



# Juvenile Idiopathic Arthritis (JIA)

This leaflet is for children, young people and their parents and carers. It explains what Juvenile Idiopathic Arthritis (JIA) is, how it can affect you and what treatments and monitoring are available. If there is anything you do not understand or if you have any questions or concerns, speak to your doctor or nurse in the Paediatric Team.

#### What is JIA?

The word **arthritis** means that your joint is swollen, warm and doesn't work as well as it used to. We don't know why this happens, but when it happens to children under 16-years old, and lasts for more than 6 weeks it is called Juvenile Idiopathic Arthritis or JIA for short. There are lots of different types of JIA, which all affect the body differently. It can sometimes even affect the eyes. This is called 'uveitis'. Often, children do not have any symptoms of uveitis, but it can cause eyes to be sore, red or cause blurred vision.

Symptoms of JIA include hot and swollen joints, morning stiffness (a feeling of not being able to get going normally, as though the joints need oiling), and reduction in the range of movement at a joint. This may cause some children to limp. In a rare type of JIA, symptoms also include fever and a rash. We call these symptoms a 'flare' of arthritis.

#### Why does it happen?

In some children, the immune system that usually fights off infections can sometimes get confused and start attacking the joints. This is often triggered by a recent viral infection, but we do not know why this affects some people and not others. It is more likely that you may get JIA if there is a family history of conditions such as rheumatoid arthritis, psoriasis, ankylosing spondylitis or inflammatory bowel disease in a parent.

## What medications will I need?

There are lots of different options for treatment. Some of the most common medications that we give for JIA are:

- **Ibuprofen:** this is an anti-inflammatory medication. The commonest version is Nurofen. It is taken three times a day with food. It can help treat minor joint flares, help with pain and mobility while you are waiting for a joint injection.
- Steroids:
  - Intra-articular steroid injection: We can give an injection of steroid into the joint (intraarticular) to directly treat the inflammation. For children, this is usually done by a specialist team in Southampton Hospital. Depending on your age, and number of joints with arthritis, an intra-articular steroid injection can be done under a general anaesthetic, or with local anaesthetic and Entonox (gas and air) or with a virtual reality head set for distraction.

- **Prednisolone:** This is a steroid tablet taken by mouth, every day, for a period of a few weeks which helps get inflammation under control quickly. If the rheumatology team are particularly worried about your joints, we can also give this as an intravenous infusion (through a drip) over the course of three days.
- **Methotrexate** is a special medication called an 'immunosuppressant' that can be given as a tablet, a liquid or as an injection and it is taken once a week. This medication will stop your body from attacking itself. If you need Methotrexate, you will usually need to stay on it for up to two years.

Some of these medications require you to have blood tests to ensure your body is not reacting to them. We will discuss this with you and your parents/carers at your appointment.

## Will my JIA go away?

Many children will grow out of JIA with the correct treatment. Treatment can take anywhere between three months to two years, or sometimes even longer depending on the individual and the treatment needed. Everyone is different. You will continue to be monitored until we are completely happy that the disease is no longer active. We will then follow you up for at least two years after you stop treatment in case the arthritis comes back.

# Useful websites for more information and further help

<u>www.jia.org.uk</u> <u>www.versusarthritis.org</u> <u>CCAA | Supporting Children With Arthritis | Juvenile Idiopathic Arthritis | JIA CCAA | Children's</u> <u>Chronic Arthritis Association | JIA Charity - https://www.ccaa.org.uk/</u> Juvenile Arthritis Research (jarproject.org)

# The JIA monitoring team at the Royal Berkshire Hospital

Dr Helen Wolfenden, Consultant Paediatrician Alice Bloomer, Paediatric Physician Associate

## How to contact us

You can contact us with questions about blood tests, medication requests, vaccinations etc at: rbb-tr.paedsrheum@nhs.net

This is not an emergency helpline and is only monitored during working hours. We aim to respond to emails within three working days.

If you are concerned about your joints and think you are having a flare, please contact us as soon as possible; we prioritise these concerns.

Alternatively you can call **0118 322 7531 and select option 2** to leave a message with the Paediatric Admin Team.

### How to book blood tests for medication monitoring:

If you have been told to have a blood test, you can book it one of two ways:

 The preferred method for booking blood test appointments is through the online booking system which can be found at <u>https://www.swiftqueue.co.uk/royal\_berkshire.php</u>.
There is always a wait for appointments, so **please book well in advance**.

If you are **5-12 years old,** please click on 'Child blood tests'.

If you are **12 years or over**, please click on 'Adult blood tests' unless you have additional needs.

2. If you have been told that you need to have a blood test done very soon (less than 8 weeks) as you have just started treatment, or you have additional needs, you will need to call our Observation Bay on 0118 322 8998. You will need to tell them that you are under the care of Dr Wolfenden and are taking an immunosuppressant.

The Observation Bay is open for blood tests 10am-10pm, 7 days a week.

Please note, at times the nursing staff are unable to answer the phone due to clinical demand and you may need to call back. Quieter times tend to be in the morning.

Please email us if you are unable to get an appointment within the timeframe needed.

#### Methotrexate monitoring blood tests

If you are starting Methotrexate, you will need regular blood tests to ensure that the medication is not affecting your liver or infection fighting cells. We monitor your blood results closely to keep you safe, and will always update you with any changes.

The team will have discussed the medication with you already.

For your first appointment, please call our Paediatric Observation Bay on **0118 322 8998**, and ask for the first appointment. When you attend, please take this table with you, and for all subsequent appointments:

Weeks since starting treatment	Date and time of blood test
2 weeks	
4 weeks / 1 month	
8 weeks / 2 months	
12 weeks / 3 months	
16 weeks / 4 months	

After this, you will need a blood test every 3 months, unless the medical team advise otherwise.

To find out more about our Trust visit www.royalberkshire.nhs.uk

## Please ask if you need this information in another language or format.

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