



## Tips for Maximizing Pediatric Nephrology Appointments

The following information was prepared by Alport Syndrome Foundation (ASF) with the guidance of Medical Advisory Committee member Dr. Bradley A. Warady (Children's Mercy Hospitals and Clinics in Kansas City, MO). For further information, you are strongly encouraged to watch ASF's accompanying "[Pediatric Alport Patient Care: What You Need to Know Right Now](#)" video.

### Prepare for the Visit

- Call the office about 1 week prior to your appointment to confirm whether or not you need to take your child in for lab work ahead of time, and to confirm that lab requests have been sent to your lab of choice if you do not have hardcopies of your own.
- Bring a notebook or use a note app on your phone to take notes during the appointment.
- Bring a physical or digital copy of your child's most recent lab results with you if you have access to them.
- Bring reports from other recent appointments such as audiograms or ophthalmologic findings and discuss these with the nephrologist.
- Bring the list of lab values you've been tracking to date. *\*See next section below\**
- Bring books (such as ASF's [Children's Coloring Book Annie Has Alport Syndrome](#)), or other toys to entertain young children while you speak with the nephrologist.
- If your child will be asked to give a urine sample, provide plenty of fluids to your child the day of the visit.
- Practice capturing urine at home to familiarize them for the hospital/clinic setting.

### Track Pediatric Patient Lab Values Over Time

- As a reminder, it's important to keep records of critical lab values to track patterns and changes over time. Some parents and caregivers choose to track these values electronically in a spreadsheet, in a note on their cell phone, or simply on paper.
- Note the following lab values in your tracking system of choice: serum creatinine, eGFR, urine protein to creatinine ratio (UPCR), potassium\*, and blood pressure. If you're not sure where these values are listed on the lab report, ask the nephrologist to highlight them.
- Always remember to ask the nephrologist for a printed or electronic copy of recent blood and urine test results, if you were unable to obtain them on your own.

- Talk with the pediatric nephrologist about the presence/amount of blood and protein in the child's urine and, additionally, about their blood pressure.

*\*As high potassium can cause severe side effects, it's important to track this value over time. High or "out of range" potassium lab values may indicate a need to modify your child's diet to avoid potassium rich foods. Allport treatment medications can also alter potassium values; dosage changes, or alternative medications, may be necessary.*

#### Additional Questions to Ask the Nephrologist

- What would prompt starting a medication, increasing the dosage of a currently prescribed medication, or changing medications for my child (i.e. a specific lab value)?
- Are there any over-the-counter medications or supplements I should avoid giving my child?
- Are there any new clinical trials that could be considered for my child? If so, where can I find more information and what are the risks and potential benefits?
- Are there any accommodations we should request at school?
- When is our next visit and what is recommended treatment-wise prior to that date/time?

#### COVID Considerations to Ask Prior to the Appointment

- What is your entry and masking policy? At what age must children wear a mask? Should I wait in my car and call the clinic when I arrive?
- How many family members will be allowed to accompany the pediatric patient to the visit?