

HLRCC BROCHURE

1ST EDITION, JAN. 2013 HLRCC FAMILY ALLIANCE, BOSTON, MA USA +1 (617) 277-5667 EXT. 709

HLRCC stands for...

Hereditary Leiomyomatosis and Renal Cell Cancer. HLRCC is a rare genetic condition named in 2002 previously known as Reed's syndrome.

SOME FACTS:

1. If you have HLRCC, it does not mean that you have cancer. It does mean that you are at risk for developing a type of kidney cancer that can be very dangerous.
2. You can be diagnosed with HLRCC if you have uterine fibroids and cutaneous leiomyomas (skin bumps) confirmed by a dermatologist's biopsy. You can also be diagnosed with a genetic test.
3. **SCREENING for HLRCC** kidney tumors is essential. Right now it is recommended that individuals with HLRCC are screened once per year with an MRI with contrast. MRI slices should be 1-3 mm to detect early tumors. (NOTE: HLRCC tumors can metastasize very quickly so catching them early is important!)
4. The National Institutes of Health (Bethesda, Maryland, USA) is currently conducting a Natural History Study. Log onto their site for more info (www.nih.gov/)



HLRCC
Family Alliance
knowledge saves

An International Supportive Community

The HLRCC Family Alliance was created in 2004 and is stronger than ever thanks to new leadership and two primary "meeting" places where those connected to HLRCC can go:

***FACEBOOK:** Join us on Facebook under HLRCC Family Alliance and feel the warmth of our community.

***INSPIRE:** Another wonderful source of information is the INSPIRE site which can be found at www.hlrcinfo.org. The INSPIRE site is an online discussion group where you can exchange information about HLRCC with others impacted by the condition.

www.hlrcinfo.org

Our goal is to help our visitors partner with their medical team so that they can make informed decisions about their health.

Here you will also find our new **HANDBOOK** with 50 pages of up-to-date information about HLRCC. There are links to INSPIRE and to FACEBOOK on our website so please visit us today!

Or call us! +1 (617) 277-5667 ext. 709



UTERINE FIBROIDS in females tend to be the first symptom of HLRCC. Women with HLRCC often have very large fibroids that may cause heavy bleeding and/or interfere with fertility.



Cutaneous Leiomyomas, or skin bumps, are another symptom of HLRCC. The bumps can be skin color or red and are raised. They grow in clusters or can be solitary.



Kidney Cancer is the last symptom that is sometimes present. Only a percentage of those with HLRCC develop the cancerous tumors but screening for these tumors is important because the cancer can be aggressive.

SUGGESTED SCREENING GUIDELINES



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The suggestions in the HLRCC Handbook come from the most experienced research projects, which still are only 10 years old, and therefore do not yet have long-term follow-up experience. Some physicians are of the opinion that there is insufficient scientific data yet to define firm recommendations. Recommendations presented in this handbook should be regarded as tentative, and will most likely change over time as more data becomes available.

- MRI is recommended in order to minimize exposure to radiation.
- CT should be reserved for times when they are needed to answer some specific diagnostic question or in planning surgery.
- Ultrasound of the kidney is not recommended, as ultrasound is very much dependent upon the quality of the machine and the skill of the operator. Ultrasound is better than nothing, but is unlikely to find tumors less than 1 cm, leaving a wide opportunity for risk in HLRCC.

Upon HLRCC Diagnosis (At Any Age Greater Than 8)

- Full-body skin check by a dermatologist to note the location, number, and stage of skin bumps
- For all, MRI of the abdomen with thin cuts, looking for kidney tumors, noting number and size of any cysts or tumors seen
- Adults may be offered a CT scan as well as an MRI for their first appointment in order to have a baseline scan for comparison with any later scans
- For women starting at the age of 21, annual examinations by a gynecologist to enable screening for fibroids. You should inform the gynecologist that you have the HLRCC condition, of any family history of fibroids and stress the importance of looking for even small fibroids.

For Children at Risk Under 8

Children are “at risk” if they are not genetically tested or if they are in the 3% of families which have clear evidence of HLRCC symptoms, but no DNA alteration can be found.

Annually from age 1

- Full body skin check by the pediatrician, noting any skin bumps. If present, refer to a dermatologist familiar with HLRCC

Annually beginning at age 8

- Full body skin check by the pediatrician noting any skin bumps. If present, refer to a dermatologist familiar with HLRCC
- MRI of the abdomen with thin cuts to check for any cysts or tumors of the kidneys. If present refer kidney issues to an urologist familiar with HLRCC.