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The Patient Advocate's Role in Cancer Research

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Clinical trials [1] have helped make progress in the prevention, care, and treatment of people with cancer. This knowledge could not have been gained without the participation of patients, patient advocates, and health care professionals. To better understand how patient advocates and doctors work together to advance cancer research, Cancer.Net spoke with George W. Sledge Jr., MD, former President of the American Society of Clinical Oncology, and Mary Lou Smith, a longtime patient advocate. Dr. Sledge and Ms. Smith have worked together for many years, primarily through the Eastern Cooperative Oncology Group, a clinical cancer research organization.

Q: What are the shared goals of cancer researchers and patient advocates?

Dr. George Sledge (GS): There are several common goals. First and foremost is the conquest of cancer, a life-threatening disease. A secondary goal that supports the first is the advancement of the policies and processes involved in cancer research that will make those cures possible. And, advocates have been strong voices for that research infrastructure.

Mary Lou Smith (MLS): To expand upon those themes, cancer researchers and patient advocates share the goal of answering questions that advance patient care, improve quality of life, and enhance cancer survivorship. In addition, both parties seek to ensure that clinical studies are well-designed and ethical, minimizing patient burdens.

Q: What role do patient advocates play in cancer research?

GS & MLS: Patient advocates have made, and will continue to make, numerous contributions. For example, they have played an important role in fundraising for cancer research. At a national level, patient advocates lobby Congress to give money to cancer and raise funds through philanthropic organizations. At the local level, there are innumerable examples of advocates raising money for research at just about every cancer center in the country.

In addition, advocacy groups educate patients about various types of cancer, why clinical trials are important, where they can access clinical trials, and how they can maintain a good quality of life. In many of these areas, advocacy groups have led the way and have been a positive force for improvement.

An increasing number of advocates are also serving on the many advisory boards and committees that comprise some of the infrastructure of cancer research. For example, most cooperative groups in the United States now have advocates involved in their committees. In these settings, advocates bring the patient perspective to the planning and implementation of clinical studies. They participate in discussions about which research topics to pursue and suggest ways to minimize patient burdens in clinical trial protocols, develop patient-friendly consent forms and educational materials, and reduce disparities in clinical trial participation by increasing awareness and using culturally appropriate materials and methods. The advocates also bring a certain level of seriousness to the discussions, emphasizing the impact of the research on the lives of real men and women down the road.

Q: How has the role of patient advocates in cancer research evolved?

GS: There was a time when researchers did not recognize advocates? ability to contribute to scientific discussions to the extent that they do today. However, that has changed dramatically during the past decade. Advocates are increasingly considered a valuable and important part of the scientific peer-review process.

MLS: In addition to becoming an important part of the peer-review process, advocates are also working within the research programs. Advocacy representation is often required by the funding organization. This gives advocates the opportunity to understand the issues and represent the patient in a new way. The Research Advocacy Network, a non-profit organization that I co-founded, works to bring together all participants in the medical research process. As the head of the Advocacy Core for the Breast Cancer Center of Excellence at Indiana University, this organization leads training programs, develops patient and advocate educational materials, and gathers feedback from the community to advance the research.

Q: What opportunities do you see to enhance the relationship between cancer researchers and patient advocates?

GS: Despite the positive developments in the relationship between patient advocates and researchers in recent years, there is still room for education on both sides. Advocates can improve their knowledge of the scientific and clinical issues in cancer research so they can be well-prepared to engage in discussions with researchers. Increasingly, advocacy groups have been working toward that end. For example, the National Breast Cancer Coalition has tapped top-level scientists to help advocates better understand the current areas of research and the science behind it. Going forward, having a scientific knowledge base will increase the importance of advocates to the process. Meanwhile, researchers need to recognize the value that advocates bring to the research and reach out to them as valuable allies in this fight against cancer.

MLS: Researchers and advocates should increasingly engage in joint problem-solving around key research issues, such as boosting participation in clinical trials, enhancing participant informed consent, determining mandatory versus voluntary tissue sample requirements, providing research results to participants, and educating the public and newly diagnosed patients about biospecimen research. Some additional opportunities for collaboration include developing pilot programs to identify successful ways to disseminate research results to the community and funding advocate initiatives that aim to enhance patient understanding of cancer research. The Research Advocacy Network Advocate Institute [2] runs a class each year to train advocates in the basics of cancer research, provides the experience of attending the ASCO Annual Meeting, and helps advocates disseminate the research to the patient constituencies in their community. Additionally, jointly-sponsored forums that discuss specific examples of effective researcher-advocate collaboration can help identify best practices that can be applied in future projects. For example, Research Advocacy Network has hosted ?Advocate Grand Rounds,? symposia, and ?think tanks? to provide forums for discussing current issues in research.

Q: What advice would you give to patient advocates who want to contribute to cancer research?

MLS: I?d recommend the following:

- Develop the long view. Change does not happen overnight.
- Learn about the science so you can communicate effectively with the research community.
- Learn how the system works if you hope to make a difference and contribute to a successful change within that system.
- Establish a trust relationship by demonstrating how you can support cancer research in a meaningful way?a way that researchers value. If you are not sure what they would value, ask them.
- Be a collaborator, which means listening to the other?s point of view, communicating, checking for understanding, and making concessions. Each party gives a little to achieve the greater good.
- Recognize that this is not a social enterprise; it is a research enterprise. As a result, do not be dissuaded if the researchers do not engage in the social niceties you may have experienced in other settings.
- Above all, remember that it is not about you or your agenda; it is about finding answers for cancer patients.

About the Contributors

George W. Sledge Jr., MD, is a clinician-scientist focusing on new treatments for breast cancer and the chief of oncology in the Stanford University?s Department of Medicine. He is also a former president of the American Society of Clinical Oncology.

Mary Lou Smith, JD, MBA, is the co-founder of the Research Advocacy Network. She currently serves as co-chair of the Eastern Cooperative Oncology Group?s Patient Representative Committee and as a community member of the Institutional Review Board at Rush Presbyterian St Luke?s Medical Center in Chicago.

More Information

Being a Cancer Advocate [3]

Patient Advocacy at ASCO [4]

Advocacy and Policy [5]

Additional Resources

Research Advocacy Network: Roadmaps to Research Advocacy [6]

Research Advocacy Network: AdvocateLink [7]

Links:
[1] http://www.cancer.net/node/24863
[2] http://researchadvocacy.org/index.php?/advocate-institute/
[3] http://www.cancer.net/node/24403
[4] http://www.cancer.net/node/24848
[5] http://www.cancer.net/node/23
[6] http://researchadvocacy.org/index.php?/general-resources/roadmap-to-research-advocacy/
[7] http://researchadvocacy.org/index.php?/advocatelink/