

Managing a Rare Cancer Diagnosis

Managing a rare cancer diagnosis presents unique challenges. One survivor shares her tips for navigating the sometimes-murky waters.

By Phyllis A. Domm, with Ashley and Chris Laub

Happy New Year: January 7, 2008 (the day I became really special). On January 7, I became really special. The pathologist at Good Samaritan Medical Center in West Palm Beach, Florida, where I had been hospitalized for a complete hysterectomy the week before, informed me that my excised tumor was a malignant perivascular epithelioid tumor (PEComa)—a rare cancer—and that he was forwarding research articles to my gynecologic oncologist.

But it wasn't until the next morning, when I had the chance to have a detailed conversation with my physician, Howard Goodman, MD, that I realized just how significant this medical news was. There have been only 120 documented PEComa cases since 1994, and the World Health Organization only differentiated and named the tumor in 2002. Additionally, I had become confirmed case number *four* of cervical PEComas.

Armed with the rush of information I gleaned through a fast read of articles online, I flooded my wonderful physician with questions: What is a PEComa? What did he really learn from my surgery? What did the pathology report truly reveal? How could an 8-plus-centimeter tumor grow with virtually no symptoms (my only symptom was extensive bleeding on Thanksgiving weekend 2007)? Why did this PEComa attach itself to my cervix? What should we do? Did he suggest any additional medical opinions? Were there other search engines I should be investigating? My mind had been racing for 24 hours, and my words and questions could barely keep pace with my thoughts.

My conversation with my doctor left me feeling much better. The tumor had been completely removed, there was no lymph node involvement, and the margins were wide and clear. With my mind put off the immediate concerns that had filled my head initially, I still felt I needed more information.

What would follow during the weeks and months after my diagnosis, as I sought information and came to terms with it, was a process of research and self-discovery. What I learned, and what others diagnosed with rare cancers should be aware of, is that the diagnosis of a rare cancer can present unique challenges, medical and psychological, but that there are tools—clinical and within ourselves—to help us cope with the challenge we are facing.

Become the CEO of Your Own Healthcare Team

As a healthcare management professional, I approached my diagnosis as I do my business, and I have found that the model has helped me throughout this challenging process. Managing your care journey as a successful, competent chief executive officer

(CEO), you'll be able to approach the diagnosis with a clear, goal-oriented approach that will help you overcome obstacles and use all the resources at your disposal. The qualities of a successful CEO become even more critical in this lifesaving role you are taking on:

- *Leadership.* Lead your support team of family and friends.
- *Delegating.* Find family and friends who can take responsibility for caregiver tasks, financial matters, cheerleading, and analyzing your care decisions with you.
- *Prioritizing.* You will need to prioritize how much time you devote to research, to support, and to your personal care and wellness. It will be more important than ever to maintain a good work/life balance.
- *Communicating.* A rare cancer requires a lot of outreach and ongoing communication through electronic media. Like a CEO with a communications director, you may need to choose a friend or family member who can update your entire resource team about your status.
- *Decision-making.* As the CEO of managing your own care, you'll be called on to make many decisions about your care. You may find it useful to write down some decision-making guiding principles or to turn to family members or close friends who can help you think through issues at crucial decision points.
- *Organizing.* A competent CEO organizes not only her team but also her resources, finances, and research data.

Rare Cancer 101

Now that you have taken on the role of CEO, it's time to understand the unique challenge with which you have been presented. The federal government defines rare cancers as those with fewer than 40,000 cases per year in the United States. Some rare cancers have fewer than 100 cases. A cancer is classified as rare if it affects an unusual body site, presents as uncommon (exceptional), is difficult to diagnose, or requires special treatment (and often undefined). In short, you have been challenged by a disease that will require a commitment to research.

Do Your Homework

You're aware now of the challenge that your diagnosis presents; the next step is to educate yourself about your condition. Any good CEO knows the value of research, and this step is especially important in the case of rare cancers. The more you know, the more empowered you will be as a patient.

The following resources are a good place to start searching for and locating information about rare cancers:

- [General Internet search \(Google, Yahoo!\)](#). In my experience the information about rare cancers returned from a general search can be hard to wade through and might even be misleading. The more-specific medical and rare cancer sites (below) will provide better results.
- [PubMed \(www.ncbi.nlm.nih.gov/pubmed\)](http://www.ncbi.nlm.nih.gov/pubmed). From the Web site: "PubMed is a service of the U.S. National Library of Medicine that includes over 17 million citations from

MEDLINE and other life science journals for biomedical articles back to the 1950s. PubMed includes links to full text articles and other related resources.”

- UpToDate (www.uptodate.com). From the Web site: “UpToDate is an electronic information resource available on the [Web](#), [desktop](#), and [PDA](#). With UpToDate, you can log in from the office, exam room, or bedside and get specific, detailed answers to your clinical questions. Over eighty million patient-related problems are researched each year with UpToDate.”
- Rarer Cancers Forum (www.rarercancers.org.uk). International/global connection for all rarer cancers; includes blogs and news.
- Rare Cancer Alliance (www.rare-cancer.org). From the Web site: “RCA’s primary purpose is to disseminate information and provide support to all pediatric (childhood) and adult rare cancer patients.”
- Association of Cancer Online Resource (www.acor.org). A free lifeline for everyone affected by cancer and related disorders. Access to 159 mailing lists that provide support, information, and community to everyone affected by cancer and related disorders. Notification system for events, support groups, research.

As you locate resources and information, seek out as many pertinent research articles as possible related to your diagnosis. From these articles you can assemble a list of medical experts and centers that treat your condition and create a plan to contact them and thereafter plan your treatment.

Overcome Challenges

All CEOs are faced with challenges and obstacles, as is anyone diagnosed with a rare cancer, but there are tools and strategies available to help you. As CEO you will utilize the tools effectively to get the best care possible. Here are some of the key challenges along with some strategies from the trenches.

1. Getting an accurate diagnosis

This may be the most difficult step. How and where do you get an accurate diagnosis? By researching your diagnosis through the rare cancer Web sites listed here, you can learn who has published research on your cancer, which will lead you to an expert in the field.

PubMed is especially useful in this way. Search the database for your cancer type, and you will find peer-reviewed articles describing research on your cancer; the authors of these articles are likely good resources. A list of these doctors and their affiliated institutions can lead to appointments with the experts you seek for first, second, and even third opinions.

2. Finding excellent—and expert—care

Having received a diagnosis, where do you go for treatment? You may choose to stay with the doctor who offered you a diagnosis, or you may seek care elsewhere. This is a time when, as CEO, you will need to make a series of important decisions about your care. You will need to ask questions, seek advice from your trusted support network, and evaluate your care team carefully. It is important that you feel confident that you are

being treated by an expert in the area of your rare cancer and, if necessary, in a place that provides a multidisciplinary approach to manage the complicated nature of many rare cancer diagnoses.

Most rare cancers are more effectively treated in a specialized center. The National Cancer Institute (NCI) Web site (www.cancer.gov) is a good resource to help locate major, high-quality cancer centers and their resources (though it's important to note that not all rare cancers are treated at NCI cancer centers). In addition, the National Comprehensive Cancer Network Web site (www.nccn.org) provides information on 21 of the world's leading not-for-profit cancer centers.

When you locate a doctor or a cancer center that you think will accommodate your needs, consider asking a few questions to determine if the treatment center is the right place to seek care:

- What is the goal of treatment for my cancer?
- What are the chances the treatment will work?
- What are my various treatment alternatives and with what risks?
- After treatment, will I be cured, in remission, or relieved of my symptoms?
- How much will the treatment cost?
- How do you manage collaboration for optimal care in my case? Within the center and with other centers?
- Can I meet with my team together?
- Can I have checkups with all my doctors in one visit?

3. Accessing clinical trials

How do you find clinical trials for a rare cancer? There are often few options in clinical trials available for patients with a truly rare cancer because most trials are cancer specific. On the other hand, your rare cancer may be similar to another, more common kind of cancer. Your physician may be able to guide you to a clinical trial for more-common cancers that is possibly applicable to your rare cancer. Unfortunately, no single resource lists every clinical trial. As with other areas of research related to your rare cancer, you will need to search online, ask your healthcare team for guidance, and seek resources wherever you can find them.

Here are a few places to start:

- Coalition of Cancer Cooperative Groups: www.cancertrialshelp.org
- eCancerTrials: www.ecancertrials.com
- National Cancer Institute: www.cancer.gov/clinicaltrials
- Center Watch: www.centerwatch.com
- Acurian: www.acurian.com
- EmergingMed: www.emergingmed.com

Find Support

You've taken on the challenge of becoming the CEO of your own rare cancer journey, you've done your homework, and you've found good care. Now what? Chances are you

have already discovered that you will need a lot of support throughout this process; if you haven't already put together a support team, now's the time.

Creating your own support network is especially important for those diagnosed with a rare cancer because the most distinctive feature of a rare cancer diagnosis is often isolation—there may be few survivors and no available support network.

So who will help you throughout your journey? Whom can you count on? Who will be there throughout to help you manage the process? As CEO consider how the best teams in business are created: teams are most effective when they are *inclusive* (a variety of talents and skills), *effective* (information necessary for success is openly shared), and *communicative* (thanks to all the marvels of technology, virtual teams can be joined electronically). In forming your own team, you might also consider choosing some individuals who are experienced in unconventional thinking and relentless questioning—two attributes that are critical in addressing a rare cancer diagnosis.

In building your team, also think about who should constitute your best networking, resource, and support systems within that larger team. It can be helpful to call on people from many different areas in your life:

- Your medical contacts
- Your spiritual advisors
- Your family
- Your friends and “inspirers”
- Online support (chat groups and blogs can be especially useful for rarer cancers)
- Your technical team (accountant and financial planner)

Unfortunately, there are few formal support groups to accommodate rare cancer survivors, although the online support network available through the Rarer Cancers Forum (www.rarercancers.org.uk) has been a wonderful resource for me.

Where Do You Go from Here?

There is no doubt that a rare cancer diagnosis will change your life. In my case, I made the decision following my diagnosis that it was *my* time—time for self-care, for wellness, and for spirituality. I was determined to find new vitality and to refocus my energies. I prepared a list of activities I would choose *not* to do, and I eliminated them from my life. Incredibly, the time I now need is available! The decision of what to do with my time takes on a new significance as I move forward. However your journey redefines you, remember that this diagnosis need not overwhelm you. Take on the challenge, use these strategies from business (and others you find along the way), and know that there are resources available to get you through.

*With more than 20 years' experience in human resources leadership positions in a variety of healthcare, insurance and consulting organizations, **Phyllis A. Domm** has worked diligently to design and implement programs that reflect the highest level of integrity and corporate values. Her book, Human Risks and Resources: How Every C-*

Level Executive Can Assess Human Risks and Improve Their Human Resources, *has been recognized in business publications and Directors Education sessions. Phyllis has served on the Board of Equitable Resources (NYSE EQT) for the past 12 years and currently chairs the Compensation Committee. She holds an EdD from Boston University, an MA and an M Ed from Tufts University, and a BA from Mount Holyoke College. After a January 2008 extremely rare sarcoma diagnosis, Phyllis is focusing on service by devoting her time and experience to museums, hospitals, and education on rare cancers. She has teamed with Dana Farber Cancer Institute (DFCI), Massachusetts General Hospital and others to educate patients and stimulate research and resources, and a dedicated research fund—The sPECial Fund (<http://www.thespecialfund.org>) — has been created at DFCI. In addition to research, a series of articles and lectures is planned. She can be reached at phyllis.domm@thespecialfund.org. The sPECial Fund website is <http://www.thespecialfund.org>.*