The power of will

A narrative in five parts.
Chapter 1

STORY BY BILLY BAKER
ILLUSTRATIONS BY YOSUA COWAN
GLOBE STAFF

Will Lacey was just a baby when doctors diagnosed a rare form of cancer and told his family there was only one end. Nobody then could imagine the journey ahead, from hospital rooms to board rooms, research labs to government offices, a furious race between hope and death.

An odd couple, but Trump in ‘serious’ talks with Romney
Meeting not just ‘some photo op,’ a top aide says

By Matt Visser
GLOBE STAFF

WASHINGTON — In the days after the election, after Mitt Romney had called to offer his congratulations to Donald Trump, a core nucleus of Trump advisers began assembling a list of candidates for secretary of state.

They had every reason to leave Romney off it: the former Massachusetts governor had, after all, been one of Trump’s most vituperative critics and said he didn’t even plan to vote for him. But the core group of aides — which included Steve Bannon, former CEO of the digital media firm Breitbart — quickly added Romney to it, and not just to be told off campaign rivals.

When they presented the idea to Trump, there was no hesitation, according to a top-knot transition team source.

“This wasn’t just to have some photo op with Romney,’ a top aide said.

No end in sight for Harvard’s tilt with final clubs
Many on campus call sanctions a civil liberties outrage; faculty vote Tuesday

By Laura Krantz
Globe Staff

CAMBRIDGE — Utopia is in the great hall of the Fly Club, a mounted buffalo wears a Santa hat. The gleaming eyes of the taxidermied beast stare out into a cavernous room where undergraduate men line the windows with Christmas lights for a party. The ball smells of stale beer.

For more than 100 years, only the privileged few have stepped inside the 19th-century mansion, built for exclusive all-male social club on Harvard Place in Harvard Square. But this year, a Harvard College crackdown on all eight male final clubs, which are not formally part of the university, has pulled them from the shadows.

The college’s attempt to force the historic clubs to accept women has prompted a backlash, setting administration

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The power of will

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Shaffer held the answer she had given because it was no answer at all. In a matter of hours or days Tyler would die. Other children would die too, if there was no way to treat them. There had to be an answer out there, she told herself, and she would try to find it. One day there would be a child she could heal.

Dina Lacey looked down at her baby boy on the rag, and at her husband sitting on the couch, and couldn’t help herself. “He inherited your fat neck,” she said to Pat, who looked at Will and laughed, partly because it was true, and partly because it was great that he had married the kind of woman who would make jokes about his neck.

Pat is a big guy, not imposing, but more the kind who volunteers to carry the bags. He was never a troublemaker or a rebel, just someone who was perfectly happy to be getting along.

He’d had an ordinary suburban childhood in Braintree and then earned a degree in biology from the University of Massachusetts Amherst, where he specialized in making jokes about majoring in sociology. He was never accused of being an overachiever, and if asked what he wanted to do with himself, he would say something like “find a decent job, get married, have kids, and push the car for the Cape every now and then.”

That’s just what he did. He got a job at a financial firm, where he met Dina, a tall, dark-haired co-worker, and won her over with an invitation to the Flag Day party he threw every year because nobody throws parties on Flag Day.

Will was born in late August 2000, a year after they got married. They were still living in the soft glow of a couple becoming a family when Pat’s parents offered to sell them the house in Braintree where Pat grew up. It was a house with a new Lacey family starting off in that old brown house on the quiet street where kids can ride bikes and play street hockey just like he did.

It was just after Christmas and they were still getting settled in the new house when Pat first heard the crack about Will’s neck. He’d been a big baby, 10 pounds plus, and now he was a big 5-month-old. Pat laughed as he picked Will up from the rug and began to manage the rolls on his neck.

Pat hit the hump and the sick feeling in his gut almost simultaneously.

It was about the size of a grape, in the hollow near Will’s left collarbone and when Pat squeezed it between his fingers, it felt like it was stuffed with N-A-Q. He knew that nothing on a baby’s body should ever feel like that.

Dina called the pediatrician. Pat went to his computer. Will on his lap, and began to search. He figured out the lung must be in the lymph node that drained the throat from Will’s chest, and he kept reading that it could be a sign of a malignancy. Each time Pat read that, he dismissed it. The baby in his arms was just 5 months old, surely, infants don’t get cancer.

They saw Will’s pediatrician, who sent them to a surgeon who wasn’t too concerned. Will had had a training birth because he was so large. He had emerged with a lump on his

DISPATCHES FROM A NIGHTMARE

Pat Lacey created a blog and wrote almost daily about his son Will’s battle with cancer

FROM DIAGNOSIS TO RECURRENCE
MAY 3, 2006

On March 21st of 2005, three days before Will would be 7 months old, he got a chest X-ray at Children’s Hospital Boston which found a large mass in his chest. The reason for the chest X-ray was that we discovered an enlarged lymph node at the base of his neck where it meets his left shoulder. It wasn’t the pea-size kind that you sometimes find on kids after they get sick, it was in the soft spot of his neck and when I touched it (back in January for the first time) I immediately knew something was wrong. It felt about the size of a very large grape and was “squishy”. It made my stomach turn, because I knew that nothing in that location should ever feel like that.

THE MEETING YOU NEVER WANT TO HAVE
SEPT. 20, 2006

I will follow with more detail when I am able to, most likely tomorrow, but we had our meeting yesterday and suffice it to say we were not told what we wanted to hear. We discovered that one of the three spots that have MDIBL uptake (indicating areas of tumor) did in fact grow (according to some interpretations) while Will was on High Dose chemo. What does this mean? According to the head of the pediatric oncology program at Dana Farber this means that Will is now classified as “irreducible” and the best we can hope for is to delay the inevitable with various kinds of treatments.

Not the best meeting I have ever been involved with, certainly the most surreal, and without a doubt one I’ll never forget.

FALLOUT
JAN. 13, 2007

I think of a picture from the Civil War of a farmhouse outside of a battlefield that was converted into an impromptu triage area. The grotesque horror of this picture and the haunting thought of what it must have been like inside is that house have always stuck with me. I imagine that shock I feel in looking at medicine from 140 years ago will be similar to how people will feel when they look back at this era of pediatric cancer treatment.
But Will’s second birthday, at the end of August, Pat and Dina brought their boy a cake decorated with M&Ms. Two weeks later, he sat with the head of pediatric cancer at the Dana-Farber Cancer Institute. “I’m sorry, she said.

There were new spots on Will’s skin. All known cancerous therapies had failed. She asked them how to best use the time they had left.

They drove home to Reston in silence. Pat’s mother took them aside the house, and Pat and Dina went for a walk around the neighborhood.

Dina, inconceivable, radiant.

I am a mother, she shouted. And I am going to remain a mother. No one is going to take my child away from me.

But it was what you couldn’t see that made the room truly scary. The names clearly wanted nothing to do with the place. When they did step inside, they hustled out as quickly as possible.

They had reason. Will had just received an infusion of radioactive material so powerful it would be seven days before it was safe to around him. Pat was supposed to get into the room only for brief periods and to keep a constant eye on the dosimeter clipped to his collar. Dina was back in Reston because she was pregnant. It would be weeks before she could go near her son.

Pat sat in the “dead corner” of the room, directed to stay behind a lead shield that ran along the bed and blocked his view of Will. As he talked, trying to soothe the boy, the effects of the infusion started to boil. He heard Will moan.

To boil with the rules. Pat heaved his shoulder against the shield, so heavy it took all his weight to move. He reached Will and tried to clean and comfort him as the boy sobbed.

What had he done. Pat thought. Was he doing this for Will or for himself?

They returned to Reston and waited. The treatment appeared to work. The rest was not stable. There was no telling what else that much radioactivity had done to his son. The long-term side effects were potentially horrendous, though the medical expectation was that it wouldn’t matter; Will would not live long enough to find out.

At a transfer station, Geiger counters had gone crazy, and some poor gazette had to dig through the pile to find the source of the radioactivity — Will’s diapers. The truck had to be quarantined for four days.

They brought Will an envelope of the most expensive toy car they could find. Pat heaved the shield against it as best he could.

Dina, Pat, and Will on their way to a birthday party in April 2009, while Will was undergoing chemotherapy.

Dina heaved the shield as best she could.

Pulled into the driveway one evening in May, Pat heard Will shout across the yard. Daddy’s home!

The boy, pursued by his dog Molly, ran from the porch where he had been watching with Dina for Pat to arrive home from work, in the two months since Philadelphia, Will had recovered from the effects of the treatment and, for all outward appearances, was a year-and-a-half like any other.

Pat and Dina had been having hard conversations about which course to follow now. Parents who kept trying to save their children often crossed a line into a world of untold treatments almost certain to do nothing but cause more suffering. It was one the Pat and Dina could choose to cross or not. Pat saw forty lifetime of self-suffer and guilt if they made the wrong choice. He didn’t want his son to suffer while he and Dina chased false hope. But in the end, their choice was clear: They would keep trying. Pat refused to think that the hope they were chasing was false. He called it “indefensible hope,” a phrase he picked up from a John Updike story.

“There will always be a corner in a pocket of our knowledge of the odds, an indefensible hope,” the story said, “where density of expectation hangs in the air and plucks an event out of the future.”

A few months later, in the fall of 2007, Dr. Sholler journeyed from New York to Milwaukee for a meeting organized by a cancer patient who was frustrated with the pace of research. Stoller and some other oncologists had been invited to speak. They already knew many of the people in the conference room, including some parents who were raising money for their work. But there was one face she didn’t recognize. It came from Boston named Pat Lasey.

Pat had heard about her research. There was some buzz about her, sort of it positive. But he took to her immediately as she gave her presentation. He could not be more enthusiastic.

When the speeches were over, Pat asked another parent to introduce him. He did not say anything about Will, that he had relapsed, that he was in the hospital.

For now, he corrected him. He is inurable for now.

Pat passed. Sholler went on.

“Kids aren’t going to be incurable forever, she said. Why can’t it stop now? Someone has to be the first. Why not Will?”

For months, ever since Will had his second trip to the bone marrow in Philadelphia, Pat had talked to every oncologist he knew. He would find, and every one of them had told him they were very sorry but there was nothing to do. Now this woman was standing in front of him saying exactly what he wanted to hear a doctor say. He knew what she was offering was dangerous.

Hope. Indefensible hope.

And yet, why not Will?”

A friend to the story online, with more photos, illustrations and an audio version go to boston.com