IgA nephropathy, or Berger disease, causes inflammation (swelling) in the kidneys. Children with IgA nephropathy have blood and protein in their urine, and may have swelling in their body. IgA nephropathy may lead to other complications, including high blood pressure (hypertension).

All children with this disease are carefully monitored by a team of healthcare professionals. Some need to stay in hospital for a few days, but most of the time they will need to visit the hospital during the day only. Children may need to make changes to what they eat and drink, and take medicines.

For many children, IgA nephropathy is quite mild and they will get better. About 3 or 4 out of 10 children with this disease will have long-term problems with their kidneys, and will need to be monitored and have specialist treatment when it is needed.

About the urinary system

The urinary system gets rid of things that the body no longer needs, so that we can grow and stay healthy.

The kidneys are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

The two ureters are long tubes that carry urine from the kidneys to the bladder.

The bladder is a bag that stores urine until we are ready to urinate (have a wee). It sits low down in the pelvis.

The urethra is a tube that carries urine from the bladder to the outside of the body.
About IgA nephropathy

About glomerulonephritis

IgA nephropathy is a type of glomerulonephritis, a group of conditions that affect the kidneys. Inside the kidneys, there are many tiny filters called glomeruli. They help to remove extra water, salt and waste, which are passed out of the body as urine. They also make sure the body keeps what it needs, such as blood cells, protein and other important chemicals.

In glomerulonephritis, the glomeruli become inflamed (swollen) or damaged. This causes both blood and protein to leak into the urine.

About IgA nephropathy

Although it is rare and does not affect many people, IgA nephropathy is the most common type of glomerulonephritis in developed countries such as the UK. It happens in people of all ages, though it is most often diagnosed (identified) in people under 30 years of age, especially older children and teenagers. IgA, a protein made by the body, gets ‘trapped’ in the glomeruli, causing damage.

IgA nephropathy is sometimes called Berger disease. This is because a doctor called Berger first described the disease in the 1960s.

Henoch–Schönlein purpura

Children with Henoch–Schönlein purpura (HSP) may have IgA nephropathy as well as other symptoms, often including a rash on the skin, pains in their tummy and pains in their arm and leg joints.

Symptoms and complications

Symptoms and signs

Some children with IgA nephropathy do not have any symptoms and signs, especially in the early stages of the disease. Common symptoms and signs of IgA nephropathy include:

- blood in the urine (haematuria) – you cannot always see the blood, but if there is a lot, the urine may be coloured red or dark brown (like a cola drink)
- protein in the urine (proteinuria) – you cannot usually see the protein, but sometimes it can make the urine look frothy. It can be found on a simple urine test
- urinating (weeing) less often or smaller amounts
- swelling or puffiness in different parts of the body, especially around the eyes, legs and feet – this is called oedema.

Complications

Some children have complications – health problems that happen because of the condition or its treatment.

- IgA nephropathy may lead to blood pressure that is too high (hypertension).
- Occasionally, the condition gets worse quickly and the kidneys work less well than normal – this is called rapidly progressive glomerulonephritis (RPGN).

Causes

IgA nephropathy is usually caused by problems with the immune system, which normally protects the body against disease and infection. The body makes proteins called immunoglobulins that help to kill germs. In IgA nephropathy, one of these proteins, immunoglobulin A (IgA), gets trapped in the glomeruli.

Doctors do not fully understand why this happens in some children. It cannot be passed on to other children or adults. It does not usually run in families.

Tests and diagnosis

Diagnosing glomerulonephritis

Your child’s doctor can diagnose (identify) glomerulonephritis with a urine test. It is often picked up during a urine test for another reason – such as red or brown urine or a urinary tract infection (UTI). Your doctor will speak with you and your child about the symptoms and do a physical examination. Your child may also need other tests, such as blood tests and an ultrasound scan.

Diagnosing IgA nephropathy

Your doctor can diagnose IgA nephropathy with a kidney biopsy, and may recommend this test. A tiny piece of one kidney is removed from the body with a needle, and examined under microscopes. Special medicines are used so your child does not feel any pain or can sleep through the procedure.

Treatment

Where will my child be treated?

Your child will probably be referred to a paediatric renal unit, a special unit for children with kidney problems, which may be in a different hospital from your own. Your child will be looked after by a paediatric nephrologist, a doctor who treats children with kidney problems.

Your child may need to stay in hospital for a few days or longer. Most of the time, children with IgA nephropathy have their care as outpatients. This means that your child will visit the hospital during the day and go home.

About treatment

Your child may need to make changes to what he or she eats or drinks. Many children need to take medicines that aim to reduce the amount of protein lost in their urine. Occasionally, other medicines are needed.
About the future

Follow up
It is very important that your child goes back to the hospital or clinic for follow-up appointments, especially to check for proteinuria (protein in the urine). You may also need to test your child’s urine at home.

Long-term effects
Your healthcare team will speak with you and your child about any long-term effects your child might have with IgA nephropathy. IgA nephropathy can be a chronic condition, which means that it does not go away and may get worse over time.

- For most children with IgA nephropathy, the disease is quite mild and will not affect how their kidneys work.
- About three or four children in 10 with IgA nephropathy have long-term problems with their kidneys. Their kidneys stop working as well as they should – this happens slowly and there may not be any problems until adulthood. This is called chronic kidney disease (CKD). If your child has CKD, you will learn more over time about how to help manage the condition and what to expect.

» Read more about IgA nephropathy on www.infoKID.org.uk