

Vol 18, No. 1, February 2010

VHL Family Forum

VHL in Russia

Dear Joyce, January 7, 2010

I just wanted to thank you, VHL Family Alliance, and all the VHL patients for supporting my recent trip to St. Petersburg, Russia for the Second International Conference on Kidney Cancer. Although the trip was short, it was an unforgettable experience.

The conference lasted only two days: one day for the patients and the other one for the doctors. I had a privilege to give three lectures on Surgical Management of Renal Cell Carcinoma (RCC), Advances in RCC Treatment, and Management of the VHL patients. All lectures were very well received by both patients and physicians. There were many excellent questions, positive comments, and an unbelievable interest in the progress of RCC treatment in the United States.

When I showed a couple of short video clips of robotic renal surgery, some commented that we practice not just in another country, but on another planet. While accepting these comments as compliments, I realized how fortunate it is to practice medicine and surgery in the United States, and how much we have to give to patients and physicians from other countries.

Many other positive comments came after my short review of the new targeted therapies for RCC. I stressed the contributions of the VHL Family Alliance, as well as long-standing contributions of Dr. Linehan, Dr. Zbar, Urologic Oncologic Branch at the NCI, and, of course, all the VHL patients who participate in clinical trials. The entire world now uses medications for treatment of advanced renal cancer that were developed based on understanding of the molecular pathways regulated by the VHL: Avastin, Sutent, and more to come.

I would like to express my sincere gratitude to all the efforts of VHL Family Alliance and our VHL patients. The difference can only be made when all



A picture of me (right) with professor Demidov from Moscow (left), while we were on a panel during one of the sessions of the conference.



Left to right: me, Carolyn Konosky (Director, Kidney Cancer Association), Dr. Ilya Tsimafeyev (Kidney Cancer Research Bureau)

the efforts are combined, and the VHL community is certainly a wonderful example of these collective contributions.

Warmest regards and best wishes to all in this New Year!

Gennady Bratslavsky, M.D.

Senior Staff, Urologic Oncology Branch, National Cancer Institute, National Institutes of Health, Bethesda, Maryland, U.S.A. Dr. Bratslavsky, a native of Russia, spoke in Russian at this conference and helped us making contact with physicians who have patients with VHL in Russia.

Clinical Trials Open

There are three clinical trials open for people with VHL. In all three cases, candidates must have one measurable solid kidney tumor, of any size.

People with tumors of the brain, spinal cord, and eye may be included as long as they meet this requirement for a kidney tumor, since the primary focus of the trial is to measure the effectiveness of the drug on kidney tumors. Nonetheless, its effects on other tumors are very much of interest. If you consider your kidney tumors "not a problem" but another problem more urgent, it is still worthwhile to speak with these trial coordinators.

To inquire about these trials, please contact:

Dr. Eric Jonasch, Urologic Oncology, M.D.
Anderson, Houston, Texas. 832-633-4519 Trial of Sutent for VHL

Sally Fowler, R.N., Urologic Oncology, 301-435-6255. Trials of drugs from Astra Zeneca and Aveo for VHL.

Dr. Ram Srinivasan, urologic oncologist with the NIH team, will report to us in St. Louis on the status of these trials.