Prostate Cancer

Advisory Committee

1998–1999 BIENNIAL REPORT

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TDH

Prostate Cancer Advisory Committee
Texas Department of Health
1100 West 49th Street
Austin, Texas 78756
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Message from the Chair

It is with great pride that I have served the State of Texas as Chair of the Prostate Cancer Advisory Committee. Prostate Cancer remains the most common cancer among men in Texas and is the cause of 2,000 deaths each year in this state.

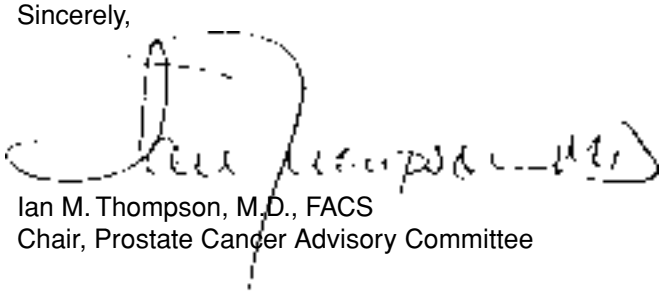
Evidence is accumulating that through lifestyle changes and nutrition, it may be possible to reduce the risk of prostate cancer. Additionally, further data suggests that early diagnosis and treatment may reduce the risk of death from this disease. The development and proliferation of prostate specific antigen testing has been the cause of the dramatic improvement and increase in detection of prostate cancer while it is still localized to the prostate (and potentially curable).

The challenge for this Advisory Committee has been to develop and disseminate the best message regarding prostate cancer control to the population of Texas. By meeting with many of the organizations that participate in the education and care of men at risk of developing prostate cancer, the Committee has developed a cogent and balanced message and is in the process of helping educate the Texas public.

The major accomplishments of the Committee have been twofold: helping to coordinate the efforts of the many organizations in the state of Texas that help in the education and care of men who have or are at risk of prostate cancer, as well as promoting the annual Prostate Cancer Awareness Campaign each June.

I would like to thank the members of the Prostate Cancer Advisory Committee who have given their time and expertise so selflessly and who participate in this effort at their own expense. I fully anticipate that the impact of their work will increase over time. I would also like to thank the members of the Texas Board of Health, Commissioner William "Reyn" Archer III, M.D. and Governor George W. Bush for their recognition of the importance of prostate cancer awareness and the need to disseminate the message of prevention, early detection, and treatment. Our Committee challenges the State of Texas — its people and leadership — to reduce the number of new cases of prostate cancer and to reduce death from the disease. We look forward to the day that no man loses his life to this disease.

Sincerely,



Ian M. Thompson, M.D., FACS
Chair, Prostate Cancer Advisory Committee

Prostate Cancer Advisory Committee

1998
Evelyn C.Y. Chan, M.D., M.S.
Hal G. Conway, M.Ed.
Odell Joseph Dean, M.D.
Eduardo Orihuela, M.D.
Claudie Simpson
Teresa L. Smith, M.S.
Ian M. Thompson, M.D., Chair
Robert R. Unterberger, Ph.D.
Armin D. Weinberg, Ph.D., Vice-Chair
Mary Ellen Wyers, Ph.D., R.N.

1999
Evelyn C.Y. Chan, M.D., M.S.
Odell Joseph Dean, M.D.
James David Kolker, M.D.
Carol Rice, Ph.D., R.N.
Claudie Simpson
Jerome H. Supple, Ph.D.
Ian M. Thompson, M.D., Chair
Karen K. Torges
Robert R. Unterberger, Ph.D.
Armin D. Weinberg, Ph.D., Vice-Chair

Mission Statement

To be an advisory committee of excellence that serves as the conduit of change by systematically reviewing and disseminating information – resulting in an informed public and leading to increased access and utilization of resources in the prevention and treatment of prostate cancer.

Historical Perspective

Recognizing the significance of prostate cancer, the 74th Session of the Texas Legislature passed Senate Bill 1685 to address this growing problem by creating an initiative with two components: (1) an education program — designed to promote public education and awareness of prostate cancer; and (2) an advisory committee — which ensures that policymakers, public health officials, health care practitioners, and all citizens of Texas are informed of the most current, accurate information on prostate cancer prevention and treatment.

The legislation requires that the Commissioner of Health, in consultation with the Texas Board of Health, develop and implement a program to educate the public on the causes, risk factors, and issues related to the early detection and treatment of prostate cancer. The Prostate Cancer Advisory Committee, comprised of eleven members who serve six-year terms, are health professionals, survivors, educators, and experts in the area of prostate cancer. The Committee serves to:

- Advise the Board of Health on agency policy concerning prostate cancer;
- Advise appropriate staff and verify the accuracy of prostate cancer information disseminated to the public; and
- Plan, develop and implement activities designed to heighten awareness and educate Texans on warning signs, the importance of early detection, and effective treatment options for prostate cancer.

The Prostate Cancer Advisory Committee, comprised of eleven members who serve six-year terms, are health professionals, survivors, educators, and experts in the area of prostate cancer.

In 1999, the 76th Session of the Texas Legislature, Senate Bill 1685 was revised by House Bill 2759: that the strategy of the Committee include components designed to reach high-risk populations in this state.

Since the Committee's inception, the members have gathered information, received presentations on topics of interest, and formulated and reviewed strategies that will help Texans deal effectively with prostate cancer in our state.

Advisory Committee in Action

The makeup of the Advisory Committee has been one of its greatest strengths. Its membership includes prostate cancer survivors, family members of survivors, physicians, educators, and cancer control professionals. This heterogeneous group of individuals has allowed the Committee to develop a well-balanced message for the Texas public with regard to the importance of and options surrounding prostate cancer prevention, early detection, and treatment.

In the last two years, focus groups reviewed materials about prostate cancer for inclusion in information packets. The Texas Department of Health (TDH) staff collated these materials, then created and sent out information packets to the public. Focus groups also identified ways to market prostate cancer materials and information to various target groups, for greatest effectiveness. A web site and an "800" telephone number were two tools developed for greater outreach, along with print materials used by TDH's Prostate Cancer Education Program.

On several occasions, nationally recognized speakers presented up-to-date information on prostate cancer prevention and early detection to the Committee, as well as to public attendees. It is from these presentations and the deliberations of the Committee that the pragmatic mission of the Committee developed.

Recognizing that a number of organizations in the State of Texas have similar missions with regard to prostate cancer prevention, detection, and treatment, the Committee has developed a coordinated approach to supporting the educational efforts of these organizations. The Committee convened a special meeting among key agencies that are involved with prostate cancer, where the agencies present discussed their respective activities and opportunities for collaboration with each other. Through the network and strengths of TDH, the Committee plans to assist these many organizations in order to enhance and strengthen each agency's ability to "get out the message".

Prostate Cancer Awareness Week begins the week following Father's Day in June of each year.

Since 1997 the Advisory Committee has promoted Prostate Cancer Awareness Week, which begins the week following Father's Day in June of each year. Through public speeches, circulation of pamphlets, radio shows, and various seminars, the Texas public learned in great detail about the importance of prevention, early detection, and treatment. TDH staff mailed out 8,000 information packets one month preceding Prostate Cancer Awareness Week to state agencies, regional and local health departments, county extension agents, hospitals, churches, and civic and social organizations (such as AARP). Specially targeted packets were sent to physicians, clinics, and ministers. The Board of Health issued a Proclamation concerning Prostate Cancer Awareness Week, and all state employees received such notice in a payroll message. Committee members helped organize a ministers' breakfast, and a collaborating agency sponsored a 5K run to raise awareness of prostate cancer. TDH staff created displays during June located in the TDH main campus lobby and in the Board of Health meeting room.

The cost of these activities during 1998-99 totaled $300,000. Committee members donated a combined total of $175,000 in time and services; and TDH donated staff time equivalent to approximately $125,000. While the legislative mandate required this activity, it was not funded.

Future Directions

- As the Prostate Cancer Advisory Committee learns of the many organizations that provide information and care to men at risk of developing or who have prostate cancer, it anticipates an increasing series of opportunities to develop new partnerships – and to work with these various organizations to leverage their strengths and resources.

- As new data develop regarding social marketing of prostate cancer prevention, early detection, and treatment efforts, the Committee will incorporate this information into the literature and other messages that it develops.

- As updated data on at-risk males' knowledge of prostate cancer is revealed through scientific survey methods, the Committee will actively share this information with policymakers, health care practitioners and the general public; the Committee will use this information to improve public health messages.

- The Committee will seek out funding sources to continue the high quality of research and its efforts toward disseminating information to the public on prostate cancer awareness and treatment options.

Two members of the Prostate Cancer Advisory Committee share their stories

Survivor Stories

Confronting Cancer:
Outlook changes when you're facing a death sentence

I saw the X-rays. It didn't take a doctor to see there were very dark spots on the pictures of my spine, shoulder, ribs, hip, thigh and pubic bone. The cancer they had found in my prostate had metastasized – the dreaded word akin to a death sentence.

I am a university president. It is easy to become so focused that you think of nothing else. A year ago, I went to the doctor to check on a few minor things. I was two years late in getting my annual physical. Other things seemed much more important. They sure don't now.

When my doctor did the prostate exam, he felt a little node. My PSA – the blood test that allows earlier detection of prostate cancer – was elevated. It wasn't much to get worried about, but it required additional checking. A sonogram determined that a biopsy was indicated. Biopsy?! This was getting serious. The doctor said that, in all likelihood, it was in the early stage and treatable. I also thought: Wasn't prostate one of those "good cancers" – slow to develop, no rush to treat and curable by surgery or drugs? The X-rays squashed all those thoughts. I was a speeding train of cancer.

" I was two years late in getting my annual physical. Other things seemed much more important. They sure don't now.... I still love my work... but I have found time for other important activities."

People say that when you get news this traumatic, your first reaction is denial. That didn't happen to me, probably because the bone scan was so graphic. They say the second reaction is anger, and that lasted only a short time. I blamed others for not getting me to have a physical a year before. I blamed a bunch of people for making my job so stressful in the past year having heard it isn't uncommon for cancer to be diagnosed after individuals have gone through stressful times. (Presumably, stress affects the immune system and lowers resistance to tumors.) But in a few days, I realized the blame was mine, so I moved on.

Besides, I had things to do. University presidents always are busy. I had to tell my family. I had to tell my senior staff members. I had to tell the board. I had to decide if I should tell the campus or just keep quiet. (That was a pretty easy decision since anyone familiar with a university knows that secrets are impossible.) Finally I had to tell myself.

When my wife and I looked at the bone scan and heard the words of the doctor, we were calm – at least I was. And while we were responding over the next few days to the business of handling a diagnosis like this, I remained calm. It was difficult to talk to my three sons by phone. It was

difficult to tell my staff. But it still hadn't hit me down deep. Then one night in my bedroom I started crying, and my wife joined in. I had run smack into the reality that I would die soon. I had planned on another 20 or 30 years, by God! Would I never see how my sons' lives turned out? Would I never see any grandchildren?

I decided to stare down the disease and look at life, and death, squarely in the eye. Things that always were important to me but that had stayed patiently in the background while I did my "presidenting" surged forward just when I needed them most. Family, friends, God, prayer – all took on the roles you would hope they would in such circumstances.

Because I am a professor, it is second nature to research a problem. I read reports and articles, looked at statistics, followed the promising research and surfed the Internet. It all was discouraging. The more I read, the more I discovered that most men with "metastatic" prostate cancer die sooner rather than later, so I did the logical thing. I stopped reading.

What I did find uplifting though, was the literature on the emotional aspects of cancer, particularly the research that has shown that attitude has a significant impact on survival rates. I thought that was a plus for me, since I always have had a positive attitude.

"...(S)upport from family and friends was as important to me as my medical treatments."

But sometimes in those first few months after diagnosis, while I lay awake in bed at night, despair swept in like a wind. Fortunately, due to the advice of a good friend, I knew those feelings would come. She had been successfully battling breast cancer and was able to serve as my "cancer buddy," anticipating and guiding me through the tough times. In fact, the support of friends and colleagues was tremendously important and it came pouring in.

From the campus and community, from around the state and around the country, expressions of concern and support were there. My name was added to prayer lists all over the country. That support from family and friends was as important to me as my medical treatments. In the past, I might have felt awkward about contacting a friend who had gotten a similar diagnosis for fear, I suppose, of appearing intrusive about a very personal matter, but I now know that was a mistake. Friendly contact and expressions of concern are healing! Don't withhold them.

Now, it is more than a year after the diagnosis. I have put myself in the wonderful care of a doctor at one of the best cancer hospitals in America. I am on the hormone therapy, which is standard treatment for my disease, but I also have completed a six-month course of chemotherapy, which isn't standard. The cancer is arrested, and I feel great. We can't know how long that will last, and so I know there will be some anxious moments to come. But I am planning to hang in there until this doctor and his colleagues around the country find that curative treatment.

I still love my work and will stay committed to it, but I have found time for other important activities, though, I know that whatever the future holds, there will be people there for me. I am a lucky man.

Jerome H. Supple, Ph.D.

Jerry Supple is President of Southwest Texas State University in San Marcos.

Battling Prostate Cancer:

Winning by living 'right now'

My saga starts in 1990, when I first noticed that I was getting up 3 or 4 times a night to urinate. Medically this is called "nocturia x 4". Old age, I thought. I was almost 70 then. I went to my internist, Dr. 1, who referred me to a local urologist, Dr. 2 – who did not give me a DRE (Digital Rectal Exam) or ask me to give blood for a PSA (Prostate Specific Antigen) test. He prescribed an antibiotic to help, but it didn't.

About a year later, still with no pain symptoms, I asked the same internist Dr. 1 for a PSA test. Originally he was against it – he was a new doctor in the HMO system I was in – but after I persisted, he said OK. It came back as >20ng/ml. ("ng/ml" stands for the units of measurement of the PSA, i.e. nanograms per milliliter). When 0-4ng/ml is normal, >20 is a shock. I asked the nurse how large the number really was, and she said it was 110. I was amazed!! This is 27 times the maximum for normal people.

Dr. 1 made an appointment for me with a urologist Dr. 3 at the HMO main base in Temple – 70 miles away. The earliest he could get me an appointment meant waiting a month. My HMO had no local in-house urologist at the time, and still does not. Dr. 3 gave me a DRE, and biopsied the prostate. On September 11, 1991, he called me with the bad news that I had prostate cancer, with a Gleason score of 5. The prostate volume was 62 cc, measured ultrasonically. Normal volume is less than 50 cc. At a husband-wife-doctor medical conference in Temple, Dr. 3 suggested an orchiectomy (testes removal).

"My support system came with me to the... hospital (for my prostatectomy). Between my wife and my son, one of them was with me every night, all night."

I wanted a second opinion and a second PSA. Dr. 3 agreed to do both. He, in turn, wanted a CT scan and a bone scan. I agreed. The bone scan was negative and the CT scan showed an enlarged prostate. New PSA was now 119.5. My second opinion was from Baylor Medical in Houston, where Dr. 4 repeated biopsies and ultrasound scan, as well as PSA, (which is exactly what I thought a good doctor ought to do). The result was a PSA now as 219ng/ml. Since September, any spare time I had was used to research prostate cancer in the Medical Library at Texas A&M University, where I was a professor of geophysics at that time – and had been for 23 years. As a result of this research, I had read Mayo Clinic's publication on DNA ploidy analysis of prostate cancer tumors. I asked my Dr. 1 internist about getting a ploidy test, as I was worried about my rising PSA – all the while I was researching the disease to find out what I should do. The ploidy test results may be a diploid, tetraploid or aneuploid shape of the tumor's DNA, which in turn is a measure of the tumor virulence. A high Gleason score corresponds to an aneuploid ploidy result. Not unexpectedly, Dr. 1 never heard of a ploidy test, but called Temple to see if they could do it. They could. When the result came in, I was happy to find the answer was diploid, meaning I had the slow-growing type of cancer.

At this point in time, we had a difference of opinions between Dr. 3 and Dr. 4. Dr. 3 of Temple believed the cancer was metastatic and spread to the bone in my back. Dr. 4 of Baylor believed it was not metastatic and wanted laparoscopy done by Baylor's Dr. 5 to check the lymph nodes. I asked Dr. 3 for an oncologist's opinion, and was referred to oncology Dr. 6. I was personally leaning toward non-metastatic disease, but found it hard to defend in the towering shadow of a 219 PSA. Dr. 6 had a father with prostate cancer, who, coincidently, had the same dark spot in his lower back, L5, that I

had. Dr. 6 consulted the CAT scan expert and asked if he could devise a scan that could distinguish between bone cancer and degenerative arthritis. He said yes. The test was scheduled, and the result was clearly not bone cancer, just degenerative arthritis. A big hurdle there. It is critical to distinguish whether one has metastatic disease or local disease. Naturally, the latter is preferred.

By this time it was November and I had decided that I would go on CHT (Combined Hormone Treatment) and start attacking the cancer. CHT is the chemical equivalent of an orchiectomy. In addition, it knocks out the testosterone produced by the adrenal glands. CHT involved a monthly (at that time) shot of Lupron to kill the testosterone production and the ingestion of 6-125 mg pills of Eulexin spaced 2 every 8 hours. I chose 7am, 3pm, and 11pm. CHT is expensive: It cost $500 per Lupron shot plus $1.50 per Eulexin pill. Add all that up, and we are talking $11,400 per year. I had already taken this to my HMO health plan people, getting their approval to pay for the Lupron as a hospital shot, but I had to pay for the Eulexin out of my pharmacy plan. Having made the CHT decision, I shopped around for a doctor that agreed with me. Dr. 7 was my new choice. On November 6, 1991, he agreed to prescribe CHT to reduce the PSA, downsize the enlarged prostate, and then to see if a radical prostatectomy (RP) was feasible at a later date. At last, we were doing something to fight the enemy. By January of 1992, CHT had dropped by PSA to 0.8ng/ml. By early February, the prostate was HALF its original size as measured by ultrasound. Ah, downsizing works! Another bone scan was taken – clear – and Dr. 7 gave the OK for an RP if I wished. Dr. 7 had a powerful argument for an RP: Why not reduce the tumor load on the immune system by having the prostate removed? I couldn't think of a good answer for that, so I agreed and we scheduled it for March. He promised no pain, and for most of the ten days in the hospital he adhered to his word. An epidural analgesic monitoring system is a wonderful thing. My support system came with me to the Temple hospital. Between my wife and my son, one of them was with me every night, all night. And the doctors and nurses in the Temple hospital were the greatest. Only once was the pain really bad, and that was almost immediately relieved when an intern doctor released some of the water in the Foley catheter which was holding it in place.

"...I consider (a PSA of 0.1) as prostate cancer in remission. Thank you, Father. Now, I get a PSA every 3 months, and when it reads 0.1 or less, I treat myself to a pistachio milkshake. This is not helpful for my cholesterol, but the ego must win sometimes."

After my release, I kept taking the CHT to kill off any left-over cancer cells. Dr. 7 stopped my Lupron and Eulexin on September 6, 1992. I was glad to be rid of the prostate and ardently hoped that Dr. 7 had removed all the cancerous tissue. There were no positive margins, i.e. the prostatic capsule boundaries were examined to see if the PC had escaped. The seminal vesicles were found cancerous and were removed. It would be a relief to not have to do any more medical library research, I thought. The PSA dropped to 0.3 in May of 1992, then to 0.1 (minimum detectable) in June and August. It bounced up to 0.2 in November, down to 0.1 in December. As a result of the RP, I was impotent and had some incontinence after the operation. It was to be a year before the incontinence finally left. I now had a new goal for my PSA. According to Dr. Stamey, the urology head of Stanford Medical School, your PSA should not be greater than 0.3 ng/ml after a radical prostatectomy. For those with a prostate, 0-4 was the goal. In January of 1993, my PSA rose to 0.3 – oops, time to worry! The next month it was 0.5. Back to the medical library, I went to check the accuracy of the PSA measurement. I found it was good to only + or - 0.3 ng/ml. Thus 0.5 could be anywhere between 0.2 and 0.8. I preferred to believe 0.2, but knew that was not logical. I talked to Dr. 8, my new local internist, and she said to keep watching it. "Look for a steady increase, don't take a single point as realistic". The next PSA was 0.8, and that did it. Something had to be done. My urology Dr. 7 said I should get radiation. Being a physicist, I knew what high intensity radiation can do to your bodily molecular structure, and I was not inclined to go this route. Dr. 7 set up a

meeting with radiologist Dr. 9. I went armed with literature reprints on radiation which showed him that there was no proof of longer survival by radiation, plus the nasty side effects that can happen. I listened to him carefully, but then rejected radiation. I went back to Dr. 7 and asked to be put back on CHT. I knew that worked and was eager to get on with it. Dr. 7 said OK. My April 1993 PSA dropped to 0.1 ng/ml.

All was going well until Thursday morning, May 21, 1993 when I found I could not urinate at all. I called the Urology Department in Temple and they told me to take a hot sitz bath. I did, but no relief. The urgency increased until I was climbing the walls. Finally I decided to go to the emergency room (ER) at the nearest local hospital. En route, while I was driving, I seriously considered going through red lights on purpose and thus getting police attention and hopefully a police escort to the ER. But I didn't. I thought that might even take longer. Pain came in surges and then stopped for a few minutes. Upon arrival at the ER, they needed all the paperwork finished before even looking at me. I screamed for a catheter and let every one know I needed relief – loud and clear, hoping to speed the action and shorten the pain period. Finally a doctor arrived, inserted a catheter, and 1200 cc came rushing out. He left the catheter in, and I went home, greatly relieved and hoping I had still retained some elasticity in my bladder. The next day my wife drove me to Temple and Dr. 7 checked me over. Took the catheter out, put liquid in, found I expelled it OK, and sent me home. That Friday afternoon, the same thing happened. I was stopped up. I went back to the same ER. This time you would think I would get faster service, having just been there the day before. Not so: they took 20 minutes to get me signed up, find a doctor, get a catheter, etc. This time, I had the catheter in all weekend. One thing is nice about the catheter, you can stay in bed all night. I don't know when the last time was, when I have slept all night long. One enjoys small pleasures however they may come. The following Monday I was back at Temple with the same problem. A male nurse showed me how to catheterize myself. Wow, it was so easy. Dr. 7 gave me a simple catheter tube and a tube of K-Y jelly and sent me home. I used the catheter several times a day for about a week before I was able to urinate normally. But it is such an easy thing to do, I wish that all men with prostate cancer could be taught how to do it. I was worried about infections, but it is really very simple. Just wash the tube with soap and water, as well as your hands. Roll in the tube of K-Y jelly and insert it. I used to think that would be very painful, but it isn't. It all goes up there very nicely, until, oops, you feel it passing the sphincter muscle and out comes the urine. It is a long way to the bladder, further than you think. To this day, I keep a flexible catheter tube handy in case I ever need it. I haven't for four years. Just the thought of that immense pain when your bladder wants to void and you can't, makes me keep it safely tucked away, just in case.

"(A) side effect of treatment…is a realization that life is short, and I should live for the present."

"(M)y wonderful ...wife supports me all the way! Thank you, Betty."

After the April 1993 PSA of 0.1, I can brag that my PSA has been there, or lower (lab result reads <0.1) for five years. This I consider as prostate cancer in remission. Thank you, Father. Now, I get a PSA every 3 months, and when it reads 0.1 or less, I treat myself to a pistachio milkshake. This is not helpful for my cholesterol, but the ego must win sometimes. After three heart attacks – one in Bombay, India, one in Eleuthra in the Bahamas, and one at home (my cardiologist jokingly says I should not go out of the country) – I have been on a Dr. Dean Ornish artery-clearing, low-fat diet, and brought my cholesterol down from 222 to 130. Much of the credit for this goes to my wonderful wife, who is on this diet with me, and supports me all the way! Thank you, Betty. The famous Framingham heart study showed that of all the 50,000 people in Framingham, Massachusetts studied since 1945, not one person – no one – had a heart attack that had a total cholesterol under 150!

Now what are the side effects of CHT? Number one is hot flashes. Like women who don't make estrogen after menopause, men who don't make testosterone after orchiectomy or CHT also get hot flashes. I now have a better appreciation for what my wife goes through. She gets much more sympathy from me. Fortunately, my body has adapted to where maybe it is once a week I feel a hot flash. No problem. Other men with prostate cancer have it much worse. But I do wish I had my testosterone back. Number two is a muscle weakness, plus a tendency to put on weight. Exercise is the answer. Number three is a realization that life is short, and I should live for the present. We all should. There is only the Now. Life is simply a series of now, now, now. I remember a good sound bite: Yesterday is history, Tomorrow is mystery, Now is a gift, that is why they call it the Present.

"I go to bed every night thanking God for another day, and wake up each morning to appreciate Nature, the trees, the flowers, my wonderful wife, a good cup of coffee, and my faithful brown dachshund. It is great to be alive and active, here in the great state of Texas."

How has having prostate cancer affected my lifestyle? Very little! While it is mandatory to get my Lupron injections every 28 days, Dr. 7 has been very helpful by giving me portable 7.5 mg Lupron shots – a kit put out by a pharmaceutical company called TAP of Osaka, Japan. This kit contains all one needs to take the shots with you on your travels. Thus I am not tied to driving to Temple every month to get the injections. In the summer of 1992, my wife was invited to come to the 700-year-old Charles University as a visiting history research professor. She accepted, and we spent 6 weeks living in Prague, Czechoslovakia in a student dormitory. I had brought my portable Lupron shot and found an M.D. from Slovakia living in the same dorm. He gladly gave me the hip injection in the dorm in Prague. We took him to dinner. Other Lupron injections have been given to me in Club Meds in the Bahamas and Mexico, and even while on a Special Expeditions cruise in Queen Charlotte Sound in the wilds of British Columbia, Canada. There, in Alert Bay, was a provincial medical outpost for the Indians, and a nurse gladly gave me the shot. The skipper of the cruise ship had radioed ahead and told the nurses that I was coming. If all else fails, my wife can give me a Lupron injection, but I find it hard to give it to myself in my own hip.

More recently, two drug developments have made it easier to fight prostate cancer. The 7.5 mg Lupron Depots as they are called, have been upgraded to one 22.5 mg depot shot that is only needed every three months (84 days, actually). So that is easier. Also the 6-125 mg capsules per day of Eulexin have been replaced by one 50 mg tablet called Casodex. So the 7am, 3pm, 11pm pill-popping routine is gone. Casodex is easier to take, also, because it does not cause the diarrhea that Eulexin sometimes causes. But Casodex is priced the same as Eulexin, so it is not cheaper. Now the Casodex tablets are ten bucks apiece, and my HMO charges Medicare $1,500 for each 84-day Lupron Depot injection.

CONCLUSION: To sum it all up, I think I have battled the prostate cancer to a standstill. Having contracted prostate cancer has changed my lifestyle, particularly in what I eat. Using the Ornish very low-fat regimen has improved not only my heart condition but also my fight against prostate cancer. Also, knowing that the cancer may at any time become metastatic and be able to grow on something other than the testosterone makes one really live "on the edge". I go to bed every night thanking God for another day, and wake up each morning to appreciate Nature, the trees, the flowers, my wonderful wife, a good cup of coffee, and my faithful brown dachshund. It is great to be alive and active, here in the great state of Texas.

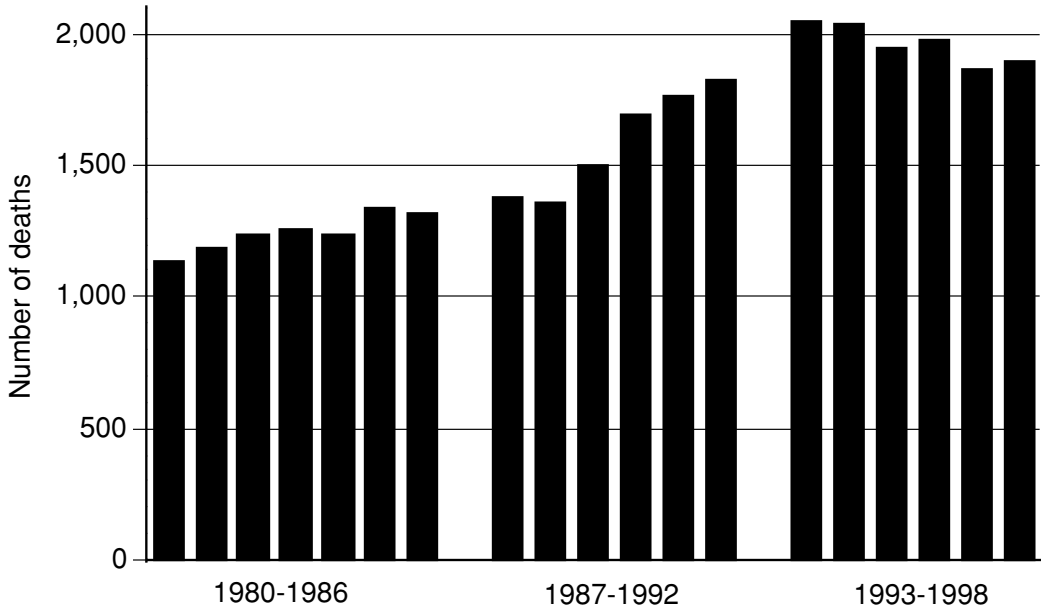
Robert R. Unterberger, Ph.D.

Robert Unterberger is retired from Texas A&M University in College Station.

Prostate Cancer Data

Prostate cancer is the most common type of cancer that occurs in American men. It is the it is the second leading cause of cancer deaths in men, after lung cancer. For reasons not yet understood, the numbers of new cases of prostate cancer and deaths from this disease are highest among African-American males; this is a trend nationwide, not limited to Texas.

In Texas this year, an estimated 12,000 men will be diagnosed with prostate cancer, and approximately 2,000 Texans will lose their lives to the disease. The graph below shows the number of deaths per year, since 1980. From 1980 to 1993, the death rate climbed annually to its current level. This death rate has been consistent since 1993, so clearly the need for prevention, early detection, and successful treatment is a priority for Texans.



Source: Texas Cancer Registry

New cases and deaths from prostate cancer are highest among African-American males.

Since the high death rate of Texas men from prostate cancer has not declined significantly since 1993, the Prostate Cancer Advisory Committee enthusiastically supported the Texas Department of Health's design of a Behavioral Risk Factor Surveillance System (BRFSS) survey that was specific to prostate cancer. Committee members had an opportunity to review the survey and give input before it was conducted in November, 1999. Telephone interviewers talked with 1,000 men in Texas, age forty or older. Survey respondents were asked questions about their general health, health care insurance, and access to health care. Then data was gathered on the demographics of the respondents (age, race, marital status, income level, county lived in, etc.). The rest of the survey asked respondents about their knowledge of prostate cancer risk factors and screening tests, their health care provider's role in prostate cancer screening, and questions for those who answered that they were diagnosed with prostate cancer. Survey results are expected by May, 2000 and will be included in the next Report.

APPENDICES

Appendix A
Texas Department of Health
Prostate Cancer Advisory Committee
1998-99

Professional Members

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Peter T. Scardino, M.D.
Andrew Von Eschenbach, M.D.

Appendix B
Texas Department of Health
Prostate Cancer Advisory Committee
1998-99

Schedule of Meetings

March 24, 1998
Hal G. Conway, M.Ed.
Odell Joseph Dean, Jr., M.D.
Claudie Simpson
Teresa L. Smith, M.S.
Robert R. Unterberger, Ph.D.
Armin D. Weinberg, Ph.D. – Vice-Chair

October 8, 1998
Hal G. Conway, M.Ed.
Claudie Simpson
Ian Thompson, M.D. – Chair
Armin D. Weinberg, Ph.D. – Vice-Chair
Mary Ellen Wyers, Ph.D., R.N.

December 9, 1998
Evelyn C.Y. Chan, M.S., M.D.
Hal G. Conway, M.Ed.
Odell Joseph Dean, Jr., M.D.
Claudie Simpson
Ian Thompson, M.D. – Chair
Robert R. Unterberger, Ph.D.
Armin Weinberg, Ph.D. – Vice-Chair
Mary Ellen Wyers, Ph.D., R.N.

March 3, 1999
Evelyn C.Y. Chan, M.S., M..D.
Hal G. Conway, M.Ed.
Claudie Simpson
Teresa L. Smith, M.S.
Ian Thompson, M.D. – Chair
Mary Ellen Wyers, Ph.D., R.N.

August 3, 1999
James Kolker, M.D.
Claudie Simpson
Jerome Supple, Ph.D.
Ian Thompson, M.D. – Chair
Karen Torges
Armin D. Weinberg, Ph.D. – Vice-Chair

November 9, 1999
Evelyn Chan, M.S., M.D.
James Kolker, M.D.
Claudie Simpson
Jerome Supple, Ph.D.
Ian Thompson, M.D. – Chair
Karen Torges
Robert R. Unterberger, Ph.D.

December 13, 1999
Jennifer Janssen, M.Ed. for Carol Rice, Ph.D., R.N.
Claudie Simpson
Jerome Supple, Ph.D.
Karen Torges
Armin D. Weinberg, Ph.D. – Vice-Chair

Appendix C
Texas Department of Health
Prostate Cancer Advisory Committee
1998-99

Partners

American Cancer Society
M.D. Anderson Cancer Center
Nurse Oncology Education Program
Physician Oncology Education Program
Texas A&M Agricultural Extension Service
Texas Cancer Council
University of Texas Medical Branch, Galveston

Presenters

Ken Condon Director, BRFSS Texas Department of Health	– BRFSS survey, specific to prostate cancer (8-3-99)
Heidi Holt Division of Cancer Prevention and Control, CDC	– Comprehensive Cancer Control grant, including funds for prostate cancer (8-3-99)
David Risser, Ph.D., M.P.H. Texas Cancer Registry Texas Department of Health	– prostate cancer statistics (10-8-98)
Ian M. Thompson Chairman, Dept. of Urology UT Health Science Center San Antonio	– prostate cancer: incidence & mortality rates, early detection & treatment (12-9-98)
Anne Williamson, M.Ed. Director, Adult Health Texas Department of Health	– social marketing proposal (3-24-98)

Appendix D
Texas Department of Health
Prostate Cancer Advisory Committee
1998-99

Action Plan

VISION

To achieve an informed public that avails itself of prevention, early detection, and treatment resources for prostate cancer in the great state of Texas.

MISSION

To be an advisory committee of excellence that serves as the conduit of change by systematically reviewing and disseminating information — resulting in an informed public and leading to increased access and utilization of resources in the prevention and treatment of prostate cancer.

GOALS

1. **Conduct an assessment in cooperation with the American Cancer Society (ACS) and the Texas Cancer Council (TCC) of access to early diagnosis and treatment of prostate cancer for men in Texas.**

   Activities
   A. Develop letter (e.g., if indigent and uninsured, who will provide service within one hour drive time?).

	Indigent	Uninsured
PSA		
Biopsy		
Treatment		

   B. Send to county/city hospitals and health departments.
   C. Develop budget for a two-year project to accomplish this goal (by next meeting).
   D. Analyze and compile results.
   E. Write report.
   F. Seek funding for high-need areas.

2. **Develop an educational package that describes options for prevention, early detection, and treatment of prostate cancer. (Year 1)**

   Activities
   Conduct a series of meetings to evaluate existing educational resources.
   1. assure representation from diverse populations
   2. solicit nominations from other organizations of individuals to attend meetings (patients and providers)
   3. collect materials from other organizations

   Steps
   1. materials sent to representatives one month prior to meeting
   2. presentation to focus group (consumers)
   3. select appropriate materials for education package

3. **Share Goal 2 findings with participating agencies and other appropriate groups.**

Activities
A. Determine who should receive information.
B. Disseminate information.
C. Evaluate whether information was useful.

4. **Conduct a mini-workshop to measure the effectiveness of the educational program.**

Activities
A. Invite participants (e.g., NCI Prevention Branch, CDC, managed care organizations, consumers, TMA).
B. Conduct workshop.
C. Determine metrics.

5. **Market the message.**

Activities
A. Identify existing community conduits for dissemination.
B. Ensure that managed care organizations are receiving information. Make sure that they have opportunities to provide input.

6. **Evaluate marketing efforts and modify as appropriate. (Go beyond testing knowledge.)**

Activities
A. Apply metrics from Goal 6.
B. Determine prevalence of PSA screening.
C. Monitor change in PSA prevalence.
D. Check HEDIS and National Center for Health Statistics indicators.
E. Modify, package, and disseminate materials.

7. **Present annual report to legislature in May during legislative sessions.**

Activity
A. Write report.
B. Present report.

Appendix E
Texas Department of Health
Prostate Cancer Advisory Committee
1998-99

American Cancer Society

Screening & Checkup Guidelines

The American Cancer Society recommends that men age 50 and older should talk with their health care provider about beginning PSA (prostate specific antigen) blood tests and DREs (digital rectal exams) every year.

Factors to consider include overall health and life expectancy.

In addition, men in high risk groups (African-Americans and those with a history of prostate cancer in close family members) should consider beginning these tests at a younger age.

The Facts:

- Prostate cancer is the most common cancer in American men, excluding skin cancer, affecting 1 in 9 men. It is most common in African Americans, men over 50, and men with a family history. It causes 37,000 deaths a year nationwide.
- Annual testing is the best way to find prostate cancer early – which may help save your life.
- Testing involves both PSA (prostate specific antigen) blood test and a rectal exam. If either test is abnormal, a biopsy is usually recommended to make a sure diagnosis.
- Testing isn't perfect. Many men with an abnormal test result may worry even though they will turn out not to have cancer. And while testing and biopsy find most cancers, they do miss some cancers.
- Unlike many cancers, doctors are not sure that all men with prostate cancer need to be treated. Testing cannot tell whether or not a cancer needs to be treated.
- There are many treatment options for early prostate cancer. Treatment cures some men. It can also cause urinary and sexual problems for some men.
- Men over 75 might not benefit from testing since prostate cancer often grows slowly in this age group.

Appendix F
Texas Department of Health
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Article: East Texas Conducts Communitywide Screening

by James Kolker, M.D.

In the summer of 1998 East Texas Medical Center (ETMC) in Tyler, Texas sponsored a two-month prostate cancer screening to coincide with Prostate Cancer Awareness Week. They offered a $5 prostate specific antigen (PSA) only screen that also involved a "new test" for prostate cancer, the Bayer complex PSA test. Response to previous prostate cancer screens had a fair turnout, and even though a larger effort was to go into publicity that year, the expected response was estimated to be around 2,000 men. When over 13,000 men signed up to be screened and over 12,000 men actually were screened, it was a completely unexpected result. This is one of the largest prostate cancer screenings reported and is all the more unlikely given the relatively small population of Tyler and low population density of surrounding East Texas community.

Although follow-up and data is still ongoing, almost 9% of participants (over 1,000 men) were found to have elevated PSA. It should be understood that this was a community screening, and it did not exclude men who already knew that they had elevated PSA. Results were reported to the patient's self-designated primary care physician and follow-up care was left to them. Some men were followed, some declined treatment, and others were referred to a urologist for further follow-up and likely biopsy.

Tyler is a city of 75,000 people serviced by two highly competitive and excellent hospital systems. There are 8 urologists in town, with over a half a dozen more in the not too heavily populated surrounding areas within 60 miles. Previously sponsored screenings included low-cost PSA and digital rectal exam (DRE). Those drew only modest interest.

The first question in the analysis of the 1998 screening effort is to determine why the response was so overwhelming. Reasons might include the very low cost of the test, the fact that no DRE was required, the effective advertising campaign, and the perception that there was a great advantage to the "new test" being offered.

Another unexpected finding was the high percentage of elevated PSA values. This is partly explainable since patients were not excluded if they already had elevated PSA or even known prostate cancer. Another reason could be that routine PSA testing was not done by many primary care physicians. A complete analysis of the data is ongoing, including assessment of the value of the complex PSA test. The 1999 Prostate Cancer Screening was again $5, but only done for one month and with much less publicity. Men who had a PSA within the last 9 months were excluded. Fewer men participated. Probably many men were now having their PSA followed at their doctor's office, leaving fewer men in the screening pool. This data is also currently being analyzed, but it is clear that many men in this screening had their first PSA done in 1998 and were now coming for their yearly test. The pattern of behavior of population of men and probably the medical community may have been significantly altered.

For more information on Prostate Cancer,
please call 1.800.242.3399

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