

To Members of the _____ Family,

I hope this letter finds all of you happy and in good health. My main reason for writing this is to inform my relatives of a hereditary medical condition that I have been diagnosed with. The condition is extremely rare in the general population, but it runs in families. Since I have it, this means that others in the family are at risks up to 50%. It is called Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC). The kidney cancer component of this disease can be fatal if not treated in time.

I am hoping that you will act on this information since this is a hereditary condition. We all have up to a 50% chance of having the gene alteration. If we have it, our children have a 50% chance of having it (and so on). Consequently, some members of a particular branch of the family may have members with the condition while others are free of it. Having a genetic test is the best way to be diagnosed with the condition. Even if you decide not to be genetically tested I encourage you to seek screening advice, actions you can take to watch for signs of trouble.

People with this condition are susceptible to the development of the following:

- **Uterine Fibroids in females**, often early onset, multiple, large and symptomatic, usually detected in the 20's and 30's and may impact the ability to have children, often lead to hysterectomy.
- **Skin Leiomyomas** (non-cancerous growth) of the skin, usually on the stomach, back, arms and legs, can be isolated or clustered lesions or can be disseminated (segmental), sometimes painful or may not hurt, and typically onset is in 30's but have been seen in children. They usually appear as small firm, pink raised growths (sometimes white) or bumps in clusters and are difficult to diagnose yourself: <http://www.dermnet.com/Leiomyomata/photos/1>
- **Kidney Cancer** - individual risk is not completely known at this time, but a high percentage of adults with this condition have been found to have kidney tumors. The average age of symptomatic kidney cancer is 44, but we think that survival is better when tumors are found before symptoms occur. Even children have been diagnosed with this type of kidney cancer

Those with HLRCC need to be screened annually for kidney tumors, preferably by a thin sliced MRI with contrast. Even small tumors have been

known to metastasize (spread) so annual screening is the very best way to catch tumors as early as possible.

The HLRCC Family Alliance is a strong organization that can help address your questions and concerns. Go to <http://www.hlrcinfo.org> to access a detailed handbook and to join the support group. You can also find information about a large on-going study at the National Institutes of Health (US-NIH) that you may be able to participate in should you test positive for HLRCC.

Please call me at _____ to discuss this letter further. You can also call their toll free number:
1-800-767-4845 extension 709

or write to:

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Love to you all.



HLRCC
Family Alliance
knowledge saves