

# PREVENT TRANSFORM CURE

#### **ABOUT US**

Arthritis Research UK is the charity dedicated to stopping the devastating impact that arthritis has on people's lives. Everything that we do is focused on taking the pain away and keeping people active. Our remit covers all conditions which affect the joints, bones and muscles, including osteoarthritis, rheumatoid arthritis, back pain and osteoporosis. We fund research into the cause, treatment and cure of arthritis and we provide information on maintaining healthy joints and bones, and living well with arthritis. We also champion the cause, influence policy change and work in partnership with others to achieve our aims. We depend on public support and the generosity of our donors to keep doing this vital work.

#### PREVENT, TRANSFORM, CURE

Going to work, playing with our children or grandchildren, going out with friends or walking to the shops are activities that we take for granted. But thousands of people with arthritis across Scotland have a daily fight against pain, fatigue and a lack of mobility because they have a musculoskeletal condition which affects their joints, bones and muscles.

Musculoskeletal conditions are the single biggest cause of disability and pain across the country, contributing to nearly half of all work-related illness in Scotland. The burden of painful conditions falls disproportionately on those who are more disadvantaged in society, while the variability of services for people with joint conditions means that not everyone can get the right support to enable them to live healthy, active lives.

Decision makers must tackle these health inequalities and ensure that all people living with arthritis and joint pain in Scotland have fair access to services to enable them to manage their condition. Work with us to champion the prevention and cure of arthritis and musculoskeletal conditions while transforming the lives of those you wish to represent. Support our manifesto by becoming an Arthritis Champion today.

#### **OUR WORK IN SCOTLAND**

In Scotland, 800,000 people live with osteoarthritis, the most common form of arthritis. There are many more living with other types of arthritis and musculoskeletal conditions.

From Aberdeen to Edinburgh to Glasgow, we have a long-standing record of working alongside people with arthritis and researchers in Scotland. We're currently funding almost £13 million of research, educational projects and training in Scotland. The research being done across Scotland is vital in our efforts to cure arthritis and find better ways to diagnose and treat the condition.

#### Our research centres

We help to fund two key research centres in Glasgow:

- The Arthritis Research UK Rheumatoid Arthritis Pathogenesis Centre of Excellence (RACE) is based at the University of Glasgow (in partnership with the University of Newcastle and the University of Birmingham). This centre aims to improve our understanding of where and why rheumatoid arthritis starts, why it attacks the joints and why it doesn't go away.
- The University of Glasgow is also the site of one of our experimental arthritis treatment centres. The aim of these centres is to support the testing and early development of new drugs in the treatment of arthritis and related conditions, speeding up the process of taking new therapies from bench to bedside.

Please see www.arthritisresearchuk.org/scotland for more information.

#### THREE THINGS YOU CAN DO TODAY

People are living in pain now, so you don't have to wait until after the election to make a difference. Below are some of the ways you can make a huge impact today:

- · Issue our template press release championing your support for local people living with arthritis, and tweet your followers using the hashtag #ArthritisChampion.
- · Ask your local integration board to undertake a full joint strategic needs assessment of people with arthritis and joint conditions, using our template letter.
- · Ask your local council's audit committee (or equivalent) to conduct an investigation into support services for people with musculoskeletal conditions.

For more information and to access the resources listed above, please see www.arthritisresearchuk.org/ScotlandManifesto

Let us know the action you've taken after reading the manifesto via action@arthritisresearchuk.org

As an Arthritis Champion you'll receive updates on issues connected with our work and you'll be listed as an Arthritis Champion on our website so your constituents living with the pain of arthritis know you are on their side.

### ARTHRITIS AND MUSCULOSKELETAL CONDITIONS IN NUMBERS – SCOTLAND

### 800,000 people in Scotland live with osteoarthritis

### £353 MILLION NHS SPEND

ON ANNUAL MUSCULOSKELETAL HEALTH BUDGET

**11th LARGEST** NHS ANNUAL PROGRAMME BUDGET IN SCOTI AND

## 600,000 primary care consultations per year on back pain

Over **7,600** hip replacements and over **7,100** knee replacements in 2013 alone

NHS hip fracture costs exceed **£73 million** per year

**48%** of work-related illness in Scotland is related to arthritis and joint pain

#### **PREVENT**

#### If elected you'll make musculoskeletal conditions a public health priority.

To make musculoskeletal conditions a public health priority we need:

- the Scottish Government, NHS Scotland and the new integration boards to place musculoskeletal conditions at the heart of their public health activities.
- · public bodies to take into account the pain caused by arthritis when producing their physical activity plans.
- a fracture liaison service linked to every hospital.

An ageing population and growing levels of obesity will mean that the number of people with arthritis will continue to increase. While these conditions don't typically shorten life, the pain they cause and the limits they place on movement can take away quality of life. Much more can be done at a national and local level to encourage people to have healthy joints, bones and muscles throughout their lives

#### Making public health a priority

Over 800,000 people in Scotland live with osteoarthritis, but the infrastructure that enables people with musculoskeletal conditions to live healthier lives and manage their conditions, such as exercise programmes and leisure facilities, doesn't always meet their needs. New integration boards and their partners must place arthritis and musculoskeletal conditions at the heart of their plans for public health, starting with a full needs assessment of people with these conditions in each joint board area.

#### Keeping people active, mobile and healthy

People can reduce their risk of developing a musculoskeletal condition by living healthier lives. For example, your risk of knee osteoarthritis is considerably higher if you're obese. Despite this, not enough is done to demonstrate to the public the link between healthy lifestyles and healthy joints, bones and muscles. Being active makes living with arthritis easier and less painful: public bodies' activity plans and the National Physical Activity Pathway need to promote the wellestablished link between exercise and pain reduction.

#### The fight against osteoporosis: preventing falls and breaks

Falls and fractures are a pressing public health issue among older people; a broken hip can have a massive impact on someone's life. Once a first break occurs it's vital that a second break is avoided. A fracture liaison service (FLS), which provides targeted assessment and treatment for those with fractures, is widely regarded as the best way to address the problem of preventing future fractures. It's both a clinically effective and a cost-effective solution. Despite this, there's local variation in the availability of FLS. We'd like to see NHS Scotland and local authorities ensure that a fracture liaison service is linked to every hospital.

#### CASE STUDY: OSTEOARTHRITIS AND PHYSICAL ACTIVITY

When Jim got to the age of 65 his increasing weight and decreasing fitness levels forced him to take drastic action. Weighing 16½ stone at just 5ft 7in, he was feeling more and more pain in his left knee.

"I was square and squat and I knew I was too heavy for my knees; the pain never stopped me walking but it was constant and nagging," says Jim, a retired company director.

Jim started to attend a local slimming group. "It was a catalyst for me – having to be weighed publicly every week and everyone in the group knowing if you have gained or lost pounds was my incentive. I found it worked very well for me."

At the same time Jim started to exercise, going for a long walk every morning. A year and a half after starting his weight loss and exercise regime, Jim had lost four stone and is now a trim 12½ stone. "It's been terrific," he says. "Losing weight and exercising worked well together - the one encouraged the other. As I lost weight the pain in my knee gradually reduced, and it's practically gone now."



#### **TRANSFORM**

#### If elected you'll campaign locally to ensure that people with arthritis get high-quality care at the time that they need it.

To transform the experiences of people living with musculoskeletal conditions now, we need:

- · continued personalisation of care through care plans.
- · a commitment to improving quality of services through a musculoskeletal-specific patient-reported outcome measure.
- · a commitment to early diagnosis and improved coordinated care.

People with musculoskeletal conditions in Scotland need more support as they seek to live lives free from pain. We believe that access to services and treatments need to be transformed, to deliver high-quality, personalised care.

#### More person-centred care

People with joint conditions are affected in different ways. But nobody knows their condition better than the person with it. This is why we want to ensure that everyone with a joint condition is offered a personalised care plan.

#### Improving quality of services

High-quality services must measure their outcomes. To support this we have developed our musculoskeletal health questionnaire (MSK-HQ), which asks people about their symptoms to produce a score (see page 9). We'd like to see a patient-reported outcome measure (PROM), such as the MSK-HQ, used throughout routine care for people with arthritis to drive improvement of services.

Self-referral to physiotherapy for people with arthritis is already available in Scotland. As well as saving time for both patients and GPs, self-referral can improve attendance levels at appointments, is associated with improved health outcomes, reduces costs and empowers people to manage their condition.

#### Fighting conditions such as rheumatoid arthritis: early diagnosis and more coordinated care

With many inflammatory conditions, such as rheumatoid arthritis, the clock starts ticking to manage their severity once symptoms develop. Early identification and treatment is urgently needed to avoid lifelong pain and disability.

#### **HEARING FROM PATIENTS ABOUT THEIR HEALTH OUTCOMES**

If we don't know the outcomes of a patient's care, we can't tell whether their treatments have improved their health condition or not. The NHS doesn't consistently measure outcomes of musculoskeletal healthcare, which means that opportunities to improve care and services are being missed. This is partly because of a lack of suitable tools that focus on the outcomes that matter to people with arthritis and musculoskeletal conditions. That's why we're working to develop a single patient-reported outcome measure (PROM) for people with musculoskeletal conditions: the Arthritis Research UK musculoskeletal health questionnaire (MSK-HQ).

The MSK-HQ can be used by people with a range of different musculoskeletal conditions across multiple care settings. By allowing people to monitor their own health, it may facilitate conversations about their symptoms with their clinicians. Bringing together this data from the MSK-HQ enables health services to monitor their performance and use the data to improve quality and value. The MSK-HQ is currently being piloted in physiotherapy and we'd like to see it built into routine assessments for people with arthritis.



#### **CURE**

#### If elected you'll champion Scotland's continued excellence in medical research.

For Scotland to continue to be a leader in medical research we need:

- · long-term support of medical research and the role of charities in medical research in Scotland.
- · the treatment costs of those taking part in clinical trials to be funded and delays addressed.
- · more high-quality data on musculoskeletal conditions to be systematically captured and used across the health service.

Arthritis Research UK is committed to funding research into the cause, treatment and cure of arthritis and musculoskeletal conditions. Our research led to a new generation of drugs that have helped millions of people worldwide with rheumatoid arthritis (see page 14). But there's still a lot we don't know about the best ways to prevent and treat these conditions. We need politicians to champion medical research, give a long-term commitment to the funding streams which maximise our investment and to argue for greater collection of data to drive research and improve healthcare.

#### Supporting charitable research in universities

Currently, Scottish universities rely on the research excellence grant, funded by the Scottish Funding Council, for much of the indirect costs of supporting research, such as heating and lighting costs. Scotland needs to maintain a sustainable research funding model to meet universities' indirect costs so that charities can continue to invest their donations in world-class research.

#### **Enabling people to benefit from clinical trials in the NHS**

Under current arrangements, when charities fund research in the NHS they should only pay for the direct costs of research. The healthcare costs for patients involved in research should be funded by the NHS locally.

Different interpretation of guidelines governing research trials means that local NHS bodies sometimes won't fund these healthcare costs, which results in additional expense and delays. This acts as a barrier to research. It's crucial that NHS Scotland works with local bodies to address delays in the system.

#### Improving treatments and lives through more collection of musculoskeletal health data

A key element of delivering ground-breaking research is using data to understand the safety and impact of different treatments on people with arthritis. However, there simply isn't enough data about the care of people with arthritis being collected at present, which limits our understanding. Improved collection of patient data and good governance will give us the best chance of improving patient care and discovering a cure.

#### **CASE STUDY: ANTI-THE TREATMENTS**

Anti-TNF therapy, pioneered and developed by researchers funded by Arthritis Research UK, has transformed the treatment of people with rheumatoid arthritis and other conditions in Scotland and across the globe. It's an example of the huge benefits that research can bring.

Margaret developed severe rheumatoid arthritis when she was 49 years old. She was prescribed an anti-TNF therapy by specialists after the effectiveness of her previous treatment wore off. "I could tell straight away that this was different. I was on it for three weeks and started to feel so much better."

The permanent joint damage Margaret has experienced means that she can no longer play golf – a reminder of the importance of early diagnosis for conditions like rheumatoid arthritis – but she enjoys light gardening and painting, which keeps her active and helps to manage her condition.





Arthritis Research UK Copeman House St Mary's Gate Chesterfield S41 7TD

www.arthritisresearchuk.org



