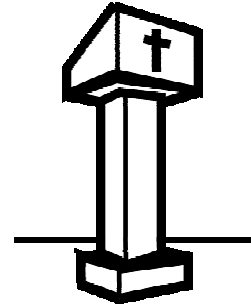


**My Journey as a Genetic Counselor—
A Sermon Preached at St. John's Parish,
Clayton, California July 25, 2010**

by Trisha Brown, MS, CGC



Father Peter has invited me to do the inaugural sermon in a series in which we, the members of St. John's, share how God intersects with our work.

I am a genetic counselor. A genetic counselor is a health care provider that has a master's degree in Human Genetics/Genetic Counseling from a graduate school accredited by the American Board of Genetic Counselors.

A genetic counselor's job is to help families identify inherited disease risk, and determine options to better define the risk, like genetic testing. If a genetic condition is suspected or diagnosed, a genetic counselor helps the individual or family understand what the diagnosis is, how it affects other family members, and options to manage or treat the disease. Genetic counselors are essentially translators- taking complex information and making it understandable for people who don't have expertise in clinical genetics.

Genetic counselors work in all kinds of settings from clinics to labs, and a few of us have become entrepreneurial and work in roles that aren't patient facing, but help do sales, marketing, and even develop new products and ideas to help communicate genetic information in novel ways that reflect our modern day world- like email, internet, and mobile apps.

Genetic counselors work in all medical specialties from cardiovascular (heart), neurology (brain and mind), hematology (blood), oncology (cancer), pediatrics (kids), and prenatal –for families planning a pregnancy or who are pregnant.

When I started in this field, genetic counseling and genetic testing was relatively new. Genetic testing and genetic counseling really started in the 1970s where you could look at chromosomes under a microscope. In this way you could identify why some people had mental and developmental delays, or you could offer prenatal diagnosis for things like Down syndrome, which is caused by having an extra chromosome, by drawing off a little bit of fluid that surrounds a baby during pregnancy- called an amniocentesis- and testing the fetal chromosomes. Very little changed between the 70s and 1990 when I entered the field.

The folks who started the field of genetic testing were very aware that genetic testing was going to be very controversial and would remind people of past eugenics movements across the globe where governments selected for genetic traits through encouraging only certain kinds of marriages, or in the extreme- genocide- the killing or –the popular form in the United States- forced sterilization of whole communities with unpopular traits.

So they created the field of genetic counseling at the same time. The field of genetic counseling was based on a strict ethical premise that the genetic counselor was not a doctor and therefore not in a position of authority, the genetic counselor was there to explain all angles of a test and resulting choice in a complete, unemotional, accurate yet empathetic way, and was non-directive- meaning that a genetic counselor, per even the current day ethical standards of the National Society of Genetic Counselors, can never tell a patient what to do. A genetic counselor can help the patient explore the outcomes of various choices from the patient's point of view on religion, culture, family relationships, and personal morals. An article I recently read described this as "a process of imagining alternative futures that transforms itself into a practice of ethical self-care." (Leotini, R. 2010)

This is a big job that has gotten bigger as the types of testing and treatment options for patients has grown exponentially, especially in the last decade.

Some of the choices that genetic counselors help people consider might be familiar to you, some might be a surprise. For example:

- Terminating a wanted pregnancy because the baby was identified to have birth defects.
- Having surgery to remove breasts, ovaries, or a section of colon or bowel to prevent inherited cancer
- Using painful limb lengthening techniques or experimental medicine to help children who would be of “little people,” or “dwarf” size be taller.
- Having a genetic test to determine if you will definitely have a disease that has no cure and can result in dramatic end of life issues, like Alzheimer’s disease or Huntington Disease—a disorder that causes uncontrollable tics and psychosis.

So how did I end up here, in this job, thinking about these complex, emotional, ethically and morally challenging issues?

As I prepared for this sermon and looked back on the road I have traveled, I can see God’s hand more clearly now that I could as events unfolded. For example, when I was in college, I had made the decision to become an immunologist and be a researcher. I even took some time from school to go back to the NIH to work in a famous immunologist’s lab who was working on gene therapy for a disease where people are born with no immunity- some of you might know this as the boy in the bubble disease. My plans derailed when I nearly failed immunology and had to change the course to “pass/fail” at the last minute to preserve my GPA. I was at a loss of what to do, and went to see my advisor who didn’t hesitate- he told me he thought I would be a great genetic counselor and that is what I should do. Matt was a co-worker at that time, and he and head of the lab where we both worked agreed and encouraged me to apply to genetic counseling programs. So I blame God for failing immunology!

I became a genetic counselor. My first jobs out of school had me staffing two clinics primarily- the craniofacial clinic where we took care of kids with birth defects of the head and neck, and prenatal. When becoming a genetic counselor, I knew that I would have to face tough issues like abortion. I knew myself, my moral and ethical center, and I knew that I would not always be in agreement with my patients. But I believed in “judge not lest ye be judged,” and I believed that God would guide my words and actions to help people make the choices that were right for them-choices that would let them sleep at night. In all the thank you letters and flowers I have received over the years, I know that for the most part I have done my job. In fact part of what a genetic counselor does is help people explore the consequences of their choices, part of the “ethical self-care” I mentioned before, and determine what kind of person they want to be in the future that maintains “hope and dignity in the face of adversity” (Leotini, R 2010). Sometimes this includes people you don’t expect to influence.

One couple, I remember clearly, was about 4 months pregnant and had traveled a great distance to our prenatal center because their local doctor told them their baby had many birth defects, and nothing could be done. I worked at a well known and famous prenatal center, and they hoped we could tell them something different. We couldn’t. Their baby that they wanted so badly, not only had severe birth defects, but was dying of congestive heart failure. There was nothing we could do, and it was unlikely that the baby was going to survive much longer, and would certainly never survive outside the womb. It is a horrible thing to be pregnant when you know it will end in stillbirth. Pregnancy is a very public thing- strangers touch you and want to share your happiness, they comment on the gender of the baby, and they ask all kinds of

personal questions. Terminating the pregnancy was presented as one of several options. This couple was Catholic, and they believed to the depths of their souls that abortion is one of the worst sins ever. The woman's sister was a doctor at the same facility, and she suggested that they consider the perspective that they would be withdrawing life support of their child in a way similar to how families withdraw life support in other medical situations when they find out that their loved one is not going to recover from a terminal event. They didn't know what to think of this idea, and didn't know what it meant to the souls of themselves and their unborn baby, but the thought of facing family, friends and the well meaning strangers in the grocery store who would ask about due dates, baby names, baby showers, nursery preparations, on and on- put them in a state of non-functioning despair. I could certainly explore all the options with them, and share with them my Christian perspective that I did not view Our Father as one who would condemn loving parents for any decision they made in this situation. I usually recommend to people to try on different decisions and live with them for a day and see how they feel- can they look themselves in the mirror? Could they ever share their decision with a close friend or relative without feeling embarrassed or ashamed? This approach didn't help this couple, they really wanted to see a Catholic priest and theirs was several days drive away.

I called several churches in the area until I found a very nice priest who was willing to come to the clinic and meet with the couple. None of his theological training had prepared him for this kind of thing, and I found myself answering many questions for him, and leading him through the possible consequences of his choices, helping him determine what kind of future person he wanted to be in the face of this particular adversity. Would taking the hard line of Catholic doctrine that any abortion is soul condemning be the right thing, and guide this couple to continue the pregnancy? Would supporting this couple in a termination decision be right, then giving them penance? How about going straight to absolution? He decided he didn't know, but God did, and he made two choices- his first was in faith, that God was taking care of us and we would all know the right choice when the time came, and his second was prayer so that we could be prepared for whatever God had in mind. So we all prayed together – the couple, the priest and I, that God's will be done and that if forgiveness, penance, or absolution was needed for any decision made or not made, that it be given by God. After this the couple decided to end the pregnancy, that day, and when we went to the clinic to schedule things, we discovered that the baby had just died.

I only stayed in the clinic seeing patients in person for 4 years, because I quickly discovered that I have a fatal flaw that causes burn out quickly in all kinds of health professionals and makes me both an excellent genetic counselor, and a very bad genetic counselor all at once. I cannot leave my patients "at the door" when I get home from work. I carry their stories with me as if they are my own, and their issues and problems become things of my dreams and nightmares and worries. I didn't know this about myself until I was already employed as a counselor, and the other thing I found that I failed to account for while doing the ethical and moral self-examination required of my career choice, was that people- both patients and doctors- would make choices extremely far outside my belief system.

I can spout the "judge not lest ye be judged" with the best, and I can hold up the credo of genetic counselors to be non-directive- but my sub-conscious can't. When I was in the clinic I would stand behind the façade of these ideals and do my job and appear non-judgmental and non-directive, but when at home I would chastise myself as a coward. I still carry with me the woman who terminated a perfectly healthy pregnancy simply because she had twins. They were perfectly normal, she just didn't want two. I do judge her and myself for simply going through the motions of my job. Could I have been more adamant about other options available? There was the case where a doctor did an experimental procedure on a woman, causing her to lose her pregnancy that had taken her many years and rounds of infertility treatments to achieve, and another case of parents who had an abortion because on prenatal diagnosis we found that mosaic, or partial, Turner syndrome was possible, where the absolutely worst case

scenario was that their daughter might be short, maybe infertile and might have some minor learning disabilities. The kind where you may or may not need special help early on in school, but you can still end up being a doctor or lawyer. The couple refused the follow up testing to verify this finding and went straight to termination. Should I have been directive in these situations and told the doctor to stop the procedure? Told his patient to run for the hills? Should I have demanded that the couple have the follow up confirmation testing for mosaic Turner Syndrome before referring them to the termination clinic? I am haunted still because we did do the confirmation testing on the abortus tissue, and the baby was normal.

I have tried to leave the field of genetic counseling several times, but I believe God keeps drawing me back for different reasons. He took me from the clinic to work for a laboratory where I was able to help shape the processes of the lab, how the results were reported, and what kind of genetic testing we did to benefit the most people. I was able to use my judgment and apply my moral center instead of suppressing it by helping implement rules, for example, that the lab would not accept prenatal diagnosis samples solely for sex selection. I got to be more directive- I was able to directly recommend to the doctors who ordered tests ideas and actions that they wouldn't have otherwise considered. I had broader influence, such as educating an adoption agency who wanted to screen all babies for genetic disease before placing them for adoption that this was not only an unavailable option, it was ill considered- we all have genetic defects at some level- where would they draw the line in the sand about what was ok and what wasn't? What exactly did they consider a genetic disorder? I also educated them that adoption agencies for special needs children, like those with Down syndrome, actually had a waiting list so perhaps they were underestimating society's desire for and acceptance of those with differences. I was also able to implement phone genetic counseling, a new concept back then, to help underserved populations- those who had no transportation or couldn't get off work to make it to the clinic to find out what they needed to know.

In my current role at my company, a health information company, I am lucky to be able to have the resources to build even greater access for patients, doctors, and even health insurance companies through the internet and soon, applications for your mobile phone or other handheld. I was honestly very torn about taking the job I have now- I had just quit the high stress job at the lab after 11 years and Matt had been offered a full time job that would have gotten him out of the "work at home" dad status that he enjoyed for a long time, and both of us were ready to switch roles. However other events were happening in our lives that drew us to continue our familiar pattern, pick up the family and move from North Carolina back to California, and take the job with some trepidation. It was a really hard move on all of us, the job has had its challenges, and Matt and I have often wondered if we made the right choice.

Just recently, for lots of reasons including preparing this sermon, I have realized that it is God working in my life again. My company was bought by a very large pharmacy benefit management company, a company that provides medication benefits for over 65 million people. They wanted to expand into genetics so bought my company as the "best in class" to help do that. In the next year or two, these 65+ million people will have access to genetic information and services in a way that hasn't been done before, and I get to help guide that.

I want to read you an excerpt from the 2007 book by Lisa Genova called *Still Alice* that I just read. This book is the fictional account, based on real patients, of a woman who is diagnosed with an aggressive, early onset, genetic (inherited) form of Alzheimer's disease. After a lot of evaluation and testing, Alice meets with her doctor:

"When I put the information together, Alice, you fit the criteria of probable Alzheimer's disease."

Alzheimer's disease. The words knocked the wind out of her. What exactly did he just tell her? She repeated his words in her head. *Probable.* It gave her the will to inhale, the ability to speak.

"So probable means that I might not fit the criteria."

"No. We use the word probable because the only way to diagnose Alzheimer's right now is by examining brain tissue by autopsy or biopsy, neither of which is an option. It's a clinical diagnosis. We don't expect to see brain atrophy on MRI until much later."

Brain atrophy.

"But this can't be possible, I am only 50!"

"You have early onset Alzheimer's. You are right that we typically think of Alzheimer's as a disease that affects the elderly, but 10% of people have this early onset form and are under the age of 65."

"How is this different than the older form?"

"It's not, except that it has stronger genetic linkage, and manifests much earlier."

Strong genetic linkage. Anna, Tom, Lydia.

"But if you only know for sure what I don't have, how can you say with any certainty that this is Alzheimer's?"

"I am sure, Alice."

Alice. The sound of her name penetrated her every cell and seemed to scatter her molecules beyond the boundaries of her own skin. She watched herself from the far corner of the room.

When she arrived home she looked at the rows of books and periodicals on her bookcase. Her knowledge of Alzheimer's disease admittedly swept the surface only lightly. She knew that the parts of the brain critical for the formation of new memories became mired in plaques and tangles. She knew that someday she would look at the faces of her husband, her children, her colleagues-faces she'd known and loved forever- and wouldn't recognize them.

And she knew there was more. There were layers of disturbing filth to uncover. She typed the words "Alzheimer's disease" into Google. Her middle finger was poised over the return key when two jolting knocks caused her to abort the mission with the speed of an involuntary reflex and hide the evidence.

When I read this, I realized what powerful impact my job has. When I was in the clinic, I saw about 1,000 patients a year. In the lab, about 1 million tests a year were managed by my department. Now my job can impact over 65 million people in the US alone, and we are expanding internationally. It is my responsibility to live on the internet pages that come up for Alice's Google search, or perhaps for yours- to be there when needed on the phone- as a voice or even as mobile application- to help people like Alice and their families reassemble their molecularly scattered selves when bad news hits. I'd like to think that I was chosen to participate in developing and guiding these new programs for a reason, and I continue to pray that my ears remain open to God, and that He will continue to guide my choices and my heart.