

Karl Schwartz

Patient Research Advocacy - Lymphoma
Curriculum Vitae, 2013

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My spouse is a seventeen-year survivor of lymphoma. Together we have experienced the uncertainties of treatment decisions, the disappointments and successes - and have considered and participated in multiple clinical trials and therefore have first-hand experience with the clinical trial consent process.

My experience with the disease includes providing online support for patients with a broad range of lymphomas: low and high risk, indolent and aggressive, including types that are managed conservatively or that can have a rapid fatal clinical course if not cured.

Advocacy activities:

- Moderator of online support forums for patients and caregivers with various kinds of lymphoma since 1997.
- President and co-founder of Patients Against Lymphoma, which provides evidence-based support and information on lymphoma, with a focus on advancing the informed and routine consideration of clinical trials. www.lymphomation.org
- Author, "Interest, Attitudes and Participation in Clinical Trials among Patients with Lymphoma," published by ASCO in 2009. <http://bit.ly/1Lk0US>

Advocate Participant:

- Patient Representative and Consultant program at the Food and Drug Administration – 2001 to present; including four advisory committee deliberations (Fragmin, Romidepsin, Pralatrexate, Pixantrone)
- Alliance Cooperative Group (formerly CALGB), Lymphoma and Patient Advocate Committees, 2010 to present
- NCI Progress Review Group for Blood Cancers, 2001
- NCI Biospecimen Best Practices:
 - Biospecimen Access: Ethical, Legal Policy, 2005
 - Custodianship and Ownership Issues in Biospecimen Research Symposium, 2007
- NCI Technical Evaluation Panel: "Development of a Common Biospecimen Coordination System for NCI Prostate SPOR," 2005

- Faculty, clinical research workshops:
 FDA, NCI, ASCO, and Duke University: "Accelerating Anticancer Agent Development and Validation Workshop," 2009
 AACR/ASCO: "Methods in Clinical Cancer Research, 2011, 2012, 2013
- AACR Joint Scientific Advisory Committee – Stand Up to Cancer, 2012
- The Patient-Centered Outcomes Research Institute (PCORI) – Certified by Training to become a Merit Reviewer, January 2013
- NCI Lymphoma Steering Committee, April 2013

Speaker:

- "Patient Perspectives on The Demand for Innovation vs. Safety," Leigh Thompson Renaissance Conference, 2005
- Trial Design Innovation Conference: "Patient Perspectives on Accelerating Safer Drug Development with Adaptive Trials, Washington DC, 2006
- "Announcing The Cancer Genome Atlas Project," National Press Club, 2005
- Patient Representatives FDA Workshop, "Close Calls - Perspectives, Preparations and Participation on FDA Advisory Meetings (Keeping an Open Mind, Preparations, What to Expect), 2008
- "Evaluating Online Medical & Support Information," sponsored by the Lance Armstrong Foundation, and Leukemia and Lymphoma Society, 2010
- Cancer and Leukemia Group B meeting, Miami, FL: "The Reasons Patients Participate in Clinical Trials – based on their unique clinical circumstances," 2010