Yom Kippur Symposium Speech Ed Wolff

The First teacher in my life, as it is in many other people's lives, was and still is my Mother, Beth Wolff. My mother grew up here in Houston and went to the University of Texas where she completed her BA in Business. She also found a husband in my father. When my father left in 1974 my mother found herself alone with a four and six year old. She had to find a way to support our family and decided real estate would be a flexible job that would allow her to make a living and have time to be there for us.

She opened her own company in 1978. Watching her work so hard to make our lives as normal as possible taught me about work and perseverance. I learned that doing things because they are the right thing to do, not for whatever reward lies at the other end, usually pays off exponentially!

Sending my sister and I away to Summer Camp was a great way for my mother to work during the summer. Echo Hill Ranch, was a small camp in Medina Texas run by Min and Tom Friedman or Uncle Tom and Aunt Min as we all called them. The Friday night services written by Rabbi Jimmy Kessler and the philosophy they taught provided a strong basic understanding of what it meant to be a good person. I consider them and Echo Hill my second teachers.

My Third teachers came from Sunday school here at Beth Israel. I had the unique opportunity to hear what all of my family had considered the voice of g-d, Rabbi Schachtel, give amazing and sometimes scary sermons from this bemah. Rabbi Karff started a couple of years before my Bar Mitvah and I learned a softer more gentle approach to Judaism.

Between Sunday school with Rabbi's Karff and Schachtel and summers with the Friedmans I found what Judaism meant to me, even if I did not realize it until years later.

Katy, my wife, and I met at Echo Hill Ranch when we were nine years old. I knew when I saw her that I loved her. She is now and always has been my best friend. When she agreed to marry me and move to Houston from Dallas, it made me the happiest person on earth!

We had dreams and ideas about what life would be. There were many nights we would sit on the wagon wheel benches at Echo Hill talking about how we would run the ranch someday. The fact is that we did for a while when Uncle Tom began to feel ill and needed help, Katy became assistant director and when he passed away in 2002, Katy worked with Roger Friedman and the rest of the Friedman family to run things.

While all of this was going on, Katy and I were ready to start thinking about little Ranchers of our own. We tried for a year or so only to find there were some difficulties we had to overcome. With a little help from modern medicine we were successful. Not only were we

told Katy was pregnant but it was twins. We were going to have a boy and a girl. Everything seemed as though it was coming together.

We even had fun telling our parents we were going to name the boy Wolfgang Otis Wolff so his initials would be WOW.

As we were leaving our house for a check up on November 4, 2004 Katy's water broke and when we arrived at the Doctor's office he announced that we were having babies today. Apparently our son had kicked his way out. The twins came two months early. Jake was born at 3 lbs 10 oz and Tenley was 3 lbs 12 oz. We ended up in the Neonatal Intensive Care Unit at Hermann Hospital and everything was a little scary. The nurses were great and Hermann did an excellent job of making us feel at ease.

After 7 or 8 days, Tenley began having trouble breathing. We started to get concerned when the Doctors asked us to step out of the NICU. As we watched, more doctors started arriving at Tenley's bedside. Katy and I saw 10 to 15 people huddled around a monitor on what we later learned was an echo-cardiogram. We were taken aside and Doctor's explained that Tenley had a Congenital Heart Defect and without surgery she would not survive.

The family immediately went to work researching what we should do and my mother set up a tour of Texas Children's Hospital for us. We were being given lots of advice from lots a different people. The one thing we wanted to make sure of is that the decisions we were making were the best for our children. We were concerned that they were our choices so that if something went wrong, no one else would second guess themselves or feel guilty about swaying us one way or the other!

I was standing next to Tenley's bed in the NICU at Hermann when a nurse who had worked there for thirty years looked at me and said you need to get this baby to Texas Children's Hospital. Within eight hours we were in an ambulance on our way to TCH. Jake stayed in the NICU at Hermann.

So here we were, two babies at two hospitals a few blocks away from each other. Our son learning how to suck, swallow and breathe and our daughter just trying to survive. We met with Dr. Charles Fraser, the Chief of Pediatric Cardiovascular surgery at Texas Children's to discuss our options. They had performed over 900 Cardiac procedures at TCH that year and yet he told us our child was a very sick little baby. Dr. Fraser explained that Tenley had a complex heart defect where the major blood vessels to her heart were in the wrong place and her aorta was too small to allow blood flow to the body. They had not performed this complex a procedure on a child this size and ideally she would need to grow before they could be more comfortable that there would be a positive outcome. The Doctors gave Katy and I a choice. We could offer palliative care and keep her comfortable or they could perform open heart surgery. We knew there was no choice for us and we told the Doctors to do everything they could.

The evening of November 22nd, 2004, we got a call from the Doctors to meet in the NICU to discuss Tenley's case. They told us that night that she had gone into congestive heart failure and they would have to operate the next morning. The next day we arrived at the hospital at 5:30am and kissed our baby as they walked her into the operating room. For 12 and a half hours Dr. Fraser worked with a team of many others to totally re-plumb our daughter's heart. It was the size of a Brussels sprout and he disconnected and reconnected all of her major blood vessels, closed two holes and enlarged her aorta.

At no time during this ordeal had I ever considered the question why us?... Several times I looked around to see children that were in worse shape than Tenley. However, on this day in the waiting room, all of these questions came to mind.

At one point Katy stepped out into the waiting area and ran into another mother and they started talking. She said she had come to TCH from out of town and that her child was supposed to be operated on today by Dr. Fraser but they had been bumped by a more emergent case. Katy immediately started to cry realizing that case was our daughter.

By the end of that day, they had done what they could do and Dr. Fraser wisely said the rest was up to Tenley. The Doctors and nurses were doing their part but she was still a very sick little baby.

It was the Friday after Thanksgiving when we got a call from the NICU at Hermann. They said that we needed to come pick up our son. I asked if he had done something wrong? Did he misbehave? They said gladly, that he had graduated and was ready to go home! As happy a day as that should have been, our daughter had gotten out of surgery two days before. The babies were born two months early and we had not prepared at all for their arrival home. This was Black Friday, the busiest shopping day of the year and Katy had to go to Target and buy the essentials while I went home and unwrapped the car seat so we could go to the hospital to collect our boy. We frantically made arrangements with family and nannies so we could take him home. We gave him a kiss, hugged him and handed him off to return to Texas Children's and continue to be the advocates for our baby girl. After five months at TCH Tenley was finally well enough to come home!

We worked with the Doctors and have stayed in close contact with Texas Children's Hospital since then. Katy has volunteered with Guest Services at Texas Children's and helped in the growth and launch of an organization started by several parents of heart patients called "It's My Heart," a support group for families affected by congenital heart defects. Over the years the group grew to 17 chapters in the United States and Canada. We have stayed in touch with many of the families and friends we made at TCH.

It was a week after the "It's My Heart Walk" in 2010, where the organization raised over \$200,000 that Katy started to feel sick. She had a severe head cold and was not making alot of sense. I was working so she called my mother who came and took her to the Emergency Clinic at Kirby and 59. The Doctor there was concerned by the way she seemed disoriented. He wanted to run a cat scan just to be safe. He assured us that it was probably nothing. After the cat scan, the doctor came in and said they found a mass that needs to be looked at further... We were sent to Methodist hospital and there we were met by a neurosurgeon who explained that Katy had a tumor a little smaller than the size of a baseball at the base of her skull and it was applying pressure on the brain stem, the optic nerve, the pituitary gland and several other important areas of the brain. The nature of the tumor and the size indicated that it had been growing for many years. Basically by growing slowly, her brain had adjusted and therefore there had really been no symptoms.

This time the situation was different. No longer did I have my partner and friend to help me make the decisions on what to do. She was the patient and I was the advocate. Our families, along with a large number of friends were there to offer support, but it was not the same. I still felt alone. The situations we had faced with our daughter we faced together. Now she and I had different roles to play. She was the patient and I was the advocate.

We met with a world renowned neurosurgeon at MD Anderson Hospital and, although her tumor was benign, it was potentially life threatening and at the least, debilitating. He told us it would be a 12+ hour surgery to attempt to remove the tumor. On March 24, 2010, we showed up at the hospital at 5:30am. I gave her a kiss and they took her back to surgery around 7am. After four to five hours, the surgeon emerged and asked Katy's sister and I to meet with him where he told us that he was unable to remove the tumor and that a blood vessel was nicked causing a stroke.

Katy emerged from the operation with her right side paralyzed and in an induced coma for two days. It was difficult not having the partner that had helped me through all of the other hard times and issues in our lives. I felt fortunate to have had the experience with our daughter because I knew what Katy would say if she could speak and I knew how she would react to what the Doctors were telling us. It was still extremely hard!

When she finally woke up she did not know where she was what year it was and had a difficult time speaking. I was not sure what the outcome would be. After about 10 days at two in the morning she woke up and called me by my name! It was a miracle for me. I started to see a little of the Katy I knew and loved again.

It has been a difficult two and a half years with lots of ups and downs...Three brain surgeries, a stroke, Proton Radiation Therapy, medication issues and scores of Doctors and medical professionals.

Tenley is doing great and is now in Second Grade taking Chinese and keeping up with her brother Jake. Katy and I continue working on things together and find strength in each others ability to overcome the obstacles we face. There are still a few more hurdles for Katy but she is doing great! While all of this was going on so many people would say they were praying for us. We had every religion under the sun covered with prayer lists and friends. Our friend Karma called me the day before one of Katy's surgeries and said she had just stopped Deepak Chopra in the Chicago Airport, told him our story and asked him to pray for Katy and he did!

There are many special people I met along the way. We were visited by our good friend Rabbi Scott whose husband David was one of our campers at Echo Hill. Hope Lipnick, who works out of MD Anderson for Jewish Family Services and performs unbelievable services for all people in the Texas Medical Center spent many hours with me discussing the role of Judaism in situations like ours.

At one very difficult time, I was very upset that all of these other religions were praying for us and they knew that miracles would be on the way... I wanted to know why I had not had these prayers from my faith... I came to temple and met with Rabbi Lyon and told him that I just don't understand! When will my religion wrap it's arms around us like so many of our Christian friends. He explained that some other religions believe that they can pray to g-d to perform miracles of healing and that if they pray hard enough g-d will provide as if the miracle will come wrapped up in a neat little box with a bow on top. He explained as Jews, we pray for g-d to give us strength. We pray for g-d to help us make the right decisions. G-d loves us but has an agreement with us that, just like any parent's relationship with a child, g-d can provide us the tools and the teachings so that we can survive these challenges in life, especially when they aren't delivered in a box with a bow on top.

This really brought the whole thing together for me. It is great to pray for wisdom, power and strength, however, it is the people like the Doctors and nurses and caregivers that g-d provides, that perform these miracles everyday.

My experiences over the past eight years have helped me discover the importance of Judaism throughout my life. Although I would not wish what we have been through on my worst enemy, I also would not trade it for the world. What Tenley, Katy and Jake have taught me has changed my life and I know we all have the power to make a difference in this world! Life is a gift for how ever long you have it and I am eternally grateful for that!

Shana Tova!