

Dinner with Katie

Oh my goodness, it was gorgeous! A beautiful, Central Oregon morning. The sun was up and shining. A clear blue sky with Mt. Bachelor in the distance. I was up at first light, and had already finished a slow run along the river. Watching, as I ran, the waters gently bubble as trout rose for the morning May fly.

Later, coffee in hand, the promise of a languid eighty degree afternoon, I sat on the porch of our cabin, comfortable and content, surrounded by my family and Oregon's natural beauty. The start of an amazing day...

...and a day that would turn out to be among the worst in my life.

This is the story of sadness, anger, opportunity and joy. It's a father's story of fear and hope, for both his child and his country.

With that morning coffee still in hand, my oldest daughter came downstairs and complained that she'd barely slept. "Why?" I asked. Well, it seems that little sister Katie had been up seven times during the night to use the bathroom. My radar lit up, you see we tease Katie for having an iron bladder. She can hold it all day, while the rest of us are running for the rest stop.

But her dad has diabetes, and knows that frequent urination and extreme thirst are early signs of the disease. And now that I thought about it, hadn't Katie been a little too thirsty that week?

Maybe, but it had been hot, we were active, and she was growing after all... it's nothing. "But you know what sweetheart" I said when Katie awoke, "why don't you let dad do a quick blood test on you, no biggie."

We did the test, watched the timer count down... 4, 3, 2, 1, and when the meter showed a blood sugar level of 310, I stumbled backward and lost my breath. It felt like I'd been stabbed in the heart.

In that instant, I knew that our (then) 10-year old daughter had type 1 diabetes, and would spend the rest of her life with a chronic disease requiring multiple blood tests every day, multiple insulin shots every day, constant care to manage high and low blood sugars. And I knew, through absolutely no fault of her own, her life expectancy was just shortened by 15-20 years.

We called the doctor and quickly packed up the car, her mom and I in shock, trying to hide our fear and our tears. We loaded up to drive straight to Emanuel Children's Hospital in Portland. And as we were leaving I said, "I'm sorry sweetie, I know you're hungry, but you'll have to skip breakfast - the food we have will keep raising your blood sugar."

In Madras we stopped at McDonald's for the restroom. Katie's so hungry, I get her a double burger and a Diet Coke. We get rid of the bun so it's just hamburger and cheese, protein no carbs. It's a lame lunch, but it's something, better than her breakfast, and seeing her eat helps us feel a little better.

That night in the emergency room, the next few days in the hospital, and the months that have followed have been times of continuous lesson and learning, even for her old man who's had the disease 35 years.

Diabetes is a cruel disease. It's also expansive and expensive.

There are three million Americans living with the type of diabetes that Katie and I have; and about 25 million when you include both types of diabetes.

The public resources we spend on diabetes are staggering. Our nation spends \$260 billion a year on diabetes care and treatment, up 41% over the last five years. \$260 billion a year of cost on state and federal taxpayers, on individual Americans, and on those of us who foot the insurance bills.

And this doesn't account for the tens of billions more in chronic and acute costs for heart disease, kidney disease, stroke, and eye disease related to diabetes.

Staggering. But not more so, for a father, than watching his daughter give herself five shots a day so she can simply stay alive. I watch her do this day-in and day-out, I watch her follow all the rules; yet still see her brought to quiet, frustrated tears when her blood sugars go sideways for no explicable reason.

That's why we decided to take an amazing trip to Washington D.C. With 200 other advocates from across the country, we lobbied congress in support of funding for diabetes research. Research for a cure, for a medical moon-shot.

We met with members of congress. In these meetings, nervous yet poised, Katie told her story. She described those days in Sunriver, the insatiable thirst and constant need for a bathroom. She described her insulin and blood testing regimen, and was excited to tell them that soon she'll be going on an insulin pump.

She asked for their help. With a little coaching from dad, she explained that only the federal government could provide the resources to find a cure.

I reminded those we met that markets work well in the short term; pharmaceuticals and medical devices are big business. But the risk and uncertainty regarding an actual cure means it's a long term thing, ten years or more at least. There's no private investment for that because there's no clear path to financial reward.

And my anger, as a citizen and father of a special needs girl, is that our federal government has wasted decades, spending far more than we have on things we shouldn't be doing. As such, the resources needed to do the things that only the federal government can do, like a medical moon shot, are at great risk.

Yet this story is far from over, and that's what helps direct anger into renewed resolve.

In Washington D.C., months after that sunny, beautiful and brutal day in Oregon; a day of tears, no breakfast, and a cautious lunch that reflected her parent's fear, I sat for dinner with Katie at the Capitol Grille on Pennsylvania Avenue.

Churchill wrote, "It is well to remember that the stomach governs the world." And if Katie's ear-to-ear smile was any indication, Churchill's thesis could not be truer.

The Capitol Grille is a tremendous place with an old world ambiance, a few deer heads on the wall, and every seat filled with congressmen, top government officials, diplomats and corporate execs.

After taking a bigger-than-normal insulin shot, she started with sides of calamari and French fries, had lobster mac & cheese as her main course, finished with a coconut sorbet, and along the way, snuck the tiniest of tiny sips of her dad's pineapple martini, the "Stoli Doley." Thankfully, nobody from Child Services seemd to be present!

This dinner was a reward, a celebration after she'd conquered Capitol Hill with poise and newfound confidence. She was a happy and content little girl.

Dinner with Katie, for me, was cathartic. Watching her delight in the food, listening as she whimsically spoke of the trip and her joy of shopping in Georgetown, I realized how far we'd come. From shock and fear, through learning and adaptation, to a point of acceptance and humble gratitude.

You see the blessings of modern medicine allowed her to enjoy a decadent dinner without much worry. And her disease had given her and her father a new discipline, a new determination, and a growing understanding that disease itself teaches much which life could never teach in any other way.

Embracing this, we march onward; fighting to change our government, to push and persuade our leaders to prioritize, to right-size, to use the power of federal government – not to be all things to all people, but to do those few, important things, those life changing things, that only the United States government has the power to do.

Doing this will not only save our country hundreds of billions of dollars, it will also help propel the dreams of a young girl and her hopeful father.

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