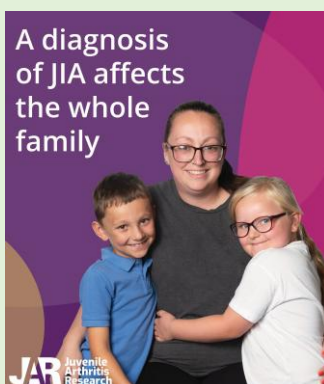


A world where no  
child has to suffer  
from arthritis

# Annual report and accounts 2024 Juvenile Arthritis Research

1 January 2024 to 31 December 2024

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



# Structure, Governance and

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 2024 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	20

## 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](http://www.jarproject.org)



# What is Juvenile Idiopathic Arthritis

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 **10,000** 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.

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

**1 in 1600** 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

Juvenile Arthritis Research is a charity supported by donations (registered charity number 1091620). We are patient- and parent-led, and focussed on the needs of both the person with JIA and their family.

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 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 we 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](http://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](http://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](http://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](http://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](http://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. Patient- and 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, and volunteers who have arthritis themselves. 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 – patient- and parent-led expertise, holistic approach, and collaborative spirit – make Juvenile Arthritis Research a powerful force in the fight against JIA.

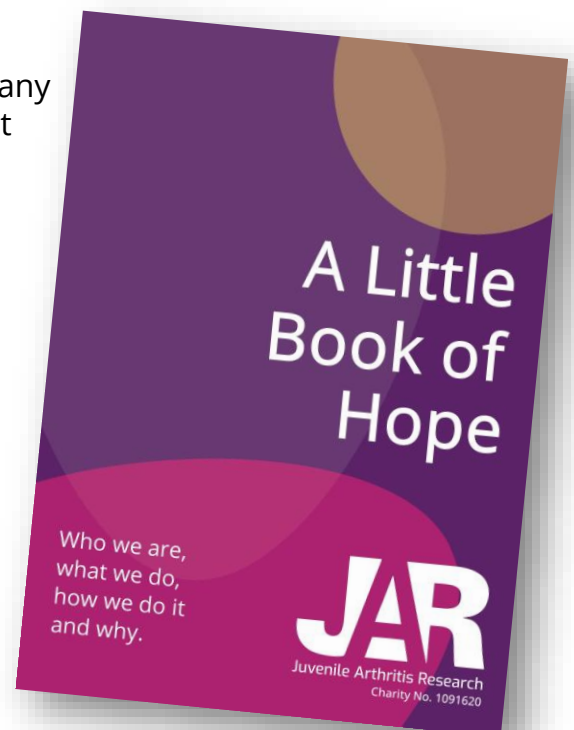
# A little of what we do...

## 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.
- provides support to families without charge to users.
- has no subscription charges.
- manages an online mental health hub and support services.
- provides access to emergency funding for crisis mental health support.
- provides A Little Box Of Hope support packs and Teen support packs. These were developed by children, young people and families.
- was the first to develop School Toolkits for JIA.
- delivers training and assemblies in schools.
- provides one-to-one support for schools and local education authorities.
- has a private peer-to-peer network for parents of children with JIA.
- provides 24/7 support for families when they need it.
- has the most engaged network of all JIA-related charities on social media.
- leads 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.
- has been invited to present at leading international rheumatology conferences.
- has worked 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.
- is involved in global health.
- advocates for patients and families.
- runs the JIA VIP Research Panel, involving many families in research and patient engagement projects, and ensuring appropriate and meaningful representation in research.

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

[www.jarproject.org](http://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 & Patient 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 developed our volunteer team this year, and grateful to them for giving so much when their own lives are already full.

In November we were delighted to attend the awards ceremony for the inaugural Benefact Charity Heroes event, where one of our young volunteers, Abbie, was a finalist in the Volunteer of the Year category.



# Partnerships



We are delighted to be part of the **Connect Immune Research Partnership**. 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.

The NCEPOD logo consists of the letters "NCEPOD" in white, bold, sans-serif font, set against a solid orange rectangular background.

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.



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. In 2024 we contributed to the *People's Experience of Diagnosis* report ([bit.ly/NVreport](https://bit.ly/NVreport))



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 work closely with **PRs**, the Paediatric Rheumatology Europe Society, and have developed projects jointly with them.



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 are members of the **Children and Young People's Mental Health Coalition**, which brings together organisations to campaign jointly and provides a strong unified voice speaking out about children and young people's mental health.

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 - those 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.

# Our year in review | Research

Our research work has continued to develop over the past year, through three main themes. Read on to hear more about each of these...

## 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 80 of our research publications.

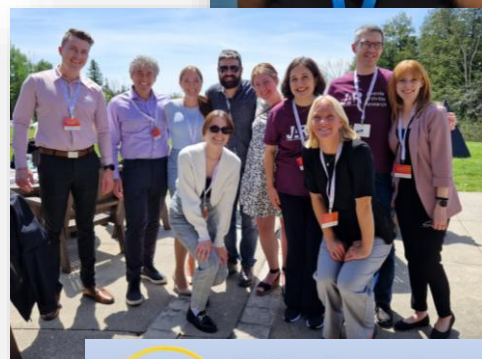
[www.jarproject.org/research/publications](http://www.jarproject.org/research/publications)

A team of our volunteers attended the British Society for Rheumatology (BSR) conference in Liverpool, taking the opportunity to not only raise awareness of our vital work, share our own research results, but to also attend numerous scientific sessions about JIA.

During 2024 we were invited to present at the international EULAR Congress in Vienna about our work in raising awareness of JIA, to a packed hall of global delegates from the field of rheumatology. Described by EULAR as 'the best of the best', not only was this highlighted in a EULAR-issued Press Release, it was also included in the formal Congress Press Conference, helping showcase our work to a wider audience. We were also invited to present our work about parental feelings when their child was first diagnosed, and long-term outcomes for adults with JIA.

An unexpected highlight was when we were invited by Cassie + Friends (a JIA patient organisation in Canada) to attend their Family Day and prestigious conference. The UCAN-CANDU team presented some of their inspirational and ground-breaking work in identifying the right medication for every child. We were the only UK charity invited to attend, due to the impact Juvenile Arthritis Research is making.

We planned, coordinated and delivered the ENCA 2024 online conference, highlighting our research and awareness activities to a global community. We were thrilled that speakers from the UCAN-CANDU project were also able to join us and share their work.



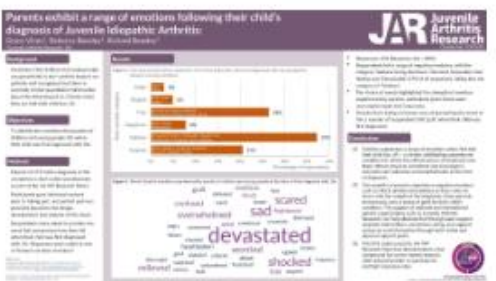
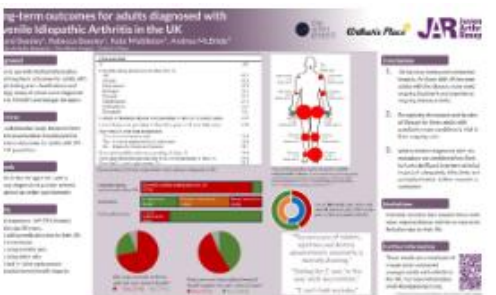
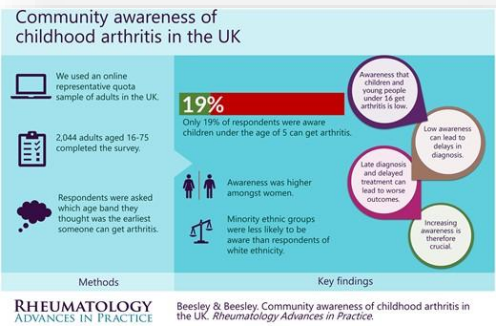
# Our year in review | Research

## Our own research

Our pioneering research in the general community into awareness that children and young people get arthritis was published in *Rheumatology Advances In Practice*, and we were invited to take part in the *Talking Rheumatology Research podcast* to discuss the project.

Our Director is currently undertaking a PhD in Epidemiology at the University of Manchester, and presented work from that project at EULAR and BSR congresses. The first [journal article](#) from this PhD has now been published, highlighting that the incidence and prevalence of JIA differs between ethnic groups. Further analysis is ongoing, with further conference publications and journal articles due throughout 2025.

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. A number of the vital research projects that we are involved in have emerged as a result of collaborations formed at conferences.



A selection of our 2024 research publications, presented at international conferences. Details can be found at <https://www.jarproject.org/research>

# Our year in review | Research

## 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 which we launched in 2023.

*“The VIP panel was able to provide hard won expertise on the patient experience and perceptions – their input has changed the design of our research study. They were also active participants and gifted communicators, which made their contribution incredibly impactful.”* Principal Investigator

You can find out more about the JIA VIP Research Panel at [www.jarproject.org/vip](http://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.



### The JIA VIP Research Panel



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



### The JIA VIP Research Panel



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





## Our year in review | 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 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. As of December 2024 we have over 230 participants taking part in research through the JIA VIP Research Panel.

During this year, members of the JIA VIP Research Panel have helped with research surveys, joined steering groups, attended focus group discussions, helped with new product development and more. Members of the Panel are hugely valued and their contribution is recognised in line with NIHR best practice guidance.

Results from the Panel have been presented all over the world, making a difference to those with JIA and influencing policy makers. Research has also been published in journals, contributing to the body of knowledge in the field of JIA. It is thanks to our Panel that this can happen.

# Our year in review | Research

## 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 including those with the University of Manchester, University of Liverpool, Sheffield Hallam University, University of Oxford, University of Glasgow, Cardiff Metropolitan University, and the Politecnico di Milano, and many more during 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, and we have helped prepare the information to be provided to families with their personal results. 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<sup>1,4</sup>, Freya Luling Feilding<sup>2,4</sup>, CLUSTER Consortium Champions<sup>4</sup>, Elizabeth C. Rosser<sup>2,4</sup>, Stephanie J. W. Shoop-Worrall<sup>3</sup>, Alyssia McNeecio<sup>2</sup>, Zoe Wanstall<sup>2</sup>, Kimme Hyrich<sup>3,4,5</sup>, Lucy R. Wedderburn<sup>2,3,5,\*</sup> and on behalf of the CLUSTER Consortium<sup>4</sup>

<sup>1</sup>Juvenile Arthritis Research



THE CLUSTER  
CONSORTIUM





# Our year in review | Research

## Patient involvement

As advocates for children and young people with JIA and their families, it is a privilege to be invited to represent them in a wide range of events and opportunities.

During 2024, some of these have included the **BSR Paediatric Rheumatology Nurses Network Meeting**, the **National Joint Registry, CHEERS** (the paediatric rheumatology network for the East of England), **University College Dublin** conference, and a number of pharmaceutical companies.

For several of these, we have been joined by young people with JIA and their parents who have also shared their experiences.

We are proud to be part of two BSR Guideline projects – the *Pain in Inflammatory Arthritis* and *Hot Swollen Joints in Children* groups. This important work helps to shape national guidelines, impacting clinical care for people with JIA and other conditions.



# 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.

For WORD Day 2024 we moderated the international webinar, in which young people spoke about living with a rheumatic condition.

We also campaigned across social media, and encouraged families to raise awareness of JIA using our resources, images of which we then shared further. As in previous years, this reach extended far beyond the UK with families taking part and sharing images with us from all over the world.

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 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 took part in a photoshoot to help us transform the building into an awareness-raising canvass.

In 2024 we have used the premises for local events and activities, and as a workspace, and it remains a central focal point in the community.



# Raising awareness

## Our year in review | Awareness

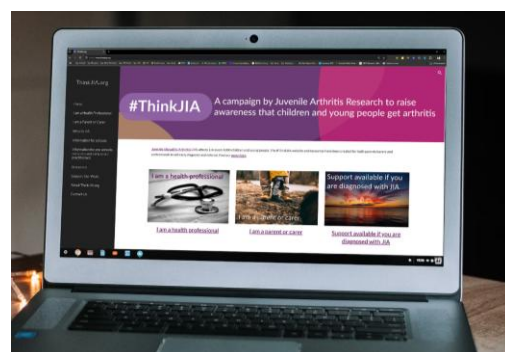
Delays in diagnosis lead to worse outcomes for children with JIA. Research has shown that low awareness in primary care can be an obstacle in getting a referral to rheumatology for a diagnosis and treatment, and our own research has found long delays for many children with JIA, in part due to low awareness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

We continue to provide guidance, resources and information to GPs, with the aim of raising awareness that children and young people get arthritis. Our plans for 2025 include increased awareness-raising amongst this priority group.

We have also continued to promote 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.



Raising awareness amongst GPs.



Our dedicated awareness-raising website, [www.thinkjia.org](http://www.thinkjia.org)

# #ThinkJIA



Our #ThinkJIA awareness campaign was highlighted in the video made by EULAR featuring our Founder's family.



## 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 various places in Kent including Tonbridge, Canterbury, Margate, and Dartford; Surrey, London, Cambridge, Norfolk, Bristol, Wales, Newcastle, Cornwall, and even as far afield as France and Dubai. All wearing our custom Juvenile Arthritis Research sports top, raising awareness of JIA. We are truly grateful to everyone who has fundraised for us and supported us this year.



Well  
Done!



Anne-Lise!



JAR Juvenile  
Arthritis  
Research



# 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.

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 **peer-to-peer 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 and shared.

In 2024 we introduced a new page on our website where translations of the Kipo storybook can be found in English, Hebrew, Arabic, French and Russian.



**LITTLE BOX OF  
HOPE**

## Our year in review | Support

In 2024 our peer network for families affected by JIA continued to grow. 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.

Throughout 2024 our quarterly **Parent Zoom** sessions have become established as a regular feature in the calendar. Much-valued by families, these video calls for parents and carers of children with JIA enable them to connect with each other and our volunteers to share their experiences and ask questions in a non-judgemental and safe environment.

In 2024, two of our volunteers have taken on responsibility for organising and hosting these important sessions, ensuring consistency and continuity throughout the year.





# Our year in review | Support

In 2024 we launched our first full year programme of local events, thanks to generous grants and a dedicated local events volunteer. These events have been popular with families, and provided a safe environment for children with JIA to meet with others with the same condition – often the first time they have ever been able to.

Our events have included a **volunteer teambuilding afternoon**, which helped facilitate friendships amongst our children with JIA whilst allowing volunteers to meet together in-person.

We held an **Easter Crafts** event, facilitated by local florist The Flower Cellar. **Animalia** delivered an animal encounters event for children with JIA and their siblings. Our **chocolate workshop** was a huge success, and was designed to allow parents to connect with one another whilst their children were taking part in the activity.

*"My daughter LOVED the session and it was a wonderful opportunity for parents AND children to meet up."* Parent



# Our year in review | Support

Rather than being a single disease, Juvenile Idiopathic Arthritis is a group of related conditions. One of these subtypes is called Still's disease (formerly called 'systemic JIA'). Over recent years a number of families and clinical teams have asked us to develop further information about Still's disease.

During 2024 we worked with patients, families and leading health professionals to develop a new dedicated resource about Still's disease. This is a fold-out leaflet, supported by a new website, [www.stillsdisease.uk](http://www.stillsdisease.uk)

As far as we are aware, this is the first such resource available anywhere in the world for patients, and we are presenting information about the work in conferences during 2025.

Tragically, Still's disease can be fatal, particularly through the rare but serious complication Macrophage Activation Syndrome (MAS). As a result, this resource has the potential to save lives as well as making a positive difference to families affected by the disease.

## Brand new resources



## Still's disease & Macrophage Activation Syndrome

An information leaflet about Still's disease, also known as systemic JIA (sJIA)

**JAR** Juvenile Arthritis Research  
Registered charity no. 1091620





## Esmé's story : Christmas 2024 campaign

“ Esmé would wake up and spend most of the night crying out in pain, completely inconsolable. We were at a loss. When her knees had swollen considerably, she was finally referred to a paediatrician, who thankfully recognised the symptoms of JIA.

We had never heard of JIA, we were in shock to start with, and then we simply thought it was a case of taking the medicine and getting back on track. We have since learned that this is a journey – one where you are constantly reassessing how arthritis is affecting your child's life and adjusting to deal with it.

Esmé started her treatment with steroids and methotrexate. It seemed to work at first, with the inflammation subsiding. We noticed for the first time that Esmé could do so much more.

Over a few months though the symptoms crept back in and Esmé's methotrexate was increased. Eventually the methotrexate was swapped for a different medicine that she tolerates very well. She found taking the medication incredibly difficult, and some of our most challenging times at the start were actually about getting the medicine in Esmé rather than dealing with the effects of the arthritis itself. And, of course, Esmé was too young to understand why she was having to deal with all of these things.

Over time, Esmé has suffered with arthritis in both ankles, both knees, both wrists and her jaw, as well as developing psoriasis along the way. Without describing every stage of the disease so far for Esmé, what I would say is that from one rheumatology appointment to the next we are never sure what the verdict will be on whether the arthritis is 'quiet' or not.

One of the things that stands out from the time of being diagnosed is discovering Juvenile Arthritis Research and receiving the Little Box of Hope support pack. It showed us there was a network for those struggling with the new diagnosis, people that cared and understood how we felt, and it provided vital information.

**Every birthday and Christmas since I can remember, Esmé's only wish is that she didn't have arthritis.**

You shouldn't underestimate the value of having a network of people who are in a similar situation to you. JIA can be an isolating disease, so if you get the opportunity to support a charity like Juvenile Arthritis Research that provides that support to others, please do so. Your contribution will make a huge difference.

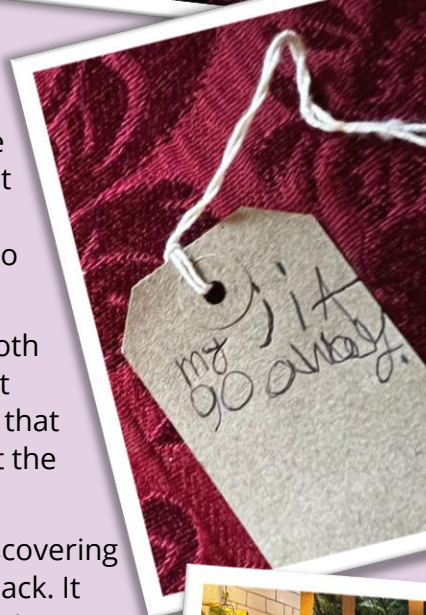
At the moment we are wrestling with arthritis in her jaw. That means more MRI scans, injections, blood tests and more of the things Esmé really does not enjoy. But what we have learned so far is that together we will get through it. It is difficult to cope with practically: attending all of the medical appointments, staying on top of the medications, explaining to all those around us what is happening. But worse is the emotional side. Every birthday and Christmas since I can remember, Esmé's only wish is that she didn't have arthritis.

It breaks my heart that she wishes so hard for this, and that every Christmas she is disappointed as all the Christmas magic in the world is not enough to give her the one thing she wishes for every year.

”

*Kate* Esmé's mum

For more stories, visit [www.jarproject.org/stories](http://www.jarproject.org/stories)





# Media and 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.

As part of our Christmas campaign, as well as sharing “Esmé’s Christmas Wish”, we encouraged others to share their child’s Christmas wish with us. We received some poignant and powerful submissions, which we shared across our social media channels, helping raise awareness that children and young people get arthritis too. Our analytics show these social posts had strong reach and engagement.

Abbie’s nomination as Benefact Group’s Volunteer of the Year generated a considerable amount of media coverage, including both print and local BBC radio. This helped highlight the voluntary work Abbie has done, the charity as a whole, and helped raise awareness of JIA more widely.



“I want that my sister’s arthritis is gone, from Mia”



“I wish I did not have arthritis but I could still come to JAR, from Aria”



# 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 2024:

- JP Morgan Chase (donation in kind through Force For Good project).
- Involve Kent
- ASDA Foundation
- Tonbridge Lions Club
- Kent County Council
- Foyle Foundation
- PReS
- Tesco Community Grant
- Kent Police Property Fund
- Postcode Society Trust, thanks to players of the People's Postcode Lottery.



# Partnerships

In addition to our incredible fundraisers and generous grant donors, we are delighted to have worked with a wide range of individuals and organisations to benefit the JIA community. This has included researchers, policy makers, influencers and health professionals.

During 2024 we also started working with Maher Tabchy, founder of Tabchilli. Maher is an incredible individual with a purpose-driven approach to life. Not satisfied with achievement in the corporate world, he moved into the pharmaceutical industry to better understand health and chronic conditions, before going a step further and delving into understanding more about gut health, fermentation and probiotics by launching his own business.

Tabchilli produces and sells fermented foods such as sauerkraut, kimchi and kombucha as well as running workshops to share teaching about the methods involved in fermentation - the power of using microbes and techniques that have stood the test of time to create flavour-packed foods that help gut-health and improve wellbeing.

This entrepreneurial start-up business recently celebrated it's 2 year anniversary and we are thrilled to announce the news that going forward Tabchilli will be giving 1% of quarterly sales to Juvenile Arthritis Research.

We are developing further partnerships with organisations to help us continue to develop the charity and the work that we do. Together, one day, we will achieve a world where no child has to suffer from arthritis.



A world where no  
child has to suffer  
from arthritis





# 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 2024, 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.

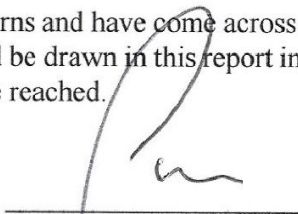
## INDEPENDENT EXAMINER'S STATEMENT

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: 31 August 2025

# STATEMENT OF FINANCIAL ACTIVITIES

	Not e	Unrestricte d funds £	Restricted funds £	2024 Total funds £	2023 Total Funds £
<u>Income from:</u>					
Donations and legacies	1	36,538	16,340	52,878	36,350
Charitable activities	2	3,430	587	4,017	25,684
JAR Shop	3	165	146	311	227
Reclaimed tax	4	175	0	175	70
Grants	5	25,100	5,950	31,050	7281
Total income		65,408	23,023	88,431	69,612
<u>Expenditure on:</u>					
Raising funds		1,039	0	1,039	5,119
Charitable activities	6	23,638	21,436	45,074	45,190
Total expenditure		24,677	21,436	46,113	50,309
Net (expenditure)/income for the year / Net movement in funds		40,733	1,587	42,320	19,303
Fund balances as at 1 January		20,550	0	20,550	1,248
Fund balances as at 31 December		61,283	1,587	62,870	20,550

- Note 1

'Donations' includes one-off donations and gifts from regular donors, as well as legacy and gifts *in memoriam*.
- Note 2

No charges are made to beneficiaries for charitable activities. Includes income from partners to undertake specific projects for the benefit of children and young people with arthritis and their families, including PReS, BSR QI JIA Learn, and projects utilising the JIA VIP Research Panel.
- 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 Tesco Community Grant, Kent Police Property Fund, Postcode Society Trust, Involve Kent, ASDA Foundation, Kent County Council Member Grant and the Foyle Foundation.
- Note 6

Charitable activities include Research, including PhD research, Awareness, Support, Advocacy and other aspects of our work.
- Note 7


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. As of 31 December 2024 the charity has no paid staff; grant applications for core funding include specific allocations for future staffing as appropriate. A proportion of the funds currently held are reserved and allocated (though not restricted) for specific future projects commencing in 2025.

BALANCE SHEETS

As at 31 December	2024 £	2023 £
<b><u>Fixed assets</u></b>		
Tangible assets	0	0
<b><u>Current assets</u></b>		
Debtors	0	0
Cash at bank and in hand	<u>62,870</u>	<u>20,550</u>
Creditors: amounts falling due within one year	<u>0</u>	<u>0</u>
Net current assets	<u>62,870</u>	<u>20,550</u>
<b>Total assets less current liabilities</b>	<u><u>62,870</u></u>	<u><u>20,550</u></u>
<b><u>Income funds</u></b>		
Unrestricted funds	61,283	20,550
Restricted funds	<u>1,587</u>	<u>0</u>
	<u><u>62,870</u></u>	<u><u>20,550</u></u>



Nigel Thomas, Chair of Trustees

Dated: 18 August 2025

## Contacting Juvenile Arthritis Research

Email      @ kipo@jarproject.org  
Website    www.jarproject.org  
X / Twitter @jarproject  
Instagram @\_jarproject  
Facebook @jarproject  
YouTube youtube.com/@juvenilearthritisresearch  
LinkedIn /company/juvenile-arthritis-research