Helpful Websites

Iowa Institute of Human Genetics (IIHG)
Information for patients, health care providers, researchers and students.
>> www.medicine.uiowa.edu/humangenetics

Genetics Home Reference
Information about how genes affect your health: What genes are, how they work, and how they can cause illnesses.

National Human Genome Research Institute
Information on the Human Genome project, including the latest research, educational materials, an explanation of the Genetic Information Nondiscrimination Act (GINA), and your rights concerning genetic discrimination.
>> www.genome.gov

Gene Tests
Information for health care providers on genetic diseases, genetic tests and genetic clinics.
>> www.genetests.org

Online Mendelian Inheritance in Man (OMIM)
An online catalog of human genes and genetic diseases, genetic tests and genetic clinics.
>> http://omim.org

NextGxDx
A comprehensive catalog of genetic tests that includes an easy-to-use search tool to compare and to order genetic tests.
>> www.nextgxdx.com

Contact
Iowa Institute of Human Genetics
University of Iowa
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Iowa City, IA 52242

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Fax: 319-335-3484
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Follow us on Twitter: @IIHG_Genetics
www.medicine.uiowa.edu/humangenetics
Common indications for testing include:

1. Testing for specific genetic renal diseases such as:
   - Tubulointerstitial/cystic diseases, including but not limited to polycystic kidney disease, medullary cystic kidney disease, renal cysts and diabetes (MODY type 5), other ciliopathies
   - Glomerular diseases, including but not limited to focal and segmental glomerulosclerosis, steroid resistant nephrotic syndrome, Fabry disease, Alport syndrome
   - Tubular ion transport, including but not limited to Gitelman, Bartter, Familial Hyperkalemic Hypertension, Renal Tubular Acidosis
   - Certain congenital anomalies of the kidney and urinary tract (CAKUT)

2. Establishing a possible cause in patients presenting with atypical renal diseases.

3. Screening potential living related donors at risk for genetic renal disease.

Why should I use KidneySeq™?

- KidneySeq™ is ideal for patients who may benefit if their cause of renal disease is discovered.
- KidneySeq™ is appropriate to validate a likely genetic diagnosis, when there are several genetic possibilities, or when there is uncertainty as to the genetic diagnosis.
- KidneySeq™ should be considered as part of the transplant evaluation of recipients to assess risk for recurrent disease and to guide screening of living-related donors.

What is the test methodology?

- KidneySeq™ uses RNA baits to ‘capture’ over 170 genes that have been implicated in genetic renal disease genes.
- The captured genes are sequenced using massively parallel sequencing.
- All genes are captured and sequenced in every patient, making KidneySeq™ very comprehensive.
- A list of KidneySeq™ genes and the diseases with which they are associated can be found at: >www.medicine.uiowa.edu/humangenetics/kidneyseq/

How do I order KidneySeq™ at UIHC?

- Place an order for KidneySeq™ by typing KidneySeq™ as a miscellaneous test in EPIC.
- Commercial Mailouts will ensure the test is sent to the IIHG.
- You must also complete a requisition form as described next.

What is required for KidneySeq™ testing?

- A completed requisition form. Forms are provided at: >www.medicine.uiowa.edu/humangenetics/kidneyseq/
- 4-6cc whole blood in a lavender top tube for persons over 10 years old
- 3-4cc whole blood in a lavender top tube for persons age 10 years or younger

Does the patient need to sign a consent form to have KidneySeq™ testing?

- No, KidneySeq™ is a clinical test and a consent form is not required.

When will the results be available?

A KidneySeq™ report will be faxed to the ordering healthcare provider within 12 weeks.

How will my patients understand the KidneySeq™ results?

- You will need to explain the results to your patient.
- If you are interested in assistance with this step, the IIHG has a Certified Genetic Counselor who can assist you.
- You may also choose to contact a genetic counselor in your area. To do so, please visit: >http://nsgc.org/p/cm/ld/fid=164

Is this test covered by insurance?

KidneySeq™ testing may or may not be covered. Pre-authorization is recommended so that you can explain to the provider why KidneySeq™ testing is needed.