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Lloyd Ney: The Father of Prostate Cancer Advocacy

By The PCRI Staff

When Lloyd was diagnosed with advanced prostate cancer in 1984, an era before PSA screening, hormone therapy and the internet, he became incredibly disturbed by the limited number of treatment options available for prostate cancer patients, and even more so, by the lack of available literature that could educate men about the disease and treatment options. So he founded PAACT, (Patient Advocates for Advanced Cancer Treatments, Inc.). With a passionate belief in patient empowerment, Lloyd set up the presses and began publishing the *Prostate Cancer Communication* newsletter. At that time, prostate cancer educational material for patients was almost non-existent.

Amanda M. Saenz and Chris Meehan of the Grand Rapids Press wrote the following about Lloyd: "Mr. Ney who owned and operated Sports News and Golden Years Senior Citizens Newsletter and who was also a self-employed mechanical engineer, was frustrated with the treatment that doctors offered him. Instead of bowing to the conventional wisdom of the day, he sought help and advice for his prostate cancer elsewhere. He made a trip to Quebec City, Canada to start a special type of hormonal therapy to combat prostate cancer. In Mr. Ney's case, the hormone therapy helped stop the cancer. When he came back to Grand Rapids, he decided to try to bring the therapy to the United States, by helping to convince the Food and Drug Administration to allow it. After founding PAACT, the organization became the first clearinghouse for prostate cancer treatment." [2] →

Recently Forbes Magazine published an article titled *When Money Motivates Cancer Treatment Options*. One striking statement was that when a "...physician has a financial investment in the equipment he or she uses, it's money – as often as science – that often motivates treatment decisions." [1]

Prostate cancer treatment is no exception. Surgeons are paid to do surgery and radiation therapists to do radiation. Where can a man turn for unbiased advice when a diagnosis of prostate cancer suddenly occurs?

Free support groups and helplines are some of the best resources because they are usually not connected to any center that is in the business of giving a specific treatment. When thinking of patient support, one very unusual man immediately comes to mind, Lloyd Ney, the personification of helpline support for patients. Lloyd originated the first known prostate cancer helpline from the basement of his home which was staffed by himself and other highly educated laymen.

Not many people know that it was complications from radiation that ultimately caused Lloyd's death in 1998. But that was fourteen years after being given a death sentence with six months to live. After fourteen years of radiation, his bladder and bowel were severely damaged, ultimately leading to multiple bouts of sepsis originating from the super pubic catheter. Dr. Labrie's hormone therapy is what kept Lloyd alive an additional 14 years, allowing him to create all the resources that are now readily available through PAACT."

At Lloyd's memorial service Dr. Stephen Strum, his close friend, was quoted, "Lloyd worked out of his basement, 7 days a week, 20 hours a day directing confused, frightened men and their loved ones – their wives, girlfriends, and children. Lloyd was a one-man powerhouse, as stubborn as a mule, set in his ways, willing to lock horns with anyone, anywhere and anytime. This was the outer crust of Lloyd Ney – tough, irascible. But inside this crust was a soft bread, the uniqueness of Lloyd Ney."

PAACT's pioneering effort in prostate cancer advocacy paved the way for many subsequent prostate cancer newsletters, support groups, books, pamphlets, magazines, and information available on the internet.

When thinking of the incredible impact of all the support groups and advocacy organizations and all the good they do, Lloyd Ney - the pioneer, the great trailblazer, has to be given credit as the guy who started it all. □

Lloyd helped establish over 140 cryosurgery sites in the U.S. which provided cryosurgical ablation of the prostate as an alternate to radical prostatectomy. PAACT was also instrumental in introducing legislation in some states mandating full disclosure by physicians of all available options for detection, diagnosis, evaluation, and treatment of prostate cancer. Working with other concerned and interested advocacy groups, he supported similar efforts at the national level.

To Learn More About PAACT – see www.PAACTUSA.org

1. <http://www.forbes.com/sites/robertpearl/2014/07/31/when-money-motivates-cancer-treatment-options/>
2. <http://www.paactusa.org/about-us/founder>



RESULTS FOR THE 2014 PCRI AND ZERO CANCER RACE IN LOS ANGELES, CA.

Thank you to all who participated!

5K Winners

1. Stephen Tippett
2. Lacue Kamani
3. Ryan Sheperd

15k Winners

1. Brianna Calvert
2. Sharon Moreno
3. Mario Trujillo

Largest Teams:

1. King's Hawaiian - 84
2. Team Velarde - 32
3. Team Jeremy - 18

NEW DEVELOPMENTS IN THE USE OF TAXOTERE

*Jeffrey Turner, M.D., Medical Oncologist,
Prostate Oncology Specialists*

Taxotere is the most widely-used chemotherapeutic agent for treating prostate cancer. It is also the most widely-used agent for breast and lung cancer. Prostate Oncology Specialists has been using Taxotere since 1998. Two large multicenter studies completed in 2004 demonstrated longer survival for men with hormone resistant prostate cancer (ROYAL) when treated with Taxotere. Recently, another large randomized trial concluded that Taxotere is even more effective when patients with metastases begin Taxotere before hormone resistance develops.

What is Taxotere?

Taxotere is an intravenous chemotherapy which is a "plant alkaloid." It works by interfering with cell division causing cell death. It also inhibits proangiogenic factors, such as VEGF, (vascular endothelial growth factor) which are necessary for tumor growth. Interestingly enough, Taxotere is synthetically derived from a substance that is extracted from the needles of the European yew tree, Taxus Baccata.

Two Philosophies of Use for Taxotere

Taxotere accomplishes two basic roles in prostate cancer. 1) To treat metastatic disease, with or without other agents, such as Carboplatin, Xeloda or Avastin. 2) As a preventative agent before the cancer becomes metastatic. Testosterone inactivating pharmaceuticals (TIP) are usually the first line of defense for men with high-risk disease (AZURE). However, in some situations TIP alone can prove to be insufficient. Adding Taxotere to TIP is called "adjuvant chemotherapy." →