

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.