Physio
heal thyself
Professor Mike Hurley
on post-hip surgery rehabilitation

Myositis
Unravelling its mysteries

Anti-TNF
The science behind its success
Welcome

A very warm welcome to the autumn edition of Arthritis Today. Since the last edition of the magazine, we have launched our new pain research centre at Nottingham University, an event which is singled out for particular mention by our chief executive Dr Liam O’Toole on page 4 as epitomising all that is best about our charity. And as part of our ongoing commitment to tackle the major problem suffered by people with arthritis–chronic pain–you can read about some novel and very exciting research into a particularly agonising and baffling condition, complex regional pain syndrome, on page 21. Dr Helen Cohen has produced some astounding findings which could have relevance for other more common types of chronic musculoskeletal conditions. Myositis is a disease that receives very little attention but can cause great pain and distress to sufferers, and Arthritis Research UK is funding a major programme of work into this poorly-understood condition. Find out more on page 15. We are hugely proud of our discovery of anti-TNF therapy as a revolutionary new treatment for rheumatoid and other forms of inflammatory arthritis, but do you know the scientific rationale for its effectiveness? We explain the science behind its success on page 10. Although anti-TNF has transformed the treatment of inflammatory arthritis for millions of people, no-one wants to be on drugs if it’s not necessary, and we are funding a trial which looks at whether it is feasible to reduce the doses of the drug – without losing the benefits. See page 25. Finally, for years academic physiotherapist Professor Mike Hurley propounded the benefits of exercise to keep osteoarthritis at bay – only to find that when his own arthritis became so severe he needed a hip surgery operation that the NHS wasn’t as good as he’d hoped in helping him with his post-op rehabilitation. Read his entertaining account of life after surgery on page 18. Enjoy your read.

Jane Tadman
Editor, Arthritis Today

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Arthritis Research UK is a medical research charity entirely supported by voluntary contributions and legacies. For further information about the charity and its work contact us at: Arthritis Research UK Copeham House, St Mary’s Court, St Mary’s Gate Chesterfield, Derbyshire S40 7TD Tel 01246 558383, Fax 01246 558607 enquiries@arthritiscaresearch.org www.arthritiscaresearch.org Registered Charity England and Wales No 207711, Scotland No. SC041516. Editor: Jane Tadman Correspondence to the editor should be sent to the address above or to j.tadman@arthritisresearchuk.org Designer: Jonathan Ogilvie Advertising sales: Steven Smith Redactive Media Group, 17 Britton Street London EC1M 5TP Printed by The Nook, Leeds None of the products and services advertised in Arthritis Today are in any way endorsed by Arthritis Research UK. Front cover: Professor Mike Hurley: a new man after his hip resurfacing operation.
Arthritis Research UK’s third national centre of excellence was officially opened earlier this year, appropriately named the Arthritis Research UK Pain Centre, with many of whom were later presented with long service awards.

Dr Stewart Adams, a former alumnus of the University of Nottingham, said: “It is persistent pain that destroys the quality of life for so many millions of people with arthritis. Despite scientific advances in so many other areas of medicine we still do not have the tools to keep our patients free from pain.”

Pain Centre director Dr David Walsh, Associate Professor in Rheumatology, said that while quite a lot was already known about the interplay of various factors that caused pain, scientists’ understanding of how all those factors contribute to the final experience of pain was incomplete. “This will be our great challenge,” he added.

We are continuing to build the profile and impact of Arthritis Research UK and working ceaselessly to ensure that we have maximum effect on our ambitious goals; for example I hope many of you will have seen or read the media coverage of our hugely promising stem cell research in Oswestry.

In order to maximise our impact, we are implementing changes within the organisation. The result is that a number of new director posts have been established and I am thrilled to announce that two directors have been appointed: Louise Holland as our Fundraising Director and Kirsty Walker, an already well established member of the charity in a previous role, as Policy and Communication Director. Please see page 7 for a brief introduction to our new team members.

For me the highlights of the summer was the launch of our new pain centre [see left]. To me this showed what Arthritis Research UK is all about. We gathered together to launch a major new research initiative focusing on our central mission – to take the pain away and help people remain active. At lunch scientists and doctors mingled with branch members, charity shop staff, arthritis sufferers, donors and trustees. The whole event was superbly organised by Arthritis Research UK staff from London, Chesterfield and the regions working in partnership with the university. We finished the event by presenting awards to some of our longest standing volunteers – the lifeblood of the charity. This was Arthritis Research UK at its best, people from many walks of life working together and united by a common goal.

The year 2010 has been the year of the mountain for Arthritis Research UK. In addition to the Yorkshire Three Peaks events earlier in the year, 93 intrepid walkers climbed 3,560 feet to the top of Mount Snowdon, in June and raised over £7,000 for Arthritis Research UK.

As if that wasn’t enough, we had three separate teams complete the national Three Peaks Challenge – Ben Nevis, Scafell Pike and Snowdon – in July.

The first group of Three Peak Challengers consisted of ten ‘Frodsham Dads’, instigated by the Prescott family of Frodsham. Karen and Stuart Prescott’s daughter Elizabeth, who is now eight years old, was diagnosed with juvenile idiopathic arthritis when she was just two, but her life has improved drastically thanks to anti-TNF drugs pioneered by Arthritis Research UK.

The “Frodsham Dads” atop Snowdon

The team were amazing and I can’t think of a nicer bunch of people with whom to be cold, wet, tired and seriously stinky. A big thank you to you all, and to those who’ve so generously donated… and let’s look forward to another challenge next year!”

Professor Andy Carr, Dr Michele Bombardieri, Dr Catherine Swales and Dr Darren Asquith reach the top of Snowdon on a clearer day!

The last group was made up of staff from Avnet Technology Solutions Limited Warrington and Blacknell offices and staff from the Reading office of Oracle Corporation.

The main push for supporting Arthritis Research UK came from Jon Bennett from Oracle whose wife Nicola suffers from rheumatoid arthritis (RA), and most of the team have parents who suffer from osteoarthritis or RA. Physiotherapist Nicola was just 26 when she developed RA and was on the brink of having to give up her job. Fortunately she was able to take part in a clinical trial of a new anti-TNF therapy adalimumab, led by Paul Emery, Arthritis Research UK Professor of Rheumatology in Leeds, which transformed her life. As Nicola explains: “We have experienced how the research led by Arthritis Research UK has changed our lives immeasurably, returning me to normality at a time when life was extremely difficult. Without these drugs I would have given up my job as a physiotherapist. Some of my patients also suffer from RA and I certainly have a better understanding of their needs now and what they go through.”

The Avnet/Oracle challenge proved an immensely tough one with sickness and horrendous weather conditions causing people to drop out but four managed to climb all three peaks, and the team raised £3,363.

Thanks to everyone who took part.

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The team were amazing and I can’t think of a nicer bunch of people with whom to be cold, wet, tired and seriously stinky. A big thank you to you all, and to those who’ve so generously donated… and let’s look forward to another challenge next year!"
As the party started swinging, it was clear who had taken their Jointace®...

News

Two new senior posts announced at Arthritis Research UK

Two new senior members of staff have been appointed at Arthritis Research UK as part of a major internal re-organisation to achieve its ambitious goals.

Kirsty Walker, who has been with the charity in a previous role for the past year, becomes Policy and Communications Director, and Louise Holland, who has 21 years of experience in her field and is best known for developing ‘Race for Life’ – the UK’s largest fundraising event – is appointed Fundraising Director.

Kirsty has 14 years of experience in healthcare communications in the private sector. Her previous job was Global Brand Manager for multi-billion pound-selling drug Crestor at pharmaceutical company AstraZeneca. Prior to managing globally recognised brands, Kirsty’s roots are in science communications where she has experience in media relations, issues management, medical education, policy development and scientific publications management.

Louise Holland has worked in fundraising for the not for profit sector for more than 20 years. She has worked for Cancer Research UK for 15 years, and was responsible for developing, leading and growing Race for Life, which has now raised over £500m for cancer research. Louise has a breadth of experience across all types of fundraising and has worked with and supported over 1,000 volunteer groups.

Chief executive Liam O’Toole said of the new appointments: “Kirsty’s background in healthcare communications makes her ideally positioned to take on the challenges that the role of Policy and Communications Director offers. Kirsty will bring a professional ‘can do’ attitude and an organised approach to the role. “Louise is ambitious for success, which is exactly what we need to meet our fundraising targets and to raise funds to allow us to do more research.”

Actress Lysette Anthony to make radio charity appeal for Arthritis Research UK

Actress Lysette Anthony, whose young son has juvenile idiopathic arthritis, is to make a charity appeal on BBC Radio 4 on behalf of Arthritis Research UK. As Radio 4 currently has almost two million listeners, the appeal could raise thousands of pounds, and introduce us and our work to a whole new array of supporters. Our radio appeal will air at 7.55am and 9.27pm on Sunday October 10, and then again at 3.27pm on Thursday 1 October 14. The appeal can also be accessed online via the BBC iplayer site.

Remember a Charity week boosting legacy income

Legacies account for 70 per cent of Arthritis Research UK’s income, and with 140 other charities we are part of a consortium working together to promote leaving gifts in a will to charity.

September 12-18 was Remember a Charity week and Arthritis Research UK played a big part in this event by promoting awareness of how legacies can make a difference to the lives of people with arthritis. Our charity shops promoted the week by handing out branded materials to all their customers and also had displays in their windows. We also took part in a photographic exhibition called “Legacies through the lens” at the OXO Tower, and contributed to a special feature in the Daily Telegraph, in which psoriatic arthritis sufferer and artist Jan Williams (pictured) – whose life was transformed by anti-TNF therapy – appeared.

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Photos of Louise and Kirsty to come.
Win a Willowbrook Recliner

Rise to your feet effortlessly in this elegant and stylish custom-built piece of furniture. Combined with the optional built-in, 5-point massage system, this luxury recliner really should be experienced by people who suffer from a lack of mobility and require a luxury solution to lifting and reclining. But don’t just take our word for it, experience a Willowbrook recliner for yourself.

And you could win one or be a lucky qualifying customer, by simply calling 0800 854 330 today or returning the freepost coupon. So why not enter now?

Draw date 3rd November 2010.

For instant entry call FREE today on 0800 854 330 or post the freepost coupon.

For a FREE home trial call 0800 854 330
• Extensive range of models
• Vast range of colours and luxury fabrics
• 5-point massage system
• Free delivery and installation
• Long & meaningful guarantee
• Removal of existing furniture if required

Since I have had the chair I now get up without strain.
Mrs McFarlane, Ayrshire

“Since I have had the chair I now get up without strain.”

Promoter: Willowbrook, Mercury House, Kingswood Road, Hampton Lovett, Droitwich Spa, Worcestershire, WR9 0BR. Promotion open to all UK residents. By entering you agree to these rules. Competition start date is 6th October 2010, all entries received after 7pm on the 2nd November 2010 will not be considered and winners will not be eligible. Only one entry permitted per household. Entries made in bulk or by third parties will be disqualified. All entries are entered into our monthly prize draw and the winner will be drawn at random at the end of each month. Your chances of winning are based on the number of entries received. We will also award 100 second place winner prizes. The winner’s prize will be a Willowbrook recliner chosen from six designs as defined from the Willowbrook range. Regional winners will be selected at the Willowbrook retail price list. The 100 second place winners will be notified of their prize and be expected to claim their prize at the Willowbrook retail price list. All prizes are non-transferable. The Promoter’s decision is final and no correspondence will be entered into. The full terms and conditions and a list of winners can be found at www.willowbrook.co.uk/winners.php. Please tick box in coupon if you DO NOT wish to receive product information from Willowbrook.

Research news

Arthritis Research UK to co-host international conference on osteoarthritis and sport

Arthritis Research UK is to co-host a major conference to investigate the prevention and management of osteoarthritis following sport or exercise.

The two-day event, to be held on October 21-22 in London, will consider existing research into the development of osteoarthritis as a result of sporting activity, as well as debating and setting the agenda for future research.

Co-hosted by the Institute of Sport and Exercise Medicine (ISEM), leading international speakers include Dr J Richard Steadman (Colorado), renowned for his knee surgery and rehabilitation work with elite sportspeople; and Jiri Dvorak (based in Switzerland), Chief Medical Officer to FIFA. The conference is hosted by Professor Alan Silman, Arthritis Research UK’s medical director, and Professor David Patterson of ISEM.

Says Professor Silman: “Although many people feel they do not have access to medical expertise, we do know how to manage sports injuries in the short term. However, the same cannot be said for managing the longer term implications. There is a lack of knowledge about prevention of longer term problems especially the development of osteoarthritis. Many people who take part in regular sporting activity end up with debilitating pain throughout their lives due to previously sustained injuries or ‘wear and tear’.

“We need to learn from the world’s experts and create a research agenda to better understand the causes and management of osteoarthritis following sport or exercise. We welcome attendance and contributions from those who have an interest in this area, and in the course of future research.”

The January 2011 edition of Arthritis Today will carry a full report on the conference.

Statins and rheumatoid arthritis trial reaches significant milestone

The multi-centre clinical trial investigating whether the cholesterol-lowering drugs statins can reduce the cardiovascular risk in patients with rheumatoid arthritis (RA) has reached its half-way recruitment stage.

The TRACE RA trial (TRial of Atorvastatin for the Primary Prevention of Cardiovascular Events in Rheumatoid Arthritis) milestone has now recruited more than 2,000 participants. Professor George Kitas, one of the principal investigators, said: “The challenge to achieve the target of nearly 4,000 patients remains high and this will only be possible with the continuing commitment of patients and colleagues within our participating centres.”

The trial has an extensive network of rheumatology collaborating centres, with around 100 UK hospitals stretching across Scotland, England, Wales and Northern Ireland. Support from the UK Clinical Research Network has helped provide the infrastructure required to deliver a large scale trial of this kind.

Patients with RA have an increased risk of cardiovascular disease (CVD) compared with the general population. Statins have been shown to be beneficial in preventing CVD in the general population and whether this benefit occurs also in RA patients has yet to be explored. Hence, the TRACE RA trial aims to investigate whether atorvastatin is more effective than placebo in the prevention of cardiovascular problems in RA patients.

This trial is jointly funded by Arthritis Research UK and the British Heart Foundation.

It also incorporates two sub-studies: TRACE RA-DAS investigates the hypothesis that atorvastatin is more effective than placebo as adjunctive therapy in reducing RA disease activity.

TRACE RA-Biobank will provide a rich resource for future studies.

“We hope that with the support of researchers and patients alike, we can help address these important research questions,” added Professor Kitas.

For further information, please go to www.dgoh.nhs.uk/tracer or contact Hawthorne Williams on 0161 2755639 or hawys.williams@manchester.ac.uk.
For most healthy people the images on the left, the cube and the duck/rabbit, cause them some mild visual confusion. Do they focus on the front or the back of the cube? Is it a duck or a rabbit? For most of us, the images “flip” from one to the other between eight and 20 times a minute.

However, for people suffering from complex regional pain syndrome (CRPS), the seemingly innocuous cube and duck/rabbit images are more confusing—and disturbing. When shown these images, 64 per cent of a group of people with this condition found their pain got worse within seconds of looking at them. Most of them had to shut their eyes or turn away because the pain got so acute.

Other weird things happened. Thirty two per cent of the group had a bizarre response in terms of blood flow when looking at the images—in one arm their blood flow went up, and in the other arm it went down—which is unheard of. And 40 per cent of the group described the cube as “flipping” so many times a minute that they couldn’t count it. Some people also had muscle spasms and sweating. However, groups of people with osteoarthritis and rheumatoid arthritis reported absolutely no difference in their pain levels when exposed to the same images.

Dr Helen Cohen has spent the past three years investigating how CRPS

Rheumatoid arthritis patients to benefit from NICE about-turn

People with rheumatoid arthritis are to have wider access to biologic drugs, following a change of heart from the National Institute for Health and Clinical Excellence (NICE) has reversed a previous NICE appraisal of tocilizumab.

The National Institute for Health and Clinical Excellence (NICE) has recommended rituximab (brand name MabThera), adalimumab (Humira), etanercept (Enbrel), infliximab (Remicade) and abatacept (Orencia) as possible treatments for rheumatoid arthritis patients who have not benefited from previous treatment with anti-tumour necrosis factor (anti-TNF) therapy.

NICE has also recommended tocilizumab (RoActemra), in combination with methotrexate, as an additional treatment option in patients who have not benefited from anti-TNF therapy and who have failed to respond to, or are unable to take, rituximab.

Dr Carole Longson, director of the institute’s Health Technology Evaluation Centre, commented: “We hope that this wider choice of options will mean that people will be able to manage their rheumatoid arthritis more effectively.”

Dr Longson added that the recommendation of tocilizumab as an alternative for patients who have failed to respond to anti-TNF therapies “means that another treatment option is now available for people with rheumatoid arthritis”. This second piece of guidance reverses a previous NICE appraisal of tocilizumab.

A spokesman for Arthritis Research UK, which developed and pioneered anti-TNF therapy for rheumatoid arthritis, welcomed the NICE decision.

“Preventing people from accessing drugs that can help them stay in work and be cost-effective in patients who have not benefited from previous treatment with anti-TNF therapy. Not all patients are able to take rituximab, however, so the guidance recommends adalimumab, etanercept, infliximab or abatacept as alternatives. Dr Longson added that the recommendation of tocilizumab as an alternative for patients who have failed to respond to anti-TNF therapies “means that another treatment option is now available for people with rheumatoid arthritis”. This second piece of guidance reverses a previous NICE appraisal of tocilizumab.

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A spokesperson for Arthritis Research UK, which developed and pioneered anti-TNF therapy for rheumatoid arthritis, welcomed the NICE decision. She also ran a series of tests to check the functioning of the parietal lobe of the brain, a particular area involved in integrating sensory functions such as auditory, visual and touch information. It can be affected when a person suffers a stroke, and cause apparently bizarre symptoms such as ignoring one side of the body completely, and difficulty using language and numbers.

She gave the patients ten different, simple tests involving letters, numbers, identifying objects with their eyes close, copying and drawing, and so on. The results, says Helen Cohen, were “amazing.”
Case study

Cath Taylor, now 49, has lived with severe CRPS for many years, and until 2007 ran the national support group RSD UK. As well as having to cope with crippling, constant pain, she has very bad alodinia – where sufferers cannot bear the affected limb to be touched or even slightly brushed – in Cath’s case her right arm.

Cath, from Sheffield, was one of Dr Cohen’s first patients and has spent two three-week periods as an inpatient at the RNHRD in Bath undergoing intensive rehabilitation.

More recently she has been taking part in Dr Cohen’s Arthritis Research UK studies and has benefited from the results of the writing tests and optical illusions. Many things fell into place as a result: with the support of her son she managed to run a joke and fancy dress shop in Meadowhall shopping centre until earlier this year. It was a standing joke with her employees that she was always getting texts back as she would returned because they had written numbers wrong, they often rang the wrong numbers of mobile phones, and got their debit cards swallowed up by cash dispensers because they kept getting the PIN numbers wrong,” says Dr Cohen. “Prior to them developing CRPS this never happened. We found parietal lobe dysfunction in significant numbers of CRPS patients, which is not apparent in standard neurological examination.”

So can this knowledge, fascinating as it is, be used to improve the treatment of people with CRPS, which is currently largely ineffective? Dr Cohen acknowledges the need for further research, and in the use of high tech imaging and scanners to find out more about what is going on in the brains of CRPS patients. Meanwhile she is hopeful that rehabilitation approaches used to “re-train” the brains of stroke patients may be effective, and is planning to set up a new CRPS clinic at the Royal National Orthopaedic Hospital in Stanmore, Middlesex, where she now works as a full-time clinician.

“I think the most exciting thing about this research is that it’s a start in regularly and unknowingly get the numbers mixed up. At least now she knows why.

“One of the big problems I have is that I cannot go to the normal doctor and tell him what has happened because he would say I have flipped,” explains Cath. “I trapped my hand in the till but my mouth and face were in agony. I had a tooth out and my arm swollen up. One of the tests I had in Bath involved chill cream being rubbed on the inside of my right wrist and I felt the pain and swelling on my left wrist. You try and explain that. I end up getting quite emotional about it.

“I want to feel reassured by this research because many doctors put my problems down to being psychological. This research is undoubtedly progress, but equally I feel very confused still.”

Cath needs constant painkillers and muscle relaxants to get through the days and, despite periods of depression, remains positive that as researchers find out more about this baffling condition, effective treatment will finally follow.

Cold tea cleans...WHAT?

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Dr Helen Cohen with some of the optical illusions used to test patients’ reactions.

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“I think the most exciting thing about this research is that it’s a start in understanding a little-understood condition, and goes a long way to describing the bizarre symptoms and sheer complexity of the brain/pain networks which we haven’t understood before,” concludes Helen Cohen. “This will help us to approach our rehab and treatment more effectively. And it is lovely to be able to say to patients: ‘Yes, I believe you, and you can believe it yourself now, you are not going mad, there is something on going here,’ which reassures them tremendously.”

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What is complex regional pain syndrome?

Complex regional pain syndrome (CRPS), formerly known as reflex sympathetic dystrophy (RSD), is a rare but severe type of rheumatic diseases which causes excruciating limb pain for sufferers and often, but not always, develops after a minor injury. It also leads to temperature changes, sweating and swelling, and in extreme cases, the affected limb has to be amputated. Even lightly brushing the skin can trigger extreme pain, in a process known as alodinia.

My grandma kept her home spotless, her clothes were pressed, and even in her 80s her complexion was that of someone 30 years younger. Granadad had the best garden for miles around, she was able to fix just about anything with his bins and beds from the garage and they both lived well into their 90s with hardly an illness to their name.

They used traditional simple tips and tricks that had been passed down through the generations. Many of these tips and tricks have been lost, so that’s why I’ve completed all my grandparent’s household tips plus more in The Traditional Household Handbook.

Here are a few tips from the book:

● Make your toilet bowl sparkle with coke. 

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● Dr Cohen says “Prior to them developing CRPS this never happened. We found parietal lobe dysfunction in significant numbers of CRPS patients, which is not apparent in standard neurological examination.”

So can this knowledge, fascinating as it is, be used to improve the treatment of people with CRPS, which is currently largely ineffective? Dr Cohen acknowledges the need for further research, and in the use of high tech imaging and scanners to find out more about what is going on in the brains of CRPS patients. Meanwhile she is hopeful that rehabilitation approaches used to “re-train” the brains of stroke patients may be effective, and is planning to set up a new CRPS clinic at the Royal National Orthopaedic Hospital in Stanmore, Middlesex, where she now works as a full-time clinician.

“I think the most exciting thing about this research is that it’s a start in understanding a little-understood condition, and goes a long way to describing the bizarre symptoms and sheer complexity of the brain/pain networks which we haven’t understood before,” concludes Helen Cohen. “This will help us to approach our rehab and treatment more effectively. And it is lovely to be able to say to patients: ‘Yes, I believe you, and you can believe it yourself now, you are not going mad, there is something on going here,’ which reassures them tremendously.”

What is complex regional pain syndrome?

Complex regional pain syndrome (CRPS), formerly known as reflex sympathetic dystrophy (RSD), is a rare but severe type of rheumatic diseases which causes excruciating limb pain for sufferers and often, but not always, develops after a minor injury. It also leads to temperature changes, sweating and swelling, and in extreme cases, the affected limb has to be amputated. Even lightly brushing the skin can trigger extreme pain, in a process known as alodinia.
Stacey Farrington has more reason than most to hope that Arthritis Research UK's new research into myositis has a practical, positive outcome.

Until two years ago, the mother-of-three from Wigan, now aged 30, had a normal active lifestyle, enjoying spending time with her family, and working as a doctor's receptionist.

Then she went down with what she thought was flu and wrongly diagnosed variously as glandular fever and a viral infection. She was perpetually weak and tired, had night sweats, and often struggled to breathe. Matters came to a head when she woke up and found she could not get out of bed. Finally admitted to hospital, tests and scans revealed that she had a condition called dermatomyositis, which affects the skin and muscles.

Unfortunately for Stacey, as for many sufferers of myositis, diagnosis did not bring automatic relief. The drugs – steroids, intravenous immunoglobulin and immunosuppressants – reduced her symptoms a little, but didn’t provide the “miracle” she wanted. She developed swallowing problems and for a time had to be fed through a tube. She is currently hoping that a new drug regime of mycophenolate will kick in, but is having to come to terms with the fact that she has to adapt to living with a chronic condition and that life as she knew it before may never be the same again. Husband John has had to give up

Mysteries of myositis unravelled

Myositis is a rare, little-known muscle condition that can have a devastating effect on patients’ lives. Current therapies have only limited success. Now new research aims to unravel its causes, leading to better treatment.

Stacey Farrington: hoping to be well again

Spending time with her family, and working as a doctor’s receptionist.

Then she went down with what she thought was flu and wrongly diagnosed variously as glandular fever and a viral infection. She was perpetually weak and tired, had night sweats, and often struggled to breathe. Matters came to a head when she woke up and found she could not get out of bed. Finally admitted to hospital, tests and scans revealed that she had a condition called dermatomyositis, which affects the skin and muscles.

Dr Bob Cooper: leading the research into myositis

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work to look after her as she is unable to do very much for herself due to ongoing muscle weakness and difficulties with swallowing and breathing. Weight loss has also been a problem. “I kept thinking, OK, I have this condition, they give me tablets; it will get better,” says Stacey. “But after about a year down the line you realise that will not happen.”

Stacey’s rheumatologist, Dr Robert Cooper at Salford Royal Foundation Trust (formerly Hope Hospital), says that her lack of a good response to existing treatments is not uncommon in myositis patients, although most do show some improvement, and some even achieve a full remission, albeit on life-long treatment.

“Myositis has been relatively neglected in terms of research”

Dr Cooper is the principal investigator of a new five year Arthritis Research UK £450,000 programme grant, which aims to understand better the causes of myositis – in particular by examining which genes govern which individuals get the disease; which genes govern whether affected patients will do well or badly; and which genes govern treatment response.

“The fact that the drugs work so poorly reflects our lack of understanding of what causes myositis, and this has slowed down the development of more effective new drugs,” he explains. Another big problem he and his team face is the small number of myositis patients on which to base their research, as there are probably no more than 2,500 existing cases in the UK.

“Most rheumatologists will see only five or six patients in their whole career, which makes it very difficult to recruit the hundreds or even thousands of cases needed to do robust genetic research into myositis,” he says.

Colleague and fellow rheumatologist Dr Hector Chinoy, who co-runs the Manchester-based myositis research programme, agrees. “The fact that the drugs work so poorly reflects our lack of understanding of myositis.”

As a result of the collaboration, blood samples from patients around 60 UK and EU rheumatologists are sent to a European Myositis Consortium to establish important collaborations with specialist colleagues around Europe and, more recently, with those in the US. Thus, the European Myositis Consortium has to date recruited about 1,000 cases, with similar case numbers being available in the US.

Myositis changes your life.

“My little girl said to me recently: ‘I wish it could be like before mummy got ill!’”

Stacey is keeping her fingers crossed that the same will happen for her. Her eyes fill with tears when she says: “You look like there is nothing wrong with you; so it’s hard to explain to people. My little girl said to me recently: ‘I wish it could be like before mummy got ill.’ Myositis changes your life.”

What is myositis?

Myositis is a rare auto-immune condition that affects the muscles and the skin, and in severe cases, the heart, lungs and gut. It can also affect the muscles in the throat, making it difficult to swallow.

Polyomyositis affects many muscles in the body, especially the shoulders, hips and thighs, while in addition dermatomyositis also causes skin rashes on the face and the back of the hands. Some people with myositis are also at an increased risk of cancer.

Steroids, immune-suppressant drugs such as methotrexate, and immunoglobulin infusions are the most common treatment, but they are not always effective.

Clinically and genetically myositis shares features with rheumatoid arthritis, lupus and scleroderma.

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Joint replacement

Practise what you preach

Professor Mike Hurley thought he knew all there was to know about rehabilitation after joint replacement operation. Then he had one himself and found he had to fend for himself...

A long time ago during a misspent (though highly enjoyable) youth I had a serious motorcycle accident. My right leg was smashed in several places, including my right hip which was shattered and dislocated. The surgeons, having saved my leg (and my life) confidently predicted I would develop osteoarthritis and need hip surgery in my forties. If saving my life and my leg was so easy why was the road to recovery so difficult? Experiencing the pain, the discomfort, the stiffness, the inability to move or do the things you take for granted, is a frightening experience. I dwelt on all the bad things that could happen – I’d get a blood clot, dislocate my hip, rip the sutures open, fall, while on crutches, which I did reluctantly and grumbling, in the early stages things were depressingly slow, painful and frightening. I dwelt on all the bad things that could happen – I’d get a blood clot, dislocate my hip, rip the sutures open, fall. While on crutches, the easiest, commonest of activities – going to the toilet, washing, standing up, sitting down, stairs, dressing, going out, making a cup of tea, the simplest chores – required help, effort and time. The world around me moved frighteningly fast with due regard for me and my predicament! I survived of course. Nothing burst open or popped out, and I gradually came to realise what I could do, how to do things and cope with my temporary situation.

From previous experience I knew the importance of exercise. So I was surprised and disappointed at the little advice I received about exercise, which was vague, there were no written instructions and no follow up. Knowing I was a physiotherapist specialising in exercise therapy maybe the physiotherapists assumed I knew what to do, or maybe they felt embarrassed giving me advice. No matter who you are, at times like this your confidence and beliefs are undermined. I needed to be told exactly what to do, when, how, how often, how many, how long for and how to progress. I needed reassurance I was doing the correct things correctly. I wasn’t getting what I needed to get me back to full recovery – adequate rehabilitation.

I did the exercises I had been shown me in hospital, bended my knee as far as I could, tensing the muscles in my thigh and buttock, strengthening the muscles around my hip especially ones which take your leg out to the side (the abductors) and which move your leg backwards (the extensors) because these are very important. Unfortunately I often forget to exercise (”busy doing nothing”), so I set my mobile phone alarm to go off every two hours and remind me to exercise. Over the next couple of weeks I increased the exercises, but they soon became boringly repetitive. I needed more interesting exercises to stimulate me physically and mentally. But what? I searched internet websites dedicated to arthritis and hip surgery. Some were good and appropriate – one American

Professor Mike Hurley puts himself through his paces in his garden, strengthening his thigh and hip muscles.
My personal and clinical experience taught me the importance of exercise can have in reducing pain and restoring normal function. Exercise is not a cure all. It requires hard work, time and effort. But it works.

Mike Hurley is Professor of Rehabilitation Sciences at the St George’s University of London.

The science behind the success of anti-TNF therapy

Anti-TNF therapy, pioneered and developed by Arthritis Research UK, has transformed the treatment of inflammatory arthritis for millions of people across the globe. But how does this important class of drugs work? Dr Lisa Croucher explains the science behind its success.

Inflammation – the good and the bad

When the body is invaded by bacteria or viruses, our immune system recognises the threat and triggers a response— inflammation—to protect our tissues. The physical signs of inflammation—redness, heat and swelling—tell us that the immune system is doing its job properly. Once the invasion is seen off, any damaged tissue is repaired, the debris is cleared away and the inflammation fades away. Our immune system protects us safely as long as it is able to recognise the difference between foreign invaders and our own tissues.

In autoimmune diseases, the clear dividing line between friend and foe becomes blurred, and the immune system becomes dangerously confused about the true identity of its enemy, turning inwards to attack the tissues of the joint.

In rheumatoid arthritis (RA) and other inflammatory joint diseases with an auto-immune dimension, the initial ‘mistaken identity’ is compounded by defects, probably genetically inherited, in the way that the cells of the immune system communicate with each other. A vicious cycle of deranged cell communication, prolonged inflammation and tissue damage is set in motion that is very difficult to stop.

How to tackle this chaos? Painkilling analgesics relieve symptoms, non-steroidal anti-inflammatory drugs (NSAIDS) throw a ‘fire-blanket’ over the inflammation, but neither will slow down or stop the underlying disease. Steroids interfere with the inflammatory process to some extent, and are often rapidly effective, but their long term use can be problematic. Conventional disease-modifying anti-rheumatic drugs (DMARDS) such as methotrexate have a marked effect on inflammation, but we are still not clear how they work. Strangling the major ‘fuel lines’ that feed the fire of inflammation has been the focus of scientists and clinicians over the last two decades, and a deeper understanding of the processes at work in inflammation, as well as major advances in drug development technology over this period, has helped to turn the goal into a reality. Biologic drugs are the result, and for Tumour necrosis factor alpha is released by white blood cells, mainly macrophages, during inflammatory immune responses, and acts as a signalling molecule. Its release is triggered by injury or bacterial endotoxins. One of its actions is to kill tumour cells, hence its name. TNF-alpha is also involved in a number of inflammatory illnesses, including rheumatoid arthritis, psoriasis and Crohn’s disease.

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Anti-TNF therapy

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inflammatory joint diseases, the most important of these is anti-TNF alpha.

**TNF alpha—a major culprit**

First recognised in the 1960s and 1970s for its toxic effects on cancer cells, research worldwide during the 1980s revealed the naturally occurring protein, tumour necrosis factor (TNF), to be an inflammation fuel-line—a master regulator of inflammation and an important cell-to-cell communicator, or cytokine, in the body’s defences against infection. But TNF has a dark side. In the late 1980s and early 1990s, Professor Ravinder Maini, Professor Marc Feldmann and colleagues at the then Arthritis Research Campaign’s Kennedy Institute demonstrated that excessive production of a particular type of TNF, TNF alpha, drives the damaging inflammatory-system characteristic of inflammatory joint disease. TNF alpha directs the production of several key immune molecules, including the cytokines interleukin-1 (IL-1) and interleukin-6 (IL-6). In turn, IL-1 and IL-6 stimulate the production of enzyme molecules, ‘biological scissors’ that destroy cartilage and bone, and attract and activate more immune cells to perpetuate the cycle of inflammation. TNF alpha is at the very centre of this system—driving not only the recruitment and activation of inflammatory cells, but controlling their destructive activities.

**Targeting TNF alpha in the fight against inflammatory joint disease**

In 1992, Professors Maini and Feldmann, with their colleague Dr Richard Williams, published laboratory research demonstrating a marked reduction in joint inflammation with a molecule that blocks the activity of TNF alpha. Not only did this groundbreaking work confirm the importance of TNF alpha in the inflammatory process, but set in motion the development of a new generation of targeted drugs for joint disease. In the same year, the Kennedy Institute carried out the world’s first trial of an anti-TNF alpha drug, infliximab, in a small group of people with rheumatoid arthritis; this was quickly followed by a larger trial in Europe. Both trials demonstrated the dramatic anti-inflammatory effects of anti-TNF alpha. The remainder of the 1990s saw the development of other drugs designed to block the activity of TNF alpha and their approval over the last decade for the treatment of a range of inflammatory joint diseases, including RA, juvenile idiopathic arthritis, psoriatic arthritis and ankylosing spondylitis.

**What is anti-TNF alpha?**

Within its large armoury of cells and molecules, the immune system has a very sophisticated weapon at its disposal—the antibody. Antibodies are produced in response to ‘intelligence’ gathered from the enemy, usually a molecule on the invader’s surface that alerts the immune system to its foreignness—or in the case of auto-immune diseases such as RA, a molecule that has been mistakenly identified as foreign. Each type of antibody is a unique weapon, designed specifically to neutralise only one type of target molecule.

Scientists and clinicians are now ‘borrowing’ natural technology from the body’s own immune resources and exploiting the power of the antibody to control many diseases, including inflammatory joint diseases. The anti-TNF alpha drugs infliximab (Remicade), adalimumab (Humira) and certolizumab pegol (Cimzia) are all monoclonal antibodies, so-called monoclonal antibody molecules that ‘borrow’ natural technology from the enemy, usually a molecule on the invader’s surface that alerts the immune system to its foreignness—or in the case of auto-immune diseases such as RA, a molecule that has been mistakenly identified as foreign. Each type of antibody is a unique weapon, designed specifically to neutralise only one type of target molecule.

**Other biologic drugs for inflammatory joint disease**

The success of anti-TNF alpha therapy and our greatly improved understanding of the complexity of the inflammatory process have led to the development of several other biologic drugs for inflammatory joint disease. Currently, the first option for treatment with a biologic in the UK must be one of the anti-TNF alpha preparations. It is not always clear why a patient does not respond to a particular anti-TNF alpha drug, telling us that the mechanisms by which the drugs work are still not fully understood. Second-line biologics for those patients who do not see a significant improvement in their disease with anti-TNF alpha target a range of different cells and molecules central to the inflammatory process. The monoclonal antibody rituximab (MabThera) destroys antibody—producing B cells, removing the source of the destructive auto-antibodies that target the body’s own tissues. Tocilizumab (RoActemra) targets the activity of IL-6, and abatacept (Orencia) interferes with the processes involved in the activation of T cells, a key component of the immune response in inflammatory joint disease. Abatacept has recently been approved for the treatment of rheumatoid arthritis and juvenile idiopathic arthritis in patients where other treatment options have failed.

**The future**

Most of the biologic drugs mentioned have been approved in the UK for the treatment of at least one type of musculoskeletal disease; the National Institute for Health and Clinical Excellence (NICE) has recently approved their use for a range of other musculoskeletal diseases, in isolation or in combination with other disease modifying drugs such as methotrexate. Meanwhile, work is ongoing to develop new, more effective and better tolerated biologic drugs for inflammatory joint diseases.

Dr Lisa Croucher is a research manager for strategy and evaluation at Arthritis Research UK
The use of anti-TNF therapies is constantly being refined and improved. Jane Tadman reports on a new clinical trial that aims to reduce the dosages of these drugs, while maintaining patients’ quality of life.

However effective anti-TNF drugs are in controlling the symptoms of inflammatory arthritis – and their life-changing impact cannot be underestimated – their remarkable success comes at a cost. Between £10,000 and £12,000 per year per patient is required. Nor are long-term side-effects known. And no patient wants to be on medication a moment longer than they need to be.

That was the thinking behind a new multi-centre clinical trial about to get underway in hospitals around England led by eminent rheumatologist and current President of the British Society for Rheumatology, Professor David Scott.

The trial aims to find out if it is either feasible or desirable – or both – to reduce the doses of anti-TNF given to patients whose disease is currently under control, and even able to come off the medication all together.

If the results are positive it could lead to rheumatoid arthritis (RA) patients being weaned off their expensive drugs – making considerable savings and enabling more people to access them.

Professor Scott, principal investigator of the dose-tapering trial funded by a three-year grant of more than £430,000 from Arthritis Research UK, says weaning people slowly off anti-TNF drugs or even just reducing their dose could have significant benefits.

“No-one wants to be on a drug – however effective – forever, and from the perspective of people with arthritis receiving these drugs, using lower doses should reduce the risk of serious side effects,” says Professor Scott, Professor in Clinical Rheumatology at King’s College Hospital in Denmark Hill, south London.

“So we are asking patients whose disease is well-controlled by anti-TNF drugs or even just reducing their dose could have significant benefits. CALORATURE WAGONS

Luxuriously converted, sleeps 2, 4, 6, 8 in motorhome style. Berkshire.”
Professor Scott said that a positive result should mean that dose-tapering was adopted in hospitals around the country. “Reducing the maintenance dose and thereby increasing cost-effectiveness may persuade regulatory bodies such as NICE to modify existing national guidance so that more people with arthritis can access these effective treatments,” he added.

Lorraine Fanchetti, from Oxford in her mid 30s, a patient at King’s College Hospital, who has had severe RA for the past 20 years, says she would be very interested to see the results of the tapering. Lorraine is one of the thousands of people in the UK whose life was transformed by the advent of anti-TNF therapy, and would not relish the possibility of being on a reduced dose of the drug that is maintaining her ability to lead a normal life and hold down a demanding job as a central heating designer with British Gas. She has been on etanercept for the past five years and during that time her quality of life has improved dramatically. “I rarely have to take painkillers and the arthritis is very well controlled, which I put down to Professor Scott’s being quite aggressive in his treatment,” explains Lorraine. “It was very much a softly softly approach to my treatment at first and it wasn’t until the medical team said: ‘right let’s try something completely new’ that things changed.”

Lorraine is so happy with the treatment she has received at King’s College Hospital that she is happy to make the 65-mile round trip to the hospital for her appointments since moving from south London to Surrey. She appreciates that the dose-tapering trial might be the way forward. “In the long run, I would probably be willing to try having my dose reduced – as long as there was an option to stop as my one concern would be that if I had a flare-up it would have to be managed very quickly,” she says.

“Etanercept is working brilliantly for me right now, but the less medication you have on, the better,” said Amanda Hilton, west London.

I have psoriatic arthritis and have experienced exactly the same effect when taking antibiotics as the lady who wrote the letter to the Q&A in issue 149. I find that if I have a tummy bug or any other complaint eg a sore throat, that is not severe enough to see a doctor and clears up by itself, I am usually left with mild to moderate pain in my joints. If I have a course of antibiotics at a later date for some other problem, eg a dental infection, the antibiotics seem to flush out my joints and leave me pain free–until the next bug comes along! I know I would have difficulty convincing my GP of this, but it has worked for me several times over the last few years. Could there be any reason for this? I would imagine even the mildest bug attacking the body would head for the most vulnerable areas?

Loraine Morgan, Jarrow, Tyne and Wear

The notion that there is a link between infection and arthritis has been around for a long time. Indeed, in psoriatic arthritis it has been proposed that streptococcal, which can be a cause of sore throats, and can trigger psoriasis, may also play a part in the onset of the arthritis. And the skin lesions of psoriasis are full of bacteria so that it has been suggested that these somehow trigger the joint complications. However, no convincing link has been demonstrated to date.

The deterioration you notice with infections, and the subsequent improvement you notice after treatment, may just be part of the changes we notice with any infection, whatever the cause and however it is treated, at all.

I am 44, and due to some depression last year I started walking everywhere. Has any research been done—and if so what are the results—of people who have walked most of their life and have or do they develop arthritis more so and suffer in old age, more so than people who have never walked in their life? Does walking cause arthritis in itself? I have been diagnosed with RA due to one of the epilepsy drugs I’ve taken for 37 years, and have to take Vitamin D and calcium supplements to aid the bone strength. Do you think I’m aiding the bones now anyway by walking everywhere? I’m not worrying about old age – just curious to know if walking in earlier years makes arthritis worse in old age. It won’t stop me walking everywhere whatever the results – because I’m hooked on it now and do about 44 miles a week.

Amanda Hilton, west London

That is certainly a good number of miles to walk on a weekly basis. The link between sport, running and arthritis has been investigated extensively. I am not sure that this has been done for people who only walk but I would think the situation is comparable. In short (because I could use this whole page to answer your question) there is no evidence that moderate exercise harms the joints. Indeed there is evidence that it is good for the joints, muscles and bones. And, of course, it is also good for the heart and lungs. Only if the joints are injured, such as with football players, does the association between exercise and damage become apparent. So, my advice is to carry on walking.

Editor’s Note: Arthritis Research UK is co-hosting a conference in October, Tackling Osteoarthritis in Sport, which will address these questions. See page 9.

My four-year-old daughter who has severe juvenile idiopathic arthritis is doing well on etanercept but I worry about the fact that she is too young to be on such a heavy-duty drug at such a young age, and also about long-term side effects. Can you reassure me that this is the best option for her?

Mandy Cohen, Edinburgh

You will be aware that I can’t comment on individual cases as I am not familiar with the details of your daughter’s case. However, I can say that etanercept, and similar drugs, have transformed the care of children with JIA (as well as adults with other forms of arthritis of course). However, their use is only in its infancy and you are right to be wary of the long-term side effects. So far, this class of drugs seem to show no worrying long term side effects. The British Society for Rheumatology together with the manufacturers of these drugs, have established a register to monitor problems, both short and long term. And against the worries of using these drugs for a long time are the benefits to your daughter in terms of pain and disability and the effects of the disease on her major organs – all these may have progressed without the treatment.
I read with interest the question and answer about why rheumatoid arthritis improves in pregnancy. I have been wondering about a related problem since I developed a rheumatoid condition soon after I gave birth. I have since discovered many women who have had a similar experience after childbirth and I was wondering whether there has been any research done in this area as it seems to me that in the same way the immune system is switched off during pregnancy, it is possible that it is over-activated when it all comes back. My condition has finally gone into remission five years after my son’s birth. I have since discovered many women who have had a similar problem since I developed a rheumatoid condition soon after I gave birth. I have since discovered many women who have had a similar problem since I developed a rheumatoid condition soon after I gave birth. I have since discovered many women who have had a similar problem since I developed a rheumatoid condition soon after I gave birth. I have since discovered many women who have had a similar problem since I developed a rheumatoid condition soon after I gave birth.

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Christine Barfield Great Missenden, Buckinghamshire

Cutting out oranges and tomatoes reduced my pain

I have had osteoarthritis for over 35 years and am now 86. I had my right hip renewed in 2001 and got back on my feet. A lady once said to me, “Don’t eat more oranges and tomatoes and you will see the difference.” I did what she said over six years and there was a great improvement. A couple of months ago I went back to eating them and the pain came back—so I have stopped again.

Mrs C Grayson, Billingham, Teeside

Is there an optimum dose of cider vinegar and honey?

Several people have suggested I try cider vinegar and honey to help with my arthritis. In Arthritis Today 149 a letter was written by David Vautier on the same subject. Unfortunately I am unable to find any reference to the dosage, and I would be very grateful if anyone could help me in this matter.

Mrs H M Coombs, Caerleon, Newport

Editor’s Note: We have no scientific evidence to suggest that cider vinegar and honey is helpful. However, previous correspondents have suggested dissolving a teaspoon of honey in boiling water in a drinking glass. Add cold water and a teaspoon of cider vinegar, mix thoroughly, and take before food three times a day.

Slow-release NSAID caused my stomach ulcer

I assumed, wrongly, that a slow-release medication would be preferable for treating my osteoarthritis. But after two years of taking Oruvail retard tablets I developed a duodenal ulcer and I am now left with gastritis. No surprise, perhaps, as my blood group ‘O’ predisposes to the development of duodenal ulcers. My father also had one. So the Spanish research reported in the summer edition of Arthritis Today is a timely warning to others to avoid this unpleasant side-effect with the increased risk with slow-release preparations.

David Evered, Ashford, Middlessex

Yes, relapse after pregnancy, and new onset rheumatoid arthritis after giving birth, are both well recognised. That is why we take appropriate measures to re-start any necessary treatments as soon as possible after the delivery. Clearly, there are big changes occurring in the body and the immune system during pregnancy, as I indicated in my previous answer, and it is possible that these huge swings leave the woman vulnerable to auto-immune disorders such as rheumatoid arthritis.

I am 85 years old and have had osteoarthritis for 30+ years, during which time I have had two knees and one hip replacement, and a back op. Because of the anti-inflammatory I had as I developed a duodenal ulcer five years ago so now take lanazoprazole every day. Earlier this year I had a bad attack of gout and was prescribed colchicines but after a week or even a mild anti-inflammatory drug, both available on prescription. You might also try natural anti-inflammatory such as fish oil, which can be beneficial in people with osteoarthritis.

This Q&A with Dr Helliwell will also appear on our website at www.arthritisresearchuk.org

Please write to Dr Helliwell c/o The Editor, Arthritis Today, Arthritis Research UK, St Mary’s Gate, Chesterfield, Derbyshire S41 7TD.

Shiatsu helped my thumb osteoarthritis

The letter from Diana Bowler, in the Q&A page (Arthritis Today 149) caught my attention with respect to the pain and stiffness she is experiencing in her hands and knees. I am a keen knitter and gardener. Whilst I was still working I began to notice the pain in my thumb joints and could not grip or pick uplever arch files without dropping them and scattering the contents everywhere. It was also affecting my gardening and I found I could not prune shrubs as I had done in the past as I did not have the strength in my thumbs or without being in constant pain afterwards. At that time my yoga teacher was also training to become a Shiatsu practitioner and when he qualified he invited anyone in his class who was interested to attend ‘a Days Insight to Shiatsu’. It was a very enjoyable and enlightening day and I volunteered to be the patient at the end of the session. Although you can see by my thumb joints that I have experienced arthritis I have no pain or stiffness and can enjoy knitting, gardening and carry out every day chores. Shiatsu is a deeply relaxing experience and regular sessions help to prevent the build-up of stress in our daily lives. More information can be found on the Shiatsu Society via the following link: www.shiatsusociety.org I have not looked back since my first session and wonder what my retirement would be like without experiencing shiatsu and its many benefits.

Christine Barfield Great Missenden, Bucks

My muscle aches and pains were not arthritis, but statin poisoning

A few years ago I developed severe muscle aches, pains in my joints, weakness, and enough similar symptoms for me to be referred to a rheumatic diagnostic clinic. I had to take all my pills with me. There the doctor in charge arranged a series of blood tests for me, and even a chest x-ray. Then he said: “Throw those pills away. You haven’t got rheumatism.” What I had (and what I now understand a lot of people have) is statin poisoning. Statins are dangerous drugs anyway. But twice as dangerous if they are given to people over 70 years (I am 82); or two or three times as dangerous if a patient has a history of heavy alcohol consumption (I served 32 years in Fleet Street); or if he or she is on certain other drugs, including ones which had been prescribed for me. All these restrictions are set out in the NHS website, which my doctor either didn’t know about or ignored. I would not have been aware of any of them had not one of my partner’s daughters been a nurse! I now have a different set of doctors, and although some of my poisoning has had effects which will be permanent, I am somewhat improved.

Robert Rodrigo, Burwell, Cambridgeshire

Editor’s Note: Arthritis Research UK is currently running a clinical trial to establish if giving statins to people with rheumatoid arthritis reduces the number of heart attacks and strokes; see page 11. Views expressed in the Hints Box are those of readers and are not necessarily the views of Arthritis Research UK. The Hints Box is also published online on our website at www.arthritisresearchuk.org
Dr Ulrich Hansen and Dr Philippa Hulley explain their work in an ongoing series of questions and answers with Arthritis Research UK-funded researchers.

Dr Ulrich Hansen

What does your work involve?

I am part of the Biomechanics Group within the Mechanical Engineering Department at Imperial College London. Our work is primarily focussed on the study of human joints. This relates to injuries such as those from accidents or broken bones and diseases such as osteoarthritis and osteoporosis. Our work is aimed at developing better orthopaedic surgical procedures and new implants to help the patients suffering from any of these conditions.

How long has Arthritis Research UK been funding your research?

Arthritis Research UK has funded my work related to patients with severe shoulder pain since 2004. Their pain is so severe that they require a shoulder replacement. Unfortunately, shoulder replacements are not very successful. The Arthritis Research UK-funded research is aimed at providing a better understanding of the mechanics of the shoulder joint and to develop more successful implants.

What’s the most important thing you have found out in the past 12 months? And why?

We developed a method that very clearly visualised the bone immediately adjacent to the shoulder implant in patients. This is a great help for the surgeon when deciding whether to revise an implant and several major hospitals have already changed their treatment accordingly. This new ability also provides a powerful tool for investigating a host of research questions addressing better surgeries or designing new implants.

Dr Philippa Hulley

What does your work involve?

I’m a cell biologist attempting to understand cell damage and repair signalling in bone, cartilage and tendon cells. These cells build and repair tissues damaged by diseases such as osteoporosis and osteoarthritis. Projects in the lab approach these processes from different angles, from analysis of biomarkers in selected patient tissue specimens to detailed molecular studies on cultured human cells. We increasingly work in 3-dimensional culture systems, since these are more life-like, but also more technically challenging.

How long has Arthritis Research UK been funding you?

I’ve just completed a five-year Arthritis Research UK non-clinical career development Fellowship which enabled me to make a permanent move from Cape Town and set up a new research group in Oxford. Arthritis Research UK also helpfully allowed me to combine this work with a subsequently awarded Research Councils UK (RCUK) Fellowship which has generated a tenure track post linked to St Hilda’s College.

What’s the most important thing you have found out in the past 12 months? And why?

Anti-inflammatory glucocorticoid injections are given to many people with painful joints. Although they seem to help with the pain these drugs also prevent the natural healing response of the tissues and weaken them. My group has found a very intriguing link between glucocorticoid drugs and free radical damage or oxidative stress in tendon. A class of stress-responsive DNA binding proteins called FOXOs are involved. We have found that both antioxidants (like vitamin C) and growth factors can regulate FOXOs and strongly protect tendon cells from steroid damage. With Keith Willett (Professor of Orthopaedic Trauma Surgery at the John Radcliffe Hospital) we are currently running a pilot clinical trial with patients who concentrate to see if this source of growth factors is able to protect stressed tendon cells in ruptured Achilles tendon. This will help us to design a follow-on combination trial in steroid-treated joints. Andy Carr (Nuffield Professor of Orthopaedic Surgery, Oxford) plans to start a rotator cuff co-injection trial with steroid and anti-oxidants once we have secured funding. Our aim is to retain the anti-inflammatory benefit of the steroid but protect the injected tendon from its negative side-effects. Longer term we are seeking to develop an alternative to glucocorticoid injections in such joints.

What do you hope or expect to achieve as a result of your Arthritis Research UK funding?

These Fellowships are an excellent scheme because they allow one to develop a broad platform of inter-related research, rather than being restricted to a single project. Over the last five years I’ve been able to establish key collaborations with engineers, clinicians and other basic scientists and with them to explore the inter-disciplinary interface. It has been scientifically an immensely enriching experience which will definitely lead to more effective and better targeted laboratory studies.

What do you do in a typical day?

Discussions with research students, writing up research, identifying new research questions and planning proposals takes up the biggest part. I do a fair amount of teaching as well. Research is exciting but can be frustrating – the experiments didn’t go as expected, they took too long or there was some unexpected result. Teaching presents a peaceful side to my day where everything is known.

What is your greatest research achievement?

This is a tough question as several of my PhD students have all made important findings. Perhaps I’m particularly proud of the finding that a treatment of the shoulder implant meant that it took 10 times longer before the implant came loose. These were laboratory results, but if this translates into the same improvement in patients it would mean the implant would not come loose in the lifetime of the patient.

Why did you choose to do this work?

My background is mechanics related to aeroplanes. Life directed me into orthopaedic biomechanics at Imperial College and a feeling of wanting to do something about it... this is still on my mind whenever I think of what I’m doing and where I want to go.

What do you hope or expect to achieve as a result of your Arthritis Research UK funding? And why?

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**Special strategic award**

**Professor Tim Vyse**, Section of Molecular Genetics and Rheumatology, Imperial Collage London, London; looking for the genes that cause lupus, £1,720, 265, 48 months.

**Clinician scientist fellowships**

**Dr Francesco Carlucci**, Department of Rheumatology, Imperial College School of Medicine, London; identifying the genes that may help to protect against the development of systemic lupus erythmatosus; £44,675, 36 months.

**Dr Jane Freeston**, Section of Musculoskeletal Disease, Leeds Institute of Molecular Medicine, Leeds; development of an ultrasound test to allow earlier diagnosis and prognosis of rheumatoid arthritis; £309,060, 45 months.

**Special strategic award**

**Dr Eletheria Zeggini**, Wellcome Trust Centre for Human Genetics, University of Oxford, investigating genetic causes for osteoarthritis: £309,060, 45 months.

**Clinical research fellowships**

**Dr Nicola Ambrose**, National Heart and Lung Institute Imperial College London, London; the use of skin blisters to dissect the abnormal inflammatory response to monosodium urate crystals in Behcet’s Syndrome; £295,483, 48 months.

**Dr Natasha Jordan**, Centre for Molecular & Cellular Biology of Inflammation, King’s College London, London; the role of a specialised immune cell, the monocyte, in the development of lupus nephritis; £97,985, 24 months.

**Programme grants**

**Professor Anisur Rahman**, Centre for Rheumatology Research, University College London, London; exploring novel molecular mechanisms and targets to improve treatment and outcomes in patients with the antiphospholipid syndrome; £691,336, 60 months.

**Professor David Balfour**, Royal Free Centre for Rheumatology, University College London, London; do differences in “healing potential” explain why some patients with scleroderma improve and others do not?; £784,190, 60 months.

**Barbara Ansell fellowship**

**Dr Flora McErlane**, School of Biological Sciences, University of Liverpool, Liverpool; understanding the regulation of white blood cell function in rheumatoid arthritis; £196,569, 36 months.

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**Barbara Ansell fellowship**

**Dr Flora McErlane**, Dept of Rheumatology, Alder Hay Children’s Hospital, Liverpool; assessing arthritis disease activity in children with juvenile idiopathic arthritis; £68,470, 24 months.

**Foundation fellowships**

**Dr Helen Wright**, School of Biological Sciences, University of Liverpool, Liverpool; understanding the regulation of white blood cell function in rheumatoid arthritis; £196,569, 36 months.

**Miss Joanna Giles**, MRC Human Immunology Unit, University of Oxford, Oxford; an investigation in to how subtle changes to a family of immunity genes can affect the development and progression of rheumatological diseases, including rheumatoid arthritis; £174,859, 36 months.

**Ms Charlotte Davies**, School of Medicine, Health, Policy and Practice, University of East Anglia, Norwich; an investigation of performance, cost and current policy in medical devices: a case-study on hip implants for total hip replacement surgery; £126,319, 36 months.

**Fundraising news**

**Railfreight company goes full steam ahead for Arthritis Research UK**

GB Railfreight are well on track to raise some very welcome cash for Arthritis Research UK in a fantastic example of how corporate involvement can make a real difference.

The UK-based freight haulage company pledged to carry to carry out a number of fundraising activities for the charity at the beginning of 2010, because the young daughter of one of their employees has juvenile idiopathic arthritis.

Little Emily Goodman, daughter of yard shift leader at the Whitemoor depot of GBR, Ben Goodman, was diagnosed with arthritis at the age of two.

The condition began in her left knee and rapidly moved to her left elbow, fingers and ankle, but now aged six she is determined to not let it ruin her life and still manages to have play fights with her two-year-old sister Sophie.

Emily, who lives with her family at March, in Cambridgeshire, attends Hinchingbrooke Hospital in Huntingdon for routine checkups and blood tests. She currently has a methotrexate injection a week at her local GP surgery, which keeps her condition under control.

Regular swimming lessons recommended by her rheumatologist to build up her weak left leg have also helped enormously, and the youngster is now strong enough to ride her bike again.

Ben put his employer in touch with Arthritis Research UK at the beginning of the year and his colleagues have since gone full steam ahead to show their support. A team selling GB Railfreight and Arthritis Research UK merchandise at the Nene Valley Steam Railway Gala Days in March and July raised £350, a fun walk around the sites of London in May netted a further £645 and a hugely successful Race Night in July raised a terrific £700; almost £1,700 in total. In November the team will be hosting another Race Night at the Peterborough Lions Rugby Club.

**Maggie Beechurer, Regional Operations Manager in Peterborough said:** “I hope we will raise lots more money in order to help other young children like Emily who have this condition. Arthritis Research UK does a fantastic job and is a very worthy cause.”

**International law firm chooses Arthritis Research UK as its charity of the year**

International law firm, Davies Arnold Cooper, have selected Arthritis Research UK as their chosen national charity for a year until next April. Each year, staff at the law firm gets a chance to vote for one local and one national charity to support throughout the year. The partnership between Arthritis Research UK and the company was given a huge vote of support by solicitor Claire Bolton who works for the firm from Bouverie Street, London, and has had juvenile idiopathic arthritis since she was a teenager.

Now 26, and with her condition controlled by anti-TNF therapy, she took part in the Bristol Half Marathon in September, and is aiming to also complete the London Marathon in April. Claire is eager to extend her support to Arthritis Research UK doesn’t only apply when she is wearing a pair of running shoes. She helped the charity by giving a talk about her condition and life as a young woman in business to the Athena Networks MadHatters’ Tea Party, a networking event in Richmond, London for businesswomen.

Other members of Davies Arnold Cooper staff will be raising money for Arthritis Research UK by taking part in other events throughout the year such as the Adidas Women’s 5K Challenge, themed coffee mornings, and a quiz night. They are also be supporting the National Gardens Scheme (Arthritis Research UK is the NGs’s charity of the year) by visiting their local gardens.

Regional fundraising manager Alan Maloney said: “It is lovely to be working with an individual such as Claire Bolton who has not let her condition stop her from achieving so much, not only in business but in personal achievements such as her running. It is hugely refreshing to see how supportive both financially and personally Davies Arnold Cooper is towards their staff in encouraging them to raise as much money as possible for our charity.”
"Just three years old when his body seized up"

No one knew what was wrong with Christopher when his temperature soared to 105 degrees and his little hands closed shut.

After spending six long weeks in hospital, juvenile idiopathic arthritis (JIA) was eventually diagnosed. This type of arthritis affects thousands of children in the UK, causing inflammation, pain and swelling to the joints.

After his diagnosis, Christopher was prescribed steroids which helped to control some of his symptoms, but the effect of the medication didn’t last for long and soon all his joints were affected and extremely painful. He has the condition severely and is frequently in a lot of pain. He has been on all the anti-TNF drugs but their benefits were short lived.

Despite his pain, his mum tells us “Christopher makes it easy for us to cope, he never complains even though he has been through so much. Everyone loves him at his school and in hospital.”

Although anti-TNF drugs transform the lives of more than 70 per cent of people who take them, there is still so much more work to do. Medical research is the only way we will improve treatments for arthritis and hopefully discover a cure.

Your donation will help children like Christopher go on to lead happy and active lives. Please donate whatever you can by completing the form below.

Please visit our website at: www.arthritisresearchuk.org where you'll find: • Patients' own experiences • Detailed reports on research projects • Information to download • Other ways to get involved

Data Protection Act: Arthritis Research UK and our trading companies would like to hold your details in order to contact you about our fundraising and research. If you would prefer us not to use your details for these purposes, please tick the box and return this letter to Arthritis Research UK.

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