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**Royal Manchester Children’s Hospital**

**Information for Patients**

**Paediatric Inflammatory Multisystem Syndrome Temporally associated with SARS-CoV-2 pandemic (PIMS-TS).**

**What is PIMS?**

It is a new condition that happens weeks after a child has been exposed to the virus that causes coronavirus (COVID-19) however may not test positive for COVID they may have positive antibodies. It causes inflammation (swelling) throughout the body which is one of the ways your immune system fights off infection. Most children and young people do not become seriously ill with COVID-19 and this syndrome is very rare and most will not be affected. This information sheet describes what we know about PIMS-TS, how it was treated while you were in hospital and things to consider.

**How is it diagnosed?**

Even though it is a new condition doctors already know a lot about it and lots of research is being carried out all over the world to find out more about it. Although your child may have had a nose and throat swab to confirm they had COVID-19 PIMS seems to develop after the virus is infectious. Doctors will need to rule out any other common conditions which may cause similar symptoms such as Kawasaki Disease, Sepsis, Malignancy and Sickle Cell Disease.   
  
There is no specific blood test that can diagnose PIMS so the doctors will have to look at the whole picture to work out if your child has it. They will look at the inflammation levels from the blood tests as well as checking how other parts of your child’s body is working as it may affect your child’s heart. Together the results along with the symptoms will allow the doctors to confirm the PIMS diagnosis so they are able to treat it.

**How is PIMS treated?**

The aim is to ‘turn off’ your child’s immune system to stop the inflammation and then to ‘reset’ it to reduce the risk of long-term damage. Here are some of the treatments that your child may have received.

* **Intravenous immunoglobulin (IVIG)** – Taken from blood donations - Contains lots of antibodies as it is the proteins in the blood that fight off infection and is given as a drip
* **Corticosteroids –** Your child might have had this as a drip of by mouth as tablets or liquid. These will calm down your immune system however might make you more susceptible to other infections. Once you no longer need steroids you may need to gradually ‘wean’ them rather than stopping suddenly so your body is able to start making its own steroids again.
* **Anti-clotting medicines** (aspirin and enoxaparin) – aspirin makes blood less ‘sticky’ so it is less likely to form clots. This will need to be stopped after six weeks if the doctors are happy. Enoxaparin is given as an injection and makes blood thinner. However, is only usually given while in hospital.
* **Gastric Protection** (Omeprazole) – To have whilst on prednisolone and aspirin as they can irritate your child’s stomach
* **Biologic Medicines** (Anakinra and Tocilizumab) – help to ‘switch off’ your immune system.

**What are the symptoms?**The main symptom of PIMS is a high temperature that lasts for a few days. Other symptoms may include:

* Rash
* Tiredness/Weakness
* Tummy pain or cramps
* Red and cracked lips
* Swollen hands and feet
* Peeling skin on your hands and feet
* Headache
* Red eyes
* Muscle aches and pains
* Diarrhoea and vomiting
* Swollen neck glands
* Unexplained irritability

**Going home after PIMS**

Your child will only be discharged home once the clinical team are happy that they are clinically well, no temperature for 48 hours and tolerating their oral medicines. The medical team will stay in contact and arrange follow up if needed. As PIMS affects all areas of the body your child may still have some symptoms including:

* Trouble concentrating
* Thinning hair or hair loss
* ‘Up and down’ emotions
* Sleeping difficulties
* Rashes and skin peeling
* Changes to your hearing
* Tingling hands and feet
* Loss of smell and/or taste
* Swallowing difficulties or voice changes
* Diarrhoea
* Change in appetite
* Muscle weakness and tiredness
* Tummy pain
* Problems with your heart, kidneys or breathing

A multi-disciplinary PIMS-TS clinic has been established at RMCH. The clinic is currently run by Paediatric Rheumatology, General paediatrics and Cardiology teams. Your child will be reviewed in clinic at:

* 1-2 weeks after discharge
* 6 weeks after discharge

6 months after discharge

**Frequently asked questions**

**Can I go back to school?**Yes, you can if you feel well enough – you will probably feel tired for a while after having PIMS so do not try to do too much too soon. Maybe try and slowly build up your time in school   
  
**Can I see family and friends?**Your child does not need to ‘shield’ or stay isolated if they have had PIMS. Although you’re not infectious you should still follow Government guidance.  
  
**What about contact with infectious diseases?**The medicines your child had to treat PIMS will damp down their immune system so ensure that they avoid contact with anyone with chicken pox, measles and TB.

**Should I have my routine vaccinations?**The treatment your child had to treat PIMS can affect how well the vaccination will work. For example, if your child had IVIG we recommend waiting three to six months before vaccination.  
If you had anakinra or tocilizumab you should wait at least six months to have any live vaccines.  
  
**Can I get PIMS again?**When you have an infectious illness such as PIMS, our bodies make ‘antibodies’ to it so that we are protected against it. So, although we know people who have had COVID-19 and PIMS make antibodies, we’re not sure how long they last. If your child starts to feel the same as they did when they had PIMS, contact your local hospital where your child received treatment.

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