



# Where to find information about Juvenile Idiopathic Arthritis (JIA)

A guide for young people

## Where you can look for information

There is a lot of information on the internet; some of the information you find might not always be reliable so try to use websites you can trust.

Here are some websites that are recommended by other young people with JIA and the Rheumatology team.

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

### Arthritis Care\*

A UK charity dedicated to supporting all people with arthritis.

- Events and workshops for young people aged 12-18 and their families
- A free information helpline  
0808 800 2000
- Factsheets about the different types of JIA
- Stories of people's experience of JIA
- Online discussion groups for young people & families

[www.arthritiscare.org.uk/managing-arthritis/children-with-arthritis](http://www.arthritiscare.org.uk/managing-arthritis/children-with-arthritis)

\*in November 2017 Arthritis Research UK and Arthritis Care merged to become one charity.

## Arthritis Research UK\*

A UK charity that invests in breakthrough treatments, the best information and vital support for everyone affected by arthritis.

- Information about JIA and medications
- Information on living with and managing JIA
- A free information helpline  
0800 520 0520
- Read young people's stories
- Videos of young people giving their experience, advice and tips

[www.arthritisresearchuk.org/arthritis-information/young-people](http://www.arthritisresearchuk.org/arthritis-information/young-people)

*“informative and concise and there is information on so many different aspects of arthritis” (Kate, 33 diagnosed aged 21)*

## JIA @ National Rheumatoid Arthritis Society (NRAS)

A UK charity that provides information and support for those with JIA.

- Information and booklets
- Range of events for children and their families
- Stories about children's and families experiences of JIA
- Information on education, work, benefits and transition.

[www.jia.org.uk](http://www.jia.org.uk) t: 0845 458 3969

## **Oxford Paediatric and Adolescent Rheumatology Centre (OxPARC)**

Information for patients who have a rheumatic condition. Developed by Dr Wilkinson and Eunice Godbold.

- Information on JIA & factsheets
- Frequently asked questions (FAQ)
- Medication and therapy information
- Teenage section

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

## **Children's Chronic Arthritis Association (CCAA)**

A UK charity that supports children and young people who have arthritis and their families.

- Information about JIA
- Two family support weekends a year
- Stories of people's experience of JIA
- Small grant awards available

[www.ccaa.org.uk](http://www.ccaa.org.uk) tel: 07958187600

## **Arthritis Research UK: Centre for adolescent rheumatology**

A 'virtual' centre that involves young people with rheumatic conditions in research.

- Information about JIA, Juvenile Systemic Lupus Erythmatosis, Juvenile Dermatomyositis and their treatments
- Tips and advice given by young people via videos
- Informative videos given by health professionals
- Opportunity to get involved in research

[www.centre-for-adolescent-rheumatology.org](http://www.centre-for-adolescent-rheumatology.org)

## Arthurs place

A UK charity that has created an online magazine and social network for young people with JIA. Written for teenagers to promote self-management.

- Articles on topics relating to arthritis
- Facts about arthritis
- Helpful tips for dealing with everyday life known as 'life hacks' e.g. about injections
- Real life stories and blogs written by young people
- Online discussion groups

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

*“great advice regarding the practical side of living with arthritis” (Kat 22, diagnosed aged 9)*

## Youth health talks

A charity that provides information about health issues, by sharing people's real-life experiences.

- Videos of young people talking about their experience of JIA
- Detailed information on JIA
- Information on monitoring, treating and living with JIA
- Messages to young people with JIA from young people who have the condition

[www.healthtalk.org/young-peoples-experiences/arthritis/topics](http://www.healthtalk.org/young-peoples-experiences/arthritis/topics)

*“the videos are helpful and it is great hearing other young people's stories” (Katherine 23, diagnosed aged 6)*

## Contact us

Rheumatology at Evelina London (RhEve)

RhEve Helpline **t:** 07918 338768

**e:** RhEve@gstt.nhs.uk

Youth Worker \_\_\_\_\_

**t:**07771 982860 **e:**

YPF@arthritiscare.org.uk

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

## Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**t:** 020 7188 3003 10am to 5pm, Mon to Fri

**e:** letstalkmedicines@gstt.nhs.uk

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department. **t:** 020 7188 8801 (PALS)

**e:** pals@gstt.nhs.uk

**t:** 020 7188 3514 (complaints)

**e:** complaints2@gstt.nhs.uk

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