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Vaccine Therapy Approved



Spreading Hope



Cancer Terms & Resources



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Cancer: It's All ~~Greek~~ Latin to Me

Adenocarcinoma, lymphoma, sarcoma, myeloma, melanoma ...

By **Kelli Fee-Schroeder, R.N.**

Many of us have heard one of these words to describe someone's cancer diagnosis. But what do these words really mean? Basically, 'cancer' refers to any one of a large number of diseases where abnormal cells grow and spread in the body and destroy normal tissue. To better describe a type of cancer, however, a specific name, based on where it starts in the body, is used when a cancer diagnosis is made.

Cancer can start almost anywhere in the body and is identified in general categories. The specific name of a cancer is then created by using different Latin prefixes that stand for the location where the cancer began.

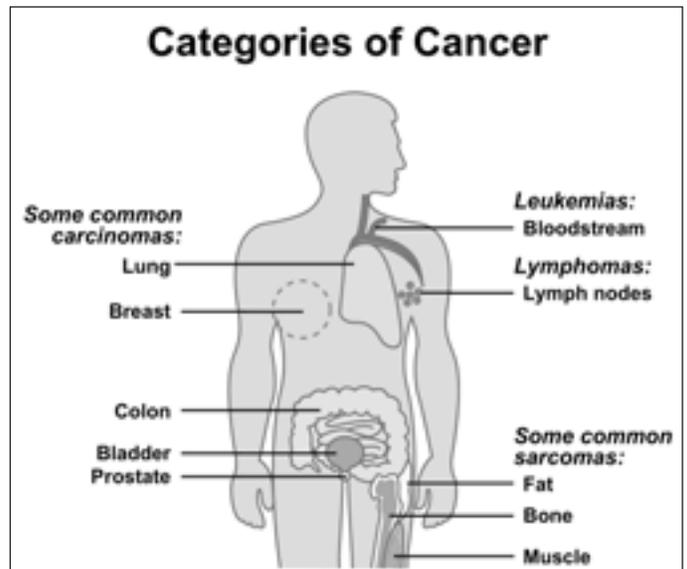
General Categories of Cancer:

Carcinoma: Cancer that begins in the skin or in tissues that line or cover internal organs. These are the most common types of cancer. Lung, breast, and colon are the most frequent cancers of this type in the United States.

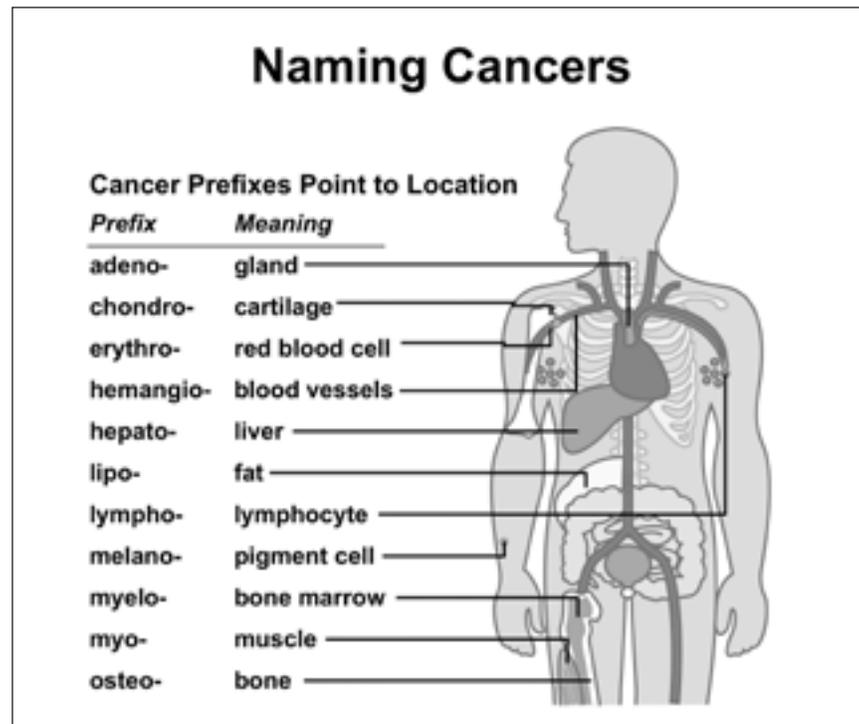
Sarcoma: Cancer arising from cells found in the supporting tissues of the body such as bone, cartilage, fat, muscle, blood vessels, or other connective tissues.

Leukemia: Cancer of the blood cells that grow in the bone marrow and collect in large numbers in the bloodstream.

Lymphoma: Cancer that arises in the **lymph nodes** and tissues of the body's immune system.



Naming Cancers



Specific names of cancers:

For example, the prefix '**osteo**' means **bone**. So a cancer starting in bone is called an **osteosarcoma** ('osteo' – referring to the specific location; 'sarcoma' – referring to the general cancer category).

Similarly, the prefix '**adeno**' means **gland**, so a cancer of gland cells is called **adenocarcinoma** – for example, breast adenocarcinoma, colon adenocarcinoma or lung adenocarcinoma.

Prefixes of cancer names and examples:

Prefix	Meaning	Example
Adeno	→ gland	→ Adenocarcinoma (breast, lung, colon, etc.)
Chondro	→ cartilage	→ Chondrosarcoma
Hemangio	→ blood vessels	→ Hemangiosarcoma
Hepato	→ liver	→ Hepatocellular carcinoma
Lipo	→ fat	→ Liposarcoma
Lympho	→ lymphocyte	→ Lymphoma (non-Hodgkin, Hodgkin)
Melano	→ pigment cell	→ Melanoma
Myelo	→ bone marrow	→ Myeloma
Osteo	→ bone	→ Osteosarcoma

Doctors need to know exactly what type of cancer a person has because specific treatments are different for different kinds of cancers.

A diagnosis of cancer is often overwhelming and confusing. Understanding the name of the cancer is the first step when searching for information and making decisions about care and treatment.

Treating Prostate Cancer Using a Person's Own Cells

by Kelli Fee-Schroeder, R.N.

Clinical research plays a key role in finding new therapies for treating cancer. Roxana Dronca, M.D., instructor in medicine and oncology, College of Medicine, Mayo Clinic, recently addressed some questions about a new FDA-approved vaccine therapy produced by Dendreon Corporation to treat advanced prostate cancer called PROVENGE® (sipuleucel-T). While not expected to be a cure, this treatment offers hope to men with advanced disease.



Roxana Dronca, M.D.

What is PROVENGE?

It is the first FDA-approved **immunotherapy** agent for treatment of advanced prostate cancer. It is the first in a new class of drugs using a person's own immune cells to fight cancer.

Has Mayo Clinic studied this therapy?

In the late 1990s, investigators led by Patrick Burch, M.D., Dennis Gastineau, M.D., and Stanimir Vuk-Pavlovic, Ph.D. began early **clinical trials** on this therapy. The results from these trials served as the foundation for the final studies that led to FDA approval. In addition, the initial PROVENGE product used in these early trials was prepared at the Mayo Clinic cell processing center.

Who can get treatment? Is this for any man with prostate cancer?

PROVENGE is intended for certain men with advanced prostate cancer whose cancer has spread to the bones or lymph nodes; do not have any symptoms; are not responding to other therapies such as hormonal therapy; and have rising **prostate-specific antigen (PSA)** levels.

How many doses are needed? How is it given?

A total of three doses are given two weeks apart. The process involves several steps. First, the patient's white blood cells (immune system cells) are collected from the blood. These cells are sent to the Dendreon lab where they are exposed to a protein designed to activate the immune system against prostate cancer. The cells are then sent back to the treatment facility and infused back into the patient. The whole process from cell collection to infusion takes about two to three days.

What is the cost?

The approximate cost is \$90,000 for the entire treatment. The Center for Medicare & Medicaid Services has opened a national coverage analysis and will determine within the next year whether the treatment will be covered. However, this does not restrict local Medicare contractors and private payers from covering this therapy, and patients are being advised to check with their insurance company before starting treatment.

Is this treatment available now?

There are about 50 centers around the U.S., including Mayo Clinic, offering this treatment. Within the first year of FDA approval, Dendreon anticipates being able to manufacture PROVENGE to support the treatment of about 2,000 patients. As the manufacturing capacity increases, the company hopes it will become more broadly available.

What is exciting about this treatment?

This vaccine therapy uses the patient's own immune system to fight cancer. It also has fewer side effects than traditional chemotherapy options. Patients with metastatic cancer live in a state of tolerance. The immune system no longer sees the tumor. To be able to educate one's own immune cells to become active against cancer cells opens up new opportunities in the treatment of this disease and hopefully other cancers in the future.

For further information on PROVENGE and the treatment, visit:

www.cancer.org/Cancer/news/News/fda-approves-prostate-cancer-vaccine

www.cancer.org/Treatment/TreatmentsandSideEffects/GuidetoCancerDrugs/sipuleucel-t

Spreading Hope, Making Connections, and Being Good to Herself

One woman's journey with pancreatic cancer

By Sarah A. Christensen



Brenda Coleman

A self-proclaimed extrovert, Brenda Coleman is a bundle of energy. She juggles her days between taking care of her family, including husband, John, and children, Andrew, 20, Catherine, 18, and Anne, 16, and serving as the Twin Cities Affiliate Coordinator for the Pancreatic Cancer Action Network. In this volunteer leadership role, she oversees efforts regarding education, outreach, advocacy, and public relations. It takes continual

energy to get and keep people engaged in pancreatic cancer issues, and it is clear where Brenda's passion came from – her own diagnosis nearly nine years ago.

In 2001, Brenda was a busy 44-year-old stay-at-home mom, with three children in elementary school. She started to notice changes with her digestion. With vague symptoms, things just seemed 'off'. Her intuition told her it was cancer. In spite of wondering how her self-diagnosis would be perceived, Brenda met with her general practitioner. She detailed her physical changes and strong suspicions due to her grandfather's history of pancreatic cancer. When test results returned showing a tumor in the **pancreas**, Brenda remembers thinking, "I don't even know what a pancreas does."

Within a week, she was seen at Mayo Clinic in Rochester, and surgery was scheduled a few days later. She returned to her home in Wayzata, Minn. to go trick-or-treating with her children, and then headed back to Mayo Clinic for surgery. "It was a strange time, being shortly after the September 11 terrorist attacks. The whole world seemed turned around for everyone," Brenda recalls.

Brenda underwent a surgical procedure, called a **Whipple**. Even though the cancer had not spread outside of the pancreas, she received a combination of chemotherapy and radiation therapy as part of a clinical trial. Because diagnosis and treatment happened so rapidly, Brenda says, "There wasn't time for me to even process the fact that I had cancer. I was probably six months past my surgery when it dawned on me that 'I have cancer.' I was just so focused on getting well that I hadn't taken it in." It was at that point she found herself able to reflect on her diagnosis.

Her supportive family and strong Catholic faith enabled her to accept her cancer, no matter what the outcome. This act of surrender allowed her to move forward confidently with her treatment. Brenda also found that her family and friends could spend energy on the emotional aspects of her diagnosis, while she primarily focused on getting well. It wasn't denial, it was putting a priority on the physical aspects of healing. She found that by pacing her days – resting while the children were in school – she had enough energy in the evening to engage with her family. "I now tell other patients to be good to yourself and allow yourself the time and space needed to heal physically and emotionally. Caregivers come to it at a different pace," she notes.

Being a very social person, Brenda longed to speak with other pancreatic patients and their families. But due to privacy laws about disclosing patient information, her physicians could not give her the names of other individuals with pancreatic cancer. Also, pancreatic cancer often has a poor prognosis, even when diagnosed early, since it typically spreads rapidly and is seldom detected in its early stages. "My very life is a visual aid," she states regarding her advocacy efforts that began several years after her treatment.

Her parents, husband and children continue to support her by being involved in awareness events, whether on Facebook, attending a Twins baseball event, or participating in a PurpleRide fundraiser for the Pancreatic Cancer Action Network. "Everything we do doesn't have to be about cancer, but you can lift up pieces of the experience and benefit from it," Brenda says.

In addition, because of the family history of pancreatic cancer, all of Brenda's siblings and children have participated in a pancreatic registry at Mayo Clinic by donating blood for research. Brenda hopes this information will someday aid in better detection or prediction of hereditary cancers.

"Because of the systematic way data is collected, registries make the research easier. As a result, new insights are possible, leading to ways we can move faster to prevention, early detection, and treatment," says Gloria Petersen, Ph.D., professor of epidemiology and principal investigator for Mayo Clinic's Specialized Program of Research Excellence (SPORE) grant for pancreatic cancer. "Including family members of the patients allows us to answer questions about genes and inherited risk."

And while no one wants a diagnosis of cancer, Brenda says that a lot of goodness has come out of rearranging some priorities in her life. Family dinners are mandatory, and more time is spent in reflection. "Cancer affects the whole family," she says. "We all had cancer and had life lessons to learn from the experience." Some of those insights learned by the Coleman family include:

- Live intentionally, appreciate every day as a gift
- Help others however you can
- Be gentle, not judgmental, with those who haven't suffered
- Be thoughtful on choices made and gifts given
- Look beyond self and live in greater good for humanity
- Encourage and listen to your children
- Live with an attitude of gratitude



Brenda's children Anne, Catherine, and Andrew show their support.



Brenda takes the opportunity to educate others at a pancreatic awareness event.

The Pancreatic Cancer Action Network is a nationwide network dedicated to advancing research, supporting patients and creating hope for those affected by pancreatic cancer. To learn more, visit www.pancreaticcancer.org.

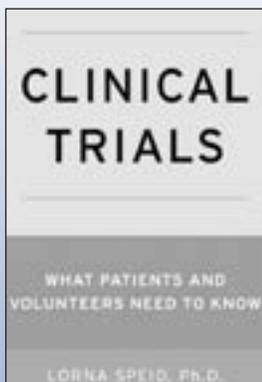


Cancer Terms

Clinical trial	A type of research study that tests how well new medical approaches work in people. Also called clinical study or clinical research study.
Gland	An organ that makes one or more substances, such as hormones, digestive juices, sweat, tears, saliva, or milk. Endocrine glands release the substances directly into the bloodstream. Exocrine glands release the substances into a duct or opening to the inside or outside of the body.
Immunotherapy	Treatment to boost or restore the ability of the immune system to fight cancer, infections, and other diseases.
Lymph	A clear fluid that carries cells that help fight infections and other diseases. Also called lymphatic fluid.
Lymph node	Lymph nodes filter lymph and they store lymphocytes (white blood cells). Also called lymph gland.
Pancreas	A glandular organ located in the abdomen. It makes pancreatic juices, which contain enzymes that aid in digestion, and it produces several hormones, including insulin. The pancreas is surrounded by the stomach, intestines, and other organs.
Prostate specific antigen (PSA)	A type of protein made by the prostate gland and found in the blood.
Whipple procedure	A type of surgery used to treat pancreatic cancer. The head of the pancreas, part of the small intestine, a portion of the stomach, and other nearby tissues are removed.

Definitions obtained from www.cancer.gov. Defined terms are in bold in the newsletter.

Book Review



Clinical Trials: What Patients and Volunteers Need to Know

by Lorna Speid, Ph.D., Oxford University Press, 2010, 179 pp. \$19.95.

Written by a pharmaceutical consultant, this book offers individuals the basic information needed to understand clinical trial development including discussion of the risks and benefits of research, the importance of informed consent and asking questions prior to participation. Topics addressed are ethical concerns and oversight of research, the role of the clinical investigator, and the drug development process. Specific chapters address clinical trials involving children, the elderly, and trials for rare disorders and vulnerable groups.

A complete glossary of clinical research terms is included along with a table of contents. Most helpful to the reader will be a list of questions to consider asking the clinical investigator prior to and during the clinical research process.

Financial Burdens of Cancer

By Jill Lovill, American Cancer Society Patient Navigator

A cancer diagnosis often brings many concerns. What will my treatment plan be? Will I lose my hair? How will I tell my family? Unfortunately, in these economic times, another key question is: Will I be able to afford my treatment?

Even with insurance, a cancer diagnosis often adds a financial burden. Specific grants may be available in your community for young adults, parents with cancer and veterans. There are a number of organizations available to help.

Financial Assistance

- **CancerCare:** A national nonprofit organization that provides financial assistance to individuals facing a cancer diagnosis. Certain types of cancer afford greater assistance with transportation, co-pays and medications. Visit www.cancercare.org or call 800-813-4673.
- **Leukemia & Lymphoma Society:** A yearly grant is available for patients facing blood cancers and diseases. Co-pay assistance is also available to offset medical costs for specific diagnoses. Visit www.leukemia-lymphoma.org.

Medication Assistance

- **Partnership for Prescription Assistance:** Pharmaceutical companies, doctors, and patient advocacy organizations help qualifying patients get free or low-cost brand name medicines. Visit www.pparx.org or call 888-477-2669.
- **NeedyMeds:** Obtain a free Drug Discount Card which can be used without financial, age or residency restrictions for more than 4,000 different drugs. Visit www.needymeds.org.
- **RxHope:** Offers an assistance finder that matches patient information with available federal, state and charitable prescription drug programs. Visit www.rxhope.com or call 732-507-7400.
- **Healthwell Foundation:** Provides financial assistance to underinsured patients living with chronic or life-threatening diseases. Visit www.healthwellfoundation.org.

Patient Advocates & Legal Assistance

- **Cancer Legal Resource Center:** Provides free and confidential information and resources on cancer-related legal issues. Call 866-843-2572 to learn about relevant laws and resources for your situation.
- **Patient Advocate Foundation:** Offers a free case manager to individuals who are having a difficult time with medical bills. The manager will work on your behalf to obtain assistance or settle bills. Call 800-532-5274.

The financial difficulties associated with a cancer diagnosis often cause anxiety and stress, which complicate your journey. The American Cancer Society (ACS) patient navigator can connect you to resources to alleviate these concerns. The society also offers a range of financial guides that can help you understand the issues surrounding cancer and guide you on how to plan ahead. The organizations listed are just a sample of the help that is available.

Please contact your local patient navigator for additional support.

Mayo Clinic in Rochester: Jeri Lensing and Angela Young, 507-266-9288.

Mayo Clinic in Arizona: Jill Lovill, 480-301-5990.

For more information on all ACS programs and services or to connect with a patient navigator in your area, call 800-227-2345 or visit www.cancer.org.



Jeri Lensing



Angela Young



Jill Lovill

Calendar of Events

February 2011

13 26.2 with Donna: The National Marathon to Fight Breast Cancer

Jacksonville Beach, Fla.

904-355-PINK (7465)

www.breastcancermarathon.com

13 Lace Up Against Breast Cancer Half Marathon & 5K Run/Walk

Rochester, Minn.

Email: runluabc@gmail.com

www.luabc.org

March 2011

Daffodil Days

American Cancer Society

800-227-2345

www.cancer.org

National Colon Cancer Awareness Month

Prevent Cancer Foundation

800-227-2732

www.preventcancer.org/colorectal

Mayo Clinic Island on Second Life™

Over the past two years, Mayo Clinic has established itself in the virtual 3D world called Second Life™. People create online personas or avatars and interact with others without the barriers of geography, language or time of day.

Currently, there are more than 18 million registered users on Second Life™. Mayo Clinic's Center for Innovation has coordinated a Virtual Mayo Clinic located on Mayo Clinic Island in Second Life™. The island includes: a re-creation of the Gonda lobby; a conference center to host presentations and educational events; meditation and social meeting areas; and a new bookstore.

Mayo Clinic has already hosted a virtual conference about colon cancer in Second Life™, along with presentations on cardiology topics, with additional topics to be added during the coming months. People are encouraged to sign up, create an avatar, and explore Mayo Clinic Island. Second Life™ account creation and help can be found on the web at secondlife.com/.



together

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together newsletter provides educational information for cancer patients, their family, caregivers and friends. Physicians, staff and cancer patients write the articles.

To submit story ideas, provide feedback or unsubscribe, call 507-266-9288 or e-mail canceredprog@mayo.edu.



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