Karl Schwartz

Patient Research Advocacy - Lymphoma
Curriculum Vitae, 2017

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I am a caregiver, educator, and research advocate with many years of experience as an advocate in clinical research.

My spouse is twenty-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.

Through the independent non-profit organization I founded, our group provides support and education 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.

Patient community 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 (since 2002) with focus on advancing the informed and routine consideration of clinical trials. www.lymphomation.org

Recent experiences as research advocate:

- Member, NCI CIRB (Centralized Institutional Review Board)
  Adult Early Phase Emphasis - 2014 to present
- ASCO-Friends of Cancer Research Modernizing Eligibility Criteria Project- HIV Working Group Member - 2016
- Alliance Cooperative Group (formerly CALGB) 2010 to Present
  Lymphoma and Patient Advocate Committees
- Study 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
- AACR - 2012 to present
  Joint Scientific Advisory Committee, Stand Up to Cancer,
- NCI Patient Advocates Steering Committee (co-chair) 2016 (completed term)
- NCI Lymphoma Steering Committee 2013 – 2016 (completed term)

- FDA Patient Representative and Consultant program
  2001 - 2017; advisory committee deliberations
  (Fragmin, Romidepsin, Pralatrexate, Pixantrone)
- Faculty, clinical research workshops:

  AACR/ASCO, 2011- 2014
  "Methods in Clinical Cancer Research,

  FDA, NCI, ASCO, and Duke University, 2009
  Accelerating Anticancer Agent Development and Validation Workshop,
- 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
- NCI Technical Evaluation Panel, 2005:
  "Development of a Common Biospecimen Coordination System for NCI Prostate SPORE,"
- The Patient-Centered Outcomes Research Institute (PCORI) – Certified by Training to become a Merit Reviewer, January 2013

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"