

## Renal Association Patient Information Programme

### Guidelines for Lead Authors

August 2017

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#### Introduction

Thank you for volunteering to be the lead author for one of our leaflets. We are very grateful for your time and expertise on this project.

Our aim is to create a series of patient-focused leaflets on a variety of topics relating to kidney health. The topics have been chosen because of their importance to the kidney patient community and the lack of easily accessible information on this topic.

#### Background Research

When your leaflet has been commissioned, you will be sent a link to a folder on Workshare containing a series of existing resources on your specific topic, or those that relate to the key words that you have provided.

These resources have been chosen based on their perceived accessibility and relevance to patient audience. They may be from national organisations such as the Kidney Care UK, National Kidney Federation, InfoKID, or Trust-specific leaflets. The majority of the resources will be UK-based to avoid conflicts with different practices overseas.

#### Your Role

We would like you to take the information in the resources provided, along with your own expertise, and create a patient information leaflet on the given topic.

The finished leaflet should be no more than 2 A4 pages in length and be accessible to a non-medical audience with an approximate reading age of 16 (11 years of schooling).

Although the exact sub-headings may vary depending on topic, please consider the following as a potential starting point:

#### Condition-focused leaflets

- How the condition affects people – signs and symptoms
- What can be done about it – treatment, drugs, procedures
- How it works – genetics, physiology

#### Treatment-related leaflets

- What is the treatment used for
- How does it work
- How often does it take place
- Risks/Benefits
- What are the alternatives

Sample information from RareRenal.org and InfoKID are included in the Appendix.

Please also consider including:

- Diagrams/pictures – an indication of what you would like to include is sufficient at this stage as the exact image can be sourced at a later date
- A Glossary to explain more medical terms
- Suggests for further reading/additional leaflet topic suggestions

Please also indicate how you would like to be credited as the author of the leaflet (Job Title, organisation etc).

### **What Happens Next**

When the initial draft is completed, please send it to Melanie Dillon, Operations Officer - [Melanie.Dillon@RenalRegistry.nhs.uk](mailto:Melanie.Dillon@RenalRegistry.nhs.uk). The leaflet will then be reviewed from an Information Standard perspective to ensure that the language is suitable for a non-medical audience.

The leaflet will then be typeset and sent back to you for review. Once finalised, it will be circulated to the Renal Association's Patient Information Subcommittee for sign-off ready for publication.

### **Contact**

For any questions please contact Melanie Dillon, Operations Officer - [Melanie.Dillon@RenalRegistry.nhs.uk](mailto:Melanie.Dillon@RenalRegistry.nhs.uk)

Thank you again for your support of this programme.

## Appendix One – Sample Information Leaflet from RareRenal.org

### Alport Syndrome – Patient Information

#### How the illness affects people

Alport **Syndrome** is a genetic condition that mainly affects the kidneys and hearing. Women are usually less severely affected than men and are more likely to only be carriers of Alport Syndrome (see **How the Disease Works** below). Some people will be the first in their family to show symptoms. For others it will be inherited from a previous family member. (Visit the **Clinicians page** for more information on prevalence)

#### Hearing

Hearing difficulties in boys are usually first noticed around the age of ten. That is around the same time that they start to show signs of kidney disease. A hearing test (**audiogram**) at this time will reveal hearing loss for high-tones while the ability to hear lower frequency sounds is less affected. We need high frequency hearing to understand speech. Hearing aids are therefore a good idea, especially for school or college. Once hearing loss has started, it usually slowly worsens over a period of ten years or more. As hearing is normal at birth and during early childhood, speech develops normally. Overall hearing loss is moderate and it is unusual for an Alport patient to become completely deaf.

#### Kidneys

One of the early signs of Alport Syndrome is having blood in the urine. In children, particularly boys, you can sometimes see the blood mixed into the urine. This occurs without any pain. At other times the blood is present but in such a small amount that it is invisible and only detected by a stick test, or by looking at the urine under a microscope. Urine tests may also find protein in the urine, and these urinary findings help doctors to consider the diagnosis. The abnormal urine tests occur long before there is any problem with kidney function.

Most men with Alport Syndrome develop kidney failure in their twenties or thirties. Women tend to develop hearing problems later than men and are less likely to get kidney failure, although both can still happen in later life.

#### Eyes

Some people with Alport Syndrome also have eye problems. These are usually minor and easily treated. They tend to occur in adults rather than children, and rarely lead to problems with vision. Small white flecks can sometimes be seen in the eyes. These have no effect on vision but can help in the diagnosis of Alport Syndrome. In

some Alport patients the lens of the eye becomes cone-shaped. If this becomes a problem, the lens can be replaced. This is like a cataract operation.

### **What can be done about it?**

Alport Syndrome is usually diagnosed by carefully reviewing the family history, testing the hearing, and checking the urine and kidney function. Confirmation is often made using a **kidney biopsy**. Because Alport Syndrome is genetic, it can be helpful to test for abnormalities in the genes known to cause it. If a genetic fault is found, other family members can be tested to see if they are likely to be affected, or if they could pass the gene on to their children. (Visit the **Clinicians page** for more information on genetic testing)

There is recent evidence that a simple treatment can slow down the disease in the kidneys. This is why it is now useful to make the diagnosis as early as possible. The treatment uses a well-known type of medicine that lowers blood pressure, called an **Angiotensin Converting Enzyme (ACE) inhibitor**. It reduces scarring in the kidneys so that they last longer. Side effects are rare, and usually a dose and make of ACE inhibitor, or a related drug known as an **Angiotensin Receptor Blocker (ARB)** can be found that is acceptable for long term use.

Decline in kidney function is not noticed by a patient until very late in the course of the illness. This is why it is important to have regular health checks where the level of kidney function will be worked out from a simple blood test. Various lifestyle adjustments can then be made that are appropriate to the stage of kidney function. For example keeping good control of blood pressure, ensuring good nutrition and preventing anaemia can all help to maintain wellbeing.

Different **Stages of Chronic Kidney Disease (CKD)** are based on levels of kidney function, ranging from mild to severe. When a patient approaches severe kidney failure, preparations will be made for renal replacement treatment. This may consist of **dialysis** or **transplantation**. Patients with Alport Syndrome usually respond well to transplantation and the condition does not recur in the new kidney.

### **How the disease works**

Each kidney contains about a million tiny filters called **glomeruli** that filter the blood stream. During the filtering process, fluid passes through the **glomerular basement membrane** which is made up of a fine mesh of **collagen fibres**. In Alport Syndrome one of these fibres, Collagen IV, is either faulty or missing because there is an error in one of the genes responsible for its production. Without normal Collagen IV, the filtering membrane is weakened. The body attempts to repair the weakened filters, however, over time they become scarred and can no longer function. Kidney function will then decline.

Collagen IV is also essential in the inner ear in the Cochlear membrane. This transmits sound vibrations to the nerve sensors in the ear. The weakening of this membrane eventually leads to hearing loss.

Carriers are people who have one abnormal copy of the Alport gene, and another normal copy. Mothers of Alport boys, for example, are always carriers.

Women who carry the disease on one of their X chromosomes usually have no or only minor kidney trouble. Tests often show small amounts of blood, and sometimes protein in their urine. However some are unlucky enough to get more severe disease and develop kidney failure. The lifetime risk of getting significant kidney disease for women who carry Alport's may be as high as 20-30%, but most never get severe trouble, and those who do are usually much older than men who are affected.

### **What's new? Opportunities for research and development**

The Alport Rare Disease Group (RDG) is working with international partners with the aim of finding new and improved treatments, and to empower patients. A first step is to compare the symptoms and genetic markers of Alports. To do this the RDG is registering patients with this condition in the National Renal Rare Disease Registry (RaDaR). The registry will be used to find suitable participants for future research trials into the effectiveness of new treatments. If you are interested in finding out more about the registry RaDaR or the activity of the RDG please visit the **Alport RDG page**.

### **Further Information**

- The website of the Edinburgh Renal Unit (**EdREN**) contains a wealth of information on Alport Syndrome, including **brief** and **detailed** overviews of the condition, information on **normal kidneys** and **Thin GBM disease**, which is often related to Alport Syndrome.
- There are two UK patient organisations. **AlportUK** is a patient charity, and **Action for Alport's** is an initiative to fund research run by Kidney Research UK. There are also a number of Facebook groups related to Alports, including **Action for Alports** in the UK and the **Alport Syndrome Foundation** in the USA.

## Appendix Two – Sample Information Leaflet from InfoKID

### Blood pressure – Information for Parents

Blood pressure is the force, or pressure that makes the blood flow round the body. Blood pressure is often shortened to BP.

- When the heart beats, or contracts, it pushes blood through blood vessels called arteries.
- When the heart relaxes between beats, blood returns to the heart through blood vessels called veins.

It is very important that your child's **blood pressure** is in a healthy range. If his or her blood pressure is too high or too low, your doctor will try to find out what is causing this.

#### High blood pressure

**Hypertension** is blood pressure that is too high. In some children, hypertension can be a serious condition. It can increase the risk of getting cardiovascular disease, especially if it continues into adulthood. Some children with hypertension have no symptoms, but it may cause headaches that do not go away, vomiting (being sick) or blurred (fuzzy) vision.

Hypertension in children is rare. If your child has high blood pressure, your doctor will try to find out what is causing it and whether it is affecting other parts of his or her body, such as the kidneys. Your child may need to make changes to his or her diet and/or take medicines.

#### Low blood pressure

**Hypotension** is blood pressure that is too low. This can happen in **acute** disease (where the illness comes on suddenly) or as a side-effect of some medicines. Some children with hypotension may have no symptoms, but some may experience:

- dizziness or light-headedness
- fainting
- blurred vision
- rapid or irregular heartbeats
- nausea (feeling sick)
- general weakness

Your doctor will try to find out what is causing it.

### Why does my child need his or her blood pressure measured?

Children may have their blood pressure measured for many reasons, including:

- during a doctor's appointment – this is routine
- when they are admitted to hospital
- before an operation.

### **Regular measurements**

Some children need regular measurements of their blood pressure, especially if:

- they already have hypertension, or high blood pressure
- they are at risk of high blood pressure – for example, because they have problems with their kidneys

### Blood pressure measurements

Blood pressure is measured using a special instrument. This can be either electronic or manual (worked by hand).

A blood pressure measurement has two numbers.

- The top number is called the **systolic pressure** – the pressure when the heart beats. This is easier to measure and is used more often in children.
- The bottom number is called the **diastolic pressure** – the pressure when the heart relaxes.

### **Changes in blood pressure**

Blood pressure changes from day to day and at different times of the day. It can also change when we feel stress and during exercise.

### How is blood pressure measured?

Although measuring blood pressure will not hurt your child, it can be challenging, especially in younger children. Your child's doctor or nurse will take a few measurements when your child is relaxed.

You do not usually need to make special preparations before your child's blood pressure measurements. A cuff will be placed around his or her arm and pumped up, so your child will feel the arm being squeezed.

You may need to measure your child's blood pressure at home, sometimes over a day. Your doctor or nurse will give you equipment to do this.

## Blood pressure and your child's health

### **Blood pressure in children**

Babies, children and young people usually have lower blood pressure than adults. They have different ranges that are considered healthy. These depend on:

- how old they are
- whether they are a boy or a girl
- how tall they are.

Your child's doctor or nurse will know the normal ranges of blood pressure for children who are the same age, sex and height as your child. They will let you know what your child's blood pressure readings mean.

### **Keeping healthy**

Your family can follow some tips to help keep your child's blood pressure healthy. These include:

- eating less salt
- eating a healthy diet
- staying active.

If your child has a kidney condition, your doctor or nurse will give you more information about how this affects blood pressure. Rarely, children need to take medicines to control their blood pressure.

## Blood pressure and kidneys

Kidneys normally control blood pressure to help make sure it is at a healthy level. They do this by regulating how much salt and water is in the blood. If the kidneys are not working properly, they may not be able to control blood pressure well.

A blood pressure measurement has two numbers.

- The top number is called the **systolic pressure** – the pressure when the heart contracts (tightens), or beats. This is easier to measure and is used more often.
- The bottom number is called the **diastolic pressure** – the pressure when the heart relaxes.

For example, a measurement of 110/75 or 110 over 75 means that the systolic pressure is 110 and the diastolic pressure is 75.

## Blood pressure instruments

Blood pressure is measured with a special instrument. There are different types.

### **Electronic**

Many blood pressure instruments are electronic, or digital, and are automated. Different versions are used in the hospital or clinic or at home. The parts include:

- a cuff that wraps around the arm
- a small machine with a screen that shows the blood pressure readings.

### **Manual**

Some blood pressure instruments are manual (worked by hand). These are not automated. The parts include:

- a cuff that wraps around the arm
- a pump to inflate air into the cuff
- a pressure gauge with a dial that shows the blood pressure readings

and devices to listen to the heartbeat:

- **stethoscope** – doctors often use this to listen to sounds in the body, including the blood flow
- **Doppler** – a special instrument is used to record sound waves (pulse).

### **Which instrument is used?**

Your doctor or nurse will use the best type and size of instrument for your child.

An electronic instrument may be used for the first blood pressure measurement. If the reading is high, a doctor or nurse may take more measurements with a manual instrument.

## Measuring blood pressure

Measuring blood pressure in young children can be challenging. Your child's doctor or nurse will take a few measurements when your child is relaxed.

If your child's first blood pressure measurement is very high or low, your doctor or nurse will check it a few more times. This is because blood pressure can change depending on the time of day, feeling stressed or after exercising.

## Preparing for the test

You do not need any special preparation before your child has their blood pressure measured. Here are some tips.

- Your child can wear a shirt with short sleeves or with sleeves that can be easily rolled up.
- Explain to your child what will happen during the test. You may say that won't hurt them but that their arm will be squeezed for a few moments.
- Help them to feel relaxed before and during the test.

## What happens?

- Your child will be asked to sit for a few minutes before the measurement is taken.
- The cuff is wrapped around your child's arm and it is pumped up. This holds back the blood flow to that area.
- The pressure on the cuff is slowly released.
- For electronic instruments, the readings appear on a screen.
- For manual instruments, a stethoscope or Doppler is used to listen to the pulse and the readings are taken from the pressure gauge. The systolic number (or top number) is recorded when the pulse is first heard. The diastolic number is recorded when the pulse is no longer heard. The Doppler can only detect the systolic pressure.

## Finding out results

You can find out your child's blood pressure straight away after the test is over.

### Measuring blood pressure at home

Blood pressure can vary throughout the day, when we exercise and when we feel stress. Some children feel stress when they visit the doctor. If they feel stress and have high blood pressure, and no other symptoms of hypertension, this is called **white coat hypertension**.

### Measuring at home

Because of this, your doctor or nurse may ask you to measure your child's blood pressure at home. They will explain what to do and how you can report the blood pressure readings. Your child will be able to do many of the activities they usually do.

Your doctor or nurse may ask a community nurse to measure your child's blood pressure at home. Or, you may be asked to use a home electronic monitor to measure your child's blood pressure at regular intervals during the day.

## Ambulatory blood pressure monitoring

You may be given a special electronic monitor that automatically measures blood pressure over a period of time, usually 24 hours. This is called **ambulatory blood pressure monitoring** (ABPM). (Ambulatory means moving about.)

This monitor will automatically measure your child's blood pressure every half hour during the day, and every hour during the night while they are sleeping. Your child will need to keep their arm still during each measurement.

ABPM gives a true picture of your child's blood pressure when awake and asleep. It is normally used for children 5 years or older.

### Measuring blood pressure in hospital

For some babies and young children it can be very difficult to take blood pressure measurements. They may become distressed in the clinic and may not be able to take the electronic measurements at home. These children need to go into hospital for 24 hours to have their blood pressure measured regularly during the day and night.

### What do the readings mean?

The normal range of blood pressure for your child depends on his or her age, sex and height. Your doctor or nurse will let you know whether your child's readings are normal and healthy.

If you would like to see the ranges of blood pressure for children from ages 1 to 17 years, download the report, **Diagnosis, evaluation and treatment of high blood pressure in children and adolescents (PDF)**. Tables for boys are on pages 10–11 and tables for girls are on pages 12–13.

Children with kidney disease and some other conditions may benefit from having a blood pressure that is at the lower part of the normal range for their age, sex and height. Your doctor or nurse will give you more information.

### Controlling blood pressure

It is important for your child's health that his or her blood pressure is controlled so it is in a healthy range. Below are some tips you can follow as a family to keep your child's blood pressure healthy.

- Reducing the amount of salt you eat can help to control blood pressure. Avoid eating or drinking lots of salted nuts, crisps, crackers, soft drinks, fast food meals, takeaways and processed foods (meals that are pre-prepared, including soups) – these often have more salt than we think. Do not add extra salt to meals that you cook, or at the dining table.

- Eat lots of fresh fruits and vegetables. Swap white bread, rice and pasta for whole-wheat varieties. Avoid food and drinks with lots of added sugar (including sweets, sugary cereals, high-sugar squash and fizzy drinks or sodas). Limit caffeine (which is found in coke drinks, tea and coffee).
- Most children should be physically active for at least 30 minutes a day. Encourage your child to get involved with sports and other activities where they are moving around.
- It is important that your child has a healthy weight for his or her age. Children (and adults) who are overweight are more likely to develop high blood pressure.
- If your child has a **kidney** condition, he or she may need to make more changes to what he or she eats and how much he or she drinks. A renal dietitian will help you with this.