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# American Association for Cancer Research: Survivor – Scientist Program Summary

by Seana Roubinek

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As a two-time cancer ovarian cancer survivor, I have had the great opportunity to get involved in legislative advocacy as well as the Survivors Teaching Students® program through the Ovarian Cancer National Alliance. Being selected to participate in the Survivor-Scientist Program with the American Association for Cancer Research was a new opportunity for me to venture into research advocacy.

This year's annual conference focused largely on Big Data and patient-targeted therapies including genome sequencing and immunotherapy. Big Data is the massive amounts of useful data that are generated every day by cancer researchers around the world. However, due to the volume, its complexity and lack of centralization leaves much of it unanalyzed. There are no consistent standards for gathering, maintaining, and mining through the information. In addition, the smaller institutions that are performing research do not have access to the data. Big data presents a great opportunity for researchers if there is a way to share all of the information that is gathered while maintaining patient privacy.

There is a lot of research focused on targeting the cellular pathways which cause many types of cancer; by blocking the pathway, cancer may either be halted or slowed. Patient-targeted therapies are where much of the research is being conducted because even with the same cell type in different people, response to therapies differ. My particular interest is in ovarian cancer research and there is a lot of hope! PARP inhibitors are oral medications that are being studied predominantly in women with BRCA 1 and BRCA 2 mutations who either have active ovarian cancer or who are currently showing no evidence of disease to determine if the PARP inhibitors prolong remission (I am in a clinical trial for the latter).

Immunotherapy is also being studied. This involves personalized treatment using a patient's cells from tumors, adding a drug, and giving it to the patient. Promising research is showing that some patients still have a response to the vaccine even after stopping treatment.

According to Drew Pardoll, M.D., PhD. with Johns Hopkins School of Medicine, the single most impactful research in cancer where 80% of patients respond is targeting the PD-L1 (programmed death ligand) and/or the PD-1 (programmed death) which are proteins that are believed to suppress the immune system. By inhibiting these proteins, the cancer cannot grow because the immune system is able to target the cancer cells and prevent them from spreading. There are currently six companies that are manufacturing medicines for cancers including melanoma, ovarian cancer, brain cancer, bladder cancer, and non-

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Hodgkins lymphoma. These medicines are still being studied but the research is very promising!

While at the conference, I had the amazing opportunity to present a poster about my own journey through clinical trials. My poster detailed how little progress has been made in ovarian cancer, my own search for answers, and how to make clinical trials more patient friendly. I spoke to many people including researchers, pharmaceutical company employees, and patients. The clinical trial process is a bumpy one at best for ovarian cancer survivors due to qualifying criteria including:

- “Measurable disease” – This often requires that a tumor must be visible on a scan - which can then be imaged again to show reduction or growth. However, not all cancers, including mine, grow like this. Mine grows like moss or sandpaper with very small tumors that cannot be seen on a scan but can be seen when my gynecologic oncologist performs surgery.
- CA125 blood marker – This is only good in about 80% of women so other measures are needed.
- Distance – Traveling to a clinical research facility/location can present difficulty for a woman who is already undergoing treatment with potential side effects and fatigue. It may also involve taking time off of work which is usually not reimbursed by the trial.
- Previous treatments – Trials can exclude patients who have had certain chemotherapy or experimental drugs.

As bumpy as the clinical trial process is, I encourage patients to try and get into one because patients have access to the most innovative research and may be monitored more closely than patients undergoing traditionally treatments. Cancer research projects are now often composed of multi-disciplinary teams: computer experts, programmers, researchers, and scientists. All stakeholders should be at the table from the beginning and this includes patient advocates. If the goal is to help patients, allow them to be a part of the process from the very beginning which leads me to conclude with my standout moment at the conference:

A gentleman from a pharmaceutical company stopped by my poster to ask me questions about my experience with clinical trials and I was totally honest about all three trials that I have been in. He said that he had seen many trials canceled due to low accrual. I asked him, “Do you have patient advocates like myself at the table when you are designing clinical trials?” He crossed his arms, rocked back on his heels, and looked me in the eye when he said, “No.” Using a gentle voice, I said, “Perhaps you should.” He then handed me his business card and asked me to email him to follow up on our conversation so that he can pass along a patient’s perspective to people that he works with. Perhaps I have made a difference in helping to make future trials patient friendly.