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An Advocate Looks Back at 25 Years of Patient and Survivor Communications [1]

Editor's Note: This is the first in a new series of Patient Advocate Guest Columns and Podcasts, launched as a forum for patient advocates to address a topic, issue, or trend within the cancer community through Cancer.Net, the patient information website of the American Society of Clinical Oncology (ASCO).

 [Listen to the Cancer.Net Podcast: An Advocate Looks Back at 25 Years of Patient and Survivor Communications With Selma Schimmel\[2\], adapted from this column.](#)

An Advocate Looks Back at 25 Years of Patient and Survivor Communications



A Patient Advocate Guest Column by Selma R. Schimmel, Founder and CEO, Vital Options International

The landscape of cancer from diagnostics to treatment barely resembles the landscape of 25 years ago, when I founded an organization called *Vital Options: Support for Young Adults with Cancer* - now known as *Vital Options International* (www.vitaloptions.org [3]) - as my personal response to being diagnosed with breast cancer at age 28. My survival of two new primary cancers since then is likely due to medical advancements over time. Patient advocacy and patient communications have changed as well, but there is still much to do in order to get society as a whole and technology onto the same page. Today, being proactive has a very different meaning than it did years ago, as the issues have grown in complexity. For instance, patients are being asked to consider prophylactic surgical interventions based on genetics, oral therapies present new challenges relating to patient compliance and adherence, and cancer is now considered a chronic disease for many people - to name just a few examples. Given this fast-changing environment, it is critically important for programs and services for patients and survivors to continue to evolve quickly as well.

Vital Options was the first organization to focus on the unique needs of young adults with cancer between the ages of 17 and 40. For a decade, *Vital Options* worked specifically with this patient population and, despite initial resistance from some in the medical community, coined the phrase "young adults with cancer." In the early 1990's, it became clear that participation in support groups was shifting downward as patients began to seek information in other ways, mainly the Internet. New concerns came to the forefront; how could we be sure that the information people were getting was correct and applicable to their situations. And, how could we protect individuals from bad information or at worst, charlatans?

It was at that time, in keeping with *Vital Options'* pioneering spirit, that the organization restructured into its current focus on cancer communications, support and advocacy for patients of all ages. Then, in 1996, *Vital Options* launched *The Group Room*[®] cancer talk radio show with a new mission: to facilitate a global cancer dialogue.

In 1998 at the 34th ASCO Annual Meeting in Los Angeles, *The Group Room* was truly privileged to be the first radio show to broadcast during that meeting. The program has been a regular ASCO Annual Meeting feature ever since, and the 44th ASCO Annual Meeting in Chicago this year marks a decade of live shows at that venue.

Vital Options and the radio show expanded its reach in 2000 with its first European broadcast at the European Society for Medical Oncology Congress, which was followed by the World Summit Against Cancer in Paris, France, where *Vital Options* is now a registered European charity. *Choix Vital*, as it is known, is based at the American Hospital of Paris and sponsors support groups throughout the city. Within Europe, France was specifically chosen because the social stigma and reluctance to talk about cancer was greatest there. *The Group Room*[®] production partners are in London at Radio Marsden and the Royal Marsden Cancer Hospital.

The Group Room[®] regularly features discussions between noted oncology leaders in the United States and Europe, along with cancer patients and advocates. Now in its 13th year, the program continues to evolve in tandem with today's advancing cancer therapies and technologies. In fact, one show in 1998 dramatically shifted the show's dialogue away from being a support group in nature, as its name suggests, as news of Harvard researcher Dr. Judah Folkman's work involving anti-angiogenesis reached the press with the claim that cancer would be "cured in two years."

Herceptin was approved in the United States, and with it, a new clinical era unfolded. Today, patients are talking about molecular and targeted therapies, biologics, pathology, genomic assays, refined imaging, nanotechnology, and pharmacogenomics. Personalized medicine is no longer an elusive concept, and outreach and support to this population must reflect that. Patients have redefined their roles as medical consumers, and cancer patient advocacy has found its international voice.

In addition, survivorship has taken on a new face, and science supports the need for greater attention on behalf of the 11 million cancer survivors in the United States today. Quality of life is a consideration that is recognized as a paramount concern, and there is new concentration on understanding the long-term medical and social consequences of cancer treatment, survival, and access to quality cancer care.

So these are the thoughts that come to mind as I reflect on my 25 years of survival and the inception of *Vital Options International*. ASCO's outreach to the public with initiatives like Cancer.Net (www.cancer.net [4]) further represents the kinds of changes and communication efforts that oncology professionals have invested in on behalf of patients, their loved ones, and the cancer advocacy community. I applaud and encourage all those in the patient education and patient advocacy fields who continue to personalize such outreach, so we can all better address each person with cancer as an individual.

Selma Schimmel can be contacted at sschimmel@vitaloptions.org [5]. The Group Room[®] cancer talk radio show is heard live on Sundays from 4:00 to 6:00 pm Eastern Time on select stations, XM Satellite Radio, and Internet simulcast at www.vitaloptions.org [6], where all shows are archived for later listening, and podcast on iTunes. # # #

If you are a patient advocate interesting in authoring a future Patient Advocate Guest Column and Podcast, please contact patientadvocates@asco.org [7] or 571-483-1358.

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Links:

[1] <http://www.cancer.net/research-and-advocacy/patient-advocates/patient-advocate-guest-columns-and-podcasts/advocate-looks-back-25-years-patient-and-survivor-communications>

[2]

http://www.cancer.net/sites/cancer.net/files/Advocate_Looks_Back_at_25_Years_of_Communications_With_SSchimmel.mp3

[3] <http://www.vitaloptions.org>

[4] <http://www.cancer.net>

[5] <mailto:sschimmel@vitaloptions.org>

[6] <http://www.vitaloptions.org/>

[7] <mailto:patientadvocates@asco.org>