

HLRCC Family Alliance News Letter 001 December 28th, 2012

To our HLRCC Family,

Holiday Greetings and Happy New Year!

We are hopeful that you've had a wonderful and healthy 2012 and wish you nothing but the very best in the up and coming year. This is our first newsletter and there will be more as we grow and move forward.

We've created a **TOP FIVE** list of things you can do to help support the HLRCC Family Alliance. Thanks for all **YOU** do to help us with this cause!

- 5.** Call your local teaching hospital and see if you can talk with dermatologists about HLRCC. Do you have leiomyomas? These skin growths are very rare and teaching hospitals love to show Dermatology students.
- 4.** Write an article about your story and send it to a local paper, or better yet, to a nationally syndicated magazine!
- 3.** Have your annual kidney screening done (1-3 mm MRI slices if possible). Follow-up with NIH is your doctor finds anything suspicious.
- 2.** Become a supporter of HLRCC Family Alliance. Just click on this site www.hlrcinfo.org and find out how! All proceeds directly support the infrastructure that supports our Family Alliance provided by the VHL Family Alliance. Funding will also allow us to travel to conferences and create a much needed Patient Registry with the VHL FA. Tiny \$, small \$, medium \$, and **large** \$ donations are all very welcome. Every bit helps!
- 1.** Eat well, exercise, and be good to your mind and body each and every day!

We appreciate you being with us so very much! Thanks again for helping us spread the news about HLRCC, and educate the world about this rare but important condition.

Sad Losses

This year was not without a lot of sadness as three people associated with the group all tragically lost their lives to kidney cancer. They were Sara Mcinnes, Alyssa Amadio and Melanie Horton. We will always remember them and send our sympathy to their families.

2012 HIGHLIGHTS

Website

We got our own website up www.hlrccinfo.org, designed by a website professional Angela Render. The main content is the online version of the HLRCC Handbook. Graham has taken over the task of website maintenance.

HLRCC Handbook and Science

After much iteration for more than a year we finally got Edition 1.0 completed for both the Handbook and the Science documents.

HLRCC Family Alliance Medical, Research and Support Board

If you look at the names of the people who kindly accepted our invitation to be on this Board, you cannot fail but to be impressed by over 20 top names in the field. We are honored to have them with us.

HLRCC Family Alliance Facebook Group

This “Closed” Facebook Group <http://www.facebook.com/groups/hlrcc/> was started in August 2011 and has grown steadily to now 110 members of which nearly 100 are directly connected to HLRCC representing 50 separate families. This group has proved to be a very popular means of communication and has largely replaced our use of INSPIRE.

HLRCC Brochure

This colored brochure has been completed and will be available at the beginning of the New Year as a download from the web site. It gives an introduction to HLRCC and the Family Alliance.

Logo

The logo design was an important part of establishing our identity. The three figures representing three generations with one of them having kidney cancer. The motto “*knowledge saves*” was adopted after researching that it had not been used elsewhere.



HLRCC
Family Alliance
knowledge saves

Coming of Age

We have re-affirmed our relationship with the VHL Family Alliance and have come to an understanding of our on-going expenses in running the non-profit business.

THE FUTURE

Patient Registries

In 2013 we plan to start patient registries for HLRCC in the US and UK. The data and samples gathered will be valuable source of information for clinicians and researchers.

Handbook and Science Edition 2.0

New editions of these documents will be produced and the web site will be updated.

Happy 2013!

Julie Rejman, Chair

Graham Lovitt, Vice Chair

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