

Getting the words out

Dr. Gerald Maguire has personal reasons for devoting his life to the research and treatment of stuttering

by Lisa Wither



A man walks into a bookstore and asks, "D-d-do you have a t-travel section?" The clerk responds, "Y-yes, sir, against that wa-wall." Angry, the customer asks, "Are y-you imitating me?" Says the clerk, "N-no, sir, never."

As the man browses, a new customer asks, "Have you a cooking section, old boy?" Without stammering, the clerk replies, "Right this way, my good fellow."

Furious, the first man scolds the clerk, "You w-were imitating m-me!"

"N-no, sir," replies the clerk, "I was imitating him."

In the annals of less-than-tasteful jokes, this one barely registers – except to persons who stutter. For them, such jokes – as common to their ears as they are corrosive to their spirits – are reminders that the verbal communication most of us take for granted is frequently beyond reach.

"People who stutter deal with enormous obstacles," says psychiatrist Dr. Gerald Maguire. "They're often viewed as less than intelligent and lacking in social skills. To protect themselves from ridicule, they may become socially anxious and introverted, which is often counter to their natural personalities."

Maguire, who can't recall a time when he didn't stutter, experienced these challenges firsthand but refused, even as a child, to be bound by them. In grammar school, he discovered that speaking in cartoon voices, a la Porky Pig, would result in peers laughing with him, not at him. And he learned the value of a thesaurus, which gave him options for problem words.

He recalls, "One year, I was assigned a class presentation on my family – but, no matter how hard I tried, I couldn't say the word 'brother.' My thesaurus defined 'brother' as a 'male sibling,' so I said I had four siblings – three boys and one girl – and aced the presentation."

A compassionate home environment provided additional support. And Maguire, who excelled academically and had many friends (but admits that dating was difficult), says he used his speech impediment as a springboard, asking himself, "I have a stutter. Now – what more can I accomplish?"

Maguire, associate professor of clinical psychiatry and human behavior as well as senior associate dean of educational affairs in the UC Irvine School of Medicine, has accomplished much. Recently, his duties expanded even further: As director of UCI's newly opened Center for the Medical Treatment of Stuttering, Maguire helms a team dedicated to research and care management. Currently the only facility in the world that seeks to optimize patient fluency through a comprehensive combination of speech therapy, counseling, medication and research, the center is a valuable resource for the approximately 3 million Americans who stutter.

Looking inward

Stuttering creates a peculiar inequality. Well-meaning people complete sentences for those who stutter. Snide jokes are suffixed with comments such as, "Where's your sense of humor?" Attempts to advance oneself are often met with discouragement, something Maguire experienced in medical school when a coursework evaluation noted his stutter "makes people uncomfortable."

And, in perhaps the cruelest irony, those who stutter are often denied the chance to respond with their greatest weapon – their intellect – because the words won't quite come.

For much of the 20th century, stuttering was viewed within the scope of Freud's repressed-need principle, which suggested the condition was a neurotic behavior that resulted from the denial of core physiological need. Contemporary medicine theorizes stuttering begins within the brain – that disruption of nerve impulses within the left cerebral hemisphere (which governs speech and motor actions), combined with genetic predisposition, cause stuttering.

"PET imaging has revealed irregularities in the brains of persons who stutter, including a surplus of dopamine – the catecholamine neurotransmitter within the brain that helps regulate movement. Medication developed expressly for this will prove crucial in future treatment protocols," says Maguire, presently chief investigator in a study of Pagocione (Indevus Pharmaceuticals), the first drug placed into clinical trials specifically to treat stuttering.

Early intervention is key. Clinicians find children who begin speech therapy as soon as stuttering appears (often as young as age three) show significant progress. Says Maguire, "Some children outgrow stuttering; others advance to where disfluency is no longer an issue. Adults who didn't receive or respond to speech therapy as youths will always stutter but may demonstrate improvement with a combination of counseling and medication."

Giving back

For Granville Kirkup, a successful Orange County businessman and Maguire's patient since 1992, the center's mission is personal. Says Kirkup, who has stuttered since childhood, "It's why I became a business owner – I couldn't manage job interviews. I decided that I'd run the company and hire people to make calls and deal with the public for me."

In his native England and later the U.S., Kirkup built an impressive resume in numerous industries, including telecommunications and software development. Also noteworthy is his philanthropic inclination: In 1999, intrigued by Maguire's investigative efforts, Kirkup gave UCI \$250,000. And, in December 2006, Kirkup donated \$1 million, a gift that will significantly benefit the center's research goals.

"I believe Dr. Maguire is on the right track in making enormous strides in care," Kirkup says. "Stuttering affects your whole life, so it's imperative that people have a place to go. Under Dr. Maguire's guidance, UCI will be known as a central location for the complete treatment of stuttering."

Moving forward

Now 42, Maguire, the man who can't recall a time when he didn't stutter, considers his future. A frequent lecturer at symposia around the world and regular contributor to medical journals, he devotes much of his time to a less-sophisticated form of communication: responding to the hundreds of e-mails he receives weekly from people who stutter – who wonder if there might be help available for this medical condition that is so personally painful and, in many ways, still so misunderstood by the world.

"The center is a vital line of defense," Maguire says. "In the coming years, we'll see medication developed purposely for stuttering that provides much better response. We'll also improve the research on genetic testing that will determine the hereditary profile, which will help direct treatment."

He reflects a moment.

"I love to teach and to guide – and what influences me is that I understand how patients who stutter feel. I believe I can make a difference – and that should take care of the next 40 years."

Facts about stuttering

- More than 3 million U.S. children, teens and adults suffer from a chronic stuttering disorder.
- Stuttering patterns are often unique to each individual, and treatment modalities are also unique to patients. However, most stuttering patterns are marked by repetitions of syllables, long silences and the contortion of a person's face as they try to speak.
- Stuttering is believed to have a genetic component; it tends to run in families.
- Stuttering affects more men than women, approximately 4 to 1.
- About 75 percent of children who stutter outgrow the disorder without intervention.
- Some 20 percent of children go through a development stage when stuttering is severe enough to be a parental concern. Here, the best prevention tool is early intervention.
- "Person who stutters" is now the correct phrase, replacing "stutterer."
- Famous folks who stuttered: Marilyn Monroe, James Earl Jones, Lewis Carroll, Carly Simon, Sir Isaac Newton, Winston Churchill, Tiger Woods, Bruce Willis, Sen. Joe Biden Jr., John Stossel, Bill Walton, John Updike.

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The good fight

Patients battling cancer have a powerful ally in Dr. Wendy Brewster

by Lisa Wither



Some gynecologic cancers are like stealth bombs. Difficult to detect. Destructive. At times, fatal. They are among the most insidious of malignancies. But they have a worthy opponent in UCI surgical oncologist and epidemiologist Wendy Brewster, M.D., Ph.D. '00.

"Often, patients with early stage gynecologic cancers – ovarian cancer, for example – experience symptoms so vague that they delay seeking attention, giving the disease opportunity to invade other organs," says Brewster. Her position with the Division of Gynecologic Oncology makes her part of a nationally renowned resource dedicated to treating women with early stage or invasive cancers (UCI Medical Center is among the nation's top health care institutions for gynecology, according to *U.S. News & World Report*).

"We're continually seeking better methods for early detection in certain populations," says Brewster, "which may allow for more successful treatment. For example, current ovarian cancer studies explore the feasibility of measuring the blood for tumor markers produced by ovarian cancer cells. We're also studying data related to genetics and lifestyle factors, such as a history of smoking or oral contraceptives. What we do know: early detection that targets characteristics in at-risk populations will influence prevention and, ultimately, a cure."

Brewster is passionate about sharing the knowledge upon which her medical career has been built. An assistant professor of obstetrics and gynecology and epidemiology, she is a prolific contributor to medical publications and frequent guest speaker at conferences around the country. She also chairs the Cancer Prevention and Control Committee, Subcommittee Disparities/Epidemiology for the Gynecologic Oncology Group, a national organization dedicated to furthering clinical research and cancer trials.

It's a daunting schedule – and ideal for Brewster, who explains, "I've always loved the order, information and logic science offers." This lifelong affinity for all things scientific and an inherent fascination for research and discovery made medicine an obvious career choice.

Brewster came to UCI via a winding route that carried her from her childhood home in Guyana to Rutgers University for undergraduate work and on to UCLA, where she received her medical degree. Initially torn between general surgery and gynecologic oncology, Brewster says, "I chose gynecologic oncology for the opportunity to care for my patients through their entire course of treatment and until cure is achieved."

During the second year of her fellowship at UCI Medical Center, while conducting research on indicators in breast cancer survivors who develop a second primary cancer, she decided to take the unusual step of pursuing an epidemiology doctorate, which she received from UCI's School of Social Ecology.

"I realized I wanted to do something more with all that research," she explains. "Completing my doctorate was a logical progression."

Today, her research reflects her conviction that early detection is vital to prevention. Recently, she led a National Cancer Institute-funded trial in which low-income women who participated in a single-visit cervical cancer screening and treatment program demonstrated an enhanced rate of treatment and 12-month follow-up (compared to conventional care methods). Brewster, who currently oversees six research trials, also is the recipient of an NCI K07 Award to study the correlation of estrogen and metabolizing factors in the development of ovarian cancer.

Outside her lab, Brewster's focus moves beyond data. Her patients' ages vary: young women confronted with diagnoses that, at best, might remove any chance of childbearing while subjecting them to a punishing round of drug and surgical intervention, and older women who must decide how much of their final months of life they wish to spend in treatment. Always challenging and sometimes heartbreaking, there is, adds Brewster, an element of humor and irony in treating these women.

Explains Brewster, "My patients are women first, and patients second. As such, our relationship will always have a unique dynamic. My patients are often so ill, waiting for yet more bad news – and their first comments to me are not about their health but rather about my current hairstyle or the color of my blouse. For a few moments, we're simply two women talking – and that's a component of the doctor-patient relationship that isn't learned in school."

She reflects a moment, then continues.

"It's the patients who are the real heroes. They deal with the pain of their illnesses with such grace. I try to give my patients the best of what they want. They, in turn, put my life in focus."

"Wendy is truly a woman for all seasons," says Dr. Philip J. Di Saia, Dorothy Marsh Chair in Reproductive Biology and chief of gynecology and gynecologic oncology. "I don't know of any other surgical oncologist in the nation who has a doctorate in epidemiology. She is a unique scientist, an excellent surgeon, a skilled clinician and a well-liked woman by both her peers and patients."

Di Saia, who oversees funding for his team's research efforts, notes that Brewster's studies of cancer within subpopulations significantly contribute to more effective treatment for at-risk groups.

"Targeting risk factors in certain groups allows us to disburse our funds more judiciously," he says. "In an ideal society, we would have screening and treatment for everyone. Efforts such as Wendy's enable us to deliver the next best thing."

Brewster has a tough battle before her: Breast cancer affects 189,000 women annually, ovarian cancer 25,000 annually – statistics that mean fewer grant dollars designated for research in gynecologic malignancies. With the funding for her NCI K07 award ending in 2007, Brewster must obtain the financial support that will enable her to carry this work forward, or, as she describes, "advance the science."

"We have the preliminary information we need to begin data analysis," she says. "Now, we must make what we've accomplished so far evolve into something greater – put the data into genetics and, ultimately, pinpoint at-risk women *before* any malignancy develops."

Let the battle begin.

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Art of healing

Johanna Shapiro's creative efforts infuse medical training with the human touch

by Lisa Wither



*Please let me remember
These thoughts
These pains
These fears
Every patient has
Even me*
— excerpted from "Stream of Unconsciousness,"
Jennifer Jolley, M.D. '04

Had Johanna Shapiro read these words in 1997 while recovering from surgery for a detached retina, she might have thought, "And even me, too."

Indeed, the surgery had a powerful and unexpected impact on Shapiro, a UCI clinical psychologist and professor of family medicine. Her prognosis was favorable; moreover, she had access to the university's wealth of science-based material to better understand her condition. Nonetheless, a sense of unease remained.

Shapiro recalls, "I suppose it was my first brush with my own vulnerability, even my own mortality. The clinical information I read left me feeling not more fulfilled — simply more informed."

Shapiro's discontent was exacerbated by a growing disenchantment for her own vocation, where she found the practice of psychology to be experiencing a decline in what she calls "the human touch" — an unspoken but essential connection between caregiver and patient. Believing she needed to reassess her professional life, Shapiro found herself at a career crossroad while still coming to terms with her personal health.

Then, while listening to an Emily Dickinson audio book, she found solace. The simple pathos of Dickinson's words touched Shapiro in some fundamental way that the fact-based literature could not — and suddenly, says Shapiro, "I discovered a different, infinitely more rewarding path."

Today, as director of the UCI School of Medicine's Program in Medical Arts and Humanities, Shapiro stewards an interdisciplinary approach to education that embraces the oft-disregarded but real relationship between art and science. The program curriculum incorporates the study of literature and art, placing emphasis on creative expression through projects such as painting, reflective essays, videography, dance and music. Humanities proponents believe medical students become better equipped to acknowledge the fears of vulnerable patients and explore rather than suppress their own emotions — an essential treatment component, according to Shapiro, who notes, "Focusing on a group of symptoms is dehumanizing and ultimately detrimental to the doctor as well as the patient."

Integrating the arts into medical education is not new, having been used in various forms for several decades. In many ways, it complements the concept of mind-body healing, encouraging its scholars to see medicine in a more human form. This transcends what some consider the conventional educational model, in which detachment and clinical observation supersede the patient-doctor connection. UCI's humanities coursework balances the rigorous science-based traditional curriculum, providing a vehicle that assists student doctors in gaining greater awareness of their patients' frailties and resulting in more edifying patient-physician relationships.

Shapiro researched parallels between medicine and the arts and discovered a plethora of sources — some fiction, some written by clinicians, patients and caregivers — ideal for incorporating into a medical school curriculum. And she found welcome encouragement from her UCI colleagues.

"Many told me, almost as a confessional, that they, too, had a great love for poetry or art, yet had lost touch with it," recalls Shapiro.

Since the program's 1997 launch, interest in the benefits of this unique approach to education and professional development has burgeoned, even though the bulk of coursework is not required for graduation. Except for an introductory lecture, a pediatrics clerkship and clinical-experience creative project, coursework is elective for credit or transcript notation. In 1999, the program debuted Plexus, a print and online journal featuring work by students, staff and faculty of the School of Medicine who find freedom and solace in creative expression.

*Tonight I looked at the stars
Insight
For the first time I felt
Connected.*
— excerpted from "Night Rain," Cristin Gail Ryan, third-year medical student

"As physicians, it's unreasonable to think we should coldly separate the physical aspects of treatment from the emotional and spiritual," says third-year medical student Meghann Kaiser. "A major benefit of humanities study is that it requires me to consider things from a perspective other than the strictly technical."

Fueled by a lifelong love of poetry, Kaiser believes her humanities studies deliver both professional and educational advantages, helping refine her communication skills while learning to maintain an emotional connection without being overwhelmed by a patient's suffering.

"The humanities allow for greater self-focus," says Kaiser, who served as Plexus editor in 2004, "including the fact that I'm human and my patient is human. This permits me to commit to finding a solution to my patient's pain — or perhaps, admit that sometimes I can't and be satisfied with that."

"The humanities don't resonate with all students," acknowledges Dr. Lloyd Rucker, associate dean of curricular affairs and a core member of UCI's medical humanities team, "but for those who do connect, it's a compelling way for them to understand their experience."

Rucker's familiarity with using creative projects as training components predates 1997, having occasionally made them part of UCI's internal medicine student rotation. A faculty co-adviser on Plexus, Rucker credits Shapiro for helping the UCI program thrive.

"Johanna is a powerful mix of clinician, observer, poet and advocate," he says, "with a knack for seeing into the qualitative aspect of personal interaction. Johanna can watch a scene evolve between individuals and draw conclusions that make sense for entire systems."

*Suddenly, his individual and humble life explodes
And all his being is transformed into a magnificent body
Soaked up in the fascinating melody of life.*
— excerpted from "Neural Transformation,"
Trung Minh Thai, M.D., Department of Psychiatry

Shapiro remains committed to communicating a crucial message: that medical students flourish in an environment that emphasizes that which is creative as well as scientific.

"There's a stereotype of medical students as science nerds — not well-rounded individuals," she explains, "when they are, in fact, very caring, creative, original souls. The humanities give students permission not only to think but also to 'feel.' And by nurturing rather than quashing this, we establish groundwork for what will someday make them truly outstanding physicians."

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