What is Alport Syndrome?

Alport Syndrome is the second most common inherited cause of kidney failure.

It occurs when a special type of collagen (Type IV collagen) normally found in all tissues but especially in the kidney, inner ear and eyes, is missing or abnormal.

One of the early signs of Alport Syndrome may be small amounts of blood or protein in in the urine during childhood. This occurs from membranes in the kidneys filtering units or glomeruli.

Blood loss is usually microscopic and so not visible, but may be greater if the child is unwell, for example if they have a viral illness. Then the urine may become pink, or smoky red, although this settles as the child recovers.

Taken from BBC website

Created by those living with Alport Syndrome and supported by:



and the Rare Diseases UK working group for Alport Syndrome



The National Alliance for people with rare diseases & all who support them



Alport Syndrome

Blood Test Results: Understanding your numbers

Produced for the First National Alport Family Support Day (1 December 2012) and Renal Patient View

For further copies, email info@alportuk.org

Know your numbers

| Key renal fu | nction numbers | |
|----------------------------|--------------------------------------|--|
| Creatanine | Less than 60 | Suggests a very small person, or someone with little muscle (including small children). |
| (Creat) | 60 – 120 | 'Normal' but there could still be reduced kidney function. This should be used in combination with estimated GFR. |
| | 120 – 200 | Mild to moderate kidney failure – but in someone with little muscle, 200 could sometimes mean more severe kidney failure. |
| | 300+ | Moderate to severe kidney failure. Most dialysis patients have Creatanine measurements over 300 all of the time. |
| Estimated GFR (eGFR) | Over 90 | Normal. |
| | 60 – 90 | Many people with eGFR 60 – 90 are normal. As eGFR of 60 – 90 should only be used as evidence of kidney disease if there are other things wrong – such as protein or blood on urine tests or other tests showing kidney disease |
| | 30 – 60 | Moderately severe kidney damage. This is known as Stage 3 CKD. |
| | 15 - 30 | Severe kidney damage, Stage 4 CKD. Anaemia and bone disease become common problems as kidney function falls below eGFR |
| | | 25. |
| | Below 15 | This is known as Stage 5 CKD. An average figure for commencing dialysis in the UK is 8 to 10, but this varies between patients. |
| Other numbe | ers it may be useful | to know and understand |
| Albumin (Alb) | Below 35 | Low levels of albumin are found in nephrotic syndrome (when the kidneys leak protein), various serious illnesses (e.g. infections) that slow down production of albumin, liver disease, and malnutrition. May cause oedema (swelling). |
| | 35 – 50 | Normal (some labs say 35-45) |
| | 50+ | High - may be a sign of dehydration. |
| Calcium (Ca) | Less than 2.1 | Low calcium causes an increase in PTH, which then moves calcium out of bones and thins them. 'Low' calcium may be normal in |
| | | patients with a low serum albumin. |
| | 2.1 – 2.6 | Normal in patients with a normal serum albumin. |
| | 2.6+ | Too high – risk of calcification of arteries and itching. |
| | 3.0+ | Likely to make you feel very unwell. |
| Haemoglobin (Hb) | Below 80 | Likely to make you feel breathless and tired. Many causes include bleeding but it can occur due to renal failure. |
| | 100 – 120 | Commonly the target for Hb in patients under treatment for anaemia using EPO. Still slightly anaemic for some people. |
| | 130 – 180 (men) 115 – 165 (women) | Normal |
| | 180+ | This is unusual in kidney disease, except sometimes after kidney transplantation. Risk of blood clotting. |
| Phosphates (PO4) | Less than 0.8 | Suggests poor food intake, or refeeding with sugar after starvation. Sometimes occurs in kidney diseases and inherited conditions. Very low levels cause severe weakness and bone problems. |
| | 0.8 – 1.4 | Normal |
| | 1.5 – 1.8 | Acceptable in dialysis patients and patients with severe renal failure. |
| | 2.0+ | Too high - risk of bone disease, and of calcium deposits forming in arteries and elsewhere. |
| Potassium (K) | Below 3.5 | Too low. Common after haemodialysis, when it is usually temporary. If below 3.0 patient may feel weak. |
| | 3.5 - 5.0 | Normal. |
| | 5.0 - 6.0 | High but usually not dangerous – getting closer to dangerous at 6.0. It is common to arrive for haemodialysis with a slightly high potassium level. |
| | 6.5+ | Dangerously high. |
| Jrea | Below 3.5 | Low. Common explanations are low protein intake from diet, or liver disease. A low urea is normal in pregnancy. |
| (BUN) | 3.6 - 5.0 | Normal. |
| | 7.0+ | High. Suggests renal failure, dehydration, high protein intake, or bleeding. Levels over 8-10 are unlikely to be due to diet alone. |
| | 25+ | Very high - suggests serious illness or renal failure. |