

STATEMENT BY

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REGARDING

THE PROSTATE CANCER RESEARCH PROGRAM

OF THE

CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS

BEFORE THE

HOUSE COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON DEFENSE

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Mr. Chairman, Members of the Committee, thank you for the opportunity to speak to you about the Prostate Cancer Research Program (PCRP) and the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense (DOD). Many people can speak effectively about the research this program has done or is doing, about its history, funding levels, and accomplishments, but I want to talk to you about how we can affect the future of prostate cancer research by looking at the personal stories of those impacted by this insidious disease. Today, I want to tell you about the two men in my life who fought prostate cancer – my husband, Tom and my son, Jeremy. When we leave here today, I hope you understand why I hold out hope for the future that research promises to give us and why I ask you to increase prostate cancer research funding so that the PCRP can lead us there.

I am a nurse, a mother, a wife and a sister. I have a personal relationship with prostate cancer after watching its horrific impact on both my son and my husband. My husband's diagnosis made a little more sense to me – he was 54. Our understanding of prostate cancer is that it affects older men – although I challenge the idea that 54 is old. The treatment my husband received was not without side effects – his nerve sparing prostatectomy left him impotent and while that persists, today at 60, Tom is alive and cancer free.

I would give anything to have my son alive and cancer free. Jeremy's prostate cancer was diagnosed 4 years after my husband's diagnosis – he was 34, and 18 months later, he was dead.

As I speak today, I do so to stand up for my son, Jeremy, and to tell you what he has given to prostate cancer research. On November 23, 2007, my sister's 50th birthday, my son gave his greatest gift to prostate cancer research. His very wasted body, no longer in pain, went to UCSF to be used for prostate cancer research at his request. Once the necessary cells were harvested, Jeremy's body was cremated and his ashes scattered beneath his beloved Golden Gate Bridge in San Francisco. Jeremy was 36 years old at the time of his death. Jeremy had one life and one body to give to prostate cancer research. He gave it all. It would be impossible for you to match the contribution he made to research an end to this disease. I simply ask as Jeremy would, for

you to invest for more prostate cancer research so that you can make a difference to other mothers, wives, sisters and daughters.

The recent celebration of Mother's Day makes this the perfect time for me to share the story of my only child with you, because he made me what I am today; his life and legacy are the reasons I am here. My sweet, smart, passionate and beautiful son is dead, so I must speak for him, because, to quote poet Robert Browning, "Motherhood: Love begins and ends with it."

When he was 33 years old, Jeremy complained of back and hip pain that would not subside. He was fit, healthy and strong. He was a climber, hiker and cyclist. A vegetarian since high school, Jeremy did not smoke, drank very little alcohol and had no other symptoms or physical complaints. His physician did an MRI of Jeremy's spine and sent him for physical therapy and acupuncture. Because my son kept such an active schedule – he was constantly working and travelling – a back injury seemed a reasonable explanation for the pain. While I suggested Jeremy receive some laboratory testing, his doctor saw no need.

Jeremy turned 34 in Burma, where he led a small group of volunteers into the jungle to deliver medicine to villages there. When he returned home, he felt tired and was still in unremitting pain. He was having night sweats, so he saw a specialist in infectious diseases, thinking his time in various jungles and forests might have given him some kind of infection or virus. Blood tests revealed that Jeremy had almost no platelets; it was a miracle Jeremy was upright, much less feeling just a little tired. His primary physician took a closer look at Jeremy's previous MRI after being notified about Jeremy's laboratory results and sent Jeremy immediately to the emergency room.

Early on, doctors thought testicular cancer or lymphoma may have been the culprit, as both are common in younger men and treatable. It is because of the lack of prostate cancer research that doctors saw little or no reason to expect prostate cancer was to blame. Jeremy's first bone biopsy revealed cells that looked like prostate cancer cells. After this, Jeremy was transfused

several times, tested for everything at all related to his symptoms and, only as a last resort did the oncologist on his case call in a urologist for consultation.

The results from the urologist's DRE were normal. This had always been the case. An ultrasound revealed a normal looking prostate, but Jeremy's PSA was 441. His very painful prostate biopsy revealed prostate cancer cells, but his Gleason score was unclear. He bled for days and could barely walk due to pain more than weakness.

A bone scan was conducted that showed nice, white bone in his arms and legs and black tumor throughout Jeremy's entire axial skeleton, with spots on his skull. Jeremy's pelvis was just tumor. My only child was diagnosed with advanced metastatic prostate cancer at the end of March 2006.

Once we had a diagnosis, we spent several days calling and cajoling, doing whatever we needed to have Jeremy seen at UCSF in the Department of Urological Oncology. Jeremy was finally transferred to UCSF, and thus began what I call "Jeremy time." I returned home to Albuquerque, packed some clothing, quit my job, kissed my husband, and returned to California to face the unknown with my son. Jeremy was released from the hospital and began outpatient treatment with Dr. Charles "Chuck" Ryan. Jeremy was started on oral Casodex daily and Lupron injections monthly. This combination initially brought his PSA down; however, by June, these medications no longer worked and the side effects made Jeremy miserable.

By July 2006, Jeremy was newly engaged to be married, looking and feeling good, exercising and hopeful. He spent the summer of 2006 building his strength for the start of chemotherapy treatment. He was married on a Saturday in September and later that month started treatment with taxotere.

Throughout his ordeal, Jeremy would be treated with various combinations of taxotere and other chemotherapy agents. His UCSF team treated him aggressively and passionately. Although his initial PSA on diagnosis was 441, it went down to 6.5 almost immediately upon treatment. It

then gradually doubled upon itself over and over until it surpassed its original number close to Jeremy's death. Unfortunately for Jeremy, much of the research into diagnosis and treatment lagged behind the progression of his disease.

The 18 months following Jeremy's diagnosis were full of night sweats, pain, nausea, treatment, and sadness. But Jeremy refused to let this disease get the best of him. Although he could not sit for long periods due to his pelvic pain, he continued to enjoy meals out, good movies and his work. We took long walks, picking berries in late summer; we worked on reducing the amounts of money due for medical bills and slogged through copious amounts of insurance paperwork. Jeremy started an acupuncture internship and published an article about prostate cancer treatment with concurrent alternative therapy as an adjunct.

Things began to slip for Jeremy about a year after diagnosis. There were nights he would sit in a hot tub with Epsom salts and sob with pain and desolation. All I could do was sit with him. On good days, he dedicated time to research. Jeremy discovered numerous prostate cancer research projects – each one of which became a source of hope. Throughout Jeremy's battle with prostate cancer, we consistently found hope in the unseen. We celebrated when Jeremy was approved to participate in the clinical trial of the drug Provenge. We had high hopes for this promising drug, which were well founded given that Provenge was recently approved for use in the treatment of advanced metastatic prostate cancer patients. Jeremy was approved to participate in this trial after hormone treatment ceased to be effective and early chemotherapy treatment was failing. Our hopes were dashed when we discovered that Jeremy was in the control group and did not actually receive Provenge. We found another reason to hope for Jeremy's future when we discovered an experimental treatment at the University of Oregon. He was accepted into this program which would have provided a mini-allogenic total marrow transplant. Of course, the approval came months after we sought this course of treatment and only days before Jeremy's death.

In September 2007, he had surgery on his spine when tumors put too much pressure on the spinal cord. Doctors put a morphine pump in his abdomen to pump morphine sulfate directly into his hip and low spine, which was most painful.

He had a few days where he could sit and move about without pain. He was surrounded by friends and family. He played his guitar, ate, and wrote. After two weeks in the hospital, the staff of the ward managed to get Jeremy into one of two special rooms, large enough for a guest to sleep in and appointed much like a hotel room. We knew that patients were put in those rooms so they could die surrounded by loved ones. We were assured that this was not the case with Jeremy; he was just so well-known and beloved after his several hospital stays. We were able to remain in denial a little longer; this was the palliative care floor, after all.

Jeremy learned to accept being experimented on with grace, even when elephant doses of powerful pain relievers did not touch the amount of excruciating bone pain that he was experiencing at all hours every day. He slept through most of his first wedding anniversary weekend, unable to take part in the celebration with his wife. Still, he worked hard to remain positive.

This is how my son was. He was a tireless worker – even in death. For the 33 years he was healthy on this earth, he worked tirelessly for human rights and environmental sustainability. He brokered an agreement between several guitar companies and Greenpeace whereby no old growth wood will go into the manufacturing of future guitars. He was known by his friends and co-workers as a compassionate, loving and generous man. If you Google his name, among many of his accomplishments, you see that he was given a special award to honor him by the Rainforest Action Network.

Six weeks before his death, I literally had to sneak him out of the hospital and wheel him up to the stage so that he could be honored. After a standing ovation of more than 300 people, Jeremy stood and spoke with such power that we forgot, for a moment, how weakened his body was by tumor and treatment. At his living wake, just a few weeks later, Jeremy could barely stay awake

as people came up to the dais upon which he reclined to give testimonials to him. Yet, when he spoke, he was focused upon the need for change in our world. His speech was selfless and full of gratitude toward the hundreds of people who had showed up to honor him.

After receiving his award at the ceremony and returning to the hospital, the staff came and spoke with him, his wife, his father and me about preparing for his end of life. It was the speech where they kindly ask if you want to spend the rest of your life in the hospital, being probed, prodded and kept alive painfully, or at home, with friends and comfort. Jeremy and Beth made their choice – he wanted to go home.

During the final weeks of his life, Jeremy was in agony. There were no comfortable positions that didn't cause pain. He vomited and retched repeatedly and with extreme force as the radiation treatments to prevent the tumors on his spine from paralyzing him had also affected his abdomen. He took medication for pain, nausea, constipation and appetite, anxiety and sleep. His mouth hurt. He began to wander at night, even on medication and maybe because of it. His friends organized into teams so that two or three of us would be with Jeremy around the clock. I slept so little that Jeremy's friends nicknamed me "Zombie Mom." Jeremy's morphine pump wasn't working and he also was incontinent of stool and urine. My proud, strong son would stand, docile, at the toilet while his wife or I wiped a continuing stream of stool running down his legs until it stopped so that we could put a fresh diaper on him. On excursions outside, we had diapers, a change of clothing, medication and water all packed up to go with us. Jeremy's ankles became so swollen and painful that he could barely move, although he still wanted to wander at night.

In Jeremy's final days, his diet consisted largely of mashed potatoes, which is all he wanted most of the time. He also ate his favorite cookies that I baked for him and a special granola that his step sister made for him. He slept on a hospital bed in his living room, provided by hospice. He would pull himself up and, with help, shamle on swollen feet into the bedroom to kiss his wife goodnight. In lucid moments, he would sit at his computer and try to do a little work or e-mail.

Finally, he opted to stop taking in food and asked hospice to increase his morphine so that he could sleep away his last days.

It was Thanksgiving week of 2007. None of us were feeling particularly thankful. Jeremy did sleep, but was restless much of the time. He had fallen out of bed a week earlier when the friends with him couldn't stop the fall in time and his neck hurt every time he shifted in bed. He began to have that nauseatingly sweet smell of ketosis as his already thin body wasted in front of our eyes. The day before Thanksgiving, he woke up in the afternoon and told my husband and I very clearly that he was dying and "it was alright." He said some loving things to each of us and then went back to sleep.

Later that evening, when friends were singing and playing music, he actually got up and sang, and was with us for a short time. On Thanksgiving, he did not wake up. His eyes remained lidded, not completely closed and his mouth hung open. I rarely left his side. My daughter-in-law ordered a feast from Whole Foods and we all tried to eat. No one had much appetite and we were all exhausted. There were beautiful flowers and candles decorating the space and there was, at every instant, so much love in the room. And we waited. On Friday, my sister's 50th birthday, the autumn weather was gentle and the space was quiet and respectful. We read to Jeremy, we sang to him, we wandered around tired, sad, wondering and waiting. That evening, at about 7:00 p.m., Jeremy's breath changed and I knew instinctively that this was it. He died peacefully, his wife holding his right hand and I holding his left, as I had promised him. His dad, stepdad, step-siblings and friends were all there, as were my sister and best friend. A helium balloon that had been floating about in the room for several days slipped out the window and floated skyward. Jeremy had a peaceful look on his face for the first time in months. His forearms felt solid, like always, although his gaunt face belied his frail state.

We send our sons off to war knowing they may not come back, or they may come back less whole than when they left home. We send them off to college, not knowing where they will go from there. But still, we have hope for their futures. We have hope for their lives. My son chose a dangerous path; an activist, he was threatened, shot at and he was often in jungles,

forests and other isolated locations. He was not safe. I knew this and feared for him, but at the same time I was proud. I was proud and I had hope for his future and the future of the world he was helping to create for his children.

Prostate cancer robbed me of that hope and that future. I learned in nursing school that prostate cancer is an “old man’s disease.” I know it is still perceived that way by most. About 1-percent or 300 men under the age of 40 die annually from prostate cancer. There should be none. If 300 doesn’t sound like a large enough number for you to focus on increased research funding – if the 300 mothers like me who have to spend the rest of their lives wondering why they outlived their children aren’t enough to motivate you to increase funding – please think about the 27,360 men who will die this year from prostate cancer. That makes prostate cancer the second-leading cause of male cancer-related death in the United States.

It is because of research that we know what does not work. There is no question that the PSA is not a good enough diagnostic tool, but it’s currently all that we have. There is no question that there are aggressive cancers that we cannot “watch and wait”. Prostate cancer kills more men than any cancer except lung cancer and has a mortality rate comparable to breast cancer in women.

What I have described to you today is the life of someone dying of a highly aggressive form of prostate cancer. His cancer was aggressive, but not rare. His own oncologist is the same age as Jeremy and in his practice has already treated – and lost – four patients under the age of 40. Too many YOUNG men are dying of prostate cancer. Too many MEN are dying of prostate cancer. In 2010, more than 27,000 men – fathers, brothers, husbands and sons, will die from prostate cancer in the United States. Perhaps if a more accurate test for prostate cancer existed, my child would have known about his cancer earlier and he could be here talking to you, himself; I’ll never know because there just aren’t enough funds to do all of the research that needs to be done. Perhaps, had the research been done on newer prostatectomy methods, my husband would not be impotent. Again, I do not know. All I know is the reality I deal with every day.

Each month I read another article about the inadequacy of the PSA as a screening test for prostate cancer and every day I wait for a better test. And every day I question why more and more funding seems to go to a few types of cancer – none of which are the largest killer of men in this country. It's one thing to criticize the test we currently have to screen men for this insidious killer – and quite another to find a viable solution. Unless you increase funding for the Prostate Cancer Research Program, I fear good research is being left unfunded.

No one will ever ask you to make the type of sacrifice that Jeremy made for prostate cancer. No one will ask you to put your families through the type of agony we came to know in watching our baby boy suffer through pain, embarrassment, shame and deterioration. I come to you today, representing my son's legacy, representing families who have lost loved ones and representing those who have not yet experienced the tragedy that is living through prostate cancer, to ask you to allocate additional funding to research this deadly disease. The sacrifice I ask of you is a painless one – and one that will make a difference in the lives of so many.

Thank you for your time.