



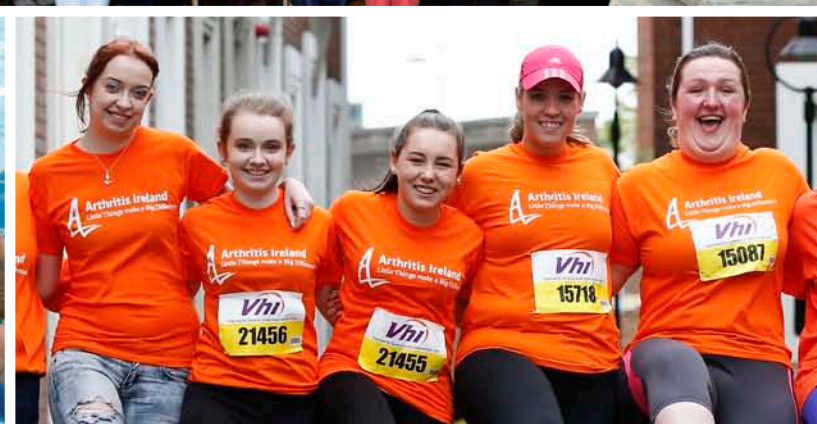
Arthritis Ireland
Little Things make a Big Difference



“WE ARE THE FACE OF ARTHRITIS”

A 2015 REVIEW OF ARTHRITIS IRELAND'S
IMPACT IN THE COMMUNITY

2015



THE REAL FACE OF ARTHRITIS

THE FACTS ARE STARK,
THE FIGURES ARE
EQUALLY STARK:

- Arthritis accounts for **1 in 3** GP visits.
- Arthritis, as part of the musculoskeletal group of diseases (MSDs), costs the exchequer more than **€700m** every year in lost working days and forced retirements.
- About **165,000 (18%)** people with arthritis in Ireland are under 55.
- Arthritis affects more than **1,000** Irish children under 16.
- By the year 2030, **1 in 4** Irish people aged 18 and older will have doctor-diagnosed arthritis.
- There are currently **12,600** people waiting in crippling pain to see a Rheumatology Consultant, including **455 children**.
- There are more than **100 different types of arthritis**, such as osteoarthritis and a range of inflammatory diseases like rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, fibromyalgia and juvenile arthritis.
- **No cure exists for any form of arthritis.**

1 in 3

GP visits
related to
arthritis.



€700m

The cost of arthritis
to the Exchequer
yearly in lost
working days.

**18%
under 55**

**18% (165,000)
of people with
arthritis in
Ireland are
under the age
of 55.**

1,000+

The number of
children that
are affected by
arthritis.



No cure

No cure exists
for any form of
arthritis.



22%

depression

Arthritis causes serious levels of depression and social isolation. According to research conducted by Arthritis Ireland, 22% of people with arthritis say they are sad and depressed.

40%

constant worry

4 in 10 admit that they sometimes find it hard to keep going and that their arthritis is a constant worry for them.

25%

diagnosed arthritis

By the year 2030, 1 in 4 Irish people aged 18 and older will have doctor-diagnosed arthritis.

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“OUR MISSION TOGETHER

I'M VERY PROUD TO SHARE WITH YOU OUR 2015 IMPACT REPORT AND OPEN UP THE DOORS TO OUR WORK HERE IN ARTHRITIS IRELAND.

2015 WAS ANOTHER IMPACTFUL YEAR AND SAW ARTHRITIS IRELAND VENTURE FURTHER INTO OUR QUEST TO FIND A CURE FOR THIS OFTEN DEBILITATING DISEASE WITH THE APPOINTMENT OF OUR SECOND CHAIR IN RHEUMATOLOGY.

In addition to our funded Chair in Rheumatology in University College Dublin (UCD), we saw the appointment of Professor Ursula Fearon as Chair of Molecular Rheumatology in Trinity College Dublin (TCD).

We have also begun the work of establishing a national research nurse network, in close co-operation with our colleagues in the Irish Society for Rheumatology. This is a great addition to our research and will see us work closely with Irish patients to conduct groundbreaking research.

Over the coming five years, we will make the single biggest investment in our history by funding these posts and other exciting projects to the tune of €2.5m.

Already our investment is showing results with the discovery this year of a new novel gene by the team in UCD that is important in the inflammatory process. We are also supporting the work being carried out linking the incidence of arthritis amongst children with Down Syndrome. ”



John Church, Chief Executive Officer

Arthritis is a serious lifelong disease, but it doesn't have to be a life sentence if we fight it together.

We open our doors to you...



“OUR NUMBER ONE GOAL CONTINUES TO BE TO MAKE ARTHRITIS A CAUSE WORTH SUPPORTING. THIS IS IMPORTANT NOT ONLY TO CREATE A MORE FAVOURABLE FUNDRAISING ENVIRONMENT TO FUND OUR SERVICES, BUT ALSO TO ENGAGE THE KEY STAKEHOLDERS IN GOVERNMENT AND THE HEALTH SERVICE TO ENSURE PEOPLE LIVING WITH ARTHRITIS GET THE SERVICE THEY DESERVE.

Awareness
Advocacy
Volunteers
Research
Fundraising
Services

WE AIM TO MAKE THIS SHIFT IN PUBLIC PERCEPTION BY DOING THE FOLLOWING, BETTER:

AWARENESS:

2015 saw the introduction of our new awareness video “**Children get arthritis too**” depicting the lives of young children living with arthritis.

ADVOCACY:

Our work in advocating for **better access to services** saw a tremendous shift in 2015. We achieved this through the production of our pre-election campaign and our close work with the paediatric consultants in Our Lady’s Children’s Hospital, Crumlin, where we are calling for a dedicated out-patient unit.

FUNDRAISING:

Our traditional fundraising events such as our **National Raffle** and **Jasper Pins** have grown this year and we are making significant progress with **corporate fundraising**. We also hope to roll out some fun new events in 2016 too, so keep an eye out and encourage your company/friends/family to get involved.

COMMUNITY:

Our work this year has seen a number of new community branches set up as well as the development of land-based and water-based exercise programmes, with our colleagues in the **Irish Society of Chartered Physiotherapists**. Watch out for these in 2016!

WE ALSO HAD A VERY SUCCESSFUL LAUNCH OF THE NEW MICRO-TRIATHLON CHALLENGE, WHICH WILL CONTINUE IN 2016 WITH AN INCREASED NUMBER OF LOCATIONS.

SERVICES:

Again this year we increased our community-based **Living Well with Arthritis** self-management courses from 28 to 40, an increase of 30%. However, the launch of our new online self-management course will bring key tools and understanding to a much wider community. Our new self-management courses for children and teens were a tremendous success and we aim to run these throughout 2016 to help even more families.

RESEARCH:

Now that we have achieved our initial goals of setting up the infrastructure for a world-class research in Ireland, we need to push forward and support our Chairs in their research, to help find new discoveries and treatments. The centre at UCD has already achieved a ‘**EULAR Centre of Excellence**’ status that recognises world-class facilities by the European organisation of clinicians and patient organisations.

None of this could happen without our fundraisers, volunteers, staff and board who support the cause and organisation in so many ways. This Impact Report will showcase in detail where our money comes from, how we spend our money and how we are structured to ensure maximum transparency and ultimately maximum impact for people living with arthritis. Another impactful year in our mission to fight arthritis.



John Church
CEO, Arthritis Ireland

OUR PURPOSE

AT ARTHRITIS IRELAND, OUR VISION IS OF A FUTURE FREE FROM ARTHRITIS. UNTIL THAT IS ACHIEVED, WE ARE HERE TO HELP PEOPLE TAKE CONTROL OF THEIR DISEASE WHILE WE INVEST IN RESEARCH TO FIND NEW TREATMENTS AND, ULTIMATELY, A CURE.

WE DO THIS BY:

- Providing people with arthritis with self-management tools and supports to ease the physical pain and social isolation caused by arthritis.
- Using ongoing research to increase our understanding of the causes of the disease as we work towards finding a cure.

OUR SCOPE:

- We provide support to people living with all rheumatic and musculoskeletal diseases (MSDs) and related conditions, including osteoporosis, which affect people's ability to live well.
- We fund pioneering research to increase the knowledge base and use that knowledge to transform the lives of people living with the disease.
- We support the education of healthcare professionals and provide information to people living with arthritis, their families and carers.

OUR AMBITION:

- To reach out to every person living with and affected by arthritis in Ireland.
- To create a population who are actively taking control of their disease and inspiring others living with chronic diseases.
- To ensure the medical community see Arthritis Ireland as an integral part of the prescription.
- To find new treatments and, ultimately, a cure.

OUR GOALS 2014-2016:

IN THE FINAL YEAR OF OUR THREE YEAR PLAN, OUR WORK WILL FOCUS ON:

Goal 01

Raise understanding of arthritis as a cause worth supporting with Arthritis Ireland seen as a key part of the solution;

Goal 02

Create a population who are taking control of their arthritis and living full and active lives;

Goal 03

Create a vibrant volunteer network in every community in Ireland;

Goal 04

Be leaders in understanding the causes of arthritis and, ultimately, finding a cure;

Goal 05

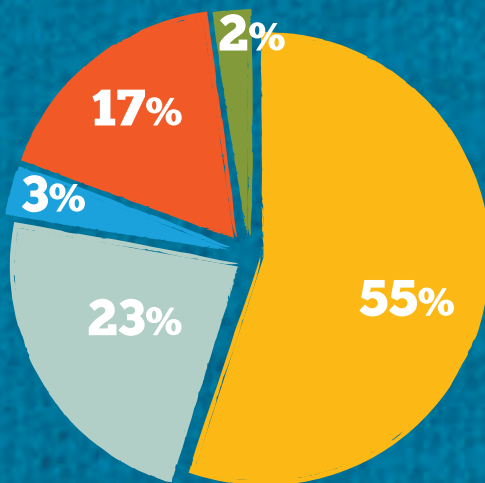
Position Arthritis Ireland as an innovative leader in the provision of patient support and healthcare initiatives in Europe.

WE ARE WORKING ON A CURE TOGETHER,

2015 DEVELOPMENTS

IN EVERY CORNER OF IRELAND, PEOPLE LIVING WITH ARTHRITIS SAY THAT FINDING A CURE FOR ARTHRITIS AND PREVENTING THE JOINT DAMAGE, PAIN AND FATIGUE THAT THIS AWFUL DISEASE INFLICTS, IS THEIR NUMBER ONE WISH.

€2.5million THE BREAKDOWN FOR RESEARCH FUNDING



55% Atlantic Philanthropies

23% Pharmaceutical Industry

3% Individual donors

17% Arthritis Ireland Fundraising

2% Public

2015 saw our quest to find a cure continue at a pace. Our second Chair of Rheumatology was appointed to TCD. This follows our first appointment in UCD in 2013. Professor Ursula Fearon joins the team at the Trinity Biomedical Sciences Institute where she will work closely with the team in UCD.

Through hard work over the last few years, we have raised almost €2.5m to invest in world-class research in Ireland. Our investment is already producing groundbreaking results. Professor Gerry Wilson and his team in UCD have identified a new protein (C5orf30) which regulates the severity of tissue damage caused by rheumatoid arthritis (RA). Following the discovery which was published in the scientific journal PNAS, RA patients most likely to suffer the severest effects of the condition can now be identified early and fast-tracked to the more aggressive treatments available.

PROFESSOR URSULA FEARON - CHAIR OF MOLECULAR RHEUMATOLOGY IN TRINITY COLLEGE DUBLIN

Professor Fearon is concentrating her research on developing state-of-the-art basic research techniques and applying them to high quality bio-banked samples to examine the mechanisms of disease in arthritis with the aim of advancing our understanding of the causes of arthritis, predicting the response to therapy and ultimately predicting who can achieve remission while potentially identifying exciting new targets for novel therapies.



Professor Ursula Fearon

NATIONAL RESEARCH NURSE NETWORK

In 2015, we laid the plans to create our own national network for research nurses. This will see a research nurse in every hospital grouping within the HSE working closely with rheumatology clinicians and health professionals in the acute hospitals to create a bio-bank of blood and tissue samples. This will enable our scientists in UCD and TCD to work on research projects specific to the Irish population. Arthritis Ireland has committed to raising €100,000 to seed fund the National Nurse Network. So far we have raised €25,500, primarily through our successful "Working On A Cure Cycle".

target €100,000

€80,000

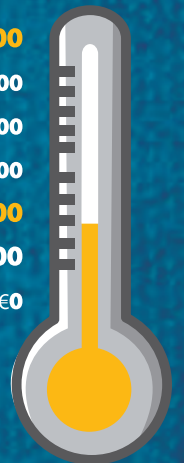
€60,000

€40,000

raised €25,500

€20,000

€0



**So far we
have raised
€25,500**

DOWN SYNDROME RESEARCH PROJECT

This year we have teamed up with the clinicians in Our Lady's Children's Hospital, Crumlin and with Down Syndrome Ireland to investigate the increased risk and incidence of arthritis occurring amongst children with Down Syndrome. This is a two-year project which we are supporting and the first of this type of collaboration with another medical charity.

HEALTH RESEARCH BOARD, JOINT FUNDING SCHEME

In 2015, we entered a joint funding scheme with the Health Research Board (HRB). This innovative joint funding scheme allows us to make an open call in 2016, inviting applicants to research areas of rheumatic diseases.

WE ARE TAKING CONTROL TOGETHER

WHAT'S NEW IN 2015

LIVING WITH A CONDITION LIKE ARTHRITIS, FOR WHICH THERE IS NO CURE, IS A LIFELONG CHALLENGE THAT NOBODY SHOULD HAVE TO GO THROUGH ALONE. HOWEVER, PEOPLE WITH ARTHRITIS CAN LEARN HOW TO MANAGE THEIR SYMPTOMS AND ADOPT HEALTHY BEHAVIOURS.

PEOPLE CAN TAKE CONTROL OF THEIR ARTHRITIS BY:

- engaging in activities that protect and promote health;
- monitoring and managing the symptoms and signs of illness;
- managing the impact of illness on their emotions and interpersonal relationships;
- and adhering to treatment regimes.

We call this ethos “**self-management**”, and it is the foundation of every aspect of our education and support programmes.

In 2015...

Record 40 Living Well with Arthritis courses to over 620 people

Over 5,000 course participants since 2006

10 Breaking the Pain Cycle workshops to over 170 people

300 hours on our Helpline, supporting & helping over 1,950 people

SELF-MANAGEMENT COURSES

In 2015, we continued to grow the number and range of self-management courses on offer. Our award-winning **Living Well with Arthritis** course covers every area of self-management such as dealing with pain, fatigue, diet, exercise, negative emotions and medication.

This year we have delivered a record number of 40 courses to 620 people living with arthritis. Since we introduced these courses in 2006, more than 5,000 people have participated in a course in their local community.

LIVING WELL WITH ARTHRITIS ONLINE

Arthritis Ireland understands that not everyone approaches learning in the same way. That is why we have developed the **Living Well with Arthritis Online** course. It brings the essential tools and information of self-management directly to your computer. The programme, which contains both video lessons and materials you can read, will take you only a few hours to complete. It is also a great refresher, with the most up-to-date information, for those who have completed the community-based course.

For people seeking a taste of what a self-management course has to offer, our half-day **Breaking the Pain Cycle workshop** is designed to help you understand your pain and identify ways to manage your arthritis better by developing a personal pain management plan.

In 2015, we delivered 10 of these workshops in local communities to 170 people living with arthritis.



KNOWLEDGE IS POWER

It is important to remember that when it comes to living with arthritis, knowledge is power. We produce a wide range of information on a variety of issues. A key development this year has been the production of **20 drug specific information leaflets**.

In 2015, we reached a total of almost 90,000 people with booklet orders and downloads and more than 140,000 people through our website.

www.arthritisireland.ie

A LISTENING EAR

Our **Helpline (1890 252 846)** is a confidential service that can provide callers with vital support from critical information to emotional support. Every member of staff on our Helpline has experience of living with arthritis, and the team's extensive knowledge is enhanced further as they are updated on new developments daily.

In 2015, they spent a total of 300 hours on the phone helping and supporting 1,950 people living with arthritis.

PATIENT EDUCATORS

In 2009, Arthritis Ireland entered into a partnership with the School of Medicine, UCD to recruit and induct Dublin based Arthritis Ireland members into a new educational initiative, the **UCD Arthritis Ireland Patient Educator Programme**.

A patient educator is a patient who volunteers to share their experience of illness with medical students. Patient educators lead teaching sessions, one-to-one or in small groups, in the early years of medical education. We estimate that each of our Patient Educators has taught more than 200 medical students (approximately half of whom are now doctors in practice) about rheumatoid arthritis, its symptoms, its impact and its treatments.

Plans are now afoot to expand the programme to the other medical schools in 2016.



WE ARE SUPPORTING CHILDREN & TEENAGERS WITH ARTHRITIS TOGETHER

2015 DEVELOPMENTS

ARTHRITIS IS OFTEN SEEN AS AN “OLDER PERSON’S DISEASE”. HOWEVER, UNFORTUNATELY IT IS ALSO A CHRONIC DISEASE IMPACTING ON YOUNG PEOPLE AND CHILDREN IN IRELAND WITH MORE AND MORE CASES APPEARING DAILY.

There are over a 1,000 children living with the condition today in this country making them the forgotten face of arthritis. Arthritis Ireland is campaigning to change this perception while providing much-needed services and educational programmes to help children, parents and their siblings live well with arthritis.

1,000

**children living with
arthritis in Ireland.**



THE YOUTH SERVICES THAT MADE A BIG DIFFERENCE IN 2015:

1. Arthritis Ireland provides specialised **hydrotherapy programmes** for children and teenagers living with arthritis, run over six weeks by chartered physiotherapists. The courses were rolled out in Leinster and Munster, with plans to expand this in 2016.
2. We provide a dedicated **helpline**, which took over **650 calls in 2015**. The helpline provides a wide range of services from emotional support, practical information, to details about entitlements and benefits. Teenagers can also contact this helpline to receive support and information on their condition.
3. **Family Days are a vital part of our programme**. They provide children with the opportunity to meet others with arthritis, often for the first time. They also provide parents with information from the experts in arthritis. Siblings are also made to feel extra special on our family days because arthritis affects them too.
5. **The Teen Road Trip** is a confidence building weekend attended by over 30 teenagers. A trip where teenagers can relax and be teenagers. They can forget about their everyday lives and get involved in lots of adventure activities that they wouldn't normally try. They are shown how to manage their disease, so they can live a full life.

We plan to expand this to two weekends in 2016, as the demand is increasing.

- 6 **Living Well with Arthritis for children and teenagers**. In 2015, we developed a new pain management workshop on the back of feedback from parents, children, teenagers and health care professionals. The workshops are delivered in a fun and interactive setting. They are delivered by young people who are living with arthritis and who have been specifically selected and trained in the programme. The focus of the workshop is to learn self-management techniques in a child centred format. The workshop teaches children, their parents and teenagers techniques to reduce their pain.

The workshop is a non-medical intervention, designed to complement the medical treatment of arthritis. During the workshop, participants learn about subjects such as breathing, posture, exercise, muscle relaxation, fatigue, and pacing.

Over 640 people have attended these days in 2015.

4. Our **Youth & Family Officer** meets with families and young people affected by arthritis to offer them individual support. It could be something as simple as a cup of tea, providing emotional support face to face or indeed practical information on managing their condition.

In autumn 2015, we piloted the programme with five workshops which was delivered to over 110 participants and plan to roll out a lot more in 2016!

7. **Tween and Teen Days**, are a great opportunity for teenagers to hang out with others who have arthritis or similar rheumatological conditions and do something fun, from Viking Splash Tours to Go Karting.
8. **Information Services** are available online at www.juvenilearthritis.ie (3,340 visitors) and in print format (3,093 booklets distributed).
9. **Youth Leaders** are a vital part of our programme. Our Youth Leaders, living with arthritis understand the kids and teenagers. They are trained up as leaders to support the young people in managing their disease. Currently, we have 35 Youth Leaders on hand.
10. **Peer to Peer Support**. We have a number of parents and young people living with arthritis around the country, trained on our Peer to Peer service. Peer support not only provides an opportunity to demonstrate that it is possible to live a life with arthritis but goes a long way to remove feelings of isolation and fear for many parents and young people.
11. A constant presence in the juvenile arthritis clinic in **Our Lady's Children's Hospital, Crumlin**, meeting over 40 families per week.



DANNY

17-YEAR OLD DANNY FIRST BECAME AWARE OF HIS CONDITION WHEN HE WAS SEVEN YEARS OLD, WEEKS BEFORE HIS FIRST COMMUNION WHEN THE PAIN WAS SO BAD THAT HE WASN'T SURE HE WOULD BE ABLE TO WALK DOWN THE AISLE.

“I was seven years old, a few weeks before my communion and I started to notice a rash on my leg. That was the first indication that something wasn't quite right.”

Eventually, I went to the doctor and I was sent to Temple Street, where I was told it was a viral infection that would go away. After a few weeks, I started to get pains but I was constantly told the same thing, that it was an infection that would go away.

One day, my mother said there must be something wrong, that I shouldn't be in this much pain. I was kept in, but it still took six months from the time I first got the rash to when I was diagnosed with juvenile arthritis. Shortly after the rash, the pain arrived and quickly began to get worse, to the extent that I wasn't sure if I'd be able to walk down the aisle for my communion.

I had to give up gaelic football and hurling as the pain started to get worse. I was suffering pain in my wrists, my fingers, my ankles, my knees and my toes. It was hard watching everyone doing what I wanted to do and that impacted me a lot.

After the diagnosis, they put me on a drug that's used to treat chemotherapy patients. It's really strong, the side effects were really bad and it wasn't helping at all. I was on that for four or five years and though it did help to ease the pain in my joints to a degree, the side effects outweighed any pain relief I was feeling. I was eventually put on a new injection that I'm still on today and thankfully, that works perfectly and has no side effects.

When I was in primary school, I never really told people about arthritis. Some of my closest friends knew, they understood that I couldn't go playing football because I was sore even if they didn't fully understand the reasons why.

Everyone in school knows about my arthritis now and my friends have been really supportive and understanding. Sometimes, for example, if I have to go for a blood test, my friends will come with me for support.



They don't understand everything but they know I'm in pain and try and help me any way they can.

Arthritis Ireland run **pain management workshops** that teach people how to deal with pain and teach them about what will and won't help and they provide advice from doctors as well. To know what you can and can't do without pushing yourself too hard is important and I know now what I can and can't do.

Arthritis Ireland put on a lot of **workshops** over the course of the year and a lot of **teen events**. I think that it's very important to meet others the same age who are going through what you're going through, to talk about what helps them and what helps you too. They also do a **Road Trip** every year. Up to 30 teenagers who suffer from some form of arthritis and arthritis-related conditions can go and meet new people and talk to people who are going through what you're going through every day, like how they cope in school. It's an adventure centre so there are things that I can do that I wouldn't have thought I'd be able to do because of arthritis, like rock climbing and zip lining, and it's great fun. I would strongly recommend anyone who is offered the chance to go on the **Road Trip** to go. It gives you the opportunity to not only meet new people but meet people who go through the same struggles as you as the result of arthritis.

There is a feeling of comfort knowing that 30 other people know what you have gone through and can relate to your story. They understand arthritis and the effects it has on your life from a personal view rather than a clinical perspective. ”

*“The **Road Trip** allowed me to gain a deeper knowledge of my conditions and showed me different ways to deal with pain and other symptoms.”*



Danny De Vaal

Our future is
BRIGHT!



WE ARE BRINGING A COMMUNITY TOGETHER

WHAT'S NEW IN YOUR AREA 2015.

ARTHRITIS IRELAND RELIES ON A DEDICATED VOLUNTEER FORCE OF OVER 400 COMMITTED PEOPLE AROUND IRELAND TO DELIVER SUPPORT AND INFORMATION AT A LOCAL LEVEL IN THEIR COMMUNITIES.



20 branches. **29** walking groups.

100% of what each branch fundraise in their communities is spent there.

Almost all of our volunteers live with arthritis and give up their valuable time to organise information events, adapted exercise activities, walking groups, deliver training courses and run fundraising events all through the year. They are the local voice of Arthritis Ireland as they raise awareness in the media and among politicians of the issues affecting people with arthritis, and related conditions, in their area.

We currently have 20 branches, 2 support groups and 29 walking groups. Each of the branches runs at least 2 information events a year featuring speakers such as **Rheumatologists, Specialist Nurses** and **Dieticians** as well as information stands from local business/services relevant to people with arthritis. The branches also run a wide variety of specially adapted exercise classes for people with arthritis including **seated yoga, Tai Chi** and **aqua aerobics**. From time to time they also organise workshops and courses on a range of complimentary therapies and adapted leisure activities such as **mindfulness, cookery** and **gardening**. They subsidise these activities from local fundraising such as grant applications and fundraising events. All of the money they raise is spent locally.

In 2015 four of our branches launched a new event designed to get people active and raise funds at the same time. The **Micro-Triathlon - "Give it a Tri"** was created by the Louth branch. The format is simple: participants walk 3 kilometres, cycle 3 kilometres and swim 3x3 lengths of a pool or do a 30 minute aqua aerobics class. Participants can opt to do all 3 stages or enter as a team of 3 with each person taking on a stage.



It is a fun, family day out and gives literally anyone the chance to become a Triathlete! We plan to double the number of branches taking part in this event next year.

2015 also saw us launch the first of our adapted exercise classes designed in conjunction with the **Irish Society of Chartered Physiotherapists**.

Five water-based courses and two land-based courses were very well received and we hope to roll-out at least 15 of these courses in 2016.

30 of our long-standing volunteers attended the **European League against Rheumatism PARE conference** which took place in Ireland this year for the first time. **Minister for Health, Leo Varadkar**, opened the event which was attended by over **150 delegates from patient representative organisations from across Europe**.

It was a wonderful opportunity for our volunteers to learn about developments in patient support, advocacy and care in other countries as well as sharing our own insights gained over the past 30 years since Arthritis Ireland was founded.



“I NEVER THOUGHT I'D CALL MYSELF AN ATHLETE

BY HER OWN ADMISSION, LOUISE GRIFFIN IS NOT A SPORTY PERSON. FIVE YEARS OF DEALING WITH RHEUMATOID ARTHRITIS MEANS THAT SORE JOINTS AND DAILY STIFFNESS ARE MORE FAMILIAR FIXTURES THAN RUNNERS AND BICYCLES.



Louise Griffin

And yet, she has completed the biggest physical challenge of her life - Arthritis Ireland's **Micro-Triathlon**. She swapped the armchair for a 3km walk, 3km cycle and a swim, with her eyes firmly set on the finishing line. It was an incredible goal for a woman whose condition is so severe that it has at times prevented her from walking up and down the stairs.

Louise first began experiencing aches and pains at the age of 45.

She recalled: “It was a general stiffness and soreness that came on me quite suddenly. My ankles were stiff, they just wouldn't move. I had to go up and down the stairs sideways, like a crab. I'd have trouble changing gear or turning the steering wheel while driving.”

After she was diagnosed, Louise armed herself with as much information as possible by signing up for Arthritis Ireland's **Living Well with Arthritis** course and joined the walking group in Malahide for a weekly stroll.

With this positive approach, Louise had every reason to be proud of herself. But when she heard about Arthritis Ireland's first ever Micro-Triathlon, she set her sights on a new goal. It was the start of a whole new voyage of discovery. She explained:

“Turning 50 had a lot to do with it. I wanted to do something I'd never done and that I never thought I could do. I initially thought I'd do the walking bit of the Micro-Triathlon as part of a group. Then I thought I'd give the cycling a go so I bought a second-hand bike.”



From there, it was a case of going for broke as Louise decided to attempt the swim.

“Swimming is gentle on the muscles, and I used to swim a lot but now I've gotten the bug for it again so was delighted to have completed all three parts”, she revealed.

Louise found that the Micro-Tri challenge was an excellent opportunity to practice self-management skills. She is also keenly aware that the event helped to increase awareness about arthritis, as well as raising much-needed funds for services nationwide.

“It was a great way to get family and friends involved. Even though people know you have arthritis and that you're coping with it, it's good to jog their memory and remind them that you have a chronic disease.”, she said. I also knew that I was doing something for others by raising money, and I was making a difference.”

And of course, she was very proud to have completed this challenge in this milestone year.

Fabulous at 50 and fit enough to tackle a Micro-Triathlon, she reckons it feels “like the icing on the cake, and proves I'm not over the hill yet and I'm looking forward to next year's event already!!”

Louise Griffin

“It was a great way to get family and friends involved. Even though people know you have arthritis and that you're coping with it, it's good to jog their memory and remind them that you have a chronic disease”, she said. I also knew that I was doing something for others by raising money, and I was making a difference.”

WE ARE CREATING BETTER UNDERSTANDING TOGETHER

IN 2015 WE CONTINUED OUR FOCUS ON SHIFTING PERCEPTIONS REGARDING ARTHRITIS, SPREADING THE MESSAGE THAT ARTHRITIS IS A SERIOUS CHRONIC DISEASE AND A CAUSE WORTH SUPPORTING. ARTHRITIS IS MORE THAN JUST A FEW ACES AND PAINS. IT IS A SERIOUS CHRONIC ILLNESS THAT MUST BE GIVEN THE RESPECT IT DESERVES.

“Arthritis only affects the elderly.”

“It's just a few aches and pains.”

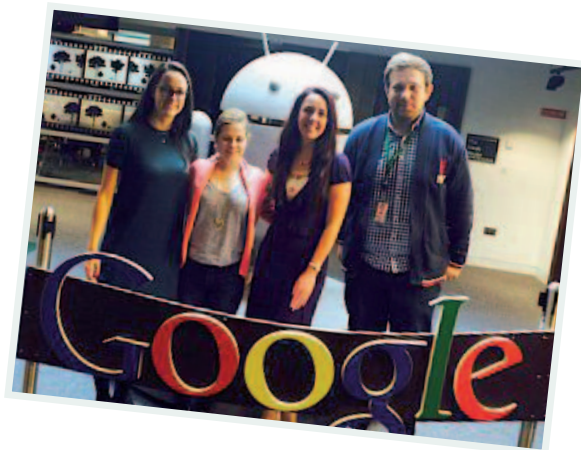
“Stay in bed and away from exercise if you have arthritis.”

We are making this change by bringing the stories of people living with arthritis in to the public arena, so their voices can be heard. Every year we run numerous media campaigns to achieve this, using local and national media, and our own publications and resources.

In 2015 we created a highly engaging and emotional awareness video “**Children get arthritis too**”, to challenge those misconceptions that it is just a few aches and pains and it is a part of getting older. This video reached over 1 million people online.

IN 2015 WE SAW A SIGNIFICANT INCREASE IN OUR SOCIAL MEDIA AND DIGITAL PRESENCE:

- Facebook fans increased by 34% to 11,586.
- Twitter followers increased by 37% to 4,238.
- Other social media platforms including LinkedIn, Instagram and our You Tube channel have also seen a significant increase.
- Our website traffic increased by 7,000 visitors to 140,000 visitors in 2015.
- We have over 15,500 subscribers to our online newsletter, with a monthly newsletter sent with all our latest updates.
- Our Big News magazine was sent to over 3,500 people every four months and was present in every rheumatology clinic in the country.



ELISHA



Sometimes my body hates me. Sometimes it twists me and it tortures me. Sometimes I ache and I hurt and I swell. Sometimes I close my eyes and wish upon a star that this body was not mine.

Heart-wrenching words like these are never easy to read. But when they are uttered by a child who lives in constant pain because of juvenile arthritis, they are especially difficult to accept.

You'll hear this emotive speech in the Arthritis Ireland 2015 awareness video "Children get arthritis too" But it's not spoken by an actor. The young voice belongs to 10-year-old Elisha Dillon, one of over a thousand children in Ireland living with arthritis.

It's often called "the invisible disease". As well as being unseen, it's also misunderstood as so many people still wrongly dismiss it as a condition of the elderly.

Battling these myths every day is a frustrating and lonely experience. And it's one of the reasons why Elisha's Mum, Paula, felt it was important for her child to have her say in the short but powerful video.

Paula explained:

"People look at her and think she's fine, because they can't see anything wrong so they think it's all in your head. Elisha has arthritis in eight joints in her body. The only places not affected are her hips and her spine.

It's not like a scar, you can't see it. But, I often think if I could put a cast on every part of her body that's affected, people would stop in the street to look. They'd be so shocked."



Paula & Elisha Dillon

Lack of understanding in the community is just one of the many problems faced by young people with arthritis. The Dillons, like so many other families, weren't aware that arthritis could affect children and didn't know where to turn for help.

Paula recalled:

*"I was in a cocoon when we got the diagnosis. I didn't talk to anybody about it and I didn't know there was anything out there for us. It wasn't until we met **Arthritis Ireland's Youth and Family Officer in Crumlin** that we began to see some light. We knew we weren't alone. And I'd like to think now that any parent watching this video will know that they're not on their own, that there is help and support available from Arthritis Ireland."*

The path since Elisha's diagnosis hasn't been an easy one. Sometimes walking is so painful that she needs a wheelchair, and at night she sleeps with splints to support the joints in her arms. Being isolated from social activities has "seriously affected her", according to her mum.

However, Arthritis Ireland's **Family Days** give her the chance to socialise with other kids who understand her pain.

It's one of many services and supports provided by Arthritis Ireland, but the organisation relies on public support to deliver them free of charge.



OUR FUNDRAISING HEROES, 2015

WE RECEIVED JUST 11% OF OUR INCOME FROM THE PUBLIC EXCHEQUER. THIS MEANS THAT WE HAD TO COME UP WITH THE OTHER **89% OURSELVES.**

THE AMAZING SUPPORT AND GENEROSITY OF OUR FUNDRAISERS, DONORS, SPONSORS, MEMBERS AND FRIENDS HAS ENSURED THAT WE RAISED APPROXIMATELY €1.9 MILLION.



spend **€1** raise **€4**

For every €1 we spend on fundraising €4 is raised.

FUNDRAISING EVENTS MAKE UP ABOUT 23% OF OUR INCOME.

Our fundraising heroes never cease to amaze us with the lengths they are willing to go to raise much needed funds to continue our work.

This year, we saw a wide range of fundraising events and activities take place in communities all over Ireland. There were quiz-nights, triathlons, vintage tractor runs and non-uniform days. We had someone **walk 33 miles in one day to honour his mother** who has lived with arthritis for 18 years. People ran marathons because their children or aunt lives with arthritis. A whole team took part in their first skydive to honour one of their work colleagues.

In the spring, our **Jasper Pin campaign** was a great success and raised vital funds for our **Children with Arthritis campaign**, and our **Annual Raffle** has raised much-needed funds to ensure our volunteer helpline can continue to answer calls.

This year also saw the highest number of **Mini Marathon** participants take to the streets of Dublin, wearing their Arthritis Ireland t-shirts with pride. 180 ladies took part to raise funds and honour friends, family members, and themselves.

Our annual **Working on a Cure Cycle** challenge saw a team made up of consultants, researchers and patients take on a 100km cycle around Wicklow to support the National Research Nurse Network. Partnering with Nightline and Flexiseq, over €25,500 has been raised to date for this important project. In October, 6 brave athletes took to the windy and wet streets of Dublin to run 26.2 miles of the **Dublin Marathon**. All took part to honour special people in their lives who have arthritis and together they raised nearly €2,000.

PERSONAL DONATIONS MAKE UP ABOUT 8% OF OUR INCOME.

In 2015 we continued to recruit regular monthly donors and have over 600 committed supporters on our system, giving an average donation of €13 per month. The promise of a regular donation allows us to plan and budget for our long-term commitments.

And because this funding comes from the public we can ensure it is spent where it is needed the most. We plan to recruit even more donors in 2016 and beyond, ensuring that Arthritis Ireland can continue to grow the many supports and services we provide to people in communities all over Ireland.

COMMUNITY FUNDRAISING EVENTS MAKES UP 9% OF OUR INCOME EACH YEAR.

Arthritis Ireland has a strong and dedicated branch network in over 20 locations around Ireland. And we are still growing.

Every year, these wonderful volunteers raise funds in their community through events like church gate collections, coffee mornings, bridge events, local challenge events and lots more.

100% of the funds that are raised locally are spent in that area on education courses, exercise programmes and branch information events throughout the year.





If you have made a donation, raised funds, sponsored a family member or colleague or have become a friend of Arthritis Ireland. Thank you.

You are one of the heroes. Without your support and the amazing support of so many just like you, we could not do what we do every day. Our courses, information events, advocacy campaigns, exercise programmes and research projects would not be possible without you.

You are making a HUGE difference to the lives of people with arthritis all over Ireland.

Thank You.

WE ARE FIGHTING FOR BETTER HEALTHCARE SERVICES

GENERAL ELECTION 2016

BY INFLUENCING AND WORKING WITH THE KEY DECISION AND POLICY MAKERS, WE HAVE BEEN ABLE TO IMPROVE HEALTHCARE SERVICES FOR PEOPLE WITH ARTHRITIS AND CREATE A BETTER WORKING ENVIRONMENT.

WE DO THIS NATIONALLY, WORKING WITH THE GOVERNMENT AND HSE AND ALSO AT A EUROPEAN LEVEL THROUGH OUR WORK WITH THE EUROPEAN LEAGUE AGAINST RHEUMATISM (EULAR).



NEARLY ONE MILLION PEOPLE IN IRELAND – ONE IN FIVE OF US – ARE LIVING WITH SOME FORM OF ARTHRITIS.



THE PATH TO BETTER CARE

Our main goal in advocating for better rheumatology services is to increase the number of rheumatologists in Ireland so that people with arthritis get fast access to the best care within their community. We have been working intensely to achieve this goal in the forthcoming General Election 2016.

ARTHRITIS IRELAND'S 100 DAY PLAN – CUT WAITING LISTS, IMPROVE TREATMENT AND SAVE MONEY

Arthritis Ireland is asking for a commitment in the first 100 days of the next Government to the appointment of 100 specialist rheumatology posts. 100 specialist consultants, nurses and therapists across the six hospital areas in the country will sever waiting lists, radically improve the daily life of thousands of arthritis patients and save the HSE millions in unnecessary costs.

IN RHEUMATOLOGY SERVICES ACROSS IRELAND WE NEED THE IMMEDIATE APPOINTMENT OF:

- 6 Consultant Rheumatologists**
- 29 Clinical Nurse Specialists**
- 12 Advanced Nurse Practitioners**
- 21 Physiotherapists**
- 32 Occupational Therapists**

Our Plan would cost approximately €7 million every year. At the moment, arthritis and other musculoskeletal conditions are costing the State over €700 million in lost days at work alone.

Nearly one million people - one in five of us - are living with some form of arthritis. There are currently 12,600 people waiting in crippling pain to see a Rheumatology Consultant, including 455 children. The cost of undiagnosed and untreated arthritis is colossal. But the pain of waiting for an adequate rheumatology service is even greater. These 100 posts will mean that people in every constituency in the country will have access to "the right person, right place, first time" model of care they need.

[Read more about why the Arthritis Ireland 100 Day Plan makes healthcare and economic sense at www.whyaREWwaiting.ie](http://www.whyaREWwaiting.ie)

PAEDIATRIC RHEUMATOLOGY CLINIC

More than 1,000 children are living with arthritis in Ireland today, making it as common as childhood diabetes in under 12 year olds. Early diagnosis and aggressive treatment is essential to prevent juvenile arthritis extending to multiple joints and result in a more positive outcome.

However, with over a two year waiting list and a substandard level of patient care and clinic conditions early diagnosis and vital treatment is unlikely. Ireland has one of the lowest levels of paediatric rheumatology resources in Europe per head of population.

That is why we have been working to gain approval and raise funds for a dedicated, appropriately staffed paediatric rheumatology clinic.



CREATING A BETTER WORKING ENVIRONMENT “FIT FOR WORK”

ARTHRITIS IRELAND CONTINUED ITS WORK TO SUPPORT PEOPLE WITH MUSCULOSKELETAL DISORDERS (MSDs, AN UMBRELLA TERM INCLUDING ARTHRITIS) SO THAT THEY CAN CONTINUE IN THEIR JOBS OR GET BACK TO WORK AFTER A PERIOD OF ABSENCE.

Work is proven to be good for your health and it is important to people with arthritis, both financially and for their quality of life and wellbeing. In Ireland, MSDs account for 7 million days in absenteeism. That amounts €295 million paid out in illness benefit every year for MSDs alone.

2015 saw the development of two comprehensive guides for employees and employers to help address these challenges.

“Working with arthritis, back pain & related conditions:

A guide for employees” provides up to-date and accurate information and advice to make sure an individual can find the help they need to stay in their job. If a person is worried or concerned following a recent diagnosis of an MSD, they can find more information about what kind of support they are entitled to. This guide also discusses the options of re-training or moving to different types of jobs within an organisation.

“Arthritis, back pain & related conditions:

A guide for employers” provides a practical source of information and guidance for employers to help them to:

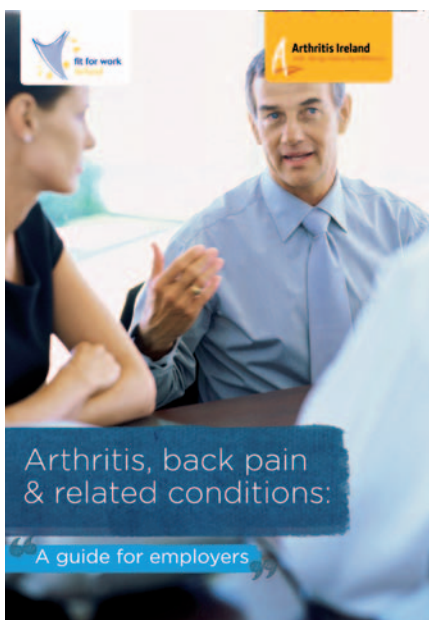
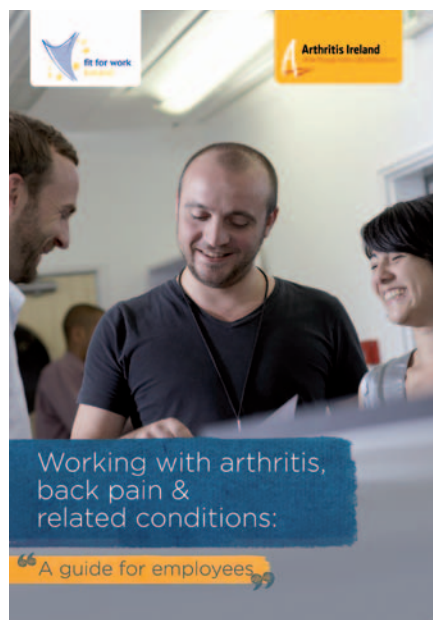
- understand what MSDs are;
- understand how MSDs may affect employees;
- support employees working with MSDs.

FIT FOR WORK ONLINE

2016 will see the launch of Fit for Work Online, a web-based educational programme. It will be designed to support individuals in work, or returning to work with an MSD, and the line managers and health professionals supporting them. The programme will be targeted at these main groups and look at the issues from their separate perspectives.

DEPARTMENT OF SOCIAL PROTECTION

Arthritis Ireland continued to advocate for early intervention in the workplace and developed stronger links with the Department of Social Protection. Arthritis Ireland will continue to work with the Department in 2016 to develop a national early intervention policy and infrastructure to support employers to intervene at an early stage.



MSDs

**(musculoskeletal diseases)
An umbrella group
including arthritis**

24

**Specialist musculoskeletal
physiotherapists
appointed**

**7 million
days
Lost in absenteeism**

€295m

**What's paid out by the
Government in Annual
Illness Benefit every
year.**

WHERE OUR MONEY COMES FROM*

WITH JUST 18% OF OUR INCOME IN 2014 COMING FROM STATE AGENCIES, EVERY YEAR ARTHRITIS IRELAND STARTS OFF WITH A CHALLENGE; **HOW TO RAISE THE OTHER 82%.**

Thankfully, with the generosity of our donors, fundraisers, sponsors, members and friends we raised €1.27 million in 2014. This was 12% down on 2013 due to the loss of our grant from the Atlantic Philanthropies and a drop in sponsorship income.

Income for 2015 is ahead primarily due to receipt of a major gift from a donor.

2015
Forecast at
€1.9m

€1.27m raised in 2014

10%

Gifts & Bequest

Those who have greatly benefited from our services wish to see our work continue by leaving us money in their will. **This has increased by 57% on 2013.**

21%

Grants

Includes a Department of Environment grant to run our helpline and pay for some core costs, plus the HSE grant to help run our *Living Well with Arthritis* self-management courses. A drop of 36% on 2013 due to the loss the Atlantic Philanthropies Grant.

9%

Community fundraising

This is the hard-earned income that our voluntary branch network earns through a variety of local fundraisers, such as church gate collections. **100% of the funds raised locally are spent locally.**

23%

Fundraising events

Includes hard-earned income from events like our annual raffle, mini marathon, Jasper pins and personal challenges.

8%

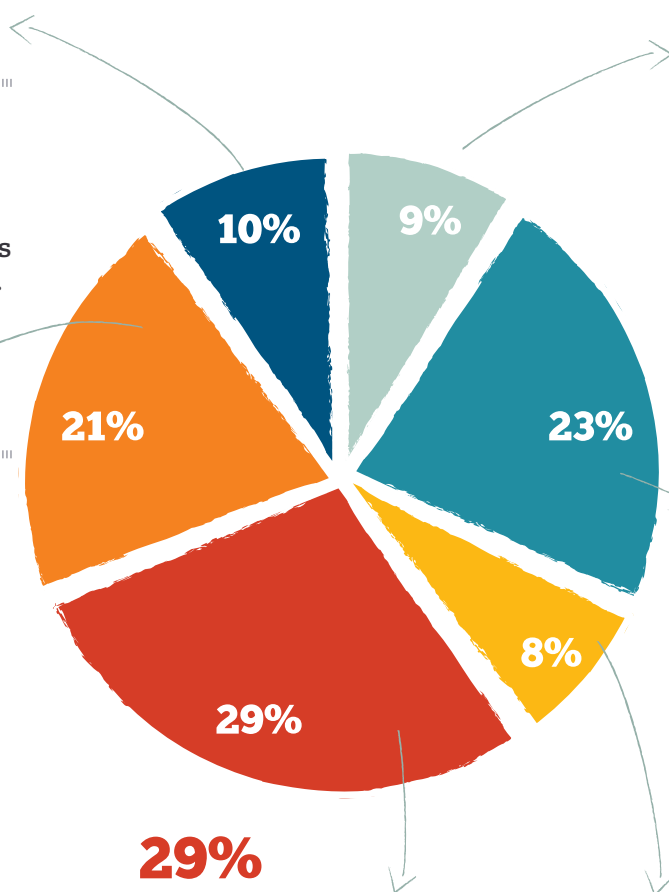
Personal donations

The income generously donated by personal donors through direct debits and membership fees.

29%

Corporate Sponsorship

Most of this income comes from our pharmaceutical partners who generously support some of our programmes including research.



*Figures for income and expenditure based on 2014 audited accounts

HOW WE SPEND MONEY

IN 2014 WE SPENT €1.68 MILLION IN ORDER TO MAKE A DIFFERENCE IN THE LIVES OF RECORD NUMBERS OF PEOPLE WITH ARTHRITIS.

We spent more than we earned this year because we are now starting to fund our world-class research programme. We also invested more in fundraising to create future sustainable resources of income.

We anticipate again spending more than we will earn in 2015 due to funding our second research Chair in Trinity College Dublin. However, this expenditure is fully met by our restricted reserves which we have built up over the years. Excluding this investment, we anticipate spending €1.38m which is less than the €1.5m we anticipate raising.

2015
Forecast at
€1.7m

€1.68m spent in 2014

5%

Administration

Every charity has its overheads, but we keep these to a minimum with €0.05 per €1 spent on essentials that keep the office ticking over such as light, heat and general maintenance. This down from €0.07 in 2013.

6%

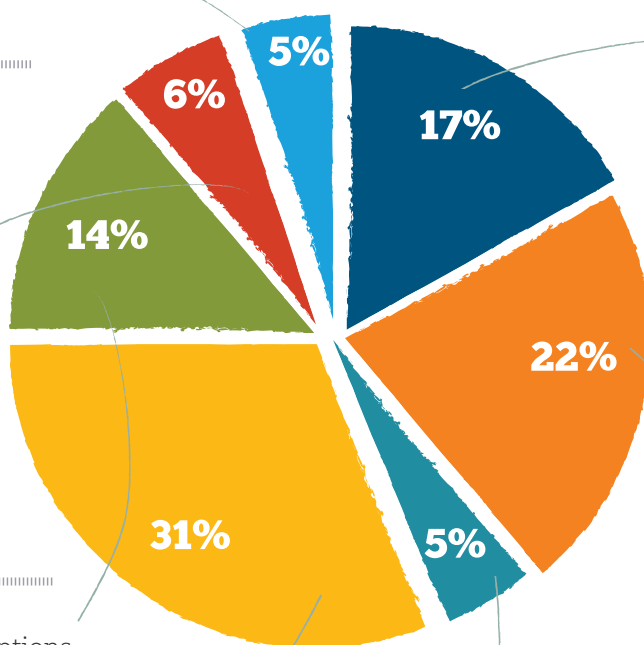
Advocacy & Awareness

Such an important area to overcome public misconceptions about arthritis and to get our government and health system to take arthritis seriously. **We anticipate increasing this spend in 2015 as we prepare for the 2016 General Election.**

14%

Community Supports

Includes our vital helpline service and our presence in communities throughout the country, including our network of branches, exercise programmes and our juvenile arthritis programme.



31%

Fundraising

In order to accumulate, we must invest and for every €1 we spend here we return €4. As with all of our expenditure items, this also includes the cost of fundraising staff who dedicate their time to **creating a sustainable income flow**, to fund our services and research.

5%

Governance

The small price to pay to ensure that your money is spent correctly. We comply with all of the charity regulator's laws and also we are properly insured to protect our volunteers, staff and board.

17%

Education & Information

Includes our award-winning *Living Well with Arthritis* self-management programme and our vital information service, including booklets and our website.

22%

Research

This is what we invest in research to find new treatments and a cure. Our spend has increased by 270% on 2013 due to funding our Chair of Rheumatology in UCD.

THE PEOPLE BEHIND OUR WORK

WE CURRENTLY HAVE 11 STAFF WHO ARE COMMITTED TO MAKING A BIG DIFFERENCE IN THE LIVES OF PEOPLE WITH ARTHRITIS.

IN 2015 WE ADDED A CORPORATE PARTNERSHIP MANAGER TO OUR TEAM TO HELP MEET OUR 2016 INCOME TARGETS.

This will help us achieve our goal of covering as much of our salary cost with corporate sponsorship and grants as possible. We also strive to dedicate as much of our salary cost to frontline services as possible (currently 81%).

OUR STAFF

Our staff members receive a salary that fairly reflects their value to the organisation. We also operate a defined contribution pension scheme and a private health insurance plan for all qualifying staff.

In order to provide the level of service necessary to support people with arthritis across Ireland, we need to recruit high calibre people at the market rate.

However, no top-ups, unvouched expenses or bonuses are paid to any member of staff at Arthritis Ireland. There has been a pay freeze in operation since June 2008.

John Church

Chief Executive Officer

Gráinne O' Leary

Head of Service Development

Stephanie Casey

Head of Community & Campaigning

Edel Mc Cabe

Communications Manager

Orla Kerbey

Fundraising Manager

Clodagh Swords

Corporate Partnerships Manager

Laura Hickey

Youth & Family Officer

Nathalie Peyret

PA to CEO & Office Administration

Sveltana Kushnirenko

Programme Administrator

Fiona Keegan

Support Services Co-ordinator

Sinead Frawley

Regional Development Officer

BELOW ARE THE SALARY BANDS OF THE STAFF AT ARTHRITIS IRELAND:

Salary Band	Staff
€30,000 - €40,000	6
€40,001 - €60,000	2
€60,001 - €80,000	2
€120,000 - €140,000	1

81%

Salaries dedicated to front line services.

€621,855*

Total salary cost:

= 37%

of our total spend

*Includes salaries, social welfare costs and pensions contributions.



JOHN CHURCH
CHIEF EXECUTIVE OFFICER



GRÁINNE O'LEARY
HEAD OF SERVICE DEVELOPMENT



STEPHANIE CASEY
HEAD OF COMMUNITY & CAMPAIGNING



EDEL MC CABE
COMMUNICATIONS MANAGER



ORLA KERBEY
FUNDRAISING MANAGER



CLODAGH SWORDS
CORPORATE PARTNERSHIPS MANAGER



LAURA HICKEY
YOUTH & FAMILY OFFICER



NATHALIE PEYRET
PA TO CEO AND OFFICE ADMINISTRATOR



SVETLANA KUSHNIRENKO
PROGRAMME ADMINISTRATOR



FIONA KEEGAN
SUPPORT SERVICES CO-ORDINATOR



SINEAD FRAWLEY
REGIONAL DEVELOPMENT OFFICER

GOVERNANCE

“IT IS IMPORTANT THAT, AS CHAIRMAN OF THIS GREAT ORGANISATION, I SHARE WITH YOU THE LENGTHS TO WHICH WE GO TO ENSURE WE ARE FULLY COMPLIANT WITH ALL LEGAL AND REGULATORY REQUIREMENTS AND THAT WE EXERCISE GOOD GOVERNANCE AT ALL TIMES. WE HAVE BUILT UP HUGE TRUST WITH THE GENERAL PUBLIC, OUR MEDICAL STAKEHOLDERS, SPONSORS AND DONORS AND WE DO NOT TAKE THIS FOR GRANTED.

Arthritis Ireland is a limited company with charity status, which means that we are subject to all the rigour and rules imposed by the Companies Registration Office. As a charity, committed to operating to the highest standards of good practice and transparency, we are also happy to confirm that we welcome and sign-up to the following codes of practice:”

John O’Flynn



JOHN O'FLYNN
CHAIRMAN

THE CODE OF GOVERNANCE FOR TYPE C ORGANISATIONS:

This is the standard code by which all charities should measure their governance arrangements and Arthritis Ireland has signed up to this and practice the ethos laid out in the code.

THE STATEMENT OF GUIDING PRINCIPLES FOR FUNDRAISING:

This is the guiding standard as developed by the Irish Charity Tax Reform Group.

STATEMENT OF RECOMMENDED PRACTICE OR SORP:

SORPs provide recommendations for accounting and reporting, in particular, how accounting standards should be applied in particular sectors. Arthritis Ireland has adopted the SORP format since 2006 and anticipates that the new Charity Regulator will recommend this format to all charities.

THE REGULATION OF LOBBYING ACT 2015 -

The Regulation of Lobbying legislation is designed to provide information to the public about who is lobbying whom about what. Arthritis Ireland has registered and practice compliance with all the directives set out in this legislation.

THE CHARITIES REGULATORY AUTHORITY (CRA)

is Ireland’s national statutory regulatory agency for charitable organisations. Arthritis Ireland has registered with the CRA and practice compliance with all the directives set out by this statutory agency.

JOHN CHURCH, OUR CEO, ALSO SITS ON THE FOLLOWING CHARITY AND RESEARCH BOARDS:



Trinity
College
Dublin

The University of Dublin

Trinity Biomedical Sciences
Institute



Arthritis Research Coalition

UCD Clinical Research Centre
Advisory Panel



Irish Charity Tax Reform Group



Irish Platform for Patient
Organisations Science & Industry

MEET THE BOARD OF ARTHRITIS IRELAND

4 Elected Directors

This type of director is nominated by the volunteer branch network and elected by our members at our AGM. Elected directors are generally people living with arthritis and bring a personal experience of the disease area to the board, but in all cases bring other skills to further the cause.

Mr Peter Boyd
Ms Anne-Marie Healy
Ms Erica Mitchell
Ms Anne Plunkett

4 Society Directors

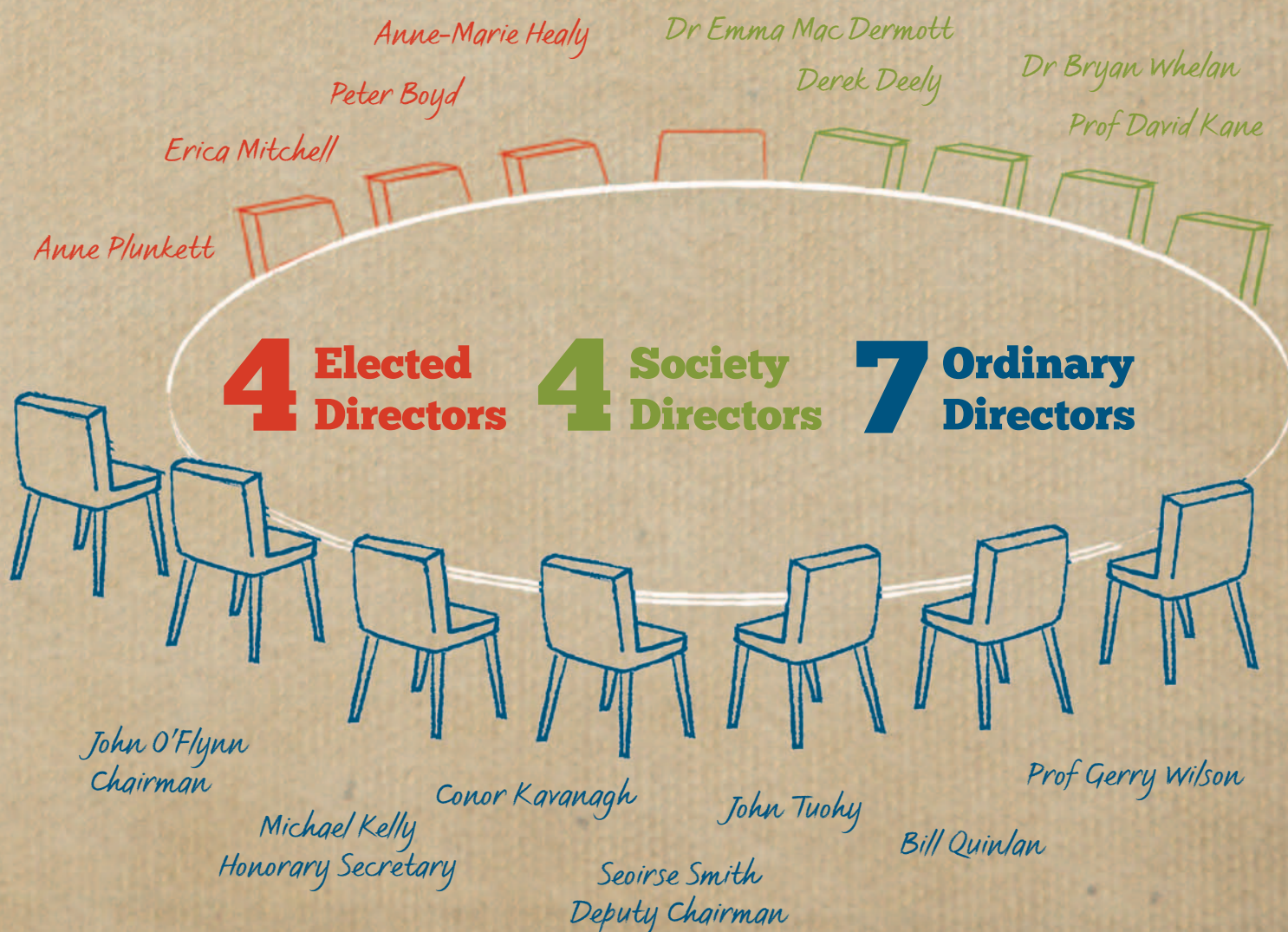
This group is made up of three representatives from The Irish Society for Rheumatology and one from The Irish Rheumatology Health Professionals Society, providing a very important link to our medical stakeholders and patients alike.

Professor David Kane (ISR)
Dr Emma Mac Dermott (ISR)
Dr Bryan Whelan (ISR)
Mr Derek Deely (IRHPS)

7 Ordinary Directors

Directors making up this grouping are co-opted from time to time based on the needs of the organisation, whether they be fundraising, marketing, governance, specialist interest areas or other needs.

Mr John O' Flynn (Chairman)
Mr Seoirse Smith (Deputy Chairman)
Professor Gerry Wilson (Medical Advisor)
Mr Conor Kavanagh
Mr Michael Kelly (Honorary Secretary)
Mr Bill Quinlan (retired in 2015)
Mr John Tuohy



Thank you





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This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



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