but with aging there are fewer REM stages in adults.

- Primary Sleep Disorders
- Narcolepsy
- Sleep apnea
- Abnormal behaviour

- Sleepwalking/talking
- Night terrors
- Secondary Sleep Disorders
- Mental disorder
- General medical conditions
- Substance users anything from caffeine to cocaine and heroin
- Sleep and FM
- Restless leg syndrome - Periodic limb movement - involuntary (if severe may need treatment)
- Bruxism (Grinding teeth)
- Alpha wave intrusion

In Fibromyositis non-refreshing sleep is a result of Alpha waves intruding into Beta wave stage causes REM state to leave. Remedies are to reduce mental activity before bed, avoid reading in bed or watching TV.

Melatonin is seen as a useful tool and is now available from many GPs or online. Short term sleeping tablets and treating underlying problems. Natural remedies such as Valerian, which performs in a similar way to Oxizipan or St John's Wort, which is often used for depression.

However, when using alternative and complementary medications it is important to check with GP and/or Pharmacist to avoid clash with prescribed medication. Chamomile, a Fish Oils High content omega 3 vital.

Report by Leanne Daniels from Horndean FM SG

Andy Potheary Pharma (Hones) Rearms, ACPP Pharmacist is a Senior Pharmacist at Worthing Hospital. Andrew's interest in fibromyalgia began in 2004 when his wife was diagnosed with the condition. He hopes to undertake research and develop a specialist role in this area in the future.

In his Pharmacist Pick & Mix presentation Andy Potheary spoke about Medicines Licensing in the UK explaining the Drug Company identifies promising new compound, applies for a patent, and carries out further laboratory trials. The company then applies for permission to carry out clinical trials. When completed they apply for marketing authorisation (MA). They can then sell the product within the EU.

He described the types of clinical trials a drug is submitted to.

Phase I: Pre-clinical testing, with healthy male volunteers – first time drug used in humans.

Phase II: Small-scale trial at a limited number of centers, in which the drug is used in patients with the disease.

Phase III: Larger-scale trial across many centers, with a wider range of patients

Phase IV: Post-marketing surveillance – product in use but rare or long-term side effects identified

Use of unlicensed medicines

These are medicines without a PL/MA. This might be because they are undergoing clinical trials, are to treat rare conditions, or because the MA has been withdrawn or surrendered. If unlicensed medicines are used, the prescribing doctor assumes full responsibility and liability for any adverse events that might occur.

What is “Named-patient Basis?”

Process that enables patients to be supplied with an unlicensed drug. “Named patient” means

the drug is being supplied (to the hospital, pharmacy, etc) for the use of a specific patient. Depending on the drug concerned, it can be fairly simple to obtain or involve lots of form filling by doctor and pharmacy.

Off-license/off-label Medicines

When a product is granted an MA, this specifies which conditions the product can be used to treat. However the product might also be used to treat other conditions. This use is termed “off-license” or “off-label” because it is not covered by the terms of the MA. Again, this means that the prescribing doctor will assume greater responsibility and liability if anything goes wrong.

Why is this relevant?

How many medicines are currently licensed for the treatment of fibromyalgia in the UK? None! He spoke about the use of ‘old drugs’ normally prescribed for other conditions but used for fibromyalgia although these may not be licensed for this. He also described the various drugs prescribed by GPs.

Group Leader of West York's FM SG Denise Rhodes wrote the following report

Gemma Kingsman, professional fundraiser, reported on Finding the Funds - and outlined what funds are available, mainly concentrating on Awards for All, which is the National Lottery.

For large pots of money £30,000 eg can be funded for up to 3 years

Smaller pots up to £5,000 can be applied for such as sessional worker funds, equipment needs, marketing the group. She advised ringing lottery help lines for how to submit and what for. They are very helpful.

Grassroots Awards are nationally available but administered locally via a local community foundation. The cash comes from wealthy donator philanthropists and organisations. Groups applying must have a written constitution with clear and simple rules and regulations, be a not-for-profit organisation, able to identify a need in the community, which the group will serve. Can make more than one application in two categories: up to £900 and from £900 - £5,000. The following year application can be made for further cash to support further needs. The Grassroots Grant might be for rent, equipment, refreshments, and volunteer costs regarding running costs.

The Lions Clubs, Rotary Group will respond to a letter for support and the website “Guide Star” is a source of information. Many Disability sites will provide sources of funding. Her company “Consultaid” charges £35 to fill in a grant application form but she referred delegates to free help in the community.

*Talking fundraising we are looking for some help from our friends. We believe we can persuade a couple of American FMS doctors to come to conference next year. We will have a damn good try. But we need to pay their airfare and expenses from the airport. We may be looking at approximately £500 per doctor. If you are coming next year and are able to do a bit of fund raising towards hearing these USA doctors who are often light years ahead of us in some things FMS, we would love to shout about what you are doing and would really welcome your support. Email me **jeannehambleton @ mac.com** if you can help. While April 2011 is some while away we need to get in the diaries of these doctors. However small your fundraising is it will all add up.*

THANKS

Finally I would like to thank FMA UK for their great support with help and wonderful conference bags, which members have said they will carry their meetings. Without their help the delegates might have had Tesco plastic carrier bags for their conference papers. Odd

everyone liked the bags but no one said anything about the paperwork we spent hours stuffing inside....

Clare Palmer's Sunday input with doctors was also appreciated. Thanks also to Teresa White and Lorely Day (Chichester FM SG), for their great work with the tombola, raffles and auction. Thanks also to Horndean members Tracy Gibbon and Andy Andrews for their major contribution to the auction with another lady fibromite whose name sadly I did not get. My gratitude to Pauline Dee and Leanne Daniels who spent hours at the front desk dealing with enquiries. There for the cause, Pauline and Glenna Frost but neither managed to see or hear any speaker or visit a workshop. Thanks also to Glenda Philpott and Martin for spending hours filming speakers to produce a DVD of the event. Watch this space for news of when it is available. Like most conference areas the room was dark for power points and mobile telephone quiet signals may have interfered with the recording but we live in hope. My apologies to all those who offered help with notes and speakers. I ran out of time and just had no time to get together to work out the details. I am sorry. I am grateful to Denise Rhodes and Leanne Daniels who took notes anyway and fired them off in time for me to get this article out in reasonable time. Thanks to Bob McKinlay and Gareth Duval for organizing the golf and Chris Crick for sorting out the deep-sea fisherman, and to the fossil hunters who understood. Also to Tony Ede (FMS SAS) and Simon Stuart (Worthing & Ferring FM SG) for taking care of projectors, laptops and power points and Bill Craven and friends for the race night. I am grateful to Karen Henderson who did a workshop and sorry Sam Piggott had a flare. Also thanks to Alan Perry for the photographs of the FollyPogs Ball he has donated and to Nene Valley FM SG who donated £63 to the research fund.

Finally my gratitude must also go to Sarah, my 'rocks' that did everything pamper for us and my husband Arthur who worked with me to list bookings and payments and the endless mails. South Downs Management, staff and the Head Chef did all they could to make us comfortable and able to enjoy the weekend, which was really great. Forgive me if I have missed anyone. *I am a fibromite and I do forget.* And a huge thanks to those who came. Without their support none of this would have happened. THANK YOU Jeanne

Well done and a big thanks from everyone.