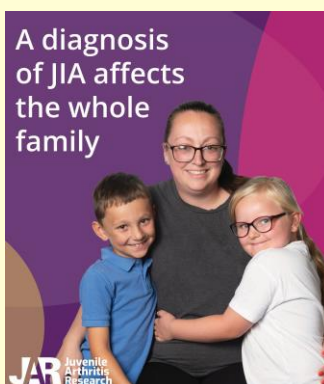


A world where no
child has to suffer
from arthritis

Annual report and accounts 2023 Juvenile Arthritis Research

1 January 2023 to 31 December 2023

The *only* UK-wide charity
focussing solely on JIA.



JAR Juvenile
Arthritis
Research

Charity number 1091620

Structure, Governance and Management

Juvenile Arthritis Research is a charity, registered with the Charity Commission for England and Wales. Charity registration number 1091620.

The charity was constituted by a Trust Deed made on 24 October 2001, originally known as Jabez Charitable Trust. Juvenile Arthritis Research was formed on 3 January 2018.

When new trustees are to be appointed they must be professionally competent and identify with the Charity’s broad purpose.

The trustees during the period 1 January to 31 December 2023 were:

- Nigel Thomas
- Rev Robert Mitchell
- Jill Mitchell
- Timothy Bower
- Richard Kemsley

The charity is managed on a day-to-day basis by the Director, Richard Beesley.

None of the trustees have been paid any remuneration or received any other benefits from an employment with the charity or a related entity. No trustee expenses have been incurred.

There are currently no fully paid members of staff, with personnel working in a voluntary and unpaid capacity other than freelance contractors for specific activities.

Number of employees	0
Number of employees with benefits of more than £60,000	0
Number of volunteers	25

Juvenile Arthritis Research is registered with:



Every organisation in the UK that handles personal information (including names, addresses or email addresses) of individuals must by law be registered with the Information Commissioner's Office also known as the ICO, unless they are exempt. We are registered with the ICO, and you can check that using their register search tool. As well as complying with the law, being registered shows we care about the data we hold about people and we will work hard to keep it safe. We will never sell your personal data, and will never share it without your consent.



We are also registered with the Fundraising Regulator. This shows we are committed to their Fundraising Promise and work hard to ensure all our fundraising activities are carried out fairly, ethically and sustainability. Being registered also allows us to access their support services to help us become more effective in our fundraising activities.

Charitable purposes

- To advance the study of, and research into, the causes, effects and impacts of Juvenile Idiopathic Arthritis (JIA) and to work towards finding a cure.
- To provide relief for people with JIA and their families including but not limited to
 - (a) providing support, information and advocacy services,
 - (b) training and education,
 - (c) provision of wellbeing information and services, and
 - (d) improving the treatment and care of persons suffering from JIA.
- To raise awareness of JIA, its impacts, effects and treatments to people with JIA, health professionals and others who care for them, and the general public.

The Trustees have paid due attention to the requirements of the Charity Commission in respect of the need to make plain the public benefit of the activities of the Charity.

“You are changing the world for our children, making a real difference and changing lives. Thank you.”

Parent of a child with JIA.

I am
4 years
old and
I have
arthritis

A world where no
child has to suffer
from arthritis

#ThinkJIA

JAR Juvenile
Arthritis
Research
www.jarproject.org



What is Juvenile Idiopathic Arthritis (JIA)

Juvenile Idiopathic Arthritis (JIA) is an autoimmune disorder where the body's natural defences (designed to stop infections) start to attack the joints.

This causes inflammation of the joints, leading to pain, discomfort and reduced mobility.

The impacts of the condition are profound – both physically and mentally – for both children and their families.

Juvenile – means the arthritis began before the age of 16.

Idiopathic – means that the cause is unknown.

Arthritis – means that one or more joints are inflamed.

key facts

JIA can be **variable** so someone with JIA may have better days and worse days.

1 in 5 children with JIA also have uveitis (inflammation inside the eye).

Around **15,000** children under 16 have been diagnosed with Juvenile Idiopathic Arthritis in the UK.

X-rays and blood tests can appear normal even when someone has JIA.

Children with JIA sometimes miss out on **'normal life'** because of their JIA.

JIA is an **autoimmune** condition, where the body's natural defences attack the joints.

Children with JIA may have many **hospital appointments**, assessments, scans and blood tests.

JIA is **not the same** as the arthritis older people get.

Myths about JIA can lead to misunderstanding, delays and complications.

Delays in getting a diagnosis are common due to low awareness.

Many children and young people with JIA take immune-suppressing **medication** which reduces their ability to fight off infections.

JIA is **not contagious**.

There is **low awareness** of JIA amongst the public, schools and health professionals.

20 children under 16 are diagnosed with Juvenile Idiopathic Arthritis in the UK every week.

1 in 1000 children under 16 are diagnosed with JIA.

A **diagnosis** of JIA remains for life. When a young person with JIA turns 16, their diagnosis is still called 'JIA'.

Juvenile Arthritis Research : Who we are

Juvenile Arthritis Research is a charity supported by donations (registered charity number 1091620). We are parent-led, and family-focussed.

Our vision is a world where no child has to suffer from arthritis.


Once upon a time...

... a 10 year old girl was diagnosed with Juvenile Arthritis after a year of delays and misdiagnoses. With no effective treatment options and a lack of support, a lifetime of pain and joint deformity follows.

Thirty years on, history looks like it is repeating itself when her daughter is diagnosed with the same painful, debilitating condition, Juvenile Idiopathic Arthritis (JIA). The medication and treatment options have improved but the lack of awareness and lack of support for children with JIA is obvious.

In 2018, having seen first-hand in his own family with first his wife and then his daughter the devastation that JIA can cause, Richard Beesley founded Juvenile Arthritis Research. Bringing his background in biomedical research, combined with decades of experience in senior leadership in a variety of sectors, Richard started the charity in order to make a real difference to the lives of those with JIA.

Juvenile Arthritis Research now help hundreds of children in the UK and around the globe with the information and resources we have developed and the services we provide.



**A world where no
child has to suffer
from arthritis**

OUR AIMS



Research

We undertake research into JIA to understand the causes, the effects and the impacts of the condition and to work towards finding a cure.



Awareness

Raising awareness that children and young people get arthritis helps reduce delays to diagnosis, and that can lead to better outcomes for children and young people with JIA. As we increase awareness of the condition, we can help make life better for those with JIA by removing the stigma attached to having a long-term, but often invisible, health condition.



Support

At Juvenile Arthritis Research, we support children and young people with JIA and their families on their journey. We provide support packs and other resources, and are continuing to develop new ideas and projects to help those with JIA.

Advocacy

Through the work we do in research, awareness and support, we advocate for the needs of children with JIA and their families to policymakers and healthcare professionals.

our values



Boundless

We demand better. More than treatment, more than respite, more than relief, and are fearless in our pursuit of a cure.



Expert

We develop a deep and broad understanding of juvenile arthritis and how it affects children and young people. We look at research not just in the field of juvenile arthritis, but also other autoimmune and related conditions that may hold vital clues to help us find a cure for JIA.



Collaborative

We collaborate with others who share our passion and determination for making a real difference (both in the UK and globally).



Ethical

We work in an open, transparent and accountable way that builds the trust and respect of all our stakeholders. We also ensure high environmental and ethical standards throughout our organisation and with all our suppliers, never compromising on our standards and values.

I want to support a charity with high ethical and environmental standards

We are mindful of our impact on the planet whilst doing the vital work that we do



www.jarproject.org/give

JAR Juvenile Arthritis Research

I want to support a charity where the funds are needed most

We don't hold huge reserves - we need every penny that is given to us in order to do the vital work we do in research, awareness and support



www.jarproject.org/give

JAR Juvenile Arthritis Research

I want my donations to have maximum impact

With low overheads and a volunteer-run model, the funds we receive go directly towards the work that we do



www.jarproject.org/give

JAR Juvenile Arthritis Research

I want to support a charity that makes a big difference

With our proven track record, you can help change the lives of those affected by JIA by choosing to support us



www.jarproject.org/give

JAR Juvenile Arthritis Research

I want to support a charity that focuses on JIA

We are the only UK-wide charity focusing solely on Juvenile Idiopathic Arthritis



www.jarproject.org/give

JAR Juvenile Arthritis Research

What makes us unique?

Juvenile Arthritis Research is unique. Here are just some of the reasons why:

1. Parent-led with direct experience

Unlike many other charities, Juvenile Arthritis Research is driven by parents who have first-hand experience of juvenile idiopathic arthritis (JIA) in their children. This lived experience fuels our dedication and ensures a deep understanding of the needs and challenges faced by families affected by JIA, leading to more impactful programmes and support initiatives.

2. Holistic approach

At Juvenile Arthritis Research, we are passionate about finding a cure for JIA, but also recognise the complex needs of children with JIA and their families, offering a three-pronged approach:

- **Research** - Supporting high-quality research to find a cure and improve treatments for JIA.
 - **Awareness** - Raising awareness about JIA in the medical community and general public to ensure timely diagnosis, reduce stigma and isolation, and improve access to effective support.
 - **Support** - Providing practical and emotional support to families through resources, events, and a community network.
- This holistic approach addresses the immediate needs of families while simultaneously focussing on long-term solutions.

3. Collaborative and inclusive

Juvenile Arthritis Research fosters collaboration with leading researchers, clinicians, academics, and other organisations around the world. We also actively involve patients and families in research through the JIA VIP Research Panel, ensuring their voices are heard and research priorities are aligned with their needs. This collaborative and inclusive approach increases the potential for effective solutions and empowers the JIA community.

These three unique aspects – parent-led expertise, holistic approach, and collaborative spirit – make Juvenile Arthritis Research a powerful force in the fight against JIA.

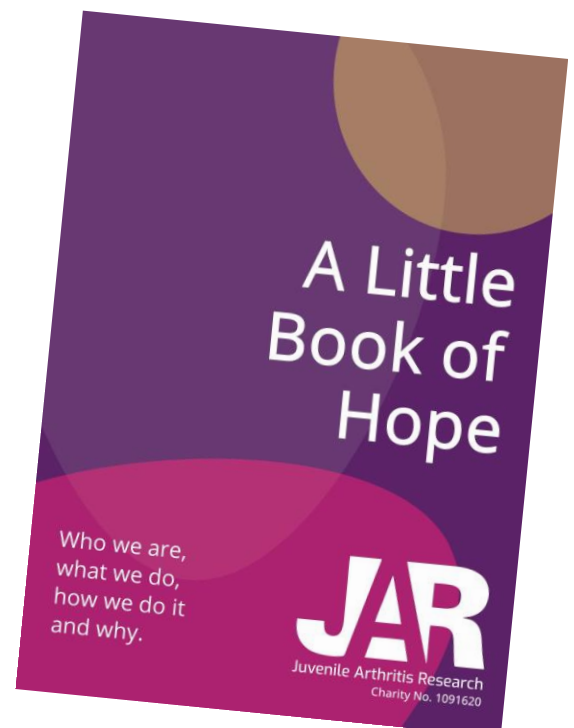
A little of what we do...

Juvenile Arthritis Research ...

- is the only UK-wide charity focussing solely on JIA.
- is the only charity that provides the physical support packs that families need and want.
- provide support to families without charge to users.
- have no subscription charges, no charge to ask for help, no charge for JIA families to attend events and activities.
- manage an online mental health hub and support services.
- provide emergency funding for crisis mental health support.
- provide A Little Box Of Hope support packs and Teen support packs. These were developed by children, young people and families.
- were the first to develop School Toolkits for JIA.
- deliver training and assemblies in schools.
- provide one-to-one support for schools and local education authorities.
- have a private secure network for parents of children with JIA.
- provide 24/7 support for families when they need it.
- have the most engaged network of all JIA-related charities on social media.
- lead on research projects and contribute to studies internationally.
- are patient partners in national and international research projects.
- are involved in developing guidelines and best practice for clinicians.
- have been invited to present at leading international rheumatology conferences.
- have been invited to work with NICE, NIHR, PReS and EULAR on essential projects.
- developed the #ThinkJIA awareness campaign and resources with rheumatologists, families, clinicians, and schools which is now recognised internationally.
- are involved in global health.
- advocate for patients and families.

Find out more about our services on our website or in our Little Book of Hope (available upon request).

www.jarproject.org



Our people

Our **Trustees** have overall legal responsibility for the charity. They oversee all aspects of our work, as well as being keen advocates for us. They bring a wealth of experience from the private and charity sectors. They include experienced charity leaders, who have worked as Trustees in other capacities for many years, who bring with them the knowledge and experience required to oversee the work of the charity. The Trustees also include business leaders and partners who have developed their own companies and are able to now utilise their management and leadership skills to support Juvenile Arthritis Research.

Our **Parent Panel** helps ensure the voices of those we support and represent are heard and are integral to our work. The panel comprises parents of children with JIA from a wide range of backgrounds. They share their personal and family experience, as well as their professional knowledge and expertise, as we develop new projects and review existing work programmes.

We **work closely** with a broad diverse group of individuals from the world of JIA. This includes children and young people with arthritis, parents, adults with arthritis, teachers, paediatric rheumatologists, physiotherapists, and other healthcare professionals. They bring a multitude of appropriate skills and knowledge, as well as personal lived experience of either being a child or young person with arthritis, being a parent of a child with arthritis, or being a healthcare or other professional caring for children with arthritis.

Our **volunteers** are the key people that make Juvenile Arthritis Research happen. They are the people who send out support packs, School Toolkits, fundraising packs, GP awareness packs, hospital resources and more. They are the people who engage with families in our private secure networks and parent Zoom events. They are the ones who manage our social media accounts, reaching thousands of families affected by JIA and raising awareness of the condition. They are often the first person who understands JIA that a family will speak to, and the most important contact in that family's life. They are the true force behind Juvenile Arthritis Research. We are proud to have grown our volunteer team this year, and grateful to them for giving so much when their own lives are already full.



A few of our volunteers at an online meeting.

Partnerships



We are delighted to have joined the **Connect Immune Research Partnership** this year. The partnership comprises charities from different autoimmune conditions, working together across specialisms to tackle multiple conditions at once. Understanding similarities and using existing knowledge of different conditions could help transform lives much faster than small groups of specialists working on separate conditions.



This year we have worked with **NCEPOD** on their study into patient care for those with JIA. We are members of the project Steering Group and contribute to the data collection methodology, design and connections.



Throughout the year we have continued to work closely with the BSR Quality Improvement project called **JIA Learn**, which aims to equip hospital teams to make incremental changes using Quality Improvement methodology to their service to benefit families. We have been part of the Steering Group, overseeing the whole project, as well as leading on engaging with families and ensuring their voice is heard throughout the project.



As members of **National Voices** we contribute to and influence national government policy and how it affects healthcare, with our particular focus being on families affected by JIA.



We work closely with **EULAR**, the European Alliance of Associations for Rheumatology. They are the leading international network for rheumatology professionals and patients. We are involved in a number of projects with them, and this year have been invited to speak at several of their events.



We are proud to be members of **ENCA**, the global network for children with arthritis and autoinflammatory conditions. They are the umbrella body that supports all patient organisations for children with arthritis, rheumatic conditions and autoinflammatory diseases across the continent of Europe and beyond. We also sit on the ENCA Board, as key decision-makers for the network.



The **British Society for Rheumatology** (BSR) is the UK's leading specialist medical society for rheumatology and musculoskeletal professionals. Our founder is a member of the BSR, allowing us to be part of the diverse community of rheumatology professionals from across the UK.



We are members of the **NCVO**, the community for charities in England, building our capacity within a supportive network of voluntary organisations.

We work closely with like-minded charities, patient organisations, research teams, universities and hospitals all over the world. By working together we can learn from each other, and collectively achieve much more. We are careful which networks we join and who we work with, and only link with those that add real value to the people we exist for - children with Juvenile Idiopathic Arthritis and their families. Any affiliation has to help us be more effective in our research, awareness and support work as well as policy-making and lobbying activities that take place behind the scenes.

Our year in review | Research

Our research work has continued to develop over the past year, through three main themes.

Our own
research

ReSeArch can mean
different things to
different people... we
are proud to Support
So many reSeArch
projects in So many
ways.

Patient
involvement

Supporting
other
projects

Our year in review | Research

Our own research

We conduct our **own research** studies to better understand the causes, the effects and the impacts of Juvenile Idiopathic Arthritis and to work towards finding a cure. This year we have started to redevelop the **research publications** area on our website to highlight our main findings. This page now promotes over 50 of our research publications.

www.jarproject.org/research/publications

During 2023 we were invited to present at the international EULAR Congress in Milan about our work with schools, to a packed hall of global delegates from the field of rheumatology. Our research in this area was highlighted in a EULAR-issued Press Release, helping showcase our work to a wider audience.

We were invited to present at a EULAR webinar and a separate AGORA¹ webinar about the impact of JIA on the family.

We were also invited to present at the PReS² Congress in Rotterdam about the impact of mental health on families with JIA, about our work in schools, and about the development of patient education materials – helping to train and support health professionals from across Europe as they support families.

Attending conferences also enables us to hear the latest research, connect with like-minded researchers and patient organisations, and improve the ways in which we can support our families.

¹ AGORA is an umbrella organisation for national and regional organisations representing patients with Rheumatic and Musculoskeletal Diseases in southern Europe.

² PReS is the Paediatric Rheumatology European Society, an international organization dedicated to advance the care and improve the health and well-being of children and young people with rheumatic conditions.



Our year in review | Research

Our own research

Early in 2023 we undertook the first ever research study in the general community into awareness that children and young people get arthritis, with results published at PReS Congress. These findings are a vital first step and help form a foundation against which future awareness-raising work can be measured.

The most recent publication from the European Patient Registry – a global project we ran during 2020 at the height of the COVID-19 pandemic, was published this year, highlighting anxiety levels amongst patients with rheumatic diseases. We launched the COVID-19 European Patient Registry on 24 March 2020, less than two weeks after the World Health Organisation (WHO) declared a pandemic. Our final weekly follow-up survey was sent to participants on 28 December 2020. A total of 4,336 participants took part in the study, completing weekly follow-up surveys, and providing us with 12.4 million data points over 41 weeks, responding to 219,427 emails, representing every inhabited continent in the world.

Our Director is currently undertaking a PhD in Epidemiology at the University of Manchester, and presented work from that project at EULAR and PReS congresses, with the first journal article from this PhD due to be published very soon.

Awareness of childhood arthritis: Results from a representative online survey in the UK.

Beesley RP^{1,2}, Beesley BM¹

¹University of Manchester, ²Imperial College

Background

Low awareness that children and young people may develop arthritis (Juvenile Idiopathic Arthritis, JIA) has been identified as a risk factor for delayed diagnosis, later commencement of treatment, and worse clinical and sociological outcomes. The level of community awareness in the UK has not been previously reported in scientific literature.

Objective

To measure awareness that children and young people may develop arthritis.

Methods

Online survey of representative quota sample of 2,044 adults aged 16-75 in the UK. Fieldwork was conducted between 10-13 February 2023 by Ipsos UK, a leading social and market research organisation, with participants giving informed consent prior to taking part.

RHEUMATOLOGY ADVANCES IN PRACTICE

British Society for Rheumatology

Article Navigation

JOURNAL ARTICLE

COVID-19-related anxiety trajectories in children, young people and adults with rheumatic diseases

Stephanie J W Shoop-Worrali, Suzanne M M Verstappen, Wendy Costello, Saskya P Angevare, Yosef Uziel, Carine Wouters, Nico Wulfrat, Richard Beesley

Rheumatology Advances in Practice, Volume 7, Issue 1, 2023, rkad007, <https://doi.org/manchester.idm.oclc.org/10.1093/rap/rkad007>

MANCHESTER

The incidence and prevalence of Juvenile Idiopathic Arthritis differs by ethnic group in England

Beesley RP^{1,2}, Beesley BM¹

¹University of Manchester, ²Imperial College

Background

JIA is a chronic inflammatory condition of the joints in children and young people. It is the most common form of arthritis in this age group. The incidence and prevalence of JIA varies by ethnic group. The aim of this study was to investigate the incidence and prevalence of JIA in England and Wales, by ethnic group.

Methods

We conducted a population-based study of JIA in England and Wales, using data from the National Health Service (NHS) and the Office for National Statistics (ONS). We identified all children and young people with JIA between 2010 and 2019, and calculated the incidence and prevalence of JIA by ethnic group.

Results

The incidence and prevalence of JIA in England and Wales, by ethnic group, are shown in the table below.

Ethnic group	Incidence (per 100,000 per year)	Prevalence (per 100,000)
White	12.5	15.2
Black	18.7	22.1
Asian	10.3	12.8
Other	14.6	17.9

Conclusions

The incidence and prevalence of JIA in England and Wales, by ethnic group, are shown in the table below. The incidence and prevalence of JIA are higher in Black children and young people compared to White children and young people.



eular | PAED

RHEUMATIC AND MUSCULOSKELETAL DISEASES (RMD)

affect all age groups

eular²³

EUROPEAN CONFERENCE OF RHEUMATOLOGY

MILAN 31 MAY - 3 JUNE

EULAR Congress 2023

eular | PAED

RHEUMATIC AND MUSCULOSKELETAL DISEASES (RMD)

the patient in the centre

eular²³

EUROPEAN CONFERENCE OF RHEUMATOLOGY

MILAN 31 MAY - 3 JUNE

Supporting other projects

Within the context of our research work, we spend a considerable amount of time supporting research work led by researchers and clinicians from universities and hospitals across the world. Due to the nature of research, we are not able to share details about a lot of the work until it is complete and published, but there is a lot of exciting potential and we are proud to support the global research community in projects that will make a tangible difference to the lives of children with JIA and their families.

Since the inception of Juvenile Arthritis Research in 2018 the number of projects we have been invited to take part in has grown. Whilst many projects are high-quality and are likely to show benefits to families, unfortunately there has also been an increasing number of low quality and low value projects, which create a burden on families with little to no return. As a result, we have become increasingly selective in which projects we support to help improve the quality of JIA research and ensure our time – and that of the families we work with – is most effective. This led to the development of the JIA VIP Research Panel.

You can find out more about the JIA VIP Research Panel at www.jarproject.org/vip





The JIA VIP Research Panel



Access a wide range of opportunities to shape future research.
Be part of the research team.
Share your experiences.



Juvenile Arthritis Research



The JIA VIP Research Panel



Reduces the burden on you.
Fewer repetitive questions.
High quality research.
Topics that matter and make a difference.



Juvenile Arthritis Research



The JIA VIP Research Panel



Your contribution will be recognised through exclusive rewards and tailored support.



Juvenile Arthritis Research



In 2023 we launched the successful and greatly valued JIA VIP Research Panel. The JIA VIP Research Panel is a longitudinal patient and parent panel survey for Juvenile Idiopathic Arthritis, developed and managed exclusively by Juvenile Arthritis Research.

The Panel contributes to current JIA research in two ways:

1. By enabling people to take part in high quality research; and
2. By supporting PPIE (Patient and Public Involvement and Engagement), helping co-develop research and enabling the voice of patients and parents to be heard.

Within 3 days of launch, over 100 families joined the JIA VIP Research Panel, with a representative spread of participants; recruitment is an ongoing and continuous process.

The Panel has already contributed to 2 internal short surveys for Juvenile Arthritis Research, and provided PPIE representatives for major multi-year projects. We are working with researchers to build our portfolio of projects in 2024, and will be presenting about the Panel at the British Society for Rheumatology conference 2024 and elsewhere.

Patient involvement

There is a growing recognition within research that patients and family members play a key role in developing, managing and delivering research projects. At Juvenile Arthritis Research, we are experienced patient partners and have been involved in a range of different projects. This year we co-authored a paper about patient involvement in research (also known as 'PPIE'), highlighting the value of patients and the unique and vital perspective they bring.

As with direct involvement in research, it is not always possible to talk about projects until they are complete. However, we are delighted to have been involved in a number of different projects with the University of Manchester, University of Liverpool, and Sheffield Hallam University in the past year.

In addition, our work with CLUSTER has continued as part of the patient Champion network. This has included supporting researchers and developing lay summaries.

More crucially, our role in OCTAVE (a national multi-disciplinary research project investigating the effectiveness of vaccination against COVID-19 for people with reduced immune systems, such as due to JIA and medications) has been pivotal. In addition to the regular Trial Study Group meetings we are part of, we helped develop the lay summary and created the infographics that highlight the main findings of the study. Analysis into the paediatric data continues, with results due in 2024. The OCTAVE study has already helped influence government policy, and led to the follow-up vaccination programme for people with reduced immunity. The OCTAVE study also reflects best practice in patient involvement, something we actively encourage and support.

Rheumatology, 2023, 00, 1-4
<https://doi.org/10.1093/rheumatology/kes4482>
Advance access publication 14 September 2023
Letter to the Editor



British Society for
Rheumatology

RHEUMATOLOGY



Letter to the Editor (Other)

Development and implementation of 'A guide to PPIE – Early Integration into Research Proposals' in a multi-disciplinary consortium

Richard Beesley^{1,4}, Freya Luling Feilding^{2,4}, CLUSTER Consortium Champions⁴, Elizabeth C. Rosser^{2,4}, Stephanie J. W. Shoop-Worrall³, Alyssia McNeeco², Zoe Wanstall², Kimme Hyrich^{3,4,5,6}, Lucy R. Wedderburn^{2,3,7,8} and on behalf of the CLUSTER Consortium⁴

¹Juvenile Arthritis Research



THE CLUSTER
CONSORTIUM



Our year in review | Awareness

Raising awareness is the biggest single thing anyone can do to make a difference to the lives of children and young people with JIA.

Increased awareness leads to earlier diagnosis, prompt treatment, and better outcomes. It reduces stigma and isolation. Increased awareness changes lives.

WORD Day is the biggest global day to raise awareness that children and young people get rheumatic disease such as JIA. We sent packs out for WORD day, reaching over 7,500 families with our awareness-raising resources. Our supporters and families flooded social media with awareness-raising images, and coordinated their own events locally. Building on the success of previous years, through our targeted social media campaign we reached tens of thousands of people who would otherwise never have heard that children get arthritis. We remain committed members of the WORD Day international planning committee, delivering the programme and webinars.



Our year in review | Awareness

In 2023 Juvenile Arthritis Research were invited to make use of an otherwise empty building in Tonbridge in Kent. According to the government statistics, 20,000 vehicles drive past the building every day. With large windows overlooking the road, this is an ideal awareness-raising location.

Local families were invited to take part in a photoshoot – thanks to Lily, Logan, Maisie, Maddison, Penelope, Aria and Trinity for taking part, and their families. We would also like to thank Janet from Hushabye Photography for giving her time and expertise to take and edit the photographs and CK Office Furniture for loaning us office furniture.

The transformation has been reported in local press, and has made a positive impression amongst local residents. It has enabled us to raise awareness in an effective way in the local community. We are also using the building as an office and a base for activities and events for local families.



Raising awareness

Our year in review | Awareness

Delays in diagnosis lead to worse outcomes for children with JIA. Research has shown that low awareness in primary care can be an obstacle in getting a referral to rheumatology for a diagnosis and treatment, and our own research has found long delays for many children with JIA, in part due to low awareness amongst GPs.

In 2023 we attended the Royal College of GPs annual conference in Glasgow, with the aim of raising awareness that children and young people get arthritis. During the conference we spoke with hundreds of GPs and medical students, sharing information and resources with them.

We have also updated our pivotal #ThinkJIA website, which raises awareness of JIA amongst frontline health professionals and the general public. Over recent years, the campaign has been highlighted in numerous international conferences as best practice, enabling other patient networks to use our resources and develop them for their own communities.

We were also invited to take part in a video with EULAR, launched on World Arthritis Day 2023. This helped highlight what life with JIA is like, as well as the difference increased awareness can make. The video can be found at www.jarproject.org/hope/videos



#ThinkJIA



Our year in review | Awareness

During the year we've had a lot of amazing people taking part in events both to raise funds and, just as crucially, to raise awareness of JIA. This has included events in Tonbridge, Manchester, Brighton, Cardiff, London, Glasgow and elsewhere. All wearing our custom Juvenile Arthritis Research sports top, raising awareness of JIA. We are truly grateful to everyone who has fundraised for us this year.



Our year in review | Support

We have sent out **Little Box Of Hope** packs to hundreds of families across the UK, helping them have the information they need and the support that is so important for them.

Our **School Toolkits** have been delivered to schools across the country, helping schools confidently support children with JIA.

We have provided one-to-one support for schools and local education authorities, giving them clear and impartial advice, information and support as they work with children with JIA. Our volunteers have delivered **presentations** in schools and assemblies. With input from health professionals, at the request of families we developed and launched a letter template to enable hospitals write to schools to provide support to children with JIA; this year that template has been downloaded over 220 times.

We continue to provide **one-to-one** support to families when they request it, delivered by our volunteers.

Our **mental health hub** has continued to grow, with links to some of the best resources available to help children with JIA and their families.

We have provided emergency support for children reaching a mental health crisis due to their JIA for whom other mental health services were not available.

We have grown our **private secure network** to support families affected by JIA.

Our resources have now been translated and adapted for use in more countries – now including Ukraine, Netherlands, Russia, Costa Rica, Mexico, Australia, India and Brazil. In the UK, our resources have been widely used with **My JIA** being downloaded over 700 times this year alone, our **Schools Factsheet** over 400 times.



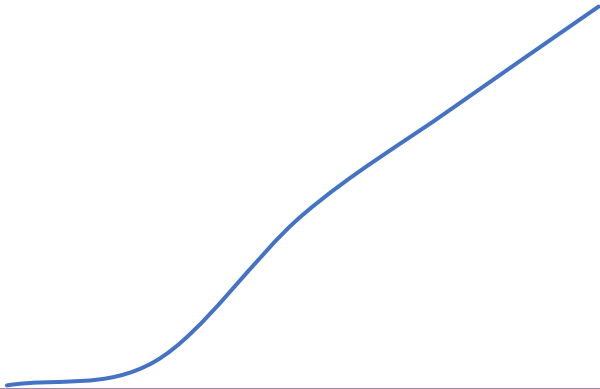
LITTLE BOX OF HOPE

Our year in review | Support

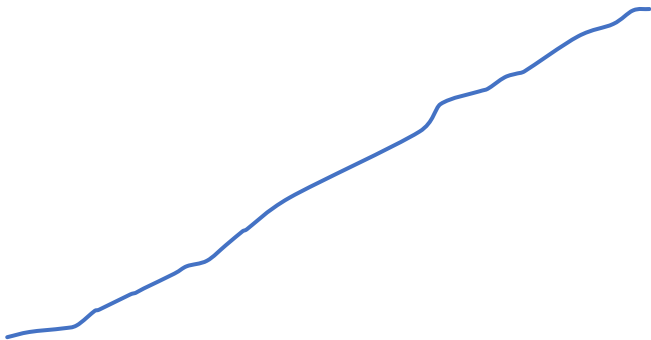
In 2023 we expanded our private secure network for families affected by JIA. This network, moderated by our volunteers, provides peer support when parents and carers need it. Available 24/7, there is always someone available to answer questions, chat or simply provide a listening ear. Life with JIA can be difficult, and having a child with JIA is hard. Our network and support services ensure no family needs to feel alone.

During 2023 we also launched our new **Parent Zoom** service. During these video calls, parents and carers of children with JIA can connect with each other and our volunteers to share their experiences and ask questions in a non-judgemental and safe environment. We plan to continue to grow the Parent Zoom service this coming year, and have a new volunteer whose role is to lead on this service.

Growth in support pack requests, 2018 to 2023.



Growth in social media followers, 2018 to 2023.



Sam's story



“ One night, Sam woke up in the night to tell me how painful his knee was. The doctors thought it was just an injury and we were sent away and told that it may take weeks to heal. Sam's knee didn't appear to get any better – in fact his left ankle became swollen too.

After many more visits to the doctor where we were told to wait and give it time to heal, we managed to get a referral to a consultant. The first consultant we saw didn't even look at Sam's ankle. It was only after managing to get a second opinion that we were eventually referred to rheumatology.

As parents we were confused, worried and completely frustrated. I spent hours and hours on the phone trying to get Sam the care he needed. Sam had mornings where he couldn't walk for hours. If he tried to walk, he would have to hold on to things to support him as he hobbled from one piece of furniture to the next. Sam is usually very active, always out on the farm or enjoying the trampoline, football and running around. We knew something was wrong but had no idea what. It was heartbreaking to see him struggling so much.

Once we received the diagnosis of oligoarticular Juvenile Idiopathic Arthritis, we were absolutely stunned; we had no idea children could get arthritis or how serious it could be. That day was one of our worst days. I felt so anxious. I was worried for Sam and what the future would bring. I had a list of questions and no-one to ask.

Finding Juvenile Arthritis Research was absolutely amazing and I will always be grateful to the teacher who first told us about the charity. Juvenile Arthritis Research has helped our family in millions of ways. From the exceptional information on the website, to the volunteers who answered question after question and reassured me.

They helped me to understand technical terms I'd never heard of before and explained everything from blood test results to medication, to flares, injections, the impact of chicken pox, uveitis, as well as giving me guidance and helpful tips.

Most of all, Juvenile Arthritis Research gave us hope. They gave us hope that Sam can live a good life despite the challenges of having JIA. I needed that reassurance. They helped me focus on the positive and put all the negatives into perspective.

When Sam received a Little Box of Hope from Juvenile Arthritis Research, it helped him realise that there are other children out there with JIA. The books and information included in the support pack helped Sam understand his condition and explain it to others.

Having access to meaningful information and someone with personal experience, who had the patience, understanding and a willingness to give up their own valuable time was a lifesaver.

Because JIA can be an invisible illness, it made it hard for school to fully understand. The School Toolkit pack from Juvenile Arthritis Research was brilliant and helped the school understand Sam's condition.

Sam is doing well at the moment on his new medication. He is absolutely able to do all the things he loves; he plays the guitar and drums, plays football, skateboarding, going to music gigs, helping on the farm and looking after animals.

I will be forever grateful to Juvenile Arthritis Research and I will never be able to thank them enough for the support they have given us.

Michaela Sam's mum



For more stories, visit www.jarproject.org/stories

Social media

Our social media presence has continued to grow, and we continue to have the most engaged network of families across our social media channels. We use our social media to support all aspects of our work.

In 2023 we brought our hard-hitting Christmas social media campaign to a conclusion, showing that life with JIA does not stop at Christmas. In addition to the images shared in previous years, we added the final image in this series – the 'Shocking Stocking'.

In total, over 24,000 people saw the images and associated text and video. We received many comments and messages from families, for whom the thought-provoking images resonated – their experience, like ours, is that JIA does not stop at Christmas... with the continued need for injections, medications, blood tests, X-rays, MRI scans and treatments that our children endure through the festive period – a period where traditionally most people get to have some time off from work. Children with JIA never get a break from having JIA – it is a lifelong condition for which there is currently no cure. That is why our support services continue throughout the year, and our networks continue to operate.

**Juvenile arthritis
doesn't take a
break at
Christmas**

JAR
Juvenile Arthritis Research



**Juvenile arthritis
doesn't take a
break at
Christmas**

JAR
Juvenile Arthritis Research



**Juvenile arthritis doesn't
take a break at Christmas**

JAR
Juvenile Arthritis Research
Change the narrative



**Juvenile arthritis
doesn't take a
break at
Christmas**

JAR Juvenile
Arthritis
Research



Grants

Our work would not be possible without the generous support of fundraisers, donors and grant-making bodies.

We are deeply grateful to the following for providing grants to support our vital work during 2023:

- Kent Community Foundation
- South East Water
- Paddock Wood Robins
- Grace Trust

A grant has also been awarded by Tesco, due to be paid in early 2024.



south east water



— THE —
GRACE TRUST

INDEPENDENT EXAMINER'S REPORT

I report to the trustees on my examination of the financial statements of Juvenile Arthritis Research (the charity) for the year ended 31 December 2023, as set out on the Statement of Financial Activities and Balance Sheets.

RESPONSIBILITIES AND BASIS OF REPORT

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the 2011 Act).

I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

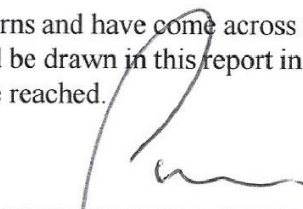
INDEPENDENT EXAMINER'S STATEMENT

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the 2011 Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Signed:



Name: Paul Clark

Address: 14 Courtwood Drive
Sevenoaks
Kent TN13 2LR

Date: 29th July 2024

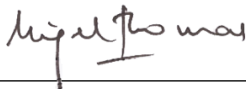
STATEMENT OF FINANCIAL ACTIVITIES

	Note	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total Funds £
<u>Income from:</u>					
Donations and legacies	1,8	29,510	6,840	36,350	14,930
Charitable activities	2	25,684	0	25,684	0
JAR Shop	3	217	10	227	309
Reclaimed tax	4	70	0	70	751
Grants	5	7281	0	7281	1,250
Total income		62,762	6,850	69,612	17,240
<u>Expenditure on:</u>					
Raising funds	6	5,119	0	5,119	560
Charitable activities	7,8	38,213	6,977	45,190	16,734
Total expenditure		43,332	6,977	50,309	17,294
Net (expenditure)/income for the year / Net movement in funds		19,430	(127)	19,303	(54)
Fund balances as at 1 January		1,121	127	1,248	1,302
Fund balances as at 31 December		20,550	0	20,550	1,248

Note 1	'Donations' includes one-off donations and gifts from regular donors, as well as legacy and gifts <i>in memoriam</i> .
Note 2	No charges are made to beneficiaries for charitable activities. Includes a transfer of £25,583 from a project account to the main Juvenile Arthritis Research charity account. Total income excluding this transfer was £37,078 with expenditure of £43,459.
Note 3	The JAR online shop was relaunched in early 2021 using a new ethical supplier and faster production process, improving the quality of products, sustainability and customer experience.
Note 4	Reclaimed tax shown is Gift Aid reclaimed direct. Where a registered third party has reclaimed Gift Aid on a donation through their systems (such as Stewardship), the total donation received includes the Gift Aid they have reclaimed. Gift Aid is not always redeemed in the financial year of the donation.
Note 5	Grants include £2500 from the Kent Community Foundation, £1000 from the Grace Trust, £250 from the Paddock Wood Robins, £500 from South East Water, and grants from partner organisations for delivery of specific projects.
Note 6	The charity contracted the skills of a freelance fundraising professional to support grant writing in 2023.
Note 7	Charitable activities include Research, Awareness, Support, Advocacy and other aspects of our work.
Note 8	Restricted funds relate to the funding of course fees, conferences, publications, travel and related costs in respect of a PhD researching the epidemiology of Juvenile Idiopathic Arthritis.
Note 9	These accounts are prepared on a receipts and payments basis.
Reserves policy	The charity will aim to maintain reserves equivalent to 3-6 months of non-staff associated funding, which provides sufficient buffer against unexpected changes to allow appropriate planning and change management to take place. Staffing payments will only be made if grants are received to cover those costs, and not from reserves. Currently the charity has no paid staff; grant applications for core funding include specific allocations for future staffing as appropriate.

BALANCE SHEETS

As at 31 December	2023 £	2022 £
<u>Fixed assets</u>		
Tangible assets	0	0
<u>Current assets</u>		
Debtors	0	0
Cash at bank and in hand	20,550	1,248
Creditors: amounts falling due within one year	0	0
Net current assets	20,550	1,248
Total assets less current liabilities	20,550	1,248
<u>Income funds</u>		
Unrestricted funds	20,550	1,121
Restricted funds	0	127
	20,550	1,248



Nigel Thomas, Chair of Trustees

Dated: 28 July 2024

Contacting Juvenile Arthritis Research

Email @ kipo@jarproject.org
Website www.jarproject.org
Twitter @jarproject
Instagram @_jarproject
Facebook f @jarproject
YouTube youtube.com/@juvenilearthritisisresearch
LinkedIn in /company/juvenile-arthritis-research