

1 THE WORLD'S DEADLIEST KILLERS



Bob Klein championed Prop 71, led it to victory, and guided the program as Chairman for almost a decade.

Nearly one in two Americans has an incurable disease or disability.¹

April, 2003.

As my wife Gloria and I sat in the outer office of Klein Financial Enterprises, Inc., it occurred to me that the German word *klein* means "small." Bob Klein was challenging the world's deadliest killers — with a weapon that was the smallest of the small.

Essentially invisible, stem cells might save lives and ease the suffering of millions, IF the research could be paid for, and IF the political obstacles could be dealt with; very large "ifs" indeed!

But giant problems were nothing new for the person I was waiting to meet.

¹Chronic diseases: the leading causes of death and disability in the United States [Internet] 2014 May 9 [updated 2014 May 9; cited 2015 Jan 30]. Available from: <http://www.cdc.gov/chronicdisease/overview/>

To fight homelessness, Bob Klein had developed a state agency, the California Housing Authority (CHA), to make low-cost home loans for the middle class and poor. Though his company could have profited, he would not accept contracts from the program he had built. He served on boards attempting to lower the threat of nuclear war, increase environmental awareness, and even preserve classic buildings.

But his world changed when his teenage son Jordan developed type 1 diabetes. That may not sound like much — insulin shots, dietary restrictions, blood tests every day — but diabetes is the number one cause of adult onset blindness, kidney failure, and the amputation of limbs.

Klein, a bar-admitted graduate of Stanford Law School, became the principal negotiator for the Juvenile Diabetes Research Foundation (JDRF), perhaps the greatest patient advocate organization in the world.

One night in 2002, a miracle occurred. It was just before the invasion of Iraq. Washington had a singular focus, the agenda of war. President George W. Bush insisted that every available dollar be concentrated on the war effort. No legislation would even be considered unless it had 100% approval on both sides of the aisle. Every Senator and Representative, Democrat and Republican alike, agreeing on something? Plainly impossible.

But JDRF and the patient advocate community were close to obtaining major funding for diabetes research, and they were not about to give up now. Much of the money they sought would go to diabetes research; the rest would go to maintaining diabetes treatment centers on Native American reservations. Due to the high prevalence of diabetes among that population, shutting down the centers would almost certainly bring deaths.

Everything came down to the vote of one Senator, Don Nickels, Republican of Oklahoma. Klein and the patient advocate community organized thousands of individual phone calls, from leaders in the Senator's business community to advocacy groups, corporate boards, and local families, swamping the Senator's appointment calendar and jamming his phone lines.

Two hours before the cutoff time, Senator Nickels withdrew his objection — and diabetes research received a 5-year commitment of \$1.5 billion.²

After this success, the parents of California's diabetic children continued working together. Sony Picture executives Doug Wick and Lucy Fisher formed a group called Cures Action Now (CAN), supported by the legendary film director Jerry Zucker and producer Janet Zucker, as well as Lauren Weissman, the sister of top stem cell scientist Irv Weissman, and more.

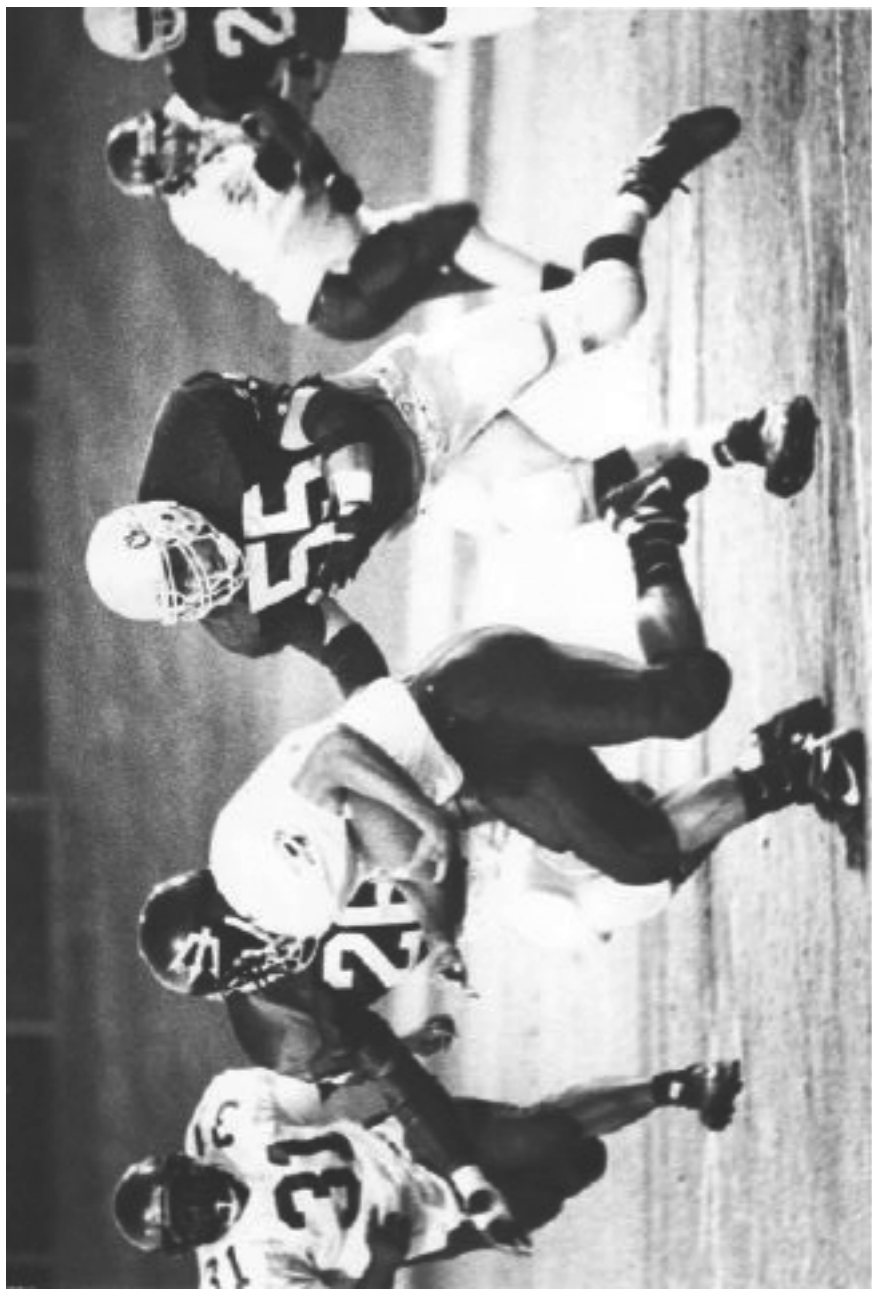
They approached Bob Klein. Would he organize a citizens' initiative to raise a billion dollars for stem cell research?

"No," said Bob.

"Too much?" came the disappointed response.

"Not enough," said Bob, "It has to be at least three billion."

²Robert Klein receives Research! America Advocacy Award [Internet] [cited 2015 Jan 30]. Available from: <http://www.cirm.ca.gov/board-and-meetings/robert-klein-receives-researchamerica-advocacy-award>



Football paralyzed Roman Reed, but he still loves the game.



Don and Roman Reed at the beginning of their journey.

A door opened.

"Bob can see you now," said the office assistant.

Wide-shouldered and craggy-featured, Robert N. Klein was seated at a long black table, scribbling something indecipherable on a yellow legal tab. He held up an index finger.

His handwriting is almost as bad as mine, I thought. My wedding proposal to Gloria had been in writing, but she could not read it, and threw my proposal away. We had been married 34 years so it worked out, but after that I typed everything important.

I looked around at the lovely office: carved wooden horses, a wall of books, a picture of young Bob Klein meeting young Bill Clinton, and a picture window above Palo Alto's green trees, swaying; a forest orchestra conducted by the winds.

"Ah!" said Bob Klein, putting down the pen and extending his hand. He has a great beaming smile, radiating warmth and energy. I sat down, expecting a mini-lecture on Bob's ideas, problems ahead, or chores that needed doing. But it was not like that.

"Tell me," he said. He leaned back in his chair, clasping hands behind his head and getting comfortable, as if this was the most important event in his day, and he had nothing but time on his hands. I knew it was an illusion. I had maybe ten minutes before his next appointment.

In a rush of words I told him about our family's most terrible night: September 10, 1994, a football game at Chabot College, Hayward, California.

Nineteen-year-old Roman Reed was the defense captain and middle linebacker. Under the floodlights he was playing his usual great game: 14 solo tackles, a bunch of assists, a diving one-arm interception, and a forced and recovered fumble.

Roman and a 341 pound giant blocker had been having an epic duel. Sometimes they crashed like trucks; other times Roman faded like smoke around the giant, reappearing



Lucy Fisher and Doug Wick, motion picture legends, and co-founders of Cures Now. With Jerry and Janet Zucker, they dreamed the dream of Proposition 71, and worked hard to make it become real.

on the other side, leaping on the runner, dragging him down. Once he dove and flicked out the ankle of the runner, breaking his balance like a cheetah tripping a gazelle.

Between plays he roared up and down the sidelines, exuding energy like flame, helmet off, challenging, inspiring — "Roman made you afraid to do less than your best," one player put it.

And then, in the surf-roar of shoulder pad collisions, on the third play of the fourth quarter — "Roman's down, it's bad!" said Gloria, "I saw it through the viewfinder!"

"Just the wind knocked out," I said, as the play was whistled dead.

The players trotted lightly to the sidelines, all but one.

Dear God, don't let it be Roman, I thought, looking frantically for him at the bench. He always liked to take his helmet off between plays, golden hair sweat-soaked, face red with exertion and competitive rage. But nobody had their helmet off, and a body lay still on the floodlit field.

I watched my feet trading places down the bleacher steps. This is a mistake, I thought, we just have to go back in time a few minutes and straighten it out.

"Don't worry, Mom," said Roman to his mother, "Nothing hurts. I don't feel a thing."

A shadow fell over us. I looked up. It was the giant blocker, number 22.

"Jesus God, Roman," he said, tears running down his face.

"Not your fault, two-two," said Roman, "Good hit," and he reached up to shake the other's hand.

I noticed something small, and terrible. My son's fingers did not move. Sparing the other's embarrassment, Roman sandwiched the giant's hand between both of his.

At the hospital, a doctor ordered Roman's shoulder pads to be sawed off. I started to object, this was expensive gear, designed to keep him safe from injury. But the doctor looked at me and I went silent, afraid he would say: what use will he have for them now?

After his helmet was also removed, a C-shaped metal tool was brought out. Roman's hazel eyes flicked briefly to me once, then straight ahead, blazing green, as shallow pits were



drilled into bone, and smoke rose from the sides of his skull. The doctor secured a clamp in the holes and fastened it to weights on the gurney below, immobilizing our son's neck.

The X-rays came, and the diagnosis:

"Your son is paralyzed," the doctor said, "He will not walk again, nor close his fingers."

To make his point, the surgeon lifted Roman's hand, told him to hold it up. Before the accident, Roman could bench-press 430 pounds. But now? When he let go, Roman's hand fell like dead meat, so fast it slapped his own face. The brain-body connection was gone.

He could breathe, which was a blessing. But if he needed to cough we had to do that for him, shoving his stomach in hard, like a punch to the gut. It hurt him; the nerves inside still worked.

A flicker of hope. As I was sitting in the hallway, a book landed in my lap: *Rise and Walk: The Dennis Byrd Story*, about another football player who had been paralyzed. Byrd's millionaire coach provided him with an experimental drug called Sygen, made from dried cow brains. The Sygen had been injected right after the accident, and Dennis Byrd walked again.

"Get that for my brother," snapped Desiree, Roman's sister, just in from college in Arizona.

More good news! There were FDA-approved clinical trials of Sygen going on right now, a nurse told me. If Roman was involved in the trials, we could get the drug free...

The medicine had to be injected no more than 72 hours after the accident. But it was raining and midnight when I called the hospital. Bring him in the morning, I was told, it will be all right. But it was not all right. We missed the cutoff deadline by one hour, and were denied.

I located the drug's inventor, Dr. Fred Geisler, at the University of Chicago. He said the cutoff time was only for the clinical trials, and that the drug might work after the deadline — if we could get FDA approval. I called U.S. Representative Pete Stark, who contacted the FDA, helping us get "compassionate use" permission for the medication, though it was not yet officially approved.

Finding a drug source in Switzerland, I ordered the medication. It was not cheap. We borrowed. No doctor wanted to write a prescription for an experimental medicine.

But a kindly Chinese-American doctor, Chi-Chen Mao signed the prescription slip.

But what about side effects? The documents only mentioned minor stomach upsets, but still things can always go wrong. The first injections needed to be done in the hospital.

When the boxes of Sygen arrived, a nurse set up Roman with an intravenous needle in his arm. "Ready?" she asked, and turned the valve.

Roman's eyes rolled back; he stopped breathing.

"Oh my god, mouth to mouth resuscitation!" I said.

Our son's eyes went back to normal. He grinned and said: "Gotcha, Pops!"

Rehabilitation was wonderful; caring therapists, great exercise. We learned about the all-important "transfers", helping him shift bodyweight from bed to shower chair. But 39 days of rehabilitation was all our insurance would provide, and Roman was still paralyzed.

When our insurance quit, we found another "rehab center" (about which I have nothing good to say), and enrolled Roman, borrowing more money.

Roman's girlfriend Terri was the bright spot in the nightmare. She and I put Roman through seven months of massive rehabilitation, both at the "gym" all day, and at our apartment in the evening. She stayed by him almost constantly, in a chair beside the hospital bed or curled up beside him on top of the covers.

The money burned away. I begged systematically; anything to get money for the rehabilitation expenses. Senator Dianne Feinstein and Representative Pete Stark donated \$500 apiece, and author Beverly Cleary sent us \$100. The kids at my school did two penny drives for us. A friend bicycled nearly to Los Angeles on a fundraiser, but his calf muscle went out and he had to stop.

Our local church? My wife and children are Catholic, though I am not, and it seemed reasonable to ask the priest's help with a fund raiser. To my astonishment, the priest got angry, saying that I was "*going against God*" by not accepting His will that my son be paralyzed!

But another church, a Presbyterian one, came through for us without even being asked. They read a newspaper article about our struggle and donated \$5,000. Also, a Mormon temple sent members to our house to help with meals and errands, kindnesses I will not soon forget.

And one bright day, Roman bench-pressed — a *broomstick*. Maybe it only weighed one pound, but his triceps were working again, long past the time the doctors said recovery was possible.

The restored arm function let him learn to drive an adapted van instead of needing an attendant. It meant, in time, he would be able to get himself out of bed in the morning without a mechanical hoist or needing me to pick up all his 235 pounds, as I had been doing.

When we visited one of our doctors, Ilyas Chaudry, Roman saluted him like a soldier. Dr. Chaudry was astonished; the recovered motion was pure triceps power, which was supposedly gone.

But he was still paralyzed.

Gloria adapted our home for wheelchair use: borrowing still more money to add on three rooms that met disability standards. The whole back wall of the house was taken off and at night the wind whistled through the plastic sheeting. But at last it was done. Roman would live in the adapted rooms of our house with Gloria and I — forever? Terri and I would share the care giver chores.

But cure? The time for that was over, I thought. We had recovered some motion in his arms, more than the doctors thought we would get. I was sure Roman would be reasonable about this when I explained it to him.

Unfortunately, when Roman was built, they forgot the "Quit" button.

Sooo.... I read science books about nerves and spinal cord injury, or more accurately, tried to. I was no doctor. How could I make sense out of these gigantic Latin words?

But there was one book I treasured. Written by Sam Maddox, *Quest for Cure* was published by the Paralyzed Veterans Association. It asked the question, "Could there be cure?" and answered "Maybe." Compared to the hopelessness I had been hearing, that was like a candle in a cave.

I attended a convention on spinal cord injury research in the seaside town of Asilomar. The words the scientists used were so big I kept falling asleep from brain overload. It was like the famous cartoon by Gary Larson of *Far Side* about a dog named Rex who digs up the roses, and the owner is yelling at Rex, who only knows one word of human — namely, Rex. All he hears in the long lecture is "Rex, blah blah Rex, blah blah..." I knew the words "spinal cord injury" and would wait for them. But I approached one scientist afterward and asked him:

"I don't understand what you guys are saying, except I know it is important. I can't help you on the science, but is there anything I can do, something you need?"

"Money," he said. "If I work six months on a grant request and it is rejected, I cannot put food on the table for my family — and the research won't happen."

Money... okay, how hard could that be?

Ever see the movie where kids are trying to raise money and somebody says, "Let's put on a show!"? With the help of my 8th grade student club True Colors, I wrote, directed, and produced *A Night for No Mexican Tears* about Mexican revolutionary Juan Cortina. It featured a live horse ridden across the stage and a 40-shooter cap gun battle. The Parent Teacher Association (PTA) counted our proceeds on stage, and we sent \$4,000 to Christopher "Superman" Reeve.

An act of kindness helped us. When Christopher Reeve's riding mount threw him, the "Superman" actor broke his neck and became paralyzed from the neck down. His brothers wanted to shoot the horse. But Reeve said no, it was an accident, and would not let them do it. Joan Irvine-Smith is a lady who loves horses. When she heard about the paralyzed Superman's kindness, she gave him a million dollars — and the Reeve-Irvine Research Center was born.

Christopher Reeve sent the cast of our show a wonderful letter, saying, in part:

"One day, Roman and I will stand up from our wheelchairs and walk away from them forever."

But the money we raised was chicken feed, compared to the need. What to do, what to do?

I read about a New York policeman, Paul Richter, who was shot while in the line of duty. A gun runner blasted him in the chest, shotgun pellets grazing the spine. Richter was firing as he went down, and the perpetrator fled. (He was caught and sent to prison, where he later had a heart attack and died on the toilet.) Richter was not paralyzed, but had extensive nerve damage and had to retire.

"Uncle" Paul wanted to fight paralysis. If the number one cause of spinal cord injury is car crash, why not charge reckless drivers a fine? Fifteen dollars a ticket sounded great, but Republican Governor George Pataki said he would only allow the bill if it was approved by every legislator, Republican and Democrat alike. Paul Richter made it happen. The bill passed unanimously.

Maybe we could do something similar? I sent letters (not emails) to all the California Assembly-folk and Senators. Most said nothing; the few who answered said no.

But one day in my 8th grade English classroom, the telephone rang. Would I mind, asked Assembly Member John Dutra of Fremont, if they made a program called the Roman Reed Spinal Cord Injury Research Act?



Paul Richter (on right) with friends: shot in the spine on duty, "Uncle" Paul established a New York spinal cord injury program, raising millions of dollars for research.

Would I mind? I screamed and pounded the wall, then ran to the office, taking over the PA system to announce the good news. Nobody understood what I was talking about, but they gathered I was happy.

Well, that was that, I thought, knowing nothing about what was to come next. The bill could only be introduced by its sponsor; after that, it had to be pushed through multiple committee hearings, passed by the California Assembly and Senate, and lastly approved by the Governor.

Paralyzed friend Karen Miner turned out to be a natural organizer, and we began. Many people helped, in large ways and small. Bob Yant, Shelly and Marco Sorani, Susan Rotchy, Fran Lopes, and many more lent the power of their groups. World champion karate star Bill "Superfoot" Wallace (he fought Jackie Chan in *The Protector*) endorsed us, as did General "Stormin' Norman" Schwarzkopf, who said, "I have led troops into many battles, but never one so important as the fight against paralysis."

There was unexpected opposition: the American Automobile Association (AAA) came out against us. They did not want their drivers (even bad ones!) interfered with. But we mounted a letter-writing campaign, targeting their Sacramento lobbyist. So many letters were pushed through the mail slot on her door that she had a hard time opening it. They changed their stance from "oppose" to "neutral".

Republicans disliked the traffic fine and came on strong against the bill at the Senate budget committee hearing. But Senate President Pro Tem John Burton held sway. As Roman and Karen and friends watched from the audience, I was astonished to hear:

"How about \$19 million a year, paid for by the General Fund?" asked Senator Burton, and the Republicans agreed to it. Nineteen million dollars? Wow.



But then came the energy crisis. Every bill which had a funding cost went into the "Suspense" file (meaning it had to be reconsidered), and ours did not come out. So, we started over again. This time, we only asked for one million dollars a year. "It's a feel-good law that doesn't cost much," one Republican aide said. He was right. One million dollars was the approximate cost of taking care of one severely paralyzed person in their first post-accident year.

But the Roman Reed Spinal Cord Injury Research Act of 1999,³ or "Roman's Law," was alive. On March 1, 2002, the opening day of the Roman Reed Lab at the University of California Irvine, I held in my hands a laboratory rat named Fighter, which had been paralyzed but walked again. It had been given human embryonic stem cells.

On the speaker-phone, Christopher "Superman" Reeve said, "Oh, to be a rat this day!" Gloria was so excited, she photographed the phone!

Back in Bob Klein's office, the telephone rang. Bob frowned, then nodded:

"I have to take this," he said, "It's my son." He picked up the receiver, from which a burst of rapid talk emerged from the phone.

"Okay," said Bob at last, "Call Doctor — and tell him... Okay? Then call me back, and tell me what he said. Right..? Love you."

In that instant, I recognized Bob Klein. He was a parent trying to help his son, like me and millions of others. The difference was that if he succeeded, everyone on earth would benefit.

He looked at his watch. I braced myself, sure he would say something about how he really appreciated my stopping by, but —

"Let's go meet the others," said Bob Klein.

³Roman Reed Spinal Cord Injury Research Act of 1999, AB 750 [statute on the Internet]. 1999 [cited 2015 Jan 30]. Available from: http://www.leginfo.ca.gov/pub/99-00/bill/asm/ab_0701-0750/ab_750_bill_20000927_chaptered.html