



# Juvenile idiopathic arthritis (JIA) – where to look for information

A guide for young people

Some of the information on the internet is not always reliable. Try to use websites you can trust rather than using a search engine.

The websites in this leaflet have been recommended by other young people with JIA, and the rheumatology team.

Knowing more about JIA and the treatments can help you feel more in control of your arthritis, rather than the other way around.

You might find that you prefer one website more than another. It's not possible to learn everything at once, so have a look at them when you need to.

If you have any questions about what you have read online, ask us at your next hospital appointment.

### **Versus Arthritis**

**web:** [www.versusarthritis.org](http://www.versusarthritis.org)

**phone:** 0300 790 0400

**information helpline:** 0800 5200 520

A community providing support for people with arthritis across the UK. They also support research into arthritis and treatments.

- Information about JIA and medicines
- Activities for young people aged 11 to 18
- Arthritis Tracker app for young people
- Information on complementary and alternative treatments
- Online community for young people and families

## **JIA at NRAS**

**web:** [www.jia.org.uk](http://www.jia.org.uk)

**phone:** 0845 458 3969

As part of the National Rheumatoid Arthritis Society, they provide information and services for children with JIA and their families.

- Information about research and drug trials, medicines, emotions and mental health, exams, bullying, education, work, benefits, and transition
- Range of events for children and their families in England
- Children and families share their experiences of JIA

“The resource hub and useful websites section is really good. You can get answers to lots of questions.” Emily aged 19, diagnosed age 11

## **CCAA – Kids with Arthritis**

**web:** [www.ccaa.org.uk](http://www.ccaa.org.uk)

**phone:** 01242 511250

Run by a group of people who, through personal experiences, have a passionate interest in helping support children with JIA and their families.

- Information about JIA
- Family support weekends
- Local groups (connect with families in your local area)
- Section for newly diagnosed families
- Award badges for children

## **PRINTO**

**web:** [www.printo.it/pediatric-rheumatology](http://www.printo.it/pediatric-rheumatology)

Information about the characteristics of paediatric rheumatic conditions. The information is available in different languages, and includes information on

- all paediatric rheumatic conditions
- drug therapies that are commonly used to treat paediatric rheumatic conditions

## **OxPARC**

**web:** [www.ouh.nhs.uk/oxparc](http://www.ouh.nhs.uk/oxparc)

Oxford University Hospital's own site with lots of information, including:

- investigations (tests), diagnosis, treatment, medicines and therapies, pain management, research
- sections for children, teenagers and parents

## **Juvenile Arthritis Research (JAR)**

**web:** [www.jarproject.org](http://www.jarproject.org)

A parent-led charity with direct experience of JIA, undertaking research, providing support and raising awareness of JIA.

- Information about JIA and uveitis
- Resources to help you manage your JIA
- Free support packs for children, teenagers, and parents
- Stories about children and young people with JIA

## **Arthur's Place**

**web:** [www.arthursplace.co.uk](http://www.arthursplace.co.uk)

An online magazine and social network for young adults with arthritis. Most of it is written by young people with arthritis.

- Blogs on topics including going to university, starting work, and travelling
- Facts about arthritis
- Helpful hacks and tools for dealing with everyday life, such as doing your own injections
- Arthur's wellness kit and guides
- Podcast and Facebook social group

“Great advice about the practical side of living with arthritis.” (Kat 22, diagnosed aged 9)

## **Centre for Adolescent Rheumatology**

**web:** [www.adolescent-rheumatology.uk](http://www.adolescent-rheumatology.uk)

Supported by Versus Arthritis, University College London Hospital, and Great Ormond Street Hospital, this virtual centre tries to involve young people in research.

- Information about JIA, Lupus and myositis and their treatments
- Videos of young people giving their tips and advice
- Advice for parents, teachers, and friends
- Videos by health professionals
- Opportunity to get involved in research

## Olivia's Vision

**web:** [www.oliviasvision.org](http://www.oliviasvision.org)

Information, support and advice for anyone affected by uveitis. Subjects include:

- information about uveitis and current treatment options
- personal stories
- latest research news

## Contact us

Rheumatology at Evelina London  
(RhEve), RhEve Helpline

**phone** 07918 338768

**email** [RhEve@gstt.nhs.uk](mailto:RhEve@gstt.nhs.uk)

Youth worker .....

**phone** 07771 982860, **email**

[ypfsengland@versusarthritis.org](mailto:ypfsengland@versusarthritis.org)

For more information on conditions, procedures, and treatments offered at our hospitals, please visit **web** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

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