No, the “Ph.D., Ph.D.” is not a typo.
Born and raised in LaCrosse, WI. Went through typical phases of career choices (astronaut, paleontologist, President of the United States, etc.), but by 12 had settled on being a mathematics professor like my Dad.

Undergraduate at Rice University in Houston, TX
Graduate school in Berkeley, CA; met my wife-to-be, Mina, in 1999.
Started dating Mina in 2002; story of how we met and started dating is a great one but much too long for this talk. The short version: I was her TA.
She got her Bachelor’s and I got my Doctorate and I started on an job track in academia at Pacific University in Forest Grove, OR, while she stayed at Berkeley and started work on her PhD.
I continued my job track at the University of Arizona, but the long-distance relationship was starting to take a toll on both of us. It was then that she decided I should “become useful” and I left my position at U of A a year early to start in the PhD program in Biostatistics at UC Davis.
(Aside) My PhD in math was actually completely useless in preparing me for studies in Biostatistics. I was in abstract algebra, and statistics is mostly based on real analysis, which I had more or less ignored during my math career. Two courses I took as an undergraduate and some of the courses I taught at Berkeley and Arizona were far more useful than any of my PhD training. (End aside)

This was working reasonably well. We were technically still long distance, but we were able to spend all of our weekends together as well as having our “board game nights” in Berkeley every Tuesday. Then, she got into medical school at UCSD.
To quote one of our favorite movies: “...but this, to me, might be considered kind of a step backwards, wouldn't you say?

Once again, we were truly long distance, and the strain was getting to both of us. I stuck it out for a year, but finally I gave up. I actually decided to leave Davis with a Master’s, but two different members of the Statistics Department that I talked to said “You can’t leave without a PhD.” Then my advisor said “So, how’d you like to graduate in December?” A tip for all you graduate students: when your advisor asks you if you want to graduate, you say “Yes!” It was a great idea, but I couldn’t wait that long to move down. We worked out a plan for me to move down to SoCal and finish my PhD while I was there.

Unfortunately, the economy was near its nadir at that point. I nearly landed a dream job in San Diego (we were actually negotiating salary), but that fell through at the last minute. The only thing I could find was a Master’s-level position in Arcadia, CA—which was OK, since (after all), I only had an MS in Biostatistics at that point; and it was close enough to San Diego that I could once again be with her on weekends (and she was too busy with medical school to have much other time anyway). My new supervisor was OK with me finishing my PhD while there (in fact, he encouraged it), so I accepted the job and moved down.
This is where things stood in July of 2008. At this point, I’d like to suspend my story and start another one that has had a profound influence on my life.
“This is the story that people should really know about this terrible disease.”

—Lisa Tichenor, personal communication
Willie’s story

- In 2003, 16-year old William “Willie” Tichenor experienced extreme pain just above his left knee
- A trip to the emergency room for X-rays and a later trip to an orthopedic specialist revealed nothing about the cause
Willie’s story

- A month later, he discovered a lump protruding above his knee
- In May 2003, just days before his 17th birthday, he was diagnosed with osteosarcoma of the distal femur
Osteosarcoma facts

- 8th most common type of pediatric cancer, with incidence of around 5.0/million/year in the 0–19 age group
  - Most common type of bone cancer
- Most commonly occurs around or during the pubertal growth spurt in the distal femur, proximal tibia, or proximal humerus
Interesting side note: osteosarcoma also occurs in dogs (and cats); the chair of our committee is actually a DVM/PhD and does his research in canine osteosarcoma.
First major surgery was to resect his knee and 12 inches of femur, then replace it with an endoprosthesis. The orthopedic surgeon failed to install all of the pins necessary to anchor the device, then left for vacation in Brazil.

Second major surgery was two days later to replace the prosthesis.

This was the most successful part of his treatment; he was walking limp-free after this.
Willie’s story

- In December 2004, the first check-up post-treatment showed that the cancer had metastasized to his lungs
- This led to another round of chemo, followed by a bilateral thoracotomy that removed 18 tumors, followed by more chemo
Willie’s story

- He continued living optimistically: performing with his band, traveling to Juarez with his church group to build a house, and starting his delayed enrollment at the University of Texas in Austin
  - He got 3 A’s and an incomplete while dealing with the pain from the tumors by periodically going into bathroom stalls to inject a powerful morphine derivative into his chest port
Willie’s story

- In December 2005, a planned thoracotomy revealed that the tumor growth in his lungs had exploded. He was out of treatment options.
- In February 2006, he returned home to Dallas. His parents could see the tumors protruding from his back.
Willie’s story

On March 15, 2006, with a parent holding each hand, Willie Tichenor succumbed to his disease. He was 19.

The story could have ended there, with Willie being a mere statistic—one of the approximately 300 children that die each year from osteosarcoma. But Willie’s parents and friends didn’t let that happen.
They formed a foundation in his memory.
The WWWW (QuadW) Foundation provides financial support to people and organizations pursuing innovative ideas and opportunities in the areas of higher education, sarcoma research, personally transforming mission experiences, and general philanthropy. Our accomplishments will reflect the light-hearted—but whole-hearted—spirit that Willie embodied.
Note that the Board is mostly Willie’s friends and classmates, so they’re probably about the same age as a lot of you students in the audience.
QuadW Childhood Sarcoma Biostatics and Annotation Office

In April 2007, a Sarcoma Expert Panel, convened by the American Association of Cancer Research at the request of QuadW, identified an effective sarcoma tissue bank as the top priority for advancing the goal of improving sarcoma survival. Based on the amount of funding QuadW could provide, the QuadW Sarcoma Biostatistics Office was created.
QuadW Childhood Sarcoma Biostatics and Annotation Office

Goals:

- Completion of pending COG sarcoma biology statistical reports
- Source of biostatistics resources for future experimental analysis
- Standardization of annotation for clinical outcome of sarcoma samples
QuadW Childhood Sarcoma Biostatics and Annotation Office

- Updating of annotation for all existing COG sarcoma samples
- Creation of a web-accessible database for researchers
Looking for opportunities to fund biology research, the QuadW Foundation discovered CureSearch, the corporate identity of the Children’s Oncology Group and the National Childhood Cancer Foundation.
The “research” is right in the name!
CureSearch for Children’s Cancer

- Not-for-profit voluntary healthcare fundraising organization that funds pioneering research and advanced treatment for children’s cancer
  - Mission is to fund and support collaborative research for all those affected by children’s cancer
  - CureSearch believes that only research cures cancer
CureSearch for Children’s Cancer

- Consists of three data analysis centers and several satellite offices for fund raising
  - Arcadia, CA (main office)
    - Study development — 13 employees
    - Phase I Consortium — 7 employees
    - Statistics and Data Center — 12 statisticians and 18 other employees
    - IT — 22 employees
    - Administration, etc. — 50 employees
CureSearch for Children’s Cancer

- Omaha, NE
  - 5 statisticians
- Tallahassee, FL
  - 17 statisticians and support staff
- Bethesda, MD
  - Administration and leadership
- Charlotte, NC; Chicago, IL; Dallas, TX; Iselin, NJ
  - Fundraising offices
COG was formed in 2000 from merger of four pediatric cancer groups. If a child is involved in a clinical trial in pediatric cancer in the US, it’s one of ours.
Why Fund Research?

- Each year, 13,500 families are told “your child has cancer”
  - That equates to 37 children and adolescents each day
- Overall survival rates have increased from 10% forty years ago to 78% today
  - 1 in 5 children still loses his or her battle with cancer
Why Fund Research?

- The majority of children with cancer are treated via clinical trial protocols.
  - 60% of children with cancer are enrolled in clinical research trials; less than 10% of adults with cancer are enrolled in trials
  - Participation in pediatric clinical trials spans an average of two to three years and requires a lifetime of follow-up care
  - Most children receive medications developed for adults which are now also used in children
Why Fund Research?

- Research trial costs vary, but range from $6,000–$10,000 per patient.
  - CureSearch currently provides about $2,000 per patient to COG member institutions from National Cancer Institute funds
  - CureSearch also provides about $1,000 per patient from private philanthropy
  - Member institutions/investigators cover the balance of $3,000 – $7,000 per patient
Why Fund Research?

- Individual investigator and institutional resources supplement the pediatric cancer clinical trial enterprise, but that is not sustainable
- With additional money, CureSearch could more fully fund the existing trials at member institutions
Resources for Patients and Families

- The majority of funds raised are used to support clinical research, but CureSearch also provides tools for patients and families to help them through the cancer experience.
Resources for Patients and Families

- **http://CureSearch.org** provides up-to-date information about
  - the numerous types of children’s cancer
  - research trials
  - definitions and descriptions of tests, procedures and treatments
  - the emotional aspects of caring for a child with cancer
Resources for Patients and Families

- **The Family Handbook**
  - Distributed to families via COG hospitals
  - Three-ring binder with information to guide parents through all stages of their child’s cancer, from diagnosis to treatment and into survivorship
Resources for Patients and Families

- **The Hope and Help Journal**
  - Given to parents at the point of diagnosis
  - Spiral-bound notebook of pages where parents can write down information, questions, and details about their child’s treatment
  - Beginning pages contain a list of useful questions for parent to ask when they first receive the news that their child has cancer
Finally, I’d like to talk about what exactly it is that statisticians do.
Statisticians

- One of the most important parts of a statistician’s job is power analysis: deciding how many subjects are needed to have a reasonable chance of discovering a difference between groups
  - This needs to be done before the experiment is started
Current analysis I’m doing has a power of less than 25% for a reasonable effect size; I’m almost certainly going to have to tell that investigator what his experiment died of. In his defense, our office didn’t exist when his study was planned. Still...
Also, believe it or not, statistics graduate students are just as fond of beer and pizza as other graduate students—possibly more so, in some cases. So get to know them, while they still have time to take on new projects.
For my dissertation research at UC Davis, I spent 10 months developing the initial version of the data processing algorithm, then 15 minutes programming the statistical testing part.
Work for the QuadW OBOA

- Was hired to
  - Clean up backlog of “legacy” biology studies that had used tissue derived from COG osteosarcoma trials but which had insufficient support for statistical analysis
  - Help with design and analysis of new studies
- Basic statistical technique: survival analysis, which looks at time to relapse, second malignancy, or death
Aside on clinical trials

- Three basic types of trials at COG:
  - Front-line therapeutic trials for newly-diagnosed patients
  - Secondary therapeutic trials for relapsed patients
  - Non-therapeutic studies (tissue banking studies, epidemiology studies, biology studies, etc.)
Problem!

- Did comprehensive survey of data for legacy studies and discovered that for patients who did not go on a front-line therapeutic trial, only 5.3% had any follow-up data.

- Furthermore, P9851—the biology trial from which many samples were derived—had closed in June 2008, and the protocol specified that we would *not* collect data.
More problems!

- Worse yet, many institutions had let their IRB approvals expire and some had not seen their patients in years
- In November of 2008, it was looking like I might be out of a job
If it had been the other way around, I probably would have been out of a job, since there was no way that sites would re-open if they had to find and re-consent patients. There would have been no data for me to analyze.
Some data we’ll never get because there are some sites that are refusing to amend and re-open P9851, and some sites which are no longer COG sites; fortunately, those represent a small portion of the data.
Data collection

PS551 Follow-up Data
Non-therapeutic patients with at least one OPTF

Significant timecots
1. Amendment 2 available
2. AG versus non-AG
3. Dose/number updated
4. Ps8591 added to SADG

Date
Percent
0 10 20 30 40 50
0 10 20 30 40 50
4.3% at start
50.0% as of 15 February 2011

Children’s Oncology Group
It turned out the site had mis-entered a form and never told us to delete the incorrect form.
I was telling a pediatric oncologist I was collaborating with about the relapse-after-death patient, and we laughed about it. After all, as a purely abstract data problem, it’s pretty funny. But when you think more closely about it, we’re talking about the death of a 12-year old patient.

The abstraction is not all bad—I personally need the emotional distance, or I don’t know if I’d be able to function. As much as my supervisor and I enjoy making fun of the statistical sophistication (or lack thereof) of my collaborators, we both have the deepest respect for the pediatric oncologists who deal with these patients on a regular basis. I can’t imagine the emotional strength it takes to do what they do.
Willie Tichenor
May 15, 1986–March 15, 2006
After 7 years, 8 months, and one day (not that I was keeping track!), I finally convinced Mina to marry me, and I worked out an arrangement with work so I could telecommute a couple of days per week, enabling me to live in San Diego with my wife. Four weeks from yesterday [i.e., on 17 March 2011], she will find out where she matches for medical Residency, and after that there may be a Fellowship in hematology/oncology. But at least we’ll face whatever comes together.
Let me finish by offering you some career advice, from the lofty position of someone who’s been in the real world for all of 2.5 years.

From the time I was 12, all I ever wanted to be was a professor of mathematics like my Dad. Going back to Davis to start a new career was one of the scariest things I’ve ever done. I had no idea whether I’d be able to stand statistics and data analysis. But everything worked out. If you had told me ten years ago that I’d be doing statistical data analysis and putting my career secondary to my wife’s so she could do what she wanted to do, I would have thought you were crazy (primarily because 10 years ago I couldn’t imagine myself dating, much less being married). But that’s where I’ve arrived in life, and I’ve never been happier.
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