

## Meet the Paediatric Rheumatology Team Rheumatology Team

This information leaflet is designed to introduce you to our team and the services we provide in the Paediatric Rheumatology department at the Great North Children's Hospital (GNCH). We offer a team approach and we all work together closely to help support you and your child. We understand this is a time when you need clear information and support. This leaflet summarises the structure of our team, how you can contact us and the services we offer.

Caring for a child with a rheumatic condition is not just a job for doctors. The doctors at the Great North Children's Hospital are part of a close-knit team of professionals all dedicated to providing the best possible treatment for your child and for you. The partnership we hope to establish with you is likely to be long-term and we hope you will work with us and talk to us; this is why our contact details are made available to you so that we can help you understand your child's diagnosis and treatments and, over time, share the responsibility for your child's condition.



[www.newcastle-hospitals.org.uk](http://www.newcastle-hospitals.org.uk)

## The Paediatric Rheumatology Team

### Clinical Specialist Nurses

Lead Nurse – Lucy Criag

Sharon Cairns, Kathy Seed &  
Jenny Hutchinson

**Phone** 0191 282 0373

This is a 24-hour advice line where you  
leave a message, which is usually  
returned within 2 working days.

### Doctors

Head of Depart – Dr Flora McErlane

Consultants: Dr Sharmila Jandial,  
Dr Ethan Sen & Dr Sunil Sampath  
Trainee doctors

**Phone** 0191 282 5318 to speak to their  
secretaries

### Physiotherapists

Rachel Cooper & trainees

**Phone** 0191 282 1285

### Occupational Therapists

Rachel Gyll & trainees

**Phone** 0191 282 1285



### Pharmacist

Karen Hartley

**Phone** 0191 282 5318

### Secretaries

Terry Bell & Alison Foreman

**Phone** 0191 282 5318

### Other staff you may come across

Nurses on ward 2B & outpatient department

Play specialists

Clinical researchers

Other consultants

## Clinics and appointments

The Paediatric Rheumatology team is based at the GNCH and is responsible for providing care to all children and young people with a variety of rheumatic conditions throughout the whole of the North-East of England, from North Yorkshire to the Scottish border and across to Cumbria. We may provide some appointments and treatments in your local area, but the majority will still need to be in Newcastle. If your appointment is not suitable, or you are unable to attend, please let us know via our secretaries as soon as possible as our clinics are often very busy.

All children and young people, regardless of how well they feel, will need to have a full examination including their joints at their clinic visit. We therefore strongly recommend bringing a **pair of shorts** to wear at the appointment. One of our physiotherapists or occupational therapists may ask further questions about how your child manages to carry out everyday activities at home, school and at leisure.

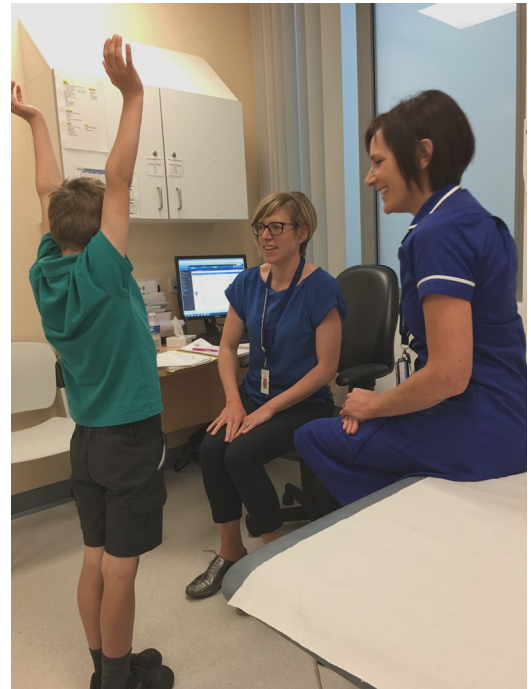
At the end of each appointment we will discuss with you your concerns and your child's priorities. This will allow us to identify problems together, and begin to plan how we can work in partnership with you, in order to treat your child best.

Each appointment is timed to allow discussion and explanation with you. However, the clinics are very busy, so each appointment needs to be timed carefully to approximately 15 – 20 minutes. Sometimes, if a child's condition or treatment is more complex, we may need to spend more time with a particular family and we very much appreciate your understanding if appointments run late. Please note that all children will have their height and weight measured as part of their appointment which usually happens before they go on to see one of the doctors or nurses.

## Who will see your child?

Your child will be seen by one of the doctors, the specialist nurses and/or therapists if necessary. The doctor will usually be one of the consultants, but we also are proud to be one of the few units in the country to train paediatric rheumatologists and in addition, as the hospital is a teaching hospital, we also have GP trainees working within our team. If you see one of our trainees your child will always be discussed with a consultant in the clinic. GNCH is closely associated with Newcastle University and we sometimes have medical students sitting in clinics for their education. It is very helpful for their learning, but we will ask your permission for the student to be present. In your clinic visit the doctor will want to find out what has happened to your child. They will ask questions about what you have noticed, why you may have been worried, who else has seen your child. This is a medical history and gives the doctor clues to your child's illness.

There may be things you wish to discuss but the doctor will want to gather the facts and information first. Once this has been done the doctor will always ask you if there is anything further you want to say. Often the doctor will need to rule things out which aren't relevant or piece together what has happened to your child. It is very common for children not to complain or for parents not to notice a problem with their child. You must not feel guilty about this. We will help you understand why this can happen and more importantly help you spot further signs.



The focus in the consultation is about your child and the doctors can't check other family members for illness or comment on their treatments.

Blood tests and sometimes other investigations can usually be done during this appointment. We are always trying to learn more about rheumatic diseases in children to improve diagnosis and treatment. So we may ask if you and your child are willing to participate in research if it is relevant to your child's condition.

Some rheumatology patients need regular eye assessments in the Ophthalmology department. We try hard to co-ordinate appointments between the two teams as we are very aware that some families travel long distances for their rheumatology care.

## Further Clinic visits

These clinics also take place in the Outpatients department at the GNCH. Even if your child's condition seems to be well controlled, it is important to have a regular review to check for subtle signs of the disease, check on their growth and to ensure their rheumatic condition does not interfere with their ability to do well at school, participate in activities they enjoy or impact on their mental health.

If your child is on medication we need to see them regularly in order to keep prescribing their medication. If you can't make an appointment it's important to ring our secretaries so we can rebook your child's appointment as soon as possible

When you come to back to clinic the doctor will want to check how your child is since we last saw them. It's really important, even if you think they are fine, that the doctor or another member of the team checks them. Children often don't complain or report symptoms so they will have a thorough examination. You will have an opportunity to discuss key issues of concern.

Sometimes your appointment may need to be changed by us and sometimes you may need to change appointment. You can ring up our secretaries who will try to rearrange your appointment. We have some flexibility but can't always accommodate individual requests.

## Adolescent Clinic

All of our patients are followed up until between the ages of 16 and 18. We now have dedicated clinics for our young people that are run separately from our other follow-up clinics. These clinics aim to allow young people to understand how to manage their disease and treatments for themselves, and offer advice for other problems of teenage life that may be impacted by their disease. Patients in this clinic will usually be seen on their own by the doctor and specialist nurse, but will always be offered the choice to have their parents present if they wish it.

## Speciality Clinics

Some of our patients have rarer conditions which involve other parts of their bodies such as the skin, muscles, kidneys and nerves. We often work with other teams to support these patients in a specialist clinic. There can be several consultants in the clinic room. The purpose of this clinic is to allow a number of experts to see your child in one visit. We will always explain who everyone is and after your first few visits you will quickly see the benefits of having the consultants caring for your child all at the same clinic visit. One consultant always takes the lead at these appointments and you will be included in the decision making.

If you are concerned or worried about this clinic please ring and speak to our specialist nurses who will adjust the clinic accordingly if possible.

## Top tips for consultations

- Keep a list of questions you may have, just in case you forget, and bring it along on the day.
- Keep your questions in order of importance – remember your child is one of many in clinic and each family only has approximately 15 - 20 minutes.
- Remember the nurses are specialists too – often they will explain or repeat information from the doctor especially about treatment.
- Some questions are asked to make sure you get the right help and support.
- You won't always see the same doctor, nurse or therapist. We are only a small team but work closely together.
- It is natural to get on better with some members of the team than others. However, it's important that everyone is treated equally. We will be professional, polite, and patient with you and expect you and your family to offer the same to our staff. If there is an issue you can raise it at the time or ask to speak to another member of the team.
- As a team, we have a duty to safeguard the physical and mental well-being of all children. We always want to work with families in doing this. Sometimes we have concerns that a child is at risk of coming to harm because for example a child is not being given the medication they need or repeatedly not being brought to appointments (clinics, X-rays/scans, hospital treatments). If we have these concerns we will try to discuss these issues with you however sometimes we may need to discuss with other professionals such as the GNCH Safeguarding Children team or local Social Care team.

## Diagnosis

Often, after your child's initially assessment, the rheumatology team will have a good idea about what the problem could be. Further tests may be required to confirm or disprove this diagnosis. It can be difficult waiting, but we will provide specific information about your child's condition when we know.

## Investigations & Tests

For many of our patients, the team will decide if further tests are needed to provide more information. This may be an X-ray, scan or blood test. Often we need to look for clues to build a picture of the condition and its effects. The team will explain to you what needs to be done and how this will be arranged. Sometimes we need to rule things out and this means you may have to wait before we can give you a definite diagnosis.

You may want a scan or investigation, but the team will decide what your child needs. This is because we don't want to put children through tests unless they are going to help us decide upon their diagnosis or treatment.



## Blood Tests

It is likely, at some point, that the doctor will want to arrange some blood tests for your child. Often this will be arranged on the same day as your clinic appointment. The nurses in the clinic are very experienced at taking blood from children of all ages. They will talk to you about the best way to make the process as smooth as possible.

The nurses often use cold spray, which is very cold, cools the skin down and can be used immediately prior to the blood test. It is a popular option to get the blood test over quickly. Cream that numbs the skin can also be used but needs to be applied and left for an hour to work. This wait can actually add to your child's anxiety so may not be the right option for your child. The nurses use distraction to reassure you and your child during the blood test and stickers are often given as rewards.

## Medications

There are a variety of medications that we use. You may be worried your child is in pain. From our experience, this isn't always the case and stiffness or reduced movement of joints, for example, may be more of an issue. The team will want to understand what symptoms you notice and then what we can actually see when we examine your child. Some medication can be given for a short time to help with stiffness or pain. If long-term pain is the main issue, stronger painkillers are not usually the best solution. The doctors will assess your child and may ask the Physiotherapists within our team, or colleagues more local to your home, to see your child and provide exercises and advice which can help with their symptoms.

### Top tips for medications

- Only give medicines to your child if advised by a medical team – do not share medicines at home.
- Follow the instructions on the pack so you know how and when to give the medication and if the medication needs to be stored in the fridge.
- Ask if you wish to use supplements or vitamins as they may interfere with medicines the team may prescribe.
- Don't stop medication abruptly without speaking to the team prescribing them.
- If you are struggling to get your child to take their medication, ring the nurses for some advice – this can be very common especially in young children.
- Remember - other children with the same condition may be on different medications.
- You may be part of an online forum for parents/patients where medication is discussed. We make decisions for patients as individuals and if you have worries or concern about your child's treatment ring our nurses for more information.

