Much more than child’s play
The new treatment centre for children with arthritis

Osteoarthritis
Treatment beyond the prescription pad

Strange name, strange condition
Explaining palindromic rheumatism
Welcome to the winter edition of Arthritis Today.

It’s been a real pleasure to have worked alongside Professor Alan Silman, our medical director and latterly director of policy public affairs and health promotion, for the past eight years. Alan, who is stepping down this month after eight years with the charity, has done so much to raise the profile of arthritis as a condition and of Arthritis Research as a charity, and in making sure that our research is more focussed towards the needs of patients. He also has a knack of being able to talk to the media about all kinds of weird and wonderful things at very short notice, and on a personal level has an ability to connect with so many different people from the most senior to the very junior. He’ll be much missed, but his legacy will live on. Read more on page 5.

In the previous edition of Arthritis Today we announced the launch of a new research centre based at Alder Hey Hospital in Liverpool to meet the needs of children with arthritis and other musculoskeletal conditions. It’s the first of its kind in the country and aims to make a profound difference to the way that youngsters are treated. On page 12 you can find out in more detail exactly what director Michael Beresford has in store, and read about how one little girl is already benefiting.

Palindromic rheumatism is a little-known and poorly-understood form of inflammatory arthritis, similar to rheumatoid many ways but different in that it comes and goes. It’s often misdiagnosed and because of its episodic nature, hard to treat effectively. We’ve now awarded some new funding to Professors Paul Emery and Karim Raza to find out more about palindromic rheumatism. Plus Anna-Marie Jones, our cover subject and regional fundraising manager from South Wales, explains how the condition has affected her life. Read more on page 16.

As all our many readers with osteoarthritis will testify, living with this common, painful, joint condition can be a wearing experience. On page 20, our resident GP Dr Tom Margham talks about treatment options beyond the prescription pad, and how self-management can play a big part in coping, including losing weight and keeping active. To those people who find the very idea of doing exercise when they’re in pain completely unthinkable – this is the article for you! Tom’s top tips for exercise are worth cutting out and pinning to your corkboard as they will really help reduce painful symptoms.

Finally, we’ve got a round-up of all the various activities from National Arthritis Week on page 28. Thanks to everyone who took part and contributed in some way.

As always, I hope you enjoy this edition of Arthritis Today. And a Happy Christmas to all our readers.

Jane Tadman, editor Arthritis Today
Innovation event kickstarts for better-designed products

Innovators and investors joined in with National Arthritis Week 2014 at our Market-place event in Nottingham to show how they can help to ease the pain of arthritis.

The aim of the day was to bring together innovators, funders, manufacturers and retailers to network, share ideas and develop partnerships which will help get more products for people with arthritis to market. Liberal Democrat MP Baroness Sal Brinton opened the conference with her story of living with rheumatoid arthritis. She spoke of how assistive devices can help to ease the pain of arthritis and keep people independent.

Feasible, usable and desirable

Aside from highlighting the need for inclusive design to make day-to-day tasks easier and to increase the size of the market for products, the conference focused on the importance of elegant design. Unattractive products can put people off – as Professor Alan Silman, medical director and head of health promotion, reported, many orthotists aren’t used after six months, and a key reason for this is that they don’t look good. Speaker Jim Davison from design company Great Fridays picked up on this, explaining how good design should make products feasible and usable but also desirable: “Design is the yeast. You can make bread without it, but people won’t want it.” Desirable design was a key feature of exhibitor Charlotte Simmonds’ easy-to-use cutter. When Charlotte was diagnosed with rheumatoid arthritis last year she found using cutterly difficult, but she didn’t want to use products that were purely functional. Her designs, which feature beautiful, ergonomic olive-wood handles, wouldn’t look out of place at Michelin-starred restaurants. Other exhibitors demonstrated a range of fantastic products and services: • MIKA Rehab showed off their interactive game aimed at older people to make exercise more interesting.

• Loughborough University displayed bespoke splints, which use 3D-technology to create custom patterns. • The University of Sheffield’s Centre for Assistive Technology and Connected Healthcare (CATCH) spoke of translating findings from research with stroke patients into useful products for people with arthritis.

Chief executive Dr Liam O’Toole said: “Arthritis Research UK is committed to speeding up the development of treatments, therapies, interventions and products which will directly benefit people with arthritis and improve their quality of life. The goal is to have an ‘user’ which is a true ‘can do’ person and an absolute pleasure to work with.”

End of an era as influential medical director steps down

Fond farewells have been paid to Arthritis Research UK’s first medical director Professor Alan Silman. Jane Tedman looks back over his time at the charity.

Warm tributes have been paid to Arthritis Research UK’s medical director Professor Alan Silman who is stepping down this month after eight years.

Professor Silman had been an enormously influential figure in the world of arthritis research prior to joining the charity. During his time at the charity he took the lead in developing its research strategy and helped to raise the profile of Arthritis Research UK as a charity and of arthritis as a condition that demands to be taken seriously.

More recently, he led the development of health promotion and policy and public affairs, as the charity extends its influencing work.

With his regular media appearances and ability to talk knowledgeably and enthusiastically about anything from the potential of broccoli as a treatment to the latest scientific developments, he also had a strong ambassadorial role and was a public face of the charity.

Executive Director of Arthritis Research UK Liam O’Toole said: “Alan will be very much missed. In his various roles over the past eight years he has made an enormous contribution to shaping the charity’s work in changing people’s lives.”

A rheumatologist and epidemiologist by training, Alan introduced a more proactive concept of directed research, channelling funds into areas of unmet patient need.

“One of the things I’m most proud of achieving is that those people who carry out research on our behalf are now much more focused on the need to have an impact on patients,” he said. “The arthritis research community has been supportive and prepared to work together to achieve this goal.”

Always an innovator, he also set up ‘USER’ – the charity’s first lay patient group, giving a voice to people with arthritis and frontline healthcare professionals in helping the charity to decide which research projects to fund.

Alan joined Arthritis Research UK in 2007, after 20 years as the director of the charity’s epidemiology unit at The University of Manchester, tasked with giving strategic direction to the charity’s research expenditure.

He realised that the research area most ripe for development was osteoarthritis, which lagged way behind that of rheuma-toid arthritis.

He set in train a number of research centres of excellence each looking at a particular area of need. The first, a primary care centre, was followed by several others in other aspects of osteoarthritis, including biomechanics, osteoarthritis and sports injuries, and “Alan will be very much missed. In his various roles over the past eight years he has made an enormous contribution to shaping the charity’s work in changing people’s lives.”

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More people with low back pain benefitting from yoga

More than 2,000 people with low back pain have benefited from a 12-week course of yoga following a successful Arthritis Research UK-funded trial.

More than 300 yoga teachers in the UK have been trained to teach the Yoga for Healthy Lower Backs (YHBL) programme since the trial results were first published in 2011.

The clinical trial, conducted by the University of York, showed that a specially developed 12-week course of yoga proved to be a more effective treatment for people with chronic low back pain compared with usual GP care. Those on the yoga arm of the trial – which involved more than 300 people – had improved function and more confidence in performing everyday tasks.

Results of the trial were published in the Annals of Internal Medicine, and a cost evaluation paper in Spine showed it was cost effective.

The trial’s yoga programme, which involved 20 experienced yoga teachers, was designed and delivered by Alison Trewhela, in collaboration with Anna Semlyen and other teachers from different schools of yoga to represent a best-practice yoga course that could be replicated. The classes were designed for complete beginners, with experienced yoga teachers given extra training in back care, and were taught in several regions of the UK.

Those attending the specially designed programme, which involved step-by-step gentle classes, were encouraged to become self-sufficient in the long term. Classes were supported with five home practice sheets, a pain-relieving ‘menu sheet’, a practice manual and a four-track CD teaching how to relax physically and mentally.

Since then, the YHBL programme has been taught across the country by a network of yoga teachers, with many acting as ambassadors and champions of YHBL to ensure its continued success and transfer of knowledge.

“Many of the thousands of students, mostly newcomers to yoga, who have participated in 12-week YHBL courses also act as referees to ensure more people benefit from YHBL’s evidence-based back-care education and self-management skills,” explained Alison.

“Many medical professionals, including GPs, hospital consultants and physiotherapists, are supportive of the YHBL course and signpost patients to it. A few YHBL teachers are teaching under the NHS, and some are teaching for council schemes and in workplace settings.” – Alison Trewhela

Arthritis Research UK moves into health promotion

While we’ve historically focussed our efforts on helping patients by concentrating on medical research, our secondary purpose has always been to provide information and education for people with arthritis and health professionals.

More recently, the charity has started to take a new and exciting direction with the development of a health promotion team. While we’ll continue to produce helpful patient information booklets and online information, we’re also planning to expand our activities by encouraging people to actively manage their arthritis to improve their quality of life.

Our health promotion team will be engaging with professionals, people with arthritis and the public in order to better understand needs and experiences of those suffering from all forms of arthritis. Over the next year, the team will be developing a number of activities and events to promote the benefits of being physically active as a means of managing pain to improve quality of life for those with osteoarthritis of the knee and/or hip.

The team have developed a strong evidence base to support their work, in addition to using data from Arthritis Research UK’s Musculoskeletal Calculator (a new online tool designed to produce estimates of how many people have arthritis), to help identify which areas of the UK will be targeted according to greatest need, for pilot studies.

The health promotion team will be conducting focus groups in order to understand people’s reasons for and against being more physically active. They have developed a three-step model called ‘Think, Plan, Do’, to help understand the process people go through before changing their behaviour and starting to do more physical activity. For example, there’s still a misconception that exercise will make arthritis worse, and for many people with severe joint pain, the options for physical activity seem limited.

Working with people with arthritis will enable us to test out messages, activities and interventions and decide on the most effective approach to improving pain and quality of life for those living with osteoarthritis.

The team’s work is in its early stages of development, but there is lots more exciting information to come over the next few months so stay tuned…

Arthritis patients ‘not taking expensive, effective medication’

Large numbers of people with severe rheumatoid arthritis are failing to take expensive medication as prescribed, according to a new multi-centre study.

In the early stages of rheumatoid arthritis patients in the study who were on a class of drugs known as anti-TNF therapies did not take them as prescribed in the first six months.

Researchers from the Arthritis Research UK Centre for Genetics and Genomics at The University of Manchester, who led the study, warned that failure to take the drugs correctly, known as ‘non-adherence’, reduced their effectiveness and may lead to a worsening of patients’ disease.

Their results were published in the journal Arthritis Research & Therapy.

One of the study’s authors, Dr Kimme Hyrich, reader in rheumatology at The University of Manchester and honorary consultant at Manchester Royal Infirmary added: “If patients don’t take their medication as prescribed it is likely to have a significant effect on whether they respond to therapy and could mean that their condition deteriorates more quickly, affecting their quality of life. Non-adherence is also a waste of scarce healthcare resources and something that needs to be addressed.”

It is not clear from the study whether patients don’t take their drugs deliberately or accidentally. Research is ongoing to try to understand more about the reasons why patients with arthritis may not always take their medications as prescribed.

The development by Arthritis Research UK-funded scientists of biologic drugs such as anti-TNF therapy, which block the tumour necrosis factor (TNF) pathway in the inflammatory process that causes rheumatoid arthritis, has revolutionised treatment worldwide in the past 10–15 years, and transformed the lives of millions of patients.

But it is expensive, costing between £8,000 and £12,000 a year per patient.

In order to help us effectively plan our activities, we would really value your thoughts. We are looking for your comments/experiences around the pros and cons of being more physically active when you have osteoarthritis. Please send your comments to Anne Kelleher, health promotion programme manager, at akelleher@arthritisresearch.org

Find out about our clinical trials

Arthritis Research UK is currently funding a considerable number of clinical trials into a variety of musculoskeletal conditions from osteoarthritis to lupus and neck pain. We’ve put together a list of trials on our website so you can find out what’s going on near you. However, trials tend to recruit locally and we can’t help you to join a specific trial or study, so the best way to be recruited is to talk to your GP or healthcare professional about it. On our website you can also find useful links to other useful sources of information about current clinical trials in the UK. arthritisresearch.org/clinicaltrials

PMR patients ‘at higher risk of heart attack and stroke’

A new UK study has highlighted the potentially elevated risk of vascular conditions such as heart attacks and stroke among people with the common inflammatory muscle disorder polymyalgia rheumatica (PMR).

Led by the Arthritis Research UK Primary Care Centre at Keele University, the research – which was recently published in the Canadian Medical Association Journal – also underlined the need for doctors to proactively manage vascular risks in patients with this disease, in order to help minimise the risk of later complications.

In order to investigate this possible link, data was assessed for 3,249 patients with PMR and 12,735 patients without who were being treated by GPs in England and Wales. After a follow-up period ranging from three to 12 years, it was found that people with PMR had a higher risk of all forms of vascular disease, including angina, heart attack, atherosclerosis and strokes.

Risk was highest in the six to 12 months following diagnosis of PMR and was similar for men and women, with patients between 50 and 90 years of age having a more than fivefold increased risk, compared with a threefold risk among patients aged 80 years and older.

This study has provided useful information for medics, as previous evidence tended to be contradictory, with most studies being small, of poor quality and based on patients in hospital only.

The authors concluded: “This early excess risk provides insight into potential mechanisms and supports the link between PMR and vascular disease, given that the inflammatory burden in PMR is highest in early disease.”

A spokesman for Arthritis Research UK commented: “These new research findings are important as PMR is an extremely common condition in people over the age of 60. Although it can be successfully treated with steroids, doctors need to be aware of these risks and manage them accordingly.”
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Terms and conditions apply (eligibility include a domestic residence in the UK, subject to survey). To apply for this ask alternative.

Help us campaign for change: ask your next MP to be an Arthritis Champion

With the general election now just over six months away, Arthritis Research UK is stepping up the campaign to make sure people living with musculoskeletal conditions are heard at this election and beyond.

Earlier this year Arthritis Research UK launched its manifesto, Prevent, Transform, Cure, setting out the key challenges presented by musculoskeletal conditions and specific action we want policy makers to take to overcome these big challenges.

Now we’re excited to confirm the launch of our new online campaign tool. The tool allows anyone to ask their own general election candidates to sign up to the manifesto and become Arthritis Champions in just a matter of minutes at www.arthritisresearchuk.org/voice.

It enables you to look up your local parliamentary candidates, and in a matter of minutes send candidates vying to be your next MP an email asking them to become an Arthritis Champion.

Many people with arthritis live with the daily pain and fatigue caused by their condition, and we believe passionately that more can be done to help them.

With this campaign tool, we want to place the power to fight for change firmly with you and your local communities.

You can make sure that in the next parliament we have hundreds of Arthritis Champions from constituencies across the country committed to our manifesto and addressing the needs of people with musculoskeletal conditions.

Get involved today and make your voice heard by using the campaign tool and emailing your parliamentary candidates. Visit www.arthritisresearchuk.org/voice.

Please ask your friends and family to email their candidates too. If you would like more information, please email the team via action@arthritisresearch.org
A reason to give this Christmas

Lorry driver Brian was crippled with rheumatoid arthritis (RA) last Christmas. He first felt pain in his wrists with the pain gradually spreading to his fingers, elbows and shoulders. In just three months, he became crippled with it. He started to limp at work, and even found picking up a pen and unscrewing lids of jars agonising. He was forced to give up his full time job.

When he eventually saw his doctor blood tests confirmed RA. He was prescribed methotrexate tablets which, fortunately, relieved his symptoms almost immediately. Brian has now been able to return to full-time employment and is back behind the wheel of his HGV.

Brian says: “After less than a month, my symptoms practically disappeared. Even though I’ll have RA forever, it’s a relief to get my life back and I’m now able to work full-time again and lead a normal life. I know I’m one of the lucky ones though. I’ll never take simple things for granted, like being able to move freely, without pain, again.”

While not everyone is as lucky as Brian, our research teams at Arthritis Research UK are working hard to pioneer treatments that can be life-changing. Your support will help the one in six of us, struggling with arthritis, be pain free this Christmas.

Every gift this Christmas makes an impact. Please use the form below or call 0300 790 0444 to give whatever you can. Thank you.

YES – I want to help find a cure for arthritis

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Quality products

There have been quite a few changes to our stairlifts since we first started making them. These days we offer a range of products in a variety of materials to blend in with your home, all of which fold neatly against the wall when not in use.

However, we still apply the same rigour when testing our products as we always have done, ensuring they meet the highest standards of quality, comfort and safety. We are so confident with the quality of our stairlifts that we offer as standard a 2 year warranty with 2 free services on all new products.

Our superior service

We understand how proud you are of your home, so we ensure that every element of the installation and service is considered, co-ordinated and perfected. Our engineers are trained to install the stairlifts quickly with the minimum of fuss. They even carry their own vacuum to ensure your home is left in the same condition as it was found. Once fitted, aftercare is provided nationwide 24 hours a day, 365 days a year through our locally-based engineers. We also only use our own UK based call centres and don’t use automated systems, so you can always speak to us whenever you need to.

Providing you with good value for money

We understand that buying a new stairlift outright doesn’t suit everyone. That’s why we offer the option to buy or rent new or expertly reconditioned stairlifts, for both curved or straight staircases, all with a 14 day satisfaction guarantee.

The Stannah Promise

Over the past 39 years, we have installed over 500,000 stairlifts. Every one of our customers relies on Stannah to stick to our commitments of product performance, value for money, support and servicing. These commitments are the foundation of our promise to you. Our promise to be ‘always true to our word’.

Thank you.

Please use the form below or call 0300 790 0444 to give whatever you can.

Put a smile on someone’s face this Christmas. Help stabilise the future of our research. Get involved!

www.arthritisresearchuk.org/donate or call our donation line on 0300 790 0444.

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Six-year-old Lily Whitehead is happily drawing a picture of a flower in the clinical research facility at Alder Hey Children’s NHS Foundation Trust in Liverpool.

Lily has had juvenile idiopathic arthritis (JIA) since she was three, and for the past year she has been coming to Alder Hey every two weeks for injections of anti-TNF therapy as part of a clinical trial, part-funded by Arthritis Research UK.

Clinical nurse specialist Jane Kelly has administered the injection of adalimumab compared to placebo a year ago, and she has not looked back since. “It’s been brilliant. Her joints and general movement are so much better and she has lots of energy,” says Jane. “To me it’s like she’s cured.”

As the clinical trial is randomised and double-blinded, Lily may be on either the active drug or the placebo. This will only be established at the end of the trial. This year, for the first time, Lily was able to take part her school sports day. Adds Jane: “It was fantastic to see her run around the track, particularly as last year it was upsetting for her as she couldn’t join in. But now she’s very sporty – she’s doing gymnastics and is having swimming lessons.”

GOING ON THE DRUG TRIAL WAS THE RIGHT THING FOR LILY

Jane and Nick had initial reservations about Lily going on a drug trial at the age of four, but staff at the clinical research facility layed their fears. “I was worried about the drugs being pumped into her, but it was the right thing. We trust the staff here and they know what’s right for her. She has made massive progress. She has her days where she says ‘Do I still have to keep going to the hospital?’ And I say, ‘As long as you are feeling like this, isn’t it better we keep going?’ And she says, ‘OK.’”

Children like Lily, and those youngsters with arthritis who have not found a drug that controls their condition, will benefit enormously from the launch of the new Arthritis Research UK National Experimental Arthritis Treatment Centre for Children (EATC) at Alder Hey, the first of its kind in the UK.

SPEDDING UP DRUGS FOR CHILDREN WITH ARTHRITIS

The EATC is dedicated to speeding up the development of new drugs for children with arthritis and related conditions, by running small clinical trials of promising drugs currently in the pipeline, and those already used in adults.

The centre has identified four priority areas – juvenile idiopathic arthritis (JIA); JIA-associated uveitis, a potentially serious eye condition that can lead to blindness; childhood lupus; and childhood bone diseases.

Liverpool is already the national co-ordinating centre for all clinical trials involving children in the UK, and benefits from the strong links with the University of Liverpool.

Professor Michael Beresford, director of the EATC, is keen to stress these links – and to point out that only a door and a corridor separate the hospital from the university’s laboratories.

“We collect samples from children with JIA and lupus and they come through the door and straight into the lab to be processed and analysed,” he explains. “Within the hospital here there’s fantastic expertise in looking after children with arthritis, and within the university there’s huge expertise in researching to understand what causes the diseases and running safe, child-friendly drug trials. The EATC is really important in bringing these elements together.

DELIVERING BETTER TREATMENT

“There’s no centre in the country or in Europe that has our focus of drawing together research that combines all the expertise needed to look at what is causing disease and taking that right through into trials, and delivering better treatment.”

Together with Professor Athimalaipet Ramanan and colleagues in Bristol, who lead on JIA-uveitis for the EATC, and Professor Nick Bishop in Sheffield, leading on childhood bone disorders, the EATC will be working very closely with paediatric rheumatology colleagues in Newcastle, London and across the country to develop new and important treatments for children and young people with these disorders.

The university’s research centre, which adjoins the hospital, is a hive of activity. Next to Professor Beresford’s office there are labs where researchers are investigating disease pathways in JIA and childhood lupus, as well as rarer conditions. And next door to the labs, there’s a room full of trial co-ordinators, where a whole range of current and future clinical trials are planned and organised. With Alder Hey’s brand-new £280 million Hospital in the Park due to open in June 2015, along with a new state of the art research and education facility, it’s exciting times for children’s health research. And the EATC is at the heart of these developments.

NEW BELIMUMAB TRIAL FOR CHILDREN WITH LUPUS

As well as housing a co-ordinating centre for the largest national cohort of children with lupus in the world – they currently have data from over 450 youngsters – and discovering fundamental steps in what causes lupus, the team has recruited the first child to an international trial of belimumab, a promising new drug for lupus in both adults and children.

One of the things the new EATC will make possible is testing drugs used in slightly more common conditions such as JIA in rarer conditions such as uveitis and lupus, as well as Behçet’s, scleroderma and juvenile dermatomyositis.

Not so long ago, drug trials involving children were rare. There was reluctance to conduct studies of medicines in children due to a number of factors, including ethical concerns about conducting trials in children, together with commercial considerations. The number of children in the UK with JIA is roughly 15,000, compared with 380,000 people with rheumatoid arthritis, making trials in children not necessarily financially viable for pharmaceutical companies.
Improving understanding to improve care

Expectations have changed of what is acceptable. Twenty years ago many children with arthritis ended up in wheelchairs, and there were few effective treatments. Today the outcome for most youngsters is far brighter.

Dr Eileen Baildam, a paediatric rheumatologist at Alder Hey, recalls that when she started working as a consultant in the 1990s there was just one clinical trial involving children.

"It was all the unit could cope with at the time, but also it was thought to be unethical to do trials on children. But oncology – cancer care – changed because every child was on a drug trial," she says. "Now, with the help of the children themselves, and the Arthritis Research UK clinical studies group, which has really promoted the importance of this work, it’s now felt to be the right of every child with arthritis and related conditions to be involved in drug trials.

Professor Beresford notes: "Every patient at Alder Hey with an inflammatory rheumatic condition is now offered the opportunity to be in a clinical trial or to take part in studies to help improve our knowledge of their disease. We hardly ever get anyone refusing to get involved in studies. It’s an integral part of our care, and our philosophy, and is an essential part of improving the whole knowledge base."

The team are keen to make the most of their links with leading adult rheumatologists running clinical trials, and the EATC has strong collaborative links with colleagues such as John Isaacs in Newcastle, Iain McNines in Glasgow and Peter Taylor in Oxford, so they can take advantage of new compounds being discovered as potential targets for new drugs.

Equally important is looking at ways to reduce children’s reliance on very old drugs which are still the mainstay of treatment for many youngsters with severe disease – steroids. Steroids are life-saving and life-transforming over short periods of time because they work quickly to suppress the immune system and hence inflammation but in large doses over long periods their side-effects can be devastating. What’s required is ‘efficacy without toxicity’, as Dr Baildam puts it.

"Steroids are still widely used via injections into the joint, intra-venously, as topical creams, or even drops in the eyes, but we want to be able to treat children without them, and to do that we have to understand the disease better and be able to select drugs that are more specific and don’t have the side-effects," adds Professor Beresford. "Within the EATC we want to improve our understanding, in order to improve our care."

Which sums up the centre’s vision in a nutshell.

As a result, until recently most drugs have only been tested for safe and effective use in adults, and there are comparatively few medicines on the market which are specifically licensed for the treatment of children with arthritis, such as etanercept. (Tocilizumab and canakinumab are both licensed for certain subsets of JIA.) As a result, unlicensed and off-label drugs were prescribed in children, which sometimes resulted in inappropriate dosing and unforeseen adverse events.

However, in 2007, European regulations were introduced which made it mandatory for all drug companies to test new drugs on children as well as adults, and as a result the clinical trial landscape has changed out of all recognition.

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New research aims to shed much-needed light on the mysterious condition that is palindromic rheumatism. Jane Tadman reports.

Like many types of arthritis, palindromic rheumatism can strike without warning, causing extreme pain in one or several joints. But what makes it different to most other types of arthritis is that it then disappears as mysteriously as it came, although these attacks, or ‘flares’, can last days or weeks.

It’s this very unpredictability, along with the intense pain, extreme fatigue and a general lack of awareness or understanding of the condition, that makes the lives of people with palindromic rheumatism so difficult.

RARE, LITTLE KNOWN AND POORLY UNDERSTOOD

Because it’s rare, little known and poorly understood even among medical specialists such as rheumatologists, palindromic rheumatism can also take a long time to be diagnosed.

Anna-Marie Jones from Cardiff was ill for around 18 months before her condition was diagnosed 11 years ago. "I developed severe pain in my lower back and felt out of sorts. It got worse and worse, and I then developed short-lived episodes of peripheral joint pain, but the GP just said it was a viral infection or lumbago," she recalls. "One of the problems though was that although I had flares that could last days, every time I had a test I wasn’t having a flare, so nothing showed up."

THE CONDITION WAS THOUGHT TO BE IN HER HEAD

At one stage Anna-Marie saw a psychiatrist as her condition was thought to be in her head. (Other people with the condition have reported that they have not been believed by the medic, often causing them to doubt themselves. Confusing test results and fluctuating symptoms lead some to wonder if they are imagining their attacks.) But she persevered and was finally diagnosed by her current consultant rheumatologist.

Her problems didn’t end there, however. Treatment – mainly anti-inflammatories and a drug called hydroxychloroquine, sometimes used to treat rheumatoid arthritis, didn’t effectively control her symptoms, and she was dogged by bouts of severe joint pain and crippling fatigue for a number of years.

"I wanted to take on a job but it was impossible because I never knew what was going to trigger it or how long it was going to last – maybe sometimes if I overdid it, I’d know I’d get a flare as a result, but generally there was no pattern to the flares," Anna-Marie explains.

Despite her continuing ill health, Anna-Marie gave birth to a daughter, Lana-May, now nine, relying heavily on family and friends to bring her up.

ANNA-MARIE DECIDED TO FIGHT AGAINST HER CONDITION

It was partly because of her daughter that Anna-Marie decided to seriously fight back against her condition.

“She came back from nursery one day with a picture she had drawn of me in bed, and she had explained to her teacher it was because ‘mummy is always in bed’. It broke my heart,” she says.

Anna-Marie started to volunteer with the Cardiff branch of Arthritis Research UK, and the charity’s then regional fundraising manager for South Wales, Fred Johnson, suggested that she investigate the possibility of going onto methotrexate, a drug used in inflammatory arthritis, which works by damping down the immune system. At the same time Anna-Marie’s flares were getting longer and more painful, and her consultant agreed to try her on the drug.

That was three years ago and the change in Anna-Marie has been remarkable. Now 44, she’s a full-time regional fundraising manager for South Wales, and her symptoms are largely under control.

Not everyone is fortunate enough to find a drug treatment that works for them, however, and many people with palin-
WHAT IS PALINDROMIC RHEUMATISM?

- It's a form of inflammatory arthritis that leads to attacks of joint pain and inflammation. In between attacks, or flares, the joints look and feel normal.
- People with palindromic rheumatism usually have no symptoms between attacks.
- During an attack the joints involved are painful, stiff and swollen. Tendons may also be inflamed, painful and swollen.
- Palindromic rheumatism gets its name from the term ‘palindrome’, meaning a word or phrase that reads the same forwards or backwards. A typical palindromic attack begins and ends in the same way, and is at its worst point in the middle.

FROM ONE ROOM TO ANOTHER

Arthritis Research UK has a new patient information booklet about palindromic rheumatism and an online report called ‘From one room to another’ based on patient experiences. The report has thrown up a number of common themes. Overwhelmingly respondents want the medical profession and general public to have a better understanding of how the condition affects their lives.

They are also keen to know more about how palindromic rheumatism develops, what the future may hold, more practical advice on how to lead a normal active life, and for more research on medication developed specifically for palindromic rheumatism. The report, which includes many moving personal stories, provides a fascinating insight into the lives of people with palindromic rheumatism.

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You can download our palindromic report summary, ‘From one room to another’ and our patient information booklet here:

arthritiscaresearch.org/palindromic

www.arthritisresearchuk.org
Betty Jones is 74-year old and has type 2 diabetes, high blood pressure and chronic kidney disease. She also suffers with painful knees. She’s been experiencing increasing pain for the last five months, which is now interfering with her sleep and everyday activities. She was diagnosed with osteoarthritis four years ago and has been managing pretty well since, using anti-inflammatory creams and occasional paracetamol.

Someone like Mrs Jones would be familiar to most GPs. We recognise the limitations of what we can offer to our patients when it comes to medications for the pain of osteoarthritis. Oral non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, naproxen and diclofenac, aren’t usually advised due to their risk of causing stomach or kidney problems. Anti-inflammatory creams and gels are modestly effective and paracetamol is often of limited value in terms of its effect on pain.

The lack of really effective drug options for osteoarthritis forces us to be more creative in the ways to help people manage their joint pain. The updated NICE guidelines on osteoarthritis, published in February 2014, clearly highlight the wide range of non-drug treatments available, from supports and bracing of the joints and insoles for shoes through to physiotherapy (especially for hip osteoarthritis) and assistive devices such as tap-turners or washing aids. My approach in practice is a pragmatic one. In the absence of ‘magic bullets’ when it comes to managing the symptoms of osteoarthritis, I aim for a combination of management options which, whilst on their own may only offer a small benefit, when used in combination may have a bigger effect.

Another guiding principle is that treatments for osteoarthritis should ideally be simple, effective (and cost-effective), safe and ideally self-administered.

So what’s happening in a joint affected by osteoarthritis? There is a constant process of wear and repair happening as the joints adapt to the stresses and strains of normal everyday life. Osteoarthritis occurs when the process of wear and repair goes out of balance – for example due to injury or being overweight – which leads to pain, stiffness and swelling in the joints.

When we discuss osteoarthritis treatment, it’s important to remember that with the exception of joint replacement, we’re not talking about treatments that actually change the disease process in the joint. Instead we focus more on symptoms, the impact of the condition on the ability to carry on with everyday activities (we medics call it ‘function’) and quality of life.

**CORE TREATMENTS**

Right at the centre of the NICE recommendations are the core treatments of exercise, weight loss (if you’re overweight), education, advice and access to information. This advice should be given to all people with osteoarthritis and will be explored in more detail in the rest of this article.

**ACCESS TO INFORMATION:**

Access to effective treatment starts with a positive diagnosis. Osteoarthritis can be diagnosed by GPs following a clinical assessment and without the need for x-rays in the majority of cases. Giving patients a positive diagnosis of osteoarthritis, rather than describing it as merely (a touch of) ‘arthritis’ or a (bit of) ‘wear and tear’ allows people to access the right information so that they can begin to find out about living and coping with their condition.
DIAGNOSING OSTEOARTHRITIS

Osteoarthritis is usually diagnosed if a person:

- is 45 or over
- has activity-related joint pain and
- has either no morning joint-related stiffness or morning stiffness that lasts no longer than 30 minutes.

Early morning stiffness lasting 30 minutes or longer may be due to an inflammatory arthritis such as rheumatoid arthritis – if you have this you should see your GP to discuss your symptoms.

WEIGHT LOSS IF OVERWEIGHT

This is an interesting part of the NICE guidelines. Most of the published research is about hip and knee osteoarthritis, and the overwhelming majority is on knee osteoarthritis, though the authors of the guideline concluded that advice to lose weight was sensible across the board. Every time we take a step, the force of three to six times our bodyweight goes through our knees, so the link between weight and load through the knee is clear. If you are overweight, reducing your body mass index (BMI) by two units reduces the risk of developing osteoarthritis of the knee by 50%, Which for a woman of average height equates to approximately 5 kg (12 lb) weight loss - a modest target. Interestingly, the link between weight loss and improvements in pain in people who already have knee osteoarthritis is less clear-cut. Weight loss of approximately 5% body weight or at least 6 kg (14 lb) leads to noticeable improvement in the way people move and feel, but the direct link with improved pain is not as strong. However, the research shows that combinations of diet AND exercise lead to more weight loss, less pain, better function, faster walking speed, further walking distance and better health-related quality of life than diet or exercise alone.

EXERCISE

Exercise is one of the most effective, safe and cost-effective weapons in our arsenal when it comes to managing the symptoms of osteoarthritis, and is roughly as effective as oral NSAIDs for knee osteoarthritis but without the side-effects. But there are challenges to overcome. Being affected by osteoarthritis can lead to a vicious cycle: it hurts more to move so a natural response is to move less, then people get weaker and stiff and quickly become deconditioned with rapid loss of muscle bulk, strength and endurance. So when they do move the muscles are weaker and joints are less stable, so they experience pain and fatigue more readily. When people with osteoarthritis first start exercising they often experience more pain; I always warn them about this so that they are encouraged to persevere.

THE KIND OF EXERCISE THAT HELPS MOST FOR OA IS GENERALLY A MIXTURE OF:

- resistance: for strength and joint stability
- aerobic: for fitness and endurance
- flexibility: for balance, range of movement and co-ordination.

The benefits of exercise far outweigh the risks, the main risk being injury. The risk of injury can be reduced by warming up and cooling down properly. ’Start low and go slow,’ gradually increasing the amount and intensity of exercise, wear well-fitting, supportive, shock-absorbing footwear and avoid high loading (e.g. jumping and twisting) to start with.

TOP TIPS FOR EXERCISE

- Any physical activity is better than none.
- Start low and go slow.
- The benefits of exercise are related to the amount that you do – i.e. more is more.
- It will take around six weeks of regular exercise to start to experience benefits – so stick with it!
- The ’dose’ of exercise is at least 30 minutes three (or more) times a week for aerobic exercise and at least 20 minutes three times a week of resistance exercise. This can be broken down into five- or ten-minute chunks
- People who stick with exercise benefit the most in the long-term. So find something you enjoy doing – and do it!
- Things like exercise diaries, pedometers, and supervised and group exercise programmes can help you to stick with exercise.
- Exercise is a perishable good. In order to be effective, exercise must be ongoing – especially in the older population who need to train harder to maintain the same benefits.

For more information about osteoarthritis and exercise go to: www.arthritisresearchuk.org
Dr Tom Marsham is Arthritis Research UK’s primary care lead and a GP in Tower Hamlets.
Q&A

Questions and Answers with Dr Philip Helliwell

Q I read an article in The Times about culturating cartilage from nasal cells to replace knee cartilage. Can it also be used for other joints and if not, why not? I have severe arthritis in my left foot and have already had the left knee replaced 12 years ago, spending six months in plaster with no weight-bearing. Fusion of the joint has been suggested, which would mean losing part of the laboratory side and they have just started their first clinical trial, the ASCOT (Autologous Stem Cells, Chondrocytes or the Two) trial, featured in Arthritis Today earlier this year. I would stress, however, that this trial is aimed at people with early osteoarthritis of the knee, not those with advanced disease. If successful, it could be applied to other joints.

A Am I sorry to hear of your predicament. New joints are always vulnerable to damage, and particularly so soon after being put in. The fall may have jeopardised the stability of the new joint but the surgery you had second time round should have corrected that. What you need now, I think, is some good physiotherapy to help you regain the function in your knee. You should perhaps check this with your surgeon but I am fairly confident that the situation can be improved. It may take a bit of time and some hard work.

Q Can you get arthritis in a hip that has been resurfaced?

A The simple answer is yes! Resurfacing is a minimalist way of replacing the joint which is less invasive, yet still effective but, unfortunately, may not last forever. Many patients who have hip resurfacing will later need to have the whole joint replaced. Resurfaced joints just have the cartilage on the femoral (thigh bone) side of the joint replaced. With total joint replacement both the femoral and the acetabular (pelvis) side of the joint are replaced with artificial components. These may be metal, plastic or ceramic. They may be cemented or uncemented. There are many products on the market and the surgeon will choose the best one for you.

Q I am 35 and had a hip replacement in 2005. The other hip is now giving me some pain. Every day I do 30 minutes on a treadmill at 2.7 mph, which is fairly modest. What I want to know is: am I going to wear out the artificial hip prematurely by doing this? To tell you the truth, if it was me, I'm thinking I would probably have a hip replacement this year. The hip pain you experience is unlikely to be due to the hip replacement. Hip pain can be due to other causes, such as osteoarthritis, gout, or even a slipped disc. The best advice is to see a rheumatologist to let them decide, as a result, whether or not surgery is necessary. In your case, it might be worth having some imaging tests to see if there is anything causing your pain. If there is nothing, then you may just need some pain relief medication.

Q Both my knees are severely swollen as a result of osteoarthritis, but I am nowhere near ready to have a knee replacement as I can still walk distances and the pain is controllable. My doctor says that there is nothing that can be done about it, even though I am too embarrassed to swim any longer or to wear a knee length skirt. I understand that acupunture helps osteoarthritis. Will it go back to the swith? Is there any other way of getting rid of it, with or without surgery?

A Josie Rice, via email

A Acupuncture can help with pain relief but the fluid removed, and the knee injected. In your case, it might be worth having some imaging tests to see if there is anything causing your pain. If there is nothing, then you may just need some pain relief medication.

Q I had a full right knee replacement 13 months ago. I then fell on this about a month later and a repair had to be done. Since then I have not been able to go out without crutches. It is not particularly painful and I feel the problem is psychological. Can you give me any practical solution to this? Any advice you can give will be very warmly welcomed or could you suggest a medical professional who might be able to help?

A Lorna Lancaster, via email

A I am 78. A very warm welcome or could you suggest a medical professional who might be able to help?

Q Do you think I am going to need another operation? It is too soon to say! However, new joints are always vulnerable to damage, and particularly so soon after being put in. The fall may have jeopardised the stability of the new joint but the surgery you had second time round should have corrected that. What you need now, I think, is some good physiotherapy to help you regain the function in your knee. You should perhaps check this with your surgeon but I am fairly confident that the situation can be improved. It may take a bit of time and some hard work.

Q Moderate, recreational running, with miles of less than 40–50 miles a week, is unlikely to cause premature osteoarthritis. And the benefits of this level of exercise on the bones and the heart will far outweigh any minor running-related problems.

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A A Many years ago I was diagnosed with polychondritis, which affected my eye, nose and throat. I was on corticosteroids for several months and was told that if there was a relapse I should take it again. I understand that the joints and heart can also be affected.

Q Relapsing polychondritis is a rare condition in which tissues containing cartilage become inflamed. As you point out, the cartilage of the ear, nose and windpipe are most commonly affected, but cartilage elsewhere, in the heart valves and joints, may be involved. Treatment is with steroids and other immunosuppressive drugs, as the condition is essentially an autoimmune disorder. An autoimmune disorder occurs where the immune system attacks normal tissue, in this case cartilage. Many arthritic conditions are autoimmune disorders, rheumatoid arthritis and lupus included, and inflammation in collagen-containing tissues (cartilage is mainly collagen, but other tissues, such as blood vessels and heart valves, can contain collagen) can occur in these conditions as well. Joint inflammation can therefore occur in poly- chondritis. The key pain you experience may be due to another cause, such as osteoarthritis, but it would be best to see a rheumatologist to let them decide, as a relapse in polychondritis should, as you say, be treated.

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Another tip on paper towels

Many of you have written to tell us how you use paper towels to help keep your hands dry. Some of you have even come up with some clever ideas for using them (see the January Hints Box). My favourite is from Tricia Rusling from Kent, who uses them under her armpits to stop her from sweating. This is a great idea – and it works for me.

Caroline Price, via email

Another tip on opening jars

I have had rheumatoid arthritis since 1994 and now my hands are so painful that opening jars is virtually impossible. I have thought about buying a jar opener, but they seem such a small purchase. I decided to look up more ideas on the internet – and I found one I hadn’t heard of before.

From Mrs BM (an expert patient at King’s College Hospital via email)

“Sea buckthorn oil for Sjögren’s syndrome?”

Regarding Sjögren’s syndrome, I wonder whether researchers are aware of sea buckthorn oil in capsule form and available as ‘Omega 7’. The capsules contain omega 3, 6, 7 and 9 and vitamin A (beta carotene), which maintains normal structure and function of the skin and mucous membranes, such as in the eyes, nose, mouth and female reproductive tract. The capsules are manufactured in Finland and imported and distributed by Pharma Nord (UK) Ltd, Morpeth, NE61 2OB. I hope this information is of interest.

Obviously the capsules should not be taken by pregnant and lactating women, and those on medication without first seeking professional advice. They are free from artificial colouring, yeast, sugar and gluten, and are suitable for vegetarians and vegans. Thank you for a most interesting publication.

Maureen Brown, Crawley, West Sussex

Pilates helped my back pain

I have lived with arthritis for over 20 years and have had rheumatoid arthritis since 1988 and am now 67 – trial and error or a friend does help. Don’t be afraid to ask – I also ask my chemists to help with caps. The cap that needs pressing down is very hard – use a knife to cut little teeth if possible and then try to use body weight against the parallel side and turn bottle rather than cap – easier and certainly works for me. Caps that need turning are very hard – use a knife to cut little teeth if possible and then try to use body weight on top to turn the cap, or ask a friend. I have had rheumatoid arthritis since 1988 and am now 67 – trial and error or a friend does help. Don’t be afraid to ask – I also ask my chemists to help with caps. He is very helpful indeed. What would I do without him! Hope this helps.

Tricia Rusling (an expert patient at King’s College Hospital), via email

Don’t take too much fish oil

I have been taking a fish oil supplement for about 15 years, the last 10 as liquid, as it is better value, but in my experience I would urge caution with the recommended dose of a 5 ml teaspoon. Several years ago I saw the results of a study which appeared to show a beneficial effect up to a certain dose and then showed less efficacy as the dose increased, which maybe should have rung alarm bells, but I ignored it. Two years ago I developed a heart arrhythmia, which I was told was normal for my age (65) and to get on with life. I went back twice more as it became more pronounced but was assured it was ok. I did the usual research to try to find an answer as in my mind I remained unconvinced. Ten months ago I saw the results of an American study that indicated fish oil in larger doses could cause a range of symptoms, which included heart arrhythmia and prostate cancer. I stopped the fish oil supplement and within a week it was improving and after a month it was back to normal and has been since then. I have not had the courage to return to a lower dose but will do eventually.

Stuart Cleverley, via email

How to get out of your vest

Taking off a chemise or vest is difficult or painful when you have general arthritis. I stitch a narrow tape or ribbon in the centre, top back of the garment. When putting it on, make sure the ribbon comes over your shoulder. Loosely knot onto a strap. When taking the garment off, free the ribbon, pull it out in front of you and slightly up and it will pull the back up as you go. I hope this is not a hint everyone has been doing for years!

Rosemary Biggs, via email

Hints Box

Summer 2014, The Arthritis Today

Views expressed in The Hints Box are those of readers and not necessarily the view of Arthritis Research UK. The Hints Box is also published online on our website at www.arthritisresearchuk.org
Thank you for becoming a Pain Killer

Shree Rajani provides a round-up of our recent National Arthritis Week.

We want to thank everyone who became Pain Killers this October and once again made National Arthritis Week a success. For the third year running, our awareness week was an opportunity to highlight the impact of arthritis and to give people with arthritis, and their friends and family, information to effectively manage their condition.

This year, we highlighted the impact of pain on the lives of people with arthritis. We understand what it’s like to live with long-term pain, so we invited everyone to be a Pain Killer and support the 10 million people living in pain every day.

We created a new look and feel for the campaign and encouraged everyone to get involved by filling in the National Arthritis Survey, sharing our pain management information or organising an event.

We held a parliamentary reception to talk to MPs and peers about the pain of arthritis and its impact.

LloydsPharmacy donated up to £1 from the sale of selected pain-management products and supported the week with staff fundraising. They also donated space on screens in 2,000 GP surgeries across the country, which helped us to signpost people to our pain information.

Our supporters and fundraisers dressed up, held bake sales, took part in zip wire challenges and held bucket collections across the country to raise thousands of pounds.

Our retail stores filled their windows with orange stock, organised events and got customers involved in the week. With your help, they raised almost £15,000.

The national and regional media supported us during the week, and we had great coverage across the country. Our medical director Professor Alan Silman was joined by our ambassador and classic singer Laura Wright for over 20 radio interviews to kick off the week. Associate medical director Dr Inam Haq was on Zee Companion, a live show on Zee TV which is broadcast to almost one million homes across Europe.

We also highlighted your stories in the media and talked about the impact that arthritis has on daily life. Sally Mills from Northamptonshire lent her support to National Arthritis Week after she was diagnosed with osteoarthritis at 42. She said: “My daily pain has meant I had to stop working, which has been very upsetting, and I can no longer drive long distances. Where I used to enjoy coastal walking, I now have to think of every little movement before I actually do it. I encouraged everyone to get involved with National Arthritis Week and join the battle against this awful condition. Everyone’s support will help Arthritis Research UK help millions of people, like me, living in pain.”

Catherine Manning, 34, from Essex, was also keen to support the week. She said: “The pain of arthritis can make everyday tasks that many people take for granted extremely difficult. My husband helps me shower, get dressed and helps with the cooking. I can no longer do the things I used to love and, at 34, it’s hard to come to terms with it. I’m proud to support Arthritis Research UK as they are dedicated to stopping the devastating impact that arthritis has on people’s lives by funding life-changing research. This National Arthritis Week, I became a Pain Killer for myself, while my husband and children all became a Pain Killer for me.”

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Over 14,000 of you completed the National Arthritis Survey last year and told us about the effect arthritis has on your everyday life, from household chores to how you get around. Out of those with moderate or severe pain, 56% struggled to sleep, 50% found weekly shopping extremely difficult and sadly 24% reported that their pain prevented them from playing with their grandkids.

At Arthritis Research UK, we know that the pain caused by arthritis is often invisible so we launched National Arthritis Week with a news story looking at the nation’s perception of pain. The results showed us that:

- The nation ranked childbirth as the most painful event they have experienced or could imagine (51%), with less than half (24%) giving a kick in the groin the same rating.
- A blood test was ranked the least painful (1%), along with paper cuts (2%) and hitting a funny bone (2%).
- Interestingly 92% of those surveyed with arthritis rated their condition as painful as childbirth, and when asked to best describe their pain, almost half of people arthritis (46%) said it felt ‘like hot knives every time I move’ and for over a third (38%) ‘the pain of arthritis caused constant fatigue and loss of energy’.
- Over half of the general population (51%) said they would find it challenging to do everyday tasks like shopping, cooking or socialising with friends if they experienced joint, neck or back pain and stiff knees – all symptoms people with arthritis deal with on a daily basis.
- Our supporters and fundraisers dressed up, held bake sales, took part in zip wire challenges and held bucket collections across the country to raise thousands of pounds.
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But that’s not all! During the week…

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Fundraising news

Young violinist strikes a musical note

A group of young musicians, led by talented violinist Alexia Martie Lopez, from Barrow-in-Furness in Cumbria, got together for the second year running to put on a live music gig in aid of Arthritis Research UK.

Seventeen-year-old Alexia, who is currently studying for her A-levels and whose father has rheumatoid arthritis, said: ‘I’ve organised this gig for the second year running as I really do want to make a difference. This is my way of giving something back to support Arthritis Research UK.’

Thanks to the support of family, friends, local companies and the Nines music venue, Alexia has had to date raised a total of more than £470 and, now a seasoned fundraiser, is planning the third annual Barrow-in-Furness music charity night for 2015.

Lantern Opera: a resounding success

The Lantern Opera, an annual highlight of the Arthritis Research UK fundraising calendar, took place in November in the beautiful surroundings of the Draper’s Hall in London. Thanks to our very generous supporters on the night, we raised over £50,000 to support the Arthritis Research UK Centre for Adolescent Rheumatology in London.

Classical singer and ambassador for Arthritis Research UK, Laura Wright, who suffered from arthritis as a child, opened the evening with a wonderful performance taken from her new EP Sound of Strength.

Guests were also entertained with salon operatic performances from the Classical Opera Company during dinner before raising funds during the charity auction, bidding on fabulous items including dinner at Le Gavroche, a bespoke garden consultation from Thomas Hoblyn and a box at Kempton Park racecourse on Boxing Day.

The great success of the event was made possible thanks to the help of a seasoned fundraiser, is planning the third annual Barrow-in-Furness music charity night for 2015.

If you would like to help put on next year’s event or would like to be notified about how to buy tickets, please contact Anna Cooper, head of major supporters, on 020 7309 2230 or acooperr@arthritiscure.org.uk

We are grateful to the following sponsors of the 2014 Lantern Opera:

Headline sponsors: Friends Life
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Portsmouth abseilers go over the top

Fifteen brave volunteers abseiled 100m down the side of the iconic Spinnaker Tower in Portsmouth for Arthritis Research UK back in the summer.

Most of those taking part have arthritis themselves and know first-hand the devastating impact the condition can have on everyday life. In spite of this, everyone completed the descent and collectively raised over £10,300.

One of the abseilers, Angela Phillips, said: “Meeting other people who have all different types of arthritis was great as we compared notes and tips on how to cope with the condition. We all managed to do the abseil, even if we were a little sore afterwards. We all feel so proud that we have achieved this challenge and that we are raising awareness and money for Arthritis Research UK.”

This is an event we will be running again next year so keep an eye out for the date to get yourself signed up for 2015.
Dr Blandine Poulet and Dr Cameron Brown explain their work in an ongoing series of questions and answers with Arthritis Research UK-funded researchers.

**Dr Blandine Poulet** is an Arthritis Research UK foundation fellow at the Royal Free and University College Medical School in London.

**What does your work involve?** My current work is trying to understand what happens during osteoarthritis. In this disease, cartilage, the tissue that lines the end of the bones to protect them during movement, is broken down. Many factors are known to impact upon joint health; joint injury, as well as ageing and genetics, are widely believed to be major determining causes of osteoarthritis. My work explores how these factors interact with cartilage breakdown to cause osteoarthritis. This understanding may help us to prevent cartilage loss during osteoarthritis.

**What do you hope or expect to achieve as a result of your Arthritis Research UK funding?** I hope that my research will contribute to understanding why osteoarthritis occurs and how we can provide better treatment. As a fellow, this funding will also contribute to establishing my career as an independent investigator in arthritis research.

**What do you do in a typical day?** I usually start by checking my emails with a cup of tea. My day is then shared between meetings with academic peers or students, reading research papers, attending courses and writing (papers or grants) planning and performing lab experiments. But my favourite part of the day is when I am ready to analyse results and discover whether the initial hypothesis was correct or not. At that moment, I am the first person in the world to know something new about how the joint functions and reacts (or fails too).

**What is your greatest research achievement?** My greatest research achievement is describing a new way to study osteoarthritis disease spectrum, we have developed an algorithm that can quantify early chemical changes in cartilage with osteoarthritis. If we can translate this to the clinic, it will be a big step forward for arthroscopy, moving it from a qualitative to quantitative tool.

**What do you hope or expect to achieve as a result of your Arthritis Research UK funding?** With the increasing interest in treating osteoarthritis at its earliest stages, and the development of new treatment procedures targeting this early degradation, we have found out in the past 12 months.

**What do you do if you weren’t a researcher?** If I wasn’t a researcher I would have done physiotherapy. Otherwise, working in my own small organic farm in the south of France wouldn’t be so bad. This would keep my scientific mind busy by devising new, better methods for sustainable farming and would combine my love for sunny, fresh air, the environment and good, healthy food. (And in the south of France wouldn’t be so bad. This would bring some interesting new problems for arthroscopy, both in clinical practice to aid treatment decisions, and in the laboratory to aid the development of new treatments.

**What do you do if you don’t really have a typical day?** I prefer a lot of long walks rather than being driven towards it. One of the main things that made me want to stick with this work was the opportunity to balance interesting and fundamental science with work that can make an immediate and positive impact on people’s lives.

**Do you ever think about how your work can help people with arthritis?** One of the great things about working on an orthopaedic hospital site is that you spend time working in the clinical needs that drive your work. Speaking with patients at a recent patient awareness day was rewarding and humbling at the same time. We have a lot of work to do.

**What would you do if you weren’t a researcher?** I think I would be a park ranger in Australia.

**About Cameron Brown** The UK has some beautiful countryside and I enjoy spending time out in it with my family and my dog. I like playing the guitar, despite being rubbish at it, and really need to get back into boxing as a physical activity is a bit too sedentary.

“In the past 12 months I have found that the way the cartilage is broken down is different depending on how osteoarthritis is initiated. This emphasises the need to categorise osteoarthritis into subtypes of disease.” – Dr Blandine Poulet

www.arthritisresearchuk.org

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Clinical studies
Dr Kimmie Hyrich, Arthritis Research UK Centre for Epidemiology, University of Manchester, Manchester: safety and effectiveness of biologic treatments in children with rheumatic disease, £187,067, 36 months.

Dr Rajshree Mootanah, Faculty of Science and Technology, Anglia Ruskin University, Chelmsford: developing a new method to improve knee realignment surgery, £133,430, 36 months.

Professor Michael Ehrenstein, Department of Medicine, University of London, London: developing a method of predicting response to anti-TNF therapy through better understanding of how inflammation is controlled in patients with rheumatoid arthritis, £188,143, 36 months.

Dr Angela Kedgley, Department of Bioengineering, Imperial College London, London: how do everyday activities put pressure on the joints of our hands? £146,143, 24 months.

Dr Frances Williams, Twin Research and Genetic Epidemiology, King’s College London, London: using new technologies to develop a diagnostic blood test for fibromyalgia, £170,921, 36 months.

Dr Niamh Nowlan, Department of Bioengineering, Imperial College London, London: how do a baby’s kicks in the womb affect the development of their bones and joints, £154,932, 36 months.

Professor Ariane Herrick, Musculoskeletal Research Group, University of Manchester, Manchester: using mobile phone technology in the assessment of Raynaud’s phenomenon, £180,331, 24 months.

Dr Louise Reynard, Musculoskeletal Research Group, Newcastle University, Newcastle: investigating how genetic changes increase the risk of hip osteoarthritis, £170,597, 36 months.

Centre of excellence
Professor David Walsh, Academic Rheumatology, University of Nottingham, Nottingham: Arthritis Research UK Pain Centre, renewal, £1,998,603, 60 months.

Special strategic awards
Professor Wendy Thompson, Arthritis Research UK Centre for Epidemiology, University of Manchester, Manchester: Childhood Arthritis Prospective Study (CAPS), supplementary funding £599,408, 37 months.

Ms Karyn Ross, National Centre for Prosthetics and Orthotics, University of Strathclyde, Glasgow: development of a wrist support for people with wrist and hand problems due to arthritis, Phase 3 supplementary funding £233,626, 36 months.

Professor Andrew Price, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford: developing a set of questions using patients’ own reports of progress that can be used across different musculoskeletal care pathways, £51,503, 18 months.

Professor Manuel Salmeron-Sanchez, School of Engineering, University of Glasgow, Glasgow: promoting regrowth of bone and tissue in fractures that do not heal, £465,012, 36 months.

Professor Charles Archer, College of Medicine, Swansea University, Swansea: using stem cells to produce durable and resilient cartilage for joint repair in osteoarthritis, £201,025, 36 months.

Professor Andrew McCaskie, Orthopaedic Research Unit, University of Cambridge, Cambridge: developing new devices to improve cartilage repair, £533,962, 36 months.

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