

Personal Perspective of a Patient Advocate



Evolution of the role of Patient Advocates

- An advocate is a supporter, believer, sponsor, promoter, campaigner, backer, or spokesperson
- Self advocating or advocating for another patient
- Speaking on behalf of a group or community of patients affected by a disease
- Modern patient advocacy rooted in patient rights movement of the 1970s leading to the Patient Bill of Rights accepted by JACHO in 1972
- Hospital-based advocates became prevalent throughout the 1970s with formation of the first professional advocate organization, “The Society for Healthcare Consumer Advocacy”
- As healthcare became more complex need for input from patients increased and the role of the patient advocate expanded to bring the patients’ voice to the table – Patient Research Advocate

Personal Experience as a Patient Research Advocate

- Self advocate
- Department of Defense CDMRP Ovarian Cancer Research Program
- Member of research consortium to study long-term survivors of ovarian cancer
- Patient advocate on numerous research projects
- Patient advocate on Alabama Study Commission of Gynecologic Cancers
- NCI Ovarian Cancer Task Force
- NCI reviewer
- FDA Patient Representative
- Participant in Pharma patient partnership programs

Preparing to Review

- Connect to the community to understand needs and desires
- Know demographics of disease population
- Stay aware of current treatment trends and research questions
- No matter what agency you are reviewing for, look for:
 - **Potential impact**
 - **Risks versus benefits**
 - **Patient engagement plan**

- NTCN Task Force or Steering Committee – reviewing clinical trial concepts
- Member of panel reviewing applications for funding
- You have the opportunity to point out ways to get patients involved early in the process
- Patient engagement plan:
 - Poor: “We plan to engage patients”
 - Better: “We have a letter of support from a patient advocate”
 - Best: A well-defined patient engagement plan that discusses involvement in clinical trial design, recruitment strategy, patient-facing materials

- Retrospective review when drug submitted for approval
- Patient representatives have a vote on the advisory committee
- Frequently see how patient engagement could have improved
 - Recruitment strategy
 - Accurate representation of demographics of population
 - Trial eligibility criteria
 - Side effect reporting

**Engage patients
early and often
throughout drug
development**

