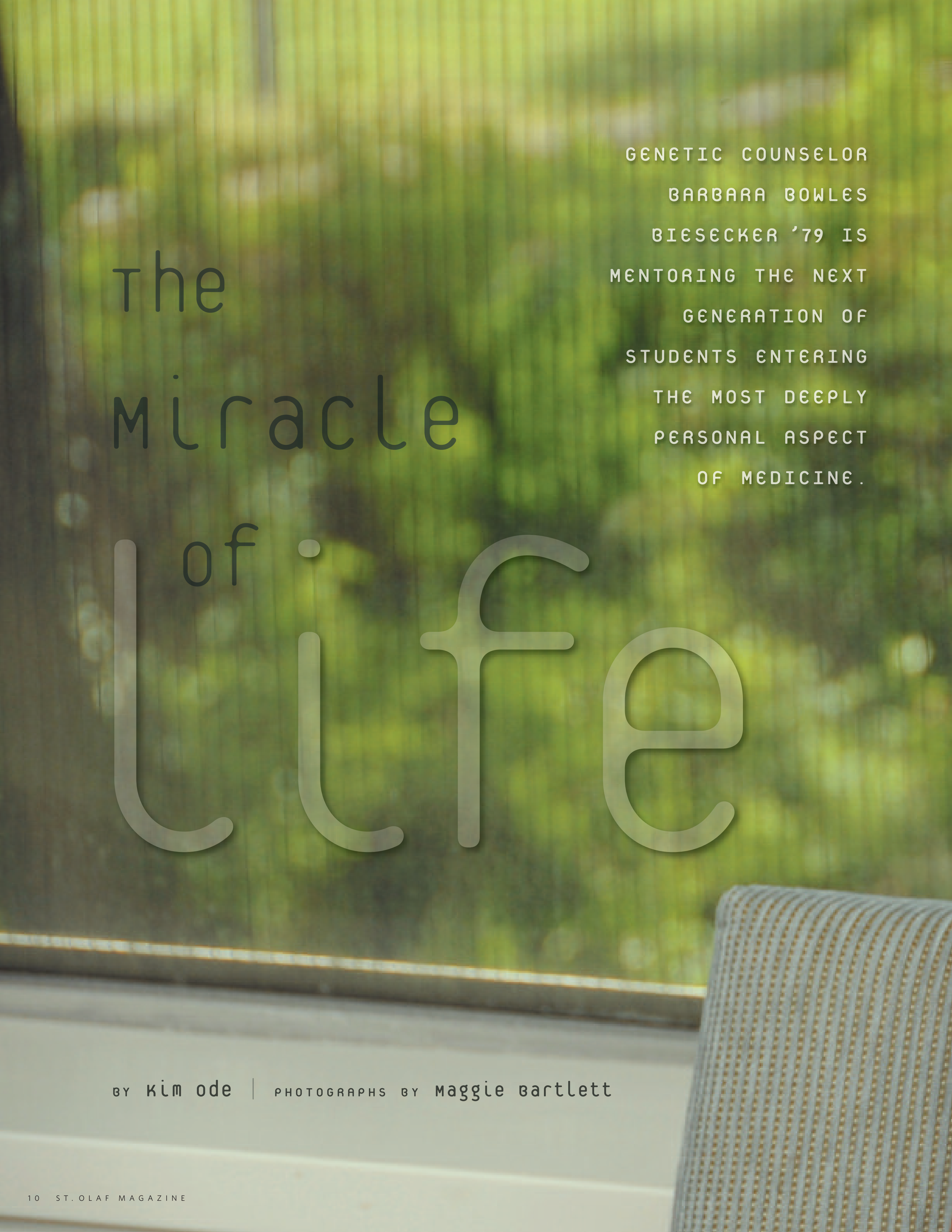


The Miracle of Life

GENETIC COUNSELOR BARBARA BOWLES BIESECKER '79 IS MENTORING THE NEXT GENERATION OF STUDENTS ENTERING THE MOST DEEPLY PERSONAL ASPECT OF MEDICINE.

BY Kim Ode | PHOTOGRAPHS BY Maggie Bartlett

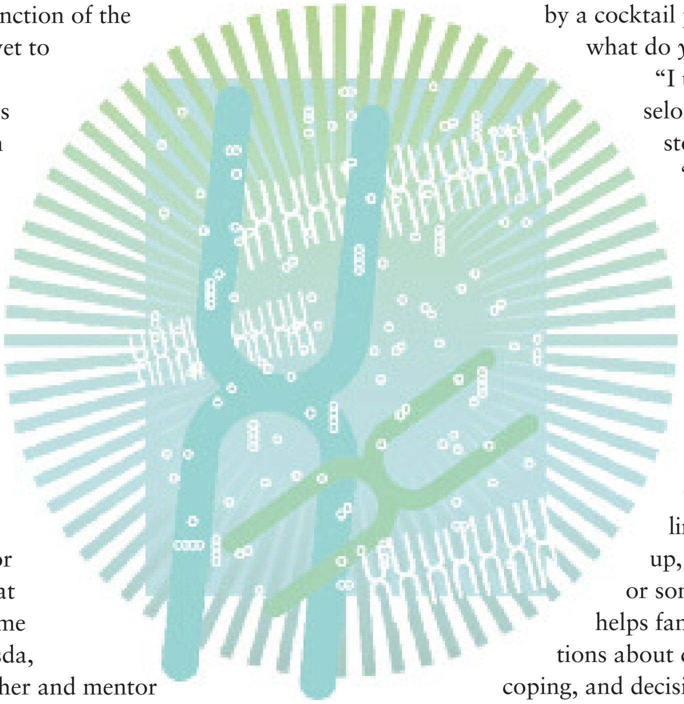
Each of us has 20,500 genes. That’s the sort of tally more associated with small towns — Northfield’s population is about 19,900. And perhaps that’s not a bad way to think about these pieces of DNA, from cowlick to toenail, that reside within us.

Each gene in the body, like each resident of a town, has a purpose. There are genes that make someone blonde and genes that make someone tall. A gene can make a person susceptible to cancer or particularly skilled at the piano. Some genes make proteins that enable other genes to function.

Each year of genetic research brings more knowledge, yet the function of the vast majority of genes has yet to be discovered.

So when Barbara Bowles Biesecker counsels a shaken couple that has just learned that they’ve passed along a copy of a gene predisposing their child to Tay-Sachs disease or cystic fibrosis, she is on the leading edge of a still-young profession.

A 1979 graduate of St. Olaf, Biesecker is a genetic counselor, one of only about 3,000 in the United States. She is director of the counseling program at the National Human Genome Research Institute in Bethesda, Maryland. She’s also a teacher and mentor to the next generation of students entering, arguably, the most deeply personal aspect of medicine.



“We take care of regular people who have terrible things happen to them,” she says, sitting in her tiny office at the National Institutes of Health. More than once in the course of an afternoon, she makes the point that people have a great capacity for adapting, but they may not realize it until a counselor walks them through the decisions they must face.

“It’s really a job of human suffering and resilience. We’re there to witness the process and help them take care of themselves.”

Genetic counseling is part of a concept called personalized medicine, in which information about a person’s genetic makeup can help physicians tailor medical care to a specific patient’s needs. Nowadays, Biesecker says, the medical field employs a “one-size-fits-all” approach to fight disease, prescribing the same medications however diverse the spectrum of patients. But if doctors knew more about a person’s particular genetic profile, they could make subtle shifts to treat the patient with strategies that are more nuanced and, hopefully, more effective. Ultimately, that may mean health care could become less costly, she says.

“Personalized medicine is limited now, but it’s going to happen furiously and fast.”

THE SCIENCE OF EMOTION

On the website of the National Institutes of Health, Biesecker’s job title is Associate Investigator, which gives you some idea of the mindset necessary for tackling the human genome. It also suggests why she glosses over her job whenever confronted by a cocktail party’s inquiry, “And what do *you* do?”

“I used to say genetic counselor, but that’s a conversation stopper,” she says, smiling. “People don’t know what to say, or they’re afraid of what comes next.”

Indeed, reports from genetic counselors indicate that people regard their genetic information as more personal than their medical information. If they’re dealing with an issue of illness linked to their genetic makeup, they often feel stigmatized or somehow at fault. Biesecker helps families talk through questions about quality of life, adaptability, coping, and decision-making. Some illnesses with a genetic component are little known, giving them a sense of secrecy and heightening the aura of stigma.

“Truth-telling is important to me,” Biesecker says, calling up Positive Exposure, a website about which she’s especially excited. Positive Exposure (*positiveexposure.org*) is a series of photographic portraits of people living with genetic conditions, everything from albinism to the obscure Hermansky-Pudlak Syndrome. The photos appear more like fashion photography than medical textbook images. To Biesecker, the photo subjects demonstrate that “they have a purpose: They’re helping others gain acceptance by being photographed themselves.”

Biesecker's research and teaching focuses on making genetic counseling as effective as possible, a growing challenge as new genetic technologies bring about an avalanche of data and questions about what testing of our genes can reveal.

The field of genetic counseling has been around for only about thirty-five years. Indeed, it was in its infancy when one of Biesecker's St. Olaf mentors, biology professor Alice Burton, first brought it to her attention, handing her an article from the *New York Times* about a new field that dealt with personal genetics, almost with the whiff of science fiction.

Biesecker had always been interested in science. In fact, she's not sure her mother has ever quite gotten over the time the cat knocked over Biesecker's high school lab experiment, upending petri dishes filled with fruit flies and filling their basement with *Drosophila.*

In college, she quickly determined laboratory work was not for her. "So I read the [*New York Times*] article and knew immediately that this was what I was going to do," she says. "And it's because [my] biology professor was so clued in to what was happening in the world. Here was something I'd never heard of, and I found out about it at this tiny college in Minnesota."

The appeal of genetic counseling was three-fold: "It was interactive, it made a difference, and it used the science I loved."

Biesecker's patients are families with a child who is ill or adults who are developing symptoms that they fear may be — or have been — passed along to their children. "A lot of my work is explaining what is happening to them and helping them make informed decisions," she says. "We often aren't able to treat these conditions."

What exactly does a genetic counselor do?

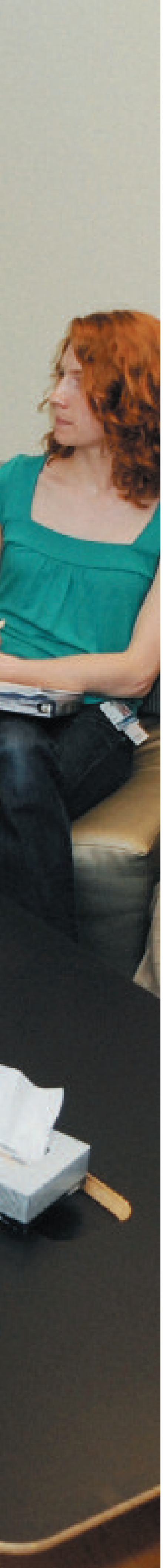
Listen. Support. Guide. It's similar to a grief counselor's work, she says, which is not surprising, since families who are confronted with a genetically linked illness usually are experiencing a sense of grief. Often, the patient or family is faced with giving up some expectation of how their lives were going to be. They need to readjust. "Those are hard things to do," she says.

There's no one answer or plan, but counseling is shaped to meet the unique needs of each individual or family. "We've all been exposed to tragedy and challenge in our lives and know the way we're most comfortable in dealing with it," Biesecker says.

For example, some people cope best when they can focus on some sort of action or task. Others may cope emotionally by sharing their feelings with friends and relatives to learn to accept things they cannot change.

"We try to figure out how to help [patients] help them-

Biesecker says she teaches very much in the mode in which she was taught at St. Olaf. "St. Olaf does mentoring better than any place I've ever known."



selves," she explains. "That may involve helping them learn how to reach out to friends, to their faith community, to neighborhood support."

Stepping away from dealing with families in trauma and looking more to the burgeoning field of personalized medicine, Biesecker says that in the future genetic counselors will help the public learn what their genes mean.

A BRAVE NEW WORLD

The National Human Genome Research Institute was founded in 1989 with the goal of determining the order, or sequence, of the three billion DNA base pairs within the human genome. That goal was achieved in April 2003 — two years ahead of projections.

What exactly did they find? Let's break it down.

Everything that lives has a genome, a specific configuration of DNA that is passed down through generations and essentially carries the instructions that each cell needs to survive.

Each of our cells contains forty-six bundles of DNA, or chromosomes — twenty-three from our mother, twenty-three from our father. You're probably familiar with the depiction of a strand of DNA looking like a twisted ladder. Each of the "rungs" is made of a pair of chemical building blocks: adenosine, thymine, cytosine, or guanine — A, T, C, and G.

How these blocks are arranged on the ladder affects how we grow, how we respond to our environment, and how we age. A DNA sequence of some three billion pairs could look something like this: ATTCAGGGTCTAATGATCGTG . . . and so on.

Although we're more alike than different — any two humans are more than 99 percent genetically the same — it's the slight variations possible within that 1 percent that make us the individuals that we are. We may carry a trait as ordinary as being a brunette or as consequential as causing a serious health problem.

Among the conditions being studied for their genetic traits are autoimmune disorders, birth defects, breast cancer, colon cancer, attention deficit hyperactivity disorder, diabetes, prostate cancer, and obesity.

Biesecker's husband, Leslie, also is involved in research at the National Human Genome Research Institute. As chief and senior investigator of the genetic disease research branch, he's working on a project that would help doctors apply the appropriate drug for a condition based on an individual's genetic profile.

For example, a man whose genes indicate that he's at an increased risk for colon cancer could be urged to have more frequent colonoscopy screenings and reduce the amount of meat he eats. A woman predisposed to heart disease could be "prescribed" to exercise more and take drugs to lower her cholesterol.

It's complicated stuff with life-threatening implications, which is why researchers also are looking for better ways to educate and counsel patients and families affected by genetic disorders.

It's a new world that, for some, requires a bit of bravery. The implications that each of us may eventually know our individual genetic profiles is dizzying while fascinating. The knowledge may lend matter-of-fact explanations to the inexplicable or enable us to make better use of our inherited traits.

Biesecker gives an example: Some people have a gene that predisposes them to take risks. Certainly, she cautions, that trait can either be reinforced or discouraged by how a person is raised. But the key concept to know is that the impulse to act is rooted not in the environment but in a gene.

Likewise, genes predispose us to certain personality traits: Are we optimists or pessimists? Night owls or early birds? Again, Biesecker cautions, outside influences also come to bear. She pauses, as if wondering how deep to go into such explanations. "It's really complicated," she says, then smiles. "Here's a wild story."

> "It's really a job of human suffering and resilience. We're there to witness the process and help them take care of themselves."

In a study looking into the genetic factors of addiction, a researcher identified people whose genes predisposed them to alcoholism. The goal was to determine whether a genetic predisposition to alcoholism meant that they also were prone to other addictive behaviors.

In the course of the study, the researcher looked at whether the subjects had been abused as children. Those who noted one incident of abuse showed they were no more likely to become alcoholics than those with no history of abuse. Those with two incidents of abuse also were no more likely to be alcoholic than the general population.

But those who had been abused three or more times showed a marked increase in becoming addicted adults. In other words, that gene lay dormant until it was "turned on" by a third incident of abuse.

So, Biesecker wonders, "What turned on the potential of that gene?"

It's the sort of question that illustrates why the human genome project makes some people nervous and raises issues of social, legal, and cultural ethics.

Digging Deeper

The ability to have our own genes mapped is available right now — for a price. *Scientific American* reported last year that several new companies will, for $1,000 and up, scan a person's genome, unearthing clues about ancestry, potential health limitations, and a limited list of inherited traits.

The following websites offer more information about your genome and your health.

Genetics and Rare Diseases Information Center

www.genome.gov/Health/GARD

This free service provides information about genetic and rare diseases. The website offers educational materials and refers people to reliable sources of information.

Health Fact Sheets

www.genome.gov/Health/FactSheets

This series of fact sheets helps health care consumers understand genetic concepts and technologies. Topics include genetic testing, genetic counseling, and overviews of specific genetic disorders.

Genetics Home Reference

http://ghr.nlm.nih.gov

This online reference, created by the National Library of Medicine at the National Institutes of Health, provides consumer-friendly information about the effects of genetic variations on human health. It contains information on the genetics of more than 200 conditions.

NHGRI Clinical Studies

www.genome.gov/ClinicalStudies

This site has information about clinical studies being conducted by the National Human Genome Research Institute. It lists eligibility criteria and contact information for each study.

Once we have the ability to track a person's genetic makeup, the thinking goes, what's the next step toward genetic engineering, selective pregnancies, super athletes, or "custom" children?

Biesecker acknowledges that, "early on, there was a concern that we were going to become genetic determinists, but that hasn't happened at all, and, actually, we see less wariness than we used to. The goal is to be able to better treat diseases that now lead to enormous costs to our health care system."

Besides, the vagaries of human biology remain wonderfully unpredictable. Any parent with more than one child who asks what everyone would like for supper knows this routine: "Hot dogs!" "No, hamburgers!" "Ick. Hot dogs!" "No way — hamburgers." How could such disparate beings come from the same gene pool?

"There's no way to control how they come together each time," Biesecker says. "That's the miracle of life."

RESEARCHER, TEACHER, MENTOR

Despite her research, Biesecker makes it a point to continue counseling families to keep her science grounded in real-world concerns. But she also has a long-range focus of nurturing the next generation of counselors, so she established the Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program.

She and her colleagues founded the graduate program fourteen years ago to provide students clinical training as well as research. These future counselors thus have a two-pronged foundation of therapeutic counseling bolstered by genetic counseling research methods.

Her students, she says, "want to change the world."

The program's five slots for the coming school year drew 100 applicants. Biesecker brims with excitement about the growing diversity among these potential counselors: There's a Chinese woman, another from Argentina, a man who taught high school in New York City, a woman from Oxford University in Great Britain, and an African American woman from Stanford University. In a field in which the vast majority of genetic counselors are Caucasian women, this bodes well for the future.

Biesecker says she teaches very much in the mode in which she was taught at St. Olaf. "St. Olaf does mentoring better than any place I've ever known," she says. "It really pays attention to what makes students click."

She recalls how science professors and mentors like Ted Johnson in biology, Don Tarr in chemistry, and Jim Dickson in psychology conveyed such a confidence in her ability and potential that she couldn't help but try to meet their expectations. Similarly, she inspires her own students by a showing a candid belief in their capabilities.

And, just as that savvy St. Olaf professor, Alice Burton, could suggest the emerging field of genetic counseling to Biesecker some thirty years ago, so she focuses on what's new and provocative to give her own students an advantage in this fast-growing field. Her mentoring skills are valued enough to have been awarded with the NIH Director's Award for mentoring in 2005.

Sometimes, though, it's a struggle to stay ahead of her students — a happy circumstance when you're working with the next generation of professionals.

"They're always asking, why, why, why, why, why? Which is great. It's a privilege to teach them," she says.

Being at the forefront of work with the human genome, does Biesecker know her own genetic sequence?

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She almost laughs, then just smiles. “No.”

Really? She’s not the least bit curious? “Not at all.”

If she did, her sequence might show a person predisposed to being tall and blonde. It may show someone with coaching skills and who enjoys the water, since she and her husband have for years helped coach their kids’ swim teams.

Her genetic profile might also indicate someone with a decided preference for the color yellow. For instance, on this hot and humid summer day in Bethesda, Biesecker looks breezy and cool in a sundress the color of daffodils. She loves sundresses, she says, because she has achieved the rare walk-to-work commute from her home across the street from the NIH campus. “I guess we’ve tried to recreate the Midwestern lifestyle,” she says of their aversion to cars or mass transit. If she walked to work in a suit, she’d arrive all sweaty, so sundresses it is.

The campus of the National Institutes of Health is vast. The security is tight, the medical care superb. But in her tiny office, Biesecker grows ever more immersed in the emotional side of science. As personal as it is, it’s sometimes difficult to explain. From her files, Biesecker pulls out a poem written by a Robert Resta, a genetic counselor in Seattle, about those who must share the news. It reads, in part:

> *I don’t want to tell you, I don’t want to tell you, I don’t*
> *want to tell you. And you don’t want to know.*
>
> *It’s not what you wanted, it’s not what you thought, it’s not*
> *what you hoped for. Things are going to be a mess.*
>
> *I’m not the news, just its messenger. I’m almost scared as you*
> *are. I’m not sure how to say it. I hope you will forgive me.*
>
> *Maybe you’ll move on, or maybe this will drag you down.*
> *Maybe you’ll try to forget me. But my words will always be*
> *caught in the back of your throat.*
>
> *I don’t want to tell you, I don’t want to tell you, I don’t*
> *want to tell you. And you don’t want to know.*


Lifelong learning is important to Barb Biesecker, who is finishing her Ph.D. in health psychology at Kings College in the United Kingdom. “It’s a nice paradigm to be a graduate student at the same time you are director of a graduate program,” she says.

Tough stuff, but Biesecker still smiles — she has an especially optimistic smile. She knows that knowledge cuts both ways, and science is all about knowing. She and others in the growing field of genetic counseling, however, are providing a crucial element: guiding people through that knowledge

It can be emotionally draining to help a stunned family traverse a future that’s suddenly changed with one glimpse through a microscope. But it can also be immeasurably fulfilling as they realize that they are not somehow at fault and that they surely are not alone.

KIM ODE is a longtime staff writer for the *Star Tribune* and a frequent contributor to *St. Olaf Magazine*.

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