Karl Schwartz

Patient Research Advocacy - Lymphoma
Curriculum Vitae, 2014

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My spouse is an eighteen-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://meeting.ascopubs.org/cgi/content/abstract/27/15S/e19514

Advocate Participant:

- NCI Patient Advocates Steering Committee (co-chair) 2014
- NCI Lymphoma Steering Committee 2013 - present
- 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) 2010 to present Lymphoma and Patient Advocate Committees
- NCI Progress Review Group for Blood Cancers, 2001
- NCI Biospecimen Best Practices, 2005 and 2007:

  - Biospecimen Access: Ethical, Legal Policy

- Custodianship and Ownership Issues in Biospecimen Research Symposium

- NCI Technical Evaluation Panel, 2005:
  "Development of a Common Biospecimen Coordination System for NCI Prostate SPORE,"

- Faculty, clinical research workshops:

  FDA, NCI, ASCO, and Duke University, 2009
  Accelerating Anticancer Agent Development and Validation Workshop,

  AACR/ASCO, 2011, 2012, 2013 to present
  "Methods in Clinical Cancer Research,

- AACR 2012 to present
  Joint Scientific Advisory Committee – Stand Up to Cancer,

- The Patient-Centered Outcomes Research Institute (PCORI) – Certified by Training to become a Merit Reviewer, January 2013

- NCI Lymphoma Steering Committee, April 2013 to present
  Patient advocate

- Member, NCI Centralized Institutional Review Board, 2014 to present
  Adult Early Phase Emphasis

Speaker:

- Leigh Thompson Renaissance Conference by invitation, 2005
  "Patient Perspectives on Trial Design: The Demand for Innovation vs. Safety

- Adaptive Trials Design Innovation Conference, Washington DC, 2006:
  "Patient Perspectives on Accelerating Safer Drug Development"

- National Press Club, 2005
  "Announcing The Cancer Genome Atlas Project"

- Patient Representatives FDA Workshop, 2008
  "Close Calls - Perspectives, Preparations and Participation on FDA Advisory Meetings (Keeping an Open Mind, Preparations, What to Expect)

- Sponsor: Leukemia and Lymphoma Society, 2010
  "Evaluating Online Medical & Support Information"

- Cancer and Leukemia Group B meeting, Miami, 2010:
  "The Reasons Patients Participate in Clinical Trials – based on their unique clinical circumstances"