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PDF generated on July 23, 2016 from <http://www.cancer.net/blog/2014-02/packing-suitcase-full-hope>



Berit Eberhardt, Manager Kidney Cancer at Das Lebenshaus (Germany)

February 12, 2014

· Berit Eberhardt

## [Packing a Suitcase Full of Hope](#) [1]

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*Berit Eberhardt is a kidney cancer patient advocate and Manager Kidney Cancer at Das Lebenshaus, a non-profit organization in Germany that supports patients with rare solid tumors such as GIST, sarcomas, and kidney cancer. She received a [Conquer Cancer Foundation Patient](#)*

[Advocate Scholarship](#) [2] to attend the 2014 Genitourinary (GU) Cancers Symposium, January 30–February 1, 2014, in San Francisco, California. This program allows patient advocates to further educate themselves on important advances in their areas of interest and share what they learned to make a difference in the lives of people affected by cancer.

I became a patient advocate because kidney cancer affected my life like nothing else ever before. My boyfriend got diagnosed at age 38. Unfortunately, he died just one year after his diagnosis. In the course of his treatment, I contacted [Das Lebenshaus](#) [3] (House of Life Association) myself, got support, and learned a lot about kidney cancer and its therapy. After his death, I felt that I needed to share all my knowledge with others who needed support. Just six months after his death, I founded a patient support group in my hometown. Two months later I became Manager Kidney Cancer at Das Lebenshaus. Since then I am also involved with the [International Kidney Cancer Coalition](#) [4]. The IKCC is a global network of independent kidney cancer patient organizations that improves the lives of patients at each national level.

Every patient advocate knows that it is essential to learn about the disease and to attend numerous trainings, seminars, and medical conferences. But the newest developments, treatments, and research are provided at the ASCO GU Symposia. That's why it was so important for me to travel from Berlin to participate at this meeting.

Plus there are some more reasons:

- For me personally, abstracts online don't show much. It's the posters, and especially the discussions with the presenters, that help me better understand their research.
- The discussions about the oral abstract sessions are also mandatory. They disclose weaknesses of the study, bring up questions, and open the mind to the different views of the medical community.
- Getting in touch with these medical experts, to learn from them, invite them for speeches, etc.
- Getting in touch with other patient advocacy groups. To benefit from everybody's knowledge about patient support, projects, etc. To teach and learn, to inspire and be inspired by others is so valuable. We all do different kinds of projects, and nobody should have to invent the wheel again.

The most important talk at this ASCO GU was the very last one! Dr. David McDermott's presentation about [optimal targeting of the PD-1/PDL-1 pathway in metastatic kidney cancer](#) [5]. I appreciated his focus on the unanswered questions about this treatment. And for ending with the vague hope that PD-1 pathway inhibitors will hopefully be approved for several solid tumors in the near future. So this is hope not only for kidney cancer patients but for many other cancer patients too. And as patient advocates we spread the word, giving hope to as many patients as we can. We inform patients in a patient-friendly language, can tell them where open trials are, and bring patients together so they don't feel alone.

That's why attending this ASCO symposium was so very important for me—to be able to pack up

this hope and take it to the people at Das Lebenshaus and also to all the other kidney cancer organizations around the world that are affiliated with the IKCC.

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- [3] <http://www.lh-nierenkrebs.org/>
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