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VIRGINIA CRAVOTTA

Award-winning journalist Virginia Cravotta has been Senior Affairs Correspondent for News 12 Long Island since 1995. A noted expert in the field of long-term care, she reports on medical and social issues that impact the aging process.

The 'Interview with an Expert' series ("IE") is not intended to provide medical advice and is not a substitute for consulting with qualified health professionals familiar with your individual medical needs. IE should not take the place of any discussion with your physician, but should be used to help guide you in discussions. All matters about your health should be under professional medical supervision. The opinions expressed by IE experts are not necessarily those of The Lustgarten Foundation. Information contained in IE cannot be guaranteed for timeliness and accuracy. Sponsors of IE do not control its content or the selection of experts.

RESOURCES

American College of Surgeons' Commission on Cancer® (CoC)
www.facs.org/cancer/index.html

The CoC is dedicated to improving cancer care and the outcome of care by setting quality standards and accrediting over 1,500 cancer programs nationwide.

Find a CoC-Accredited Cancer Program: www.facs.org/cancerprogram/index.html

Cancer.Net: www.cancer.net

Cancer.Net provides timely, oncologist-approved information to help patients and families make informed health-care decisions, such as Finding a Treatment Facility, which is also available as a free Podcast.

HealthFinder.gov

Healthfinder.gov has resources on a wide range of health topics selected from over 1,600 government and non-profit organizations to bring you reliable health information.

National Cancer Institute (NCI)-Designated Cancer Centers

http://cancercenters.cancer.gov/cancer_centers/index.html

NCI-designated cancer centers are characterized by scientific excellence and the capability to integrate diverse research approaches to focus on the problem of cancer.

> **NCI Fact Sheet: How To Find a Doctor or Treatment Facility If You Have Cancer**

www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility

The Joint Commission: www.jointcommission.org

An independent, not-for-profit organization, The Joint Commission accredits and certifies more than 19,000 health care organizations and programs in the US. Joint Commission accreditation and certification is recognized nationwide as a symbol of quality that reflects an organization's commitment to meeting certain performance standards.

> **The Joint Commission's Quality Check:** www.qualitycheck.org

Quality Check® is The Joint Commission's search engine to locate Joint Commission accredited health care organizations in the United States. Visitors can search by city and state, by name or by zip code.

About The Lustgarten Foundation

The Lustgarten Foundation, based in Bethpage, New York, is America's largest private foundation dedicated solely to funding pancreatic cancer research. Founded in 1998, the Foundation provides critical support in the search for better diagnostics and treatment of pancreatic cancer, and to date has provided more than \$38 million to more than 125 research projects at medical and research centers worldwide.

The Lustgarten Foundation and Cablevision Systems Corporation, a leading media and entertainment company, together launched curePC, a public awareness campaign that uses Cablevision's high-profile assets to draw attention to the fight against pancreatic cancer. As part of this campaign, Cablevision made a multi-year commitment to underwrite all of The Lustgarten Foundation's administrative costs to ensure that 100 percent of every dollar donated to the Foundation will go directly to pancreatic cancer research. To learn more, visit www.curepc.org.



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interview with
an Expert:

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Dr. Diane Simeone

identifying
a treatment doctor
& facility

VIRGINIA CRAVOTTA (VC):
A particular concern for individuals diagnosed with pancreatic cancer is whether they have time to research treatment centers and receive second opinions before settling on a course of action.

DR. DIANE SIMEONE (DS):
It is important that a patient who decides to be evaluated and/or treated at a high-volume center understand how long it will take to be seen. Typically, being seen within a few weeks is reasonable; longer than that is not. There are times when medical issues need to be dealt with urgently, such as when a patient is experiencing biliary obstruction, significant pain, or difficulty eating with nausea and vomiting. Generally, however, once acute medical issues are addressed, there is a window of time to seek out the best course of action.

Make sure to gather all of your medical records and lab results, and get them to the center so they can work quickly to determine whether any additional testing is needed.

VC: Once someone is diagnosed, what is the best way to select an oncologist and/or treatment center?

DS: It is important to seek care from doctors or from a center that provides very high quality care and is experienced with the care of pancreatic cancer. This is definitely a cancer requiring a multi-disciplinary treatment approach. "Multi-disciplinary" refers to relying on the input of gastroenterologists, surgeons, medical oncologists, radiation oncologists, as well as allied health care professionals including oncology nurses and social workers.

Generally, patients ask their primary care doctor for a referral to someone who they know is an expert in the care of pancreatic cancer. Alternatively, your doctor may refer you to a center that has expertise in treating pancreatic cancer. There are sources of information available to help patients sort this out if your doctor isn't familiar with the best oncologist or center with expertise in pancreatic cancer. One way to begin is to find out if there is a National Cancer Institute (NCI) – Designated Cancer Center in your area. NCI-Designated Cancer Centers are considered centers of excellence, which have received recognition for their expertise. Additionally, there are resources to help you find physicians experienced in the care of pancreatic cancer. (See 'Resources' on back page) (continued)

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It's important to know that the doctor is board certified in their specialty; the volume of pancreatic cancer patients they've treated; how many pancreatic cancer patients are seen at their center; and whether there is a team that works together to make optimal decisions about what treatment is going to be best and the timing of treatment.

You may need to meet with more than one doctor. In fact, the NCI recommends getting a second opinion to compare and contrast recommendations and get a sense of whether your doctor's recommendations are supported by others.

VC: Tell us more about NCI-Designated Cancer Centers and the advantages of being treated at a high-volume cancer center. How might a patient check the quality-of-care offered at various cancer treatment centers?

DS: Patients are best served by being seen in high-volume centers, which offer a multi-disciplinary team of physicians and allied support services. Additionally, these centers offer multi-disciplinary tumor board meetings, where you will be evaluated by doctors representing all of the different specialties who all "weigh-in" and determine your optimal treatment plan. There are numerous components to think about when it comes to best quality-of-care at treatment centers, which are highlighted in this issue. (See box, "Some Quality-of-Care Components of a Cancer Treatment Center.")

“Distance from the center of care is a common concern, and in my experience, most pancreatic experts in high-volume centers are willing to work with a local oncologist to optimize the patient's treatment plan.”

Some Quality-of-Care Components of a Cancer Treatment Center

- Experience in diagnosing and treating pancreatic cancer. For example, a specialized center within a cancer facility that is dedicated to the evaluation and treatment of patients with pancreatic cancer
- Experience in managing the symptoms and side effects of pancreatic cancer
- On-site, advanced techniques and technology, such as state-of-the-art dual-phase helical CT scanner and advanced endoscopic techniques, such as endoscopic ultrasound.
- An on-site laboratory
- Access to investigational treatments for pancreatic cancer, such as in clinical trials
- Services for pain management and palliative care



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With regard to surgery, it's particularly important to identify a surgeon with expertise in pancreatic surgery. There is data to show that the number of pancreatic resections your surgeon performs annually is an excellent predictor of surgical outcomes. Probably the biggest difference in mortality among high and low volume surgeons is due to the complexity of pancreatic surgery. Therefore, it's a good idea to ask your surgeon how many pancreatic resections he/she perform annually. At a minimum, you want them to perform 15 to 20 pancreatic resections per year. You also should ask your surgeon about their complication rates and, in particular, their 30-day operative mortality rate.

VC: These are important questions, but they can also be intimidating from the perspective of a patient, who may feel uncomfortable "challenging" an authority figure by asking about his or her "30-day survival rates" or similar statistics. Also, patients may be concerned that asking for a

referral to receive a second opinion may anger their doctor. For these reasons, patients may hesitate to ask questions and seek referrals. What advice would you offer patients with these concerns?

DS: It's my firm opinion that all experts in this field should fully expect to receive questions from the patient, and not be offended by being asked these critically important questions. Patients should come prepared with a written set of questions. One way to address this is to say, "My reading has led me to understand it is wise to ask certain questions." (See box, "Questions to Ask When Looking for a Treatment Center.")

VC: Many times, pancreatic cancer patients live a considerable distance from a major cancer center, yet understand the importance of receiving treatment at a high-volume, multi-disciplinary center. Is it possible to receive a diagnosis, second opinion and/or treatment plan at a major cancer center, then implement the plan with a cancer treatment team closer to home?

DS: Yes. Distance from the center of care is a common concern, and in my experience, most pancreatic experts in high-volume centers are willing to work with a local oncologist to optimize the patient's treatment plan. So, it's not unusual for part of the plan to be executed in a high-volume center, in particular, surgery, and for a post-operative treatment plan to be executed locally. Frequently, I see high-volume centers and local physicians working as a team to facilitate patient care. This is an ideal situation. It's important to get a treatment plan outlined by experts in the disease, but if the treatment ultimately is going to be quite similar to what would be given locally, then it makes perfect sense to have that treatment plan executed locally by a qualified oncologist.

VC: What about patients who turn to the internet and/or other sources of information to learn more about specific treatments, perhaps even identifying a protocol that they would like to receive?

DS: Some patients investigate the disease and come to their initial consultation with specific ideas regarding their treatment. I encourage patients to be well informed and proactive about learning their treatment options. I also think this approach needs to be taken in context with all of the different options for treatment. For example, some treatments may sound great, but aren't well proven, or the pre-clinical data might be weak, even though the treatments are now available in clinical trials. Patients need to do their homework as best as they can, but also allow the well-informed physician to put the entire spectrum of treatment options into an overall perspective for the patient. This includes not only potential risks and benefits of a particular treatment, but also logistical considerations such as the physical, emotional and financial burden of traveling to a specific center for a clinical trial, based on what's known about the efficacy of that trial.

VC: When a patient comes to a medical 'crossroads', and may consider changing a course of treatment, is it necessary or recommended to then change treatment teams? Also, when is it time to consider experimental therapies or clinical trials?

DS: There are times, during the course of treatment, when there needs to be a review of how things are going, especially for a disease like pancreatic cancer, where a majority of patients are not cured with surgery up-front. It is important to talk with your oncologist about whether it's time to change course and try a new treatment. Both the patient and doctor should be open to considering options both locally, and at other cancer centers, especially if the treatment team has exhausted all approaches that they have to offer.

The decision about whether to change treatment teams and/or centers is the patient's call. Part of it will depend on how comfortable the patient feels with the physician, including how knowledgeable he or she is about the range of available treatment options. And certainly, it never hurts to get a second opinion from a "fresh eye." Frankly, there remains a fair amount of variability in treatment options presented to patients based on the level and areas of expertise of the medical expert making the recommendations.

So, I encourage patients to seek second opinions, especially when they're facing a crossroads in the management of their disease. Today, there are many promising clinical trials that may offer improved treatment for individuals with pancreatic cancer. From day one, when the treatment plan is outlined, the patient should ask about different treatment options, including clinical trials. Most oncologists are familiar with clinical trials that are available, not only at their institution but around the country. The patient and his or her physician can together decide whether a clinical trial might be appropriate. Trials need not be reserved for people who have failed standard treatment. One final item worth mentioning is that there are also physicians and scientists who are trying to make inroads to better treat pancreatic cancer. As a patient, you can help by considering participation in clinical trials. These research efforts are critical to help us identify better treatments that will improve patient outcomes in the future.

Some Questions to Ask When Looking for a Treatment Center

- Has the facility been rated by state, consumer or other groups for quality-of-care?
- Has the facility been approved by a nationally recognized accrediting body, such as the American College of Surgeons (ACS) and/or the Joint Commission on Accreditation of Healthcare Organizations (JCAHO)?
- Does the facility explain patients' rights and responsibilities? Are copies of this information available to patients?
- Does the treatment center offer support services to help with day-to-day obstacles, such as providing assistance to obtain medical equipment and supplies; arranging transportation for treatment; or handling the emotional, psychological or financial issues that go along with having cancer?

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