



Lowe Syndrome Trust statement on COVID-19

There do not currently seem to be any particular additional risk of COVID-19 (coronavirus) in Lowe syndrome. Overall, there is an increased level of susceptibility to infection for any child with a chronic medical condition, so boys with Lowe syndrome are more likely to catch it, and to have symptoms for longer, but there is no reason to believe boys with LS won't recover normally.

In general, you should follow the [latest government NHS guidelines](#) on Covid-19:

- If you experience symptoms, stay at home and self-isolate. Do not go to hospital or your GP.
- Use the [111 online service](#) for further advice.

Medical

- If your child has a kidney transplant, immunosuppression means they are less able to fight off a viral infection, but it is important for their treatment – no changes should be made to taking immunosuppressants without consulting your specialist.
- Sickness can lead to reduced adherence to taking medication, so every effort should be made to keep up with their regimen despite illness. Again, any changes due to your child being unable to take their medication should be discussed with your doctor.
- Boys with LS may have more regular trips to the doctor or clinic, which means they have an additional exposure risk to COVID-19, especially if they undergo haemodialysis in a centre (from other patients and exposed healthcare workers). Please take extra precautions with handwashing both for yourself and your child.
- In general, hospitals and medical centres are now busier due to the COVID-19 outbreak. This means doctors may be less available for routine checks, to offer advice or even in emergencies. Please make sure they do have a copy of the

[LS Medical Information Sheet](#) (included below) to take with you to A&E if there is an emergency.

- Please avoid stockpiling medications, but you will need to plan ahead to make sure you will not run out. This may mean allowing extra time for pharmacies to process prescriptions due to current high demand.

Lifestyle

- Poor nutrition can reduce the effectiveness of the immune system, so a balanced diet with sufficient vitamins and minerals should be kept up as far as possible.
- Social distancing and isolating behaviours will increase time spent at home sitting down. Children do need to keep exercising and drinking water regularly even if confined to home, as this will prevent development of constipation, which is common in LS.
- Obsessive behaviours may make it harder for boys with LS to change routine, such as not going out or visiting friends/relatives, or embrace new habits, such as longer handwashing. If these things are a problem, try to prepare your child as far in advance as possible for these changes to avoid distress.
- Anxiety and mental distress due to fears about catching Covid-19 are increasing in children –take time to talk to your child and reassure them.

If you have any further questions regarding the virus, please email us on info@lowetrust.com, and we will do our best to answer. However please note that we are not authorised to provide medical advice or assistance, and further help should be sought from medical professionals.

Low Syndrome – A&E Information Sheet

Parents – please complete this and take along with a copy of the most recent clinical report regarding your child.

Patient name:	DOB:
Specialist name:	Institution:
Telephone:	Email:

Clinicians – this sheet provides background information for Lowe Syndrome, also known as Oculocerebrorenal syndrome of Lowe (OCRL). For further information, please use the details above to contact the specialist responsible for this patient, who is happy to advise on details of the medical management.

- Low Syndrome**
- Rare, X-linked recessive disorder, affecting males
 - Causes physical and mental handicaps
 - Affects the eyes, brain, kidneys, muscles and bones
 - There is currently no cure, and treatment is supportive



- Eyes**
- Born with cataracts, usually removed early in life
 - 50% of cases suffer raised intra-ocular pressure leading to glaucoma



- Kidneys**
- Kidney disorders can cause features of renal Fanconi syndrome, including:
 - o polyuria and/or polydipsia; this can lead to dehydration
 - o low-molecular weight proteinuria
 - o elevated urinary calcium, which can cause kidney stones
 - o metabolic acidosis
 - o phosphate wasting, which can cause rickets



- Abdomen**
- Pain can be due to constipation resulting from dehydration
 - Acute pain can also be caused by kidney stones, so an U/S should be considered



- Surgery/ blood**
- If surgery is required that risks major blood loss, it is important to note that many Lowe's patients have an impaired platelet function, evident from prolonged closure times in the PFA-100 system. The bleeding risk can be ameliorated with ϵ -aminocaproic acid.