

Founder



In 1984 a relatively unknown man, Lloyd Ney, was diagnosed with prostate cancer. That one diagnosis, routine for 241,740 men yearly, with estimated deaths being 28,170 each year, began a chain of events – the results of which had and are continuing to have a profound affect on the treatment of prostate cancer for millions of prostate cancer patients in the United States and the rest of the world.

In 1984 the standard treatments offered were radical prostatectomy and external beam radiation. Unfortunately, most patients diagnosed in that era were already metastatic and both therapies had very high failure rates. The early warning PSA test had not yet been invented. Typical of what happened to many prostate cancer patients, Lloyd Ney was informed by his physician that the radiation was not effective in curing him or slowing down the advance of the disease. In fact the treating physician indicated he was terminal and had a few months to live since they knew of no way to stop the spread of the disease.

Not accepting this morbid prognosis he researched the literature and spoke with doctors and other patients with the same problem. Through this effort he became aware of the work of Dr. Fernand Labrie in Canada and his pioneering combination hormonal blockade therapy. He became a patient of Dr. Labrie, accepted the total hormonal blockage protocol, and lived for another 14 years.

Disturbed by the limited treatment options for PC patients, and even more so by the lack of available literature that could educate the men about the disease and treatment options, Lloyd decided to do what he could for his fellow man.

At the first visit to Dr. Labrie's clinic he witnessed a waiting room full of American men that came there for the same treatment. Incensed at the whole scenario of limited treatment options, men having to leave the country in search of better treatments and the lack of available literature for prostate cancer patients, Lloyd announced to the waiting room full of PC patients that he, that very day, was starting a prostate cancer advocacy organization that would publish a prostate cancer newsletter and make it available to all prostate cancer patients, advocates and doctors.

Thus PAACT, INC. (Patient Advocates for Advanced Cancer Treatments, Inc.) was born. With a passionate belief in patient empowerment through knowledge and dedicated to the belief that prostate cancer patients have the right to know all the options for Detection, Diagnosis, Evaluation and Treatments for prostate cancer, Lloyd, as promised, set up the presses and began publishing the Prostate Cancer Communication newsletter. At that time educational material available for PC patients was non-existent. The Prostate Cancer Communication, a 24 page quarterly newsletter became the primary conduit for prostate cancer information to the patients, advocates and physicians. It still serves that purpose today with timely articles on the latest developments in the treatments for prostate cancer and other health issues related to the disease.

Working with concerned doctors, many of whom were leading specialists in PC treatment and who shared Lloyd's beliefs – basic concepts were established for PAACT that served as a road map for furthering the empowerment movement for the prostate cancer patients. The concepts included choices, communication, compassion and cooperation, centers of

excellence, charity and concentration of effort. Following this foundation of purpose, PAACT proceeded to undertake the activities necessary to achieve the goals implied by the tenets.

These tenets were documented in the preface of PAACT's Prostate Cancer Report (PCR), a 66 page treatise on the prostate, prostate cancer and treatment options available to the patients. Published in 1992 the PCR, a textbook for the PC patient, was delivered to all PAACT members and was included in PAACT's initial patient package of PC information. Updated information to the PCR is printed in the Prostate Cancer Communication newsletters to keep the PAACT members up to date on new developments.

Working with scores of doctors and gathering information from sources throughout the world, PAACT not only became a clearinghouse for prostate cancer prevention and treatment information for men, but also championed causes related to improved knowledge of and treatments for PC.

PAACT became the largest prostate cancer teaching and support group in the world; the first organization to introduce patient networking in relation to prostate cancer. PAACT encouraged and supported the formation of over 150 PAACT PC support groups. The PAACT member database numbers over 36,000 prostate cancer patients and is growing daily.

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

In 1985 PAACT was successful in getting the Federal Drug Administration (FDA), New Drug Application (NDA) and Investigation of New Drug (IND) trials through Dr. Fernand Labrie of Laval University in Quebec, Canada. This permitted

the use of combination hormonal therapy (CHT) on patients in the United States. Later, PAACT was able to have U.S. physicians authorized by Dr. Labrie's application authority to use CHT in the United States years before the CHT drugs were FDA approved. PAACT was the prime motivation in encouraging pretreatment with CHT to reduce both tumor and prostate gland volume, which has considerably enhanced the results of secondary therapies.

PAACT helped establish over 140 cryosurgery sites in the U.S. to provide cryosurgical ablation of the prostate (CSAP) as an alternate to radical prostatectomy for qualified patients with organ-confined disease. For some years CSAP was under the cloud of a non-coverage medical insurance policy and many men opting for CSAP were denied payment by Medicare and insurance companies.

PAACT's Legal Action Committee (LAC-PAACT) prepared legal documents (LAC-PAACT KIT) including bibliographies, copies of published studies showing the effectiveness and safety of CSAP and favorable court decisions that claimants denied payment for cryosurgery found helpful in obtaining reimbursement from Medicare and insurance companies. To date nearly every PAACT member originally denied payment has won favorable decisions using the LAC-PAACT KIT in presenting their case for reimbursement. In July 1999 the Health Care Financing Administration (HCFA) finally reversed the national non-coverage policy and approved medical coverage for CSAP as a primary treatment for clinically localized PC.

PAACT was 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, similar efforts were supported at the national level.

The PAACT organization is comprised of very capable staff

members, who share a common desire to help patients become aware of our present understanding of prostate cancer, to help patients to participate in their own health improvement and to direct them to appropriate physicians and medical centers of excellence for treatment. First time PC or advocacy callers to PAACT requesting information receive the PAACT initial patient package of prostate cancer information. The educational material is designed to provide a quick course in the detection, diagnosis, evaluation and treatment options for prostate cancer. Included in the package is the quarterly Prostate Cancer Communication newsletter. The caller is then placed on the mailing list for future newsletters.

In addition to the newsletter a vital part of PAACT's service is communication via telephone, fax and e-mail offering information, encouragement and support to prostate cancer patients, their families, friends and doctors.

The information is furnished without financial obligation. PAACT is a publicly supported 501 (c) (3) tax-exempt organization that depends solely on voluntary contributions from members and friends. The standard voluntary membership contribution is \$55.00 which covers the cost of the initial patient package of PC information. For the patient package of PC information and the Prostate Cancer Communication newsletter contact the PAACT office at P0 Box 45, Sparta, MI 49345, Phone 616-453-1477, Fax 616-453-1846, or E-mail paact@paact.help. You may also find PAACT on-line at www.paact.help.

The goals for PAACT established at its founding have not changed. Until a cure is discovered, patient empowerment through knowledge is the primary mission. In close cooperation with PAACT medical advisory board members, some of whom are on the cutting edge of new and improved treatment modalities, and researching the medical literature, PAACT will continue to identify new developments, and options in PC treatment for the prostate cancer patient. The bottom of the first page of the

Cancer Communication newsletter has the following statement: "Let's Conquer Prostate Cancer in Our Lifetime." PAACT's ultimate goal is to help make that statement a reality.

SPECIAL TRIBUTE

His Brothers He watched them die in pain alone, Who might have lived had they but known The simple facts that could have led Them to a longer life instead. He prayed, "Oh God, please send a guide To help my brothers turn the tide:" And heard a voice from heaven say, "I have, his name is Lloyd J. Ney!"

W. Millard Obituary: Ney – Mr. Lloyd J. Ney Sr., age 79, founder and President of P.A.A.C.T., found peace in the Lord, Wednesday, August 19, 1998. He was preceded in death by his wife, Ethel M. Ney. Surviving are his wife of 25 years, Janet; children, Lloyd J. Jr. and Janette Ney of Grand Rapids, Richard and Becky Profit and William Profit all of Alpine Township; grandchildren, Lloyd J. Ney III, Eric J. Ney, Colleen M. Ney, Nichole Profit and Dustin Profit; brother, Robert (Audrey) Ney of Titusville, FL; sister, Genevieve McCarthy of Long Island, NY and his special friend, Dr. Stephen Strum of CA. Mr. Ney owned and operated Sports News and Golden Years Senior Citizens Newsletter and had been a long-time member of T.P.A. as well as being active in the Knights of Columbus serving two terms, including Past Grand Knight, with Council 389. He had enjoyed serving as an usher in his church and was an avid golfer and bowler. Mr. Ney had received letters of commendation from Major John Logie, Governor John Engler, Senator Carl Levin, Rep. Vernon J. Ehlers, President Clinton, Drs. Duke Bahn and Fred Lee of Crittenton Hospital, National Prostate Cancer Coalition, American Cancer Society & U.C.I. Medical Center, Strathmore's Who's Who and the Advanced Prostate Cancer Support Group of San Diego. The Funeral Mass was celebrated on Saturday morning August 22, at 11 AM at Holy Spirit Church, 2230 Lake Michigan Dr. NW. Interment in Resurrection Cemetery. In lieu of flowers, contributions in memory of Mr. Ney may be made to

P.A.A.C.T. (Patient Advocates for Advanced Cancer Treatments).

TRIBUTE TO LLOYD – **Stephen Strum**

We are here today to show our respect, our admiration, and our love for Lloyd Ney. Let me share with you some recollections and my understanding of Lloyd's inner self.

Lloyd was diagnosed with prostate cancer in January of 1984. He received radiation therapy in February and March of that year. Eight months later Lloyd had back pain due to metastatic prostate cancer involving the thoracic spine, sacrum and left ribs. He was informed that his prognosis was terminal and to get his affairs together. Lloyd being Lloyd, he found this unacceptable. He researched the literature on prostate cancer and came upon the pioneering work of Fernand Labrie in Quebec City, Canada. Dr. Labrie's work had not been accepted at that time in the United States and was not to be endorsed until 5 years later. Lloyd went to Canada and was started on combination hormone blockade. When Lloyd realized he was not going to die, he dedicated whatever years he had left to help other men with prostate cancer. The six month prognosis Lloyd was given turned into 14 years.

Lloyd's credo became what John Donne wrote about in 1623 in the poem No Man Is An Island. Let me paraphrase this:

No man is an island unto himself; each man is part of the continent. Any man's death diminishes me, because I am involved in Mankind. And Lloyd immersed himself in helping his fellow man.

He worked out of his basement, 7 days a week, 20 hours a day directing confused, frightened men and their loved ones – their wives, girlfriends, children. Lloyd put himself at the bottom of his priority list; he epitomized self-sacrifice. An anonymous author from the Holocaust said: He, who saves one soul, saves the world. And this was Lloyd's prime directive – his mission. Lloyd was a missionary as well as a visionary. He

did not want to lose one fellow man. 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 of this crust was the soft bread, the uniqueness of Lloyd Ney. I have not met a man so dedicated in his efforts to help others to the exclusion of himself. Lloyd established the Patient Advocates for Advanced Cancer Treatments (PAACT). He worked doggedly at putting out the PAACT newsletter, and made a real effort to get cryosurgery on its feet. He is responsible for referring many patients into the capable hands of Fernand Labrie, Fred Lee, Duke Bahn and Bob Badalament, Snuffy Myers, Roy Berger, Israel Barken, Bob Leibowitz, Others who I forgot to mention, and also to me. So, Lloyd was the mother hen, the caregiver for so many people – directly and indirectly. Ralph Waldo Emerson said in his poem entitled: " A Few Words on Success" To leave the world a bit better, whether by a healthy child, a garden patch or a redeemed social condition; To know even one life has breathed easier because you lived. This is to have succeeded. Lloyd has helped so many men. He has helped the men with prostate cancer but also, all those in the life sphere of these men as well: mothers, fathers, sisters, brothers, wives, children, grandchildren, friends, and business associates – all over the world. Conservatively, Lloyd has touched the lives of millions.

What a measure of a man's success. Lloyd lit many candles. He is so much responsible to initiating and furthering the empowerment movement of the man with prostate cancer. A movement that is a paradigm for men and women working together to solve problems – it is a model for evolution of the spirit. Lloyd constantly challenged the medical establishment. He painfully listened to the horror stories of bad treatment of men with prostate cancer – hour after hour, day after day. This angered him, and often soured him on the medical professionals involved with prostate cancer. It led him to the concept of a Consumer's Union of Men with Prostate Cancer that

would report on wonderful doctors and medical centers but also on the terrible doctors. Lloyd challenged the FDA and wanted the prostate cancer movement to fast-track drugs and treatments for men with prostate cancer the way the AIDS patients have done for themselves. He inspired the formation of the legal arm of PAACT called LacPac. Lloyd did all of his work out of the Ney home, out of the basement. Lloyd had help from his staff.

I applaud the staff that could work with Lloyd because he was a difficult taskmaster. One has to look back and applaud the efforts of Galen Beverly, of Jeff Sikkema, of Fred Mills and of Lloyd's recent staff: Tony Staicer, Carol Dial and Judy Syrek. There is a quote from the famous Rabbi Hillel that goes something like this: If I am only for myself, what am I. But, if I am not for myself, who will be for me? Lloyd was hardly for himself. Lloyd would have perished years ago if it were not for the love and caring of his wife, Jan Ney. Jan was the perfect mate for Lloyd. For every strand of DNA there is a second strand, that reinforces the structure and integrity of the other strand. So it is with Lloyd and Jan. Lloyd never would have succeeded without Jan. The praises in the past and in the present to Lloyd Ney are equally bestowed upon Jan Ney. As I have told Jan many times, she is one of the angels that are easily identified on this earthly plain. Lastly, I wish to say the following. It seems like a long time ago, but at the same time, just like yesterday, that a bunch of us met with Lloyd to discuss and write the tenets or basic concepts of PAACT. These appeared in the PCR or prostate cancer report. These concepts are: choices, cooperation, concentration of effort, communication, compassion, centers of excellence, charity. A number of these concepts are now part of the reality for the man and his family with prostate cancer thanks to Lloyd. In Michigan, a man must be told his treatment options by law. Centers of excellence are being endorsed and PAACT continues to communicate with patients on the latest advances in prostate cancer. But, there is still much to

resolve – much to complete. In the PCR 5th edition the dedication poem selected by Lloyd reads: It is not enough to enjoy a pleasant moment, One must share it, and bring joy. It is not enough to simply enjoy nature, One must plant trees. It is not enough to enjoy the gifts given to us, One must give thanks. It is not enough to shed a tear for another's pain or sorrow, One must bring comfort. It is not enough to bemoan the injustices in the world, One must find ways to right the wrongs. And so it is with the candles that Lloyd has lit. It is not enough to say that one man working in his basement rose to greatness by lighting the torch of awareness of what should be done. We must carry these missions to their completion

So, I end this tribute to Lloyd with his favorite poem:

To You, From Failing Hands We Throw The Torch. Be Yours To Hold It High. If You Break Faith With Us Who Die, We Shall Not Sleep Though Poppies Grow In Flanders Field. God bless you Lloyd for being so involved in mankind, for saving so many souls, for leaving the world a much better place than how you found it, for causing so many lives to breathe easier, for being selfless and for finding ways to right the wrongs in the world. We shall not break faith with you. We will continue your cause, and soon, one day, we will see the time that prostate cancer will not be a threat to any man's life.

Your true friend,

Stephen Strum

Prostate cancer patient advocate dies at 79

by Amanda M. Saenz and Chris Meehan

The Grand Rapids Press

When Lloyd Ney was diagnosed with prostate cancer in 1983, doctors gave him six months to live. But the “feisty” Grand Rapids man knew he wouldn't succumb to the death sentence, and instead became a national advocate and researcher for prostate cancer. Mr. Ney, who had since dedicated his life to shedding light on cancer treatments by founding a national advocate

group for prostate cancer patients, battled for 15 years before dying of complications from the disease Wednesday. He was 79. "His work in cancer research and serving as an advocate for people with prostate cancer is what's kept him alive for the past 15 years," said his wife, Janet. "He lived for his work." Mr. Ney who owned and operated Sports News and Golden Years Senior Citizens Newsletter and also was 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 elsewhere. He made a trip to Quebec City, Canada, where he had read a doctor used a 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, helping convince the Food and Drug Administration to allow it. In 1984, he founded PAACT, Patient Advocates for Advanced Cancer Treatments. The organization eventually become a clearinghouse for prostate cancer prevention and treatment information for men around the world. PAACT also has been active in pushing legislation that requires doctors to disclose to patients of the prostate cancer treatments available to them. "PAACT will go on," Janet Ney said. "We have a very capable staff and many people, including doctors, who contribute to the organization on a regular basis."