NKF Patient Network – Alport Syndrome, a brand new Alport syndrome registry in partnership with the National Kidney Foundation, launched March 1, 2022.

Patient participation helps attract and advance Alport syndrome research and clinical trials. To get prepared for the registry, following are pieces of information to have at hand if you choose to participate. Collecting this information in advance will make creating your profile and inputting your information simpler for you, and will make the registry more robust for research purposes.

Please note that most of the questions in the registry are not mandatory.
Most have a box to check, "prefer not to answer."
Even if you choose not to answer many of the more detailed questions, your registration as an Alport patient is still very valuable and offers you the opportunity to opt in or opt out for being notified of specific clinical trials for which you qualify.

Questions that you may want to have information for in advance:

What type of health insurance you have i.e.
Commercial, Medicaid, US Military, Veteran's Affairs, Unsure, Prefer not to answer

What is your current stage of CKD (Chronic Kidney Disease)
***eGFR = estimated glomerular filtration rate**
Stage 1 eGFR 90 or greater
Stage 2 eGFR Between 60 and 89
Stage 3 eGFR Between 30 and 59
Stage 4 eGFR Between 15 and 29
Stage 5 eGFR less than 15 (End-Stage Renal Disease)
Don't know

Under Cause of Kidney Disease:
check the box for "Alport syndrome"

Does anyone in your family have kidney disease?
If you are unaware, it will be helpful to find out if other family members have experienced symptoms and/or been diagnosed with chronic kidney disease and/or Alport syndrome.
Examples include: Sister, Aunt, Grandfather, cousin, uncle, mother, father, rother, other

For family history/diagnosis of family history: Check “Alport syndrome” (if applicable)

Additional Detailed information about extended family’s Alport journey
-Which, if any, family members reached End-Stage Renal Disease
-Which, if any, family members received a kidney transplant
-Which, if any, family members experienced a failed transplant
-Which, if any, family members lost their lives related to kidney failure and what age

In the Diagnostics Section:

Under cardiovascular disease, if you or anyone in your family has experienced aortic aneurysm (or abdominal aortic aneurysm), this will be important to be able to note.

Dates to have at hand:
Diagnosis date of kidney disease– as close as you can estimate

Diagnosis date of Alport syndrome – if you were initially misdiagnosed or incompletely diagnosed

Date of initiation of dialysis if applicable

Laboratory results if you can have them available:
Most recent creatinine value:
(+ date of this lab result)

Most recent eGFR (estimate glomerular filtration rate)
(option to type in exact value, or choose an estimated range)
(+ date of this lab result)

Most recent albumin-creatinine ratio (UACR) value exact or approximate of your test result?
(+ date of this lab result)
(+ name of laboratory that did the test)

Did you ever have a confirmed Covid 19 diagnosis?
(+ date of this lab result)

Were you diagnosed with CKD and/or specifically Alport syndrome by biopsy” Yes/No

Were you diagnosed with Alport syndrome by genetic testing? Yes/No

Hearing Loss:
If you have hearing loss, it will help to input the **approximate age of onset** of the hearing loss. We understand this is an estimate as you may have had hearing loss before it was detected or diagnosed. There is a field to input estimated age of onset.

There are fields to input information from your latest audiogram (hearing test report). It is recommended that you have your most recent audiogram results available. If you don't have this information, you can request that your audiologist share this with you in the form of a digital PDF or by mailing you a hardcopy.

If you do not have hearing loss, but are being monitored due to Alport syndrome and have had a hearing test, it is also valuable to provide information from your latest audiogram to show a baseline of no hearing loss. Part of what needs to be studied and understood is the onset of hearing loss. At what point in our disease is hearing loss experienced and/or when does it increase? Capturing no hearing loss and/or onset of hearing loss are both extremely valuable.

Eye abnormalities:
If you are able to share any diagnosed eye abnormality you may have experienced, this will help support research. Options will include abnormalities such as: anterior lenticonus, macular degeneration or macular holes, cataract, dot and fleck retinopathy, temporal retinal thinning, corneal erosion, other, + a free text box to share additional information.

Genetics:
The following information can typically be found on a patient's genetic test results report. Each laboratory has different formats, but the following information and terminology will be present on the report.

Genetic Type:
(If you have a confirmed biopsy and/or genetic test result that confirms):
Options:
X-linked, Autosomal Recessive, Autosomal Dominant, Variant of Unknown Significance