



News Letter Autumn/Winter 2019

Sad News First

It is with deep personal regret that I inform you that the last of our founders Prof John Miles an emeritus consultant and Professor of Neurosurgery at The Walton Centre, Liverpool has sadly passed away on 24th February 2019 aged 82.

John was married to Enyd Griffith, niece of Aneurin Bevan, the founder of the NHS; and for some years worked in Cardiff. He became a consultant in Liverpool in 1971 the then Mersey Regional Department of Surgical Neurology. Appropriately for a Welshman, this unit has North Wales as part of its catchment area. At that time he was one of four neurosurgeons and sub-specialisation was several years in the future. Nevertheless he developed a passion for functional neurosurgery, and particularly for surgical treatment of pain, whilst recognising this had to be one part of what is now termed "holistic" care. In 1979 with Sam Lipton and David Bowsher, he set up the Pain Relief Foundation at Walton Hospital to raise funds for research into chronic pain. In 1981 this was followed by the Pain Research Institute to conduct research; space being at a premium, this was initially housed in a converted sewing room, but perseverance and a grant enabled new dedicated premises to be built in 1985.



John was an active and excellent technical neurosurgeon in all areas, and a highly inspirational teacher; he was instrumental in the creation of the department of neuroscience in Liverpool University. A great communicator, he was a most conscientious clinician and was loved by his patients. While being very competitive – perhaps a trait from his early sporting success – he was very modest about his talents, and very generous in his praise of others; all who worked with him acknowledge the huge amount they owe to his confidence and enthusiasm. He embraced new ideas and was always keen to try them out; the worst thing you could do was to suggest that such an idea might not work! This led to the Walton Centre being one of the first in the UK to embrace robotic surgery. The attitude led to far more successes than failures and to his many legacies. His trainees were especially grateful for this heritage. His intelligence was matched with an intolerance of idiocy, negativity and occasionally of the opinions of others, and some found this difficult to handle; to those whom he perceived as being on the side of the angels, however, he was a kind and loyal friend.

John remained a proud Welshman, and after retiring he and Enyd moved to Wales, very near where he grew up but on the 'better' side of the mountain. He made a clean break from neurosurgery – something he strongly recommended – but was a very happy recipient of the Society Medal in 2010. He became a skilled cabinet maker and restorer and a keen golfer and gardener, interests he pursued with the same passion as he had neurosurgery. Those who were his juniors will remember that he was never to be disturbed between 7 and 9pm on a Monday as he had choir practice; he resumed this interest on retirement, though sadly the Society was never blessed with a recital. John is survived by Enyd and his two sons. His mercurial character will be missed by all who had the good fortune to know him as a friend and mentor.

On A Brighter note



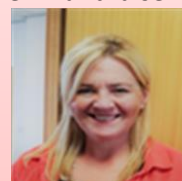
After a long search for the correct person we are pleased to announce the appointment of Dr Andrew Marshall to the Pain Relief Foundation Dr Marshall has joined us in May as a Senior Lecturer in Pain Medicine; the role is a joint role and will also see Andrew working for the Institute of Ageing and Chronic Disease at the University of Liverpool and the Walton Centre NHS Foundation Trust where he will conduct clinical work as an honorary Consultant.

Dr Marshall's research focus involves investigating the Structure & function of small nerve fibres, mainly C-Fibres, in both health and disease (e.g. in small fibre neuropathy). This work involves imaging of C-Fibres (skin and cornea) as well as functional assessments with quantitative sensory testing and microneurography.

These are very exciting times for the Pain Relief Foundation and Pain Research Institute and we welcome Dr Marshall as we look to put new strategies in place to expand the name and role of the Foundation and Institute.

Welcome to Jo Stephens

The Pain Relief Foundation would like to introduce its new Fundraiser Jo Stephens.



Jo has previously worked in the charity sector and brings with her a wealth of experience.

Jo says she is excited to become part of the team and is looking forward to the new challenges the role will bring and will welcome any volunteers and suggestions and ideas to raise vital research funds.

Jo can be contacted on:-

email; jo.stephens@painrelieffoundation.org.uk
Tel; 0151 529 5824



Exciting Research News



PROMISING TREATMENT OPTION FOR COMPLEX REGIONAL PAIN SYNDROME

Researchers at the Pain Research Institute have found a potential treatment for patients with Complex Regional Pain Syndrome (CRPS).

CRPS is a severe post-traumatic pain condition affecting one or more limbs and is associated with regional pain and sensory, bone and skin changes. The causes of CRPS, however, are yet to be fully understood. Approximately 15 % of patients with CRPS still have symptoms one year after onset that severely impact their quality of life. For these patients, prognosis is often poor and drug therapy for pain relief is rarely effective.

A team of international researchers, led by PRI Director Dr Andreas Goebel, conducted a study to better understand the immunological causes for CRPS. The researchers examined antibodies in the serum of these patients to ascertain the potential role of these proteins for causing the condition; they were particularly interested to assess 'neuroinflammation' – antibody-induced raised levels of inflammatory mediators such as Interleukin 1 (IL-1) in either peripheral tissues or brain.

The researchers transferred antibodies from patients with long-lasting CRPS to model and found that these antibodies consistently caused a CRPS-like condition. An important element of 'transferred CRPS' was glial cell activation, a type of 'neuroinflammation' in pain-related parts of the models brains. The team then discovered that 'blocking' of IL-1 with a clinically available drug, 'anakinra' helped to both prevent and reverse all of these changes in the models.

Dr Andreas Goebel, said: "Our results support previous clinical observations that patients with persistent CRPS should respond to immune treatments with a reduction of at least some of their disease features. "This approach has attractive therapeutic potential and could also have a real impact on the treatment of other unexplained chronic pain conditions; we plan now to apply for funds to test the effect of this and similar drugs in patients with CRPS."

The full study, entitled 'Transfer of complex regional pain syndrome to model via human autoantibodies is mediated by interleukin-1-induced mechanisms', has now been published in the prestigious journal 'Proceedings of the National Academy of Sciences of the United States of America' (PNAS). Also involved in this study were researchers from the University of Pécs (Hungary), University of Budapest (Hungary), University of Manchester, University of Sheffield and The Walton Centre National Health Service Foundation Trust.

More ground-breaking news to share, the Pain Relief Foundation is very thankful to have the opportunity to be able support such incredible research.

PAIN SIGNALING IN HUMANS: A SUPERFAST HIGHWAY TO THE BRAIN DISCOVERED



Pain signals can travel as fast as touch signals, according to a new study from researchers at Liverpool John Moores University's SomAffect Group (<https://somaffect.org/>), Linköping University (Sweden), and the National Institutes of Health (USA). The discovery of a rapid pain-signaling system challenges the textbook view that pain is signaled exclusively by slower conducting nerves that have only a thin layer of myelin or none. The study has been published in the scientific journal Science Advances.

Using a technique to record nerve signals from single nerve cells in awake human participants (microneurography), we now know that humans, in line with most other mammals, are equipped with ultrafast 'pain' neurons (nociceptors) that signal as fast as touch nerves that have a thick layer of myelin. Further, testing in patient groups with rare neurological deficits corroborated the role of this system in pain perception. The discovery will require a rethink of current models of chronic pain.

The study is an international collaboration funded by, among others, the Pain Relief Foundation, Swedish Research Council, ALF Region Östergötland, and the Intramural Research Program of the NIH (NCCIH).

Exploring resilience in adolescents with chronic pain and their parents.

Research studies have shown us that chronic pain has a harmful effect on the lives of many young people, resulting in emotional distress, physical disability and changed relationships.

However, some young people report feeling more able to manage the challenges posed by living with chronic pain than others do, even when levels of pain and disability are similar.

Researchers understand this ability to 'bounce back' from life challenges and difficulties is known as 'resilience'. Yet, we know very little about how resilience is understood and experienced by young people living with chronic pain and their parents.

Through a series of related studies, this studentship will provide a detailed account of how young people with chronic pain and parents understand 'resilience', how they experience resilience, and its impact on their lives.

Novel long-acting analgesic for chronic pain.

Chronic pain is a major health problem. It has a substantial impact on patients' quality of life.

Despite increased understanding of the biological mechanisms underlying chronic pain, there is still no reliable treatment. Current methods used to treat pain cause a significant number of side effects and they rarely work long-term.

It has been recently discovered that botulinum neurotoxins are able to reduce for months certain pain conditions, alongside their paralytic effects on muscles. Our research demonstrated that we can remove the paralytic effects and also enhance the long-lasting analgesia.

This provides a new and exciting therapeutic strategy for the treatment of chronic pain, especially neuropathic pain conditions unresponsive to standard treatments

Corneal Confocal Microscopy in stratifying and tracking Small nerve fibre neuropathy in Burning Mouth Syndrome.

Burning mouth syndrome (BMS) is a painful burning sensation which can affect the tongue, palate or lining of the cheeks. It can be difficult to treat with sufferers being affected long term, causing significant distress.

We have shown recently that a new test called Corneal Confocal Microscopy (CCM), which looks at the surface of the eye that is exclusively innervated by small fibre nerves, can detect small nerve fibre changes in some BMS patients.

The numbers were small in our previous study but if we can show that CCM can differentiate subgroups of BMS patients then this rapid, non-invasive method would be useful in guiding personalized treatment options for patients. It would also be useful in research to track small nerve fibre changes in disease progression or response to treatment

Professor Francis McGlone Wins Ig Nobel Prize

The 29th Ig Nobel prize ceremony happened on 12th September 2019 At Harvard University, Massachusetts , USA where our very own Francis McGlone was awarded his peace prize for "The pleasurable of scratching an itch: A psychological and topographical assessment" A statement from Professor McGlone follows:

"Scratching is one of the sweetest gratifications of nature, and as ready at hand as any" Montaigne. What is it about an itch that you simply cannot ignore – as I'm writing this I've just scratched my scalp – and why when I scratch the itchy body part does it generate such a sense of pleasure and relief (I have now just scratched my ear!)? An Ig Nobel prize was awarded this year to myself and colleagues, working with Professor Gil Yosipovitch (<http://dermatology.med.miami.edu/gil-yosipovitch-lab/>), for mapping out which parts of the body are the most pleasurable to scratch – the ankles won out over the back and the forearm.

Ig Nobel prizes honour work that "first makes always based on sound science. People you just scratch it and it goes away, but this condition. I recall a patient I was studying pain after losing his foot having stepped was the phantom itch he felt between his body part until it bleeds – in fact the



people laugh, and then makes them think" and are generally find itch funny and of little consequence, is not the case with chronic itch, a devastating when working at the PRI who suffered from phantom on a landmine, but what he was most distressed about toes! People suffering from chronic itch will scratch the resulting pain is seen as preferable to the itch.

This observation opens up interesting insights into the underlying mechanisms of how nociception gates pruriception, and why scratching an itch is so pleasant. Each of these three senses – itch, pain and pleasure – has a dedicated c-fibre and a dedicated society – the IASAT for pain (<https://www.iasp-pain.org/>) the IFSI for itch (<https://www.itchforum.net/>) and the more recently formed IASAT (<https://iasat.org/>) for pleasure. The link between pain and itch has now been finally recognised with the IASP establishing a SIG on itch (<https://www.iasp-pain.org/SIG/Itch?navItemNumber=8262>), and I hope at some stage all three societies merge into one as it is of great interest, both from a scientific basis and a clinical one, to discover how these different c-fibres 'talk to each other', particularly in chronic conditions.

Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body.

Symptoms of fibromyalgia

Fibromyalgia has many symptoms that tend to vary from person to person. As well as widespread pain, people with fibromyalgia may also have increased sensitivity to pain, extreme tiredness (fatigue), muscle stiffness, difficulty sleeping, problems with mental processes (known as "fibro-fog"), such as problems with memory and concentration, headaches and irritable bowel syndrome (IBS) a digestive condition that causes stomach pain. There may be periods when your symptoms get better or worse, depending on factors such as your stress levels, changes in the weather, how physically active you are and bloating.

Widespread pain may be felt throughout your body, but could be worse in particular areas, such as your back or neck. The pain is likely to be continuous, although it may be better or more severe at different times. The pain could feel like an ache, a burning sensation, a sharp, stabbing pain and extreme sensitivity. Fibromyalgia can make you extremely sensitive to pain all over your body, and you may find that even the slightest touch is painful. If you hurt yourself, such as stubbing your toe, the pain may continue for much longer than it normally would.

You may hear the condition described in the following medical terms **hyperalgesia** – when you're extremely sensitive to pain, or **allodynia** – when you feel pain from something that should not be painful at all, such as a very light touch. You may also be sensitive to things like smoke, certain foods and bright lights. Being exposed to something you're sensitive to can cause your other fibromyalgia symptoms to flare up.

Stiffness - Fibromyalgia can make you feel stiff. The stiffness may be most severe when you have been in the same position for a long period of time – for example, when you first wake up in the morning.

Fatigue - Fibromyalgia can cause extreme tiredness (fatigue). This can range from a mild tired feeling to the exhaustion often experienced during a flu-like illness. Severe fatigue may come on suddenly and can drain you of all your energy. If this happens, you may feel too tired to do anything at all.

Cognitive problems ('fibro-fog') - Cognitive problems are issues related to mental processes, such as thinking and learning. If you have fibromyalgia, you may have trouble remembering and learning new things, problems with attention and concentration, slowed or confused speech.

Headaches - If fibromyalgia has caused you to experience pain and stiffness in your neck and shoulders, you may also have frequent headaches. These can vary from being mild headaches to severe migraines, and could also involve other symptoms, such as feeling sick.

Irritable bowel syndrome (IBS) - Some people with fibromyalgia also develop irritable bowel syndrome (IBS). IBS is a common digestive condition that causes pain and bloating in your stomach. It can also lead to constipation or diarrhoea.

Other symptoms that people with fibromyalgia sometimes experience include dizziness and clumsiness, feeling too hot or too cold – this is because you're not able to regulate your body temperature properly, an overwhelming urge to move your legs (restless legs syndrome), tingling, numbness, prickling or burning sensations in your hands and feet (pins and needles, also known as paraesthesia), in women, unusually painful periods, anxiety, and depression.

Depression - In some cases, having the condition can lead to depression. This is because fibromyalgia can be difficult to deal with, and low levels of certain hormones associated with the condition can make you prone to developing depression. Depression can cause many symptoms, including constantly feeling low, feeling hopeless and helpless, losing interest in the things you usually enjoy.

It's not clear why some people develop fibromyalgia. The exact cause is unknown, but it's likely that a number of factors are involved. Here are some of the main factors thought to contribute to the condition.

Abnormal pain messages - One of the main theories is that people with fibromyalgia have developed changes in the way the central nervous system processes the pain messages carried around the body. This could be the result of changes to chemicals in the nervous system. The central nervous system (brain, spinal cord and nerves) transmits information all over your body through a network of specialised cells. Changes in the way this system works may explain why fibromyalgia results in constant feelings of, and extreme sensitivity to, pain.

Chemical imbalances - Research has found people with fibromyalgia have abnormally low levels of the hormones serotonin, noradrenaline and dopamine in their brains. Low levels of these hormones may be a key factor in the cause of fibromyalgia, as they're important in regulating things like mood, appetite, sleep, behaviour and your response to stressful situations.

These hormones also play a role in processing pain messages sent by the nerves. Increasing the hormone levels with medication can disrupt these signals. Some researchers have also suggested that changes in the levels of some other hormones, such as cortisol, which is released when the body is under stress, may contribute to fibromyalgia.

Sleep problems- It's possible that disturbed sleep patterns may be a cause of fibromyalgia, rather than just a symptom. Fibromyalgia can prevent you sleeping deeply and cause extreme tiredness (fatigue). People with the condition who sleep badly can also have higher levels of pain, suggesting that these sleep problems contribute to the other symptoms of fibromyalgia.

Genetics - Research has suggested genetics may play a small part in the development of fibromyalgia, with some people perhaps more likely than others to develop the condition because of their genes. If this is the case, genetics could explain why many people develop fibromyalgia after some sort of trigger.

Possible triggers - Fibromyalgia is often triggered by a stressful event, including physical stress or emotional (psychological) stress. Possible triggers for the condition include an injury, a viral infection, giving birth, having an operation, the breakdown of a relationship, being in an abusive relationship the death of a loved one. But in some cases fibromyalgia does not develop after any obvious trigger.

Associated conditions - There are several other conditions often associated with fibromyalgia. Generally, these are rheumatic conditions (affecting the joints, muscles and bones), such as osteoarthritis – when damage to the joints causes pain and stiffness, lupus – when the immune system mistakenly attacks healthy cells and tissues in various parts of the body, rheumatoid arthritis – when the immune system mistakenly attacks healthy cells in the joints, causing pain and swelling, ankylosing spondylitis – pain and swelling in parts of the spine, temporomandibular disorder (TMD) – a condition that can cause pain in the jaw, cheeks, ears and temples.

Treatment

Although there's currently no cure for fibromyalgia, there are treatments to help relieve some of the symptoms and make the condition easier to live with. Treatment tends to be a combination of: medicine, such as antidepressants and painkillers, talking therapies, such as cognitive behavioural therapy (CBT) and counselling, lifestyle changes, such as exercise programmes and relaxation techniques. Exercise in particular has been found to have a number of important benefits for people with fibromyalgia, including helping to reduce pain.

Criteria for diagnosing fibromyalgia

For fibromyalgia to be diagnosed, certain criteria usually have to be met. The most widely used criteria for diagnosis are you either have severe pain in 3 to 6 different areas of your body, or you have milder pain in 7 or more different areas, your symptoms have stayed at a similar level for at least 3 months, no other reason for your symptoms has been found. Treatment for fibromyalgia tries to ease some of your symptoms and improve quality of life, but there's currently no cure.

Your GP will play an important role in your treatment and care. They can help you decide what's best for you, depending on what you prefer and the available treatments.

In some cases, several different healthcare professionals may also be involved in your care, such as a rheumatologist – a specialist in conditions that affect muscles and joints, neurologist – a specialist in conditions of the central nervous system, psychologist – a specialist in mental health and psychological treatments.

Fibromyalgia has numerous symptoms, meaning that no single treatment will work for all of them. Treatments that work for some people will not necessarily work for others. You may need to try a variety of treatments to find a combination that suits you. This will normally be a combination of medication and lifestyle changes.

Support groups

Many people with fibromyalgia find that support groups provide an important network where they can talk to others living with the condition. Fibromyalgia Action UK is a charity that offers information and support to people with fibromyalgia.



PLEASE SUPPORT US



VOLUNTEER

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Merton College rows from Oxford to London



Merton College Boat Club took on the challenge to row from Oxford to London in just two days. From Iffley lock to Teddington lock... 32 beautiful locks, and a gruelling 160 km... a long but beautiful

journey. The team were confident they could reach London on Sunday evening!

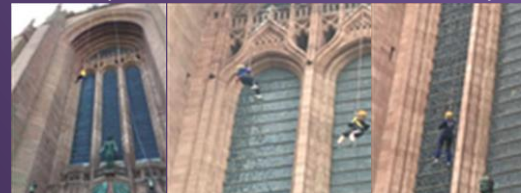
The reason why we did this; as rowers, we sometimes have to enter the 'pain cave' in order to push our bodies to perform... but when we reach our goal, we are lucky enough to go back to a pain-free life. Unfortunately, too many people are not so lucky. Chronic pain patients have to tolerate unwanted pain on a daily basis, and we are only beginning to understand the causes of their symptoms, and how to relieve them.

With this in mind, all your donations will go towards The Pain Relief Foundation, a UK based charity which funds research into the causes and treatment of human chronic pain. We would be thrilled if our two days of voluntary pain could improve the lives of those who suffer from unwanted pain on a daily basis

Pain Relief Foundation Scales Dizzy Heights

Our new Fundraiser set the ladies in the office, Julie, Lorraine and Hayley a task, along with volunteers Sarah Bennett, Emma Price and Jack Marshall all of whom have their own reasons as to why they would want to do this to abseil down the Liverpool Anglican Cathedral .

PRF relies entirely on charitable donations and fund raising. Chronic pain is defined as pain that lasts for more than 3 months. As well as physical impact, chronic pain can cause a number of problems affecting a person's well-being. These can include reduced activity, worry, loss of confidence, isolation, relationship difficulties and much more. Pain Relief Foundation (PRF) funds research at the University of Liverpool to help those suffering with chronic pain- and we all know somebody who is!!



Kyle McCullough Raises Funds for CRPS

Kyle is a 13 year old boy describes his own words why he chose to raise funds for Chronic Regional Pain Syndrome (CRPS)

"I wanted to raise money for the Pain Relief Foundation as they support Research into CRPS. I believe that with enough support and help a cure could be found."

The reason behind my decision to raise funds is because my Dad has CRPS in his ankle and it is very bad affecting his ability to walk normally and is very upsetting for him and our family to see him struggle and be in constant pain."

I want to help in any way I can so that hopefully in the future other people and families do not have live with this awful condition."



Katie's Twin Peak Challenge



Katie recently completed the Twin Peak challenge of trekking to the summits of Ben Nevis and Scafell Pike in the Lake District to fund raise for the Pain Relief Foundation. Katie has to manage M.E. so knows how difficult it can be to explain misunderstood Condition such as Chronic Pain.

Katie decided to do this to fund raise for the Pain Relief Foundation because her Dad has been in constant pain from when she was 3 (some 30 years). Even though he fights so hard to hide how much pain he is in and the devastating effect it has had on his life we as a family know only too well.

This is why I feel very passionate about the Pain Relief Foundation and recognising Chronic Pain as a serious life changing condition in its own right and to continue research to help others so that they do not have to suffer so much like my Dad

YOU CAN HELP OUR APPEAL TO CONTINUE OUR AMAZING RESEARCH INTO CHRONIC PAIN

MAKE A DONATION LEAVE A LEGACEY VOLUNTEER

IF YOU WISH TO HELP PLEASE CONTACT US: EMAIL - JO.STEPHENS@PAINRELIEFFFOUNDATION.ORG.UK

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