

Powerful Patient 2009 week 15

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It Runs in the Family – Birt-Hogg-Dubé Syndrome

Cathy Sherman of the Birt-Hogg-Dubé Syndrome Family Alliance talks with Joyce about how her family learned why so many members were getting kidney cancer, and how they formed a group to support one another and find answers.



Cathy Sherman, BHD

1) About Our Guest

Cathy Sherman is from a large extended family with members in the United States and Europe. When her husband was diagnosed with kidney cancer, she set out to learn more about the particular type of cancer he had, and get some perspective on just how to go about managing the condition.

What they learned was very important to the management of his case, and to the health of their entire extended family. Birt-Hogg-Dubé Syndrome is in fact one of the most manageable kinds of cancer – unless the doctors over-react and you go forward with overly-aggressive surgical plans.

Joyce and Cathy talk about the importance of understanding the risk factors that run in your family, and knowing the optimal techniques for living with and managing this kind of health concern. Especially when you are dealing with a rare disease, you cannot expect your doctor to know everything about the condition and how to manage it.

2) About the types of kidney cancer

Of all people with kidney cancer, about 5% are members of families with a hereditary tendency toward kidney cancer. There are three primary cell types: clear cell, papillary, and chromophobe renal cell carcinoma. An analysis of the cell type of the kidney cancer tumor will assist doctors in classifying the tumor, choosing a course of therapy, and deciding whether it would be helpful to screen other family members.

The most common cell type in kidney cancer is **Clear Cell Renal Cell Carcinoma (ccRCC)**. About 5% of ccRCC is due to von Hippel-Lindau disease (VHL). In addition to kidney cancer, people with an alteration in the VHL gene are at increased risk for tumors of the brain, spinal cord, pancreas, adrenal glands, and several other areas. See <http://vhl.org>

For information on other types of kidney cancer, see <http://vhl.org/research/rcc>

And http://en.wikipedia.org/wiki/Renal_cell_carcinoma

3) About Birt-Hogg-Dubé Syndrome

For more information about Birt-Hogg-Dubé Syndrome, go to <http://bhdsyndrome.org>

And also <http://vhl.org/research/rcc/01bhd.php>

For more information about kidney cancer, see <http://kidneycancer.org>

Cathy is one of the moderators of the Kidney-Onc listserv, a wonderful resource for people looking for information and help concerning all kinds of kidney cancer.

<http://www.acor.com>