Congratulations. You Survived Cancer!*

**Side effects may include:** COGNITIVE IMPAIRMENT, SECONDARY CANCERS, RENEWED SENSE OF PURPOSE, IMMUNE DEFICIENCY, JOINT PAIN, CARDIAC DISEASE, GREATER COURAGE THAN BEFORE, MEMORY LOSS, JOB LOSS, BROKEN RELATIONSHIPS, AND FRIENDS YOU NEVER KNEW YOU HAD.

**PLUS:** PATIENT ADVOCACY GROUPS FIND STRENGTH IN NUMBERS, SUICIDAL OR SAFE? THE WISDOM TO KNOW THE DIFFERENCE
LETTER FROM THE DEAN

Foundations and Progress

The Division of Biology and Medicine is alive with progress and promise on dozens of fronts as we approach the midpoint of the 2007-08 academic cycle. Our research enterprise alone offers abundant evidence of the momentum that is energizing all aspects of our work.

In this issue, Medical School faculty and alumni figure prominently in two articles of compelling interest to investigators, clinicians, and patients: the influence of patient advocacy groups on the research environment and the growing focus on the health challenges that face cancer survivors. Cindy L. Schwartz MD'79, an advisor to the groundbreaking National Cancer Survivor Study, is a pioneer in the creation of hospital-based survivorship clinics, including one at the Hasbro Children’s Hospital. Another alumna, Leslie B. Gordon, PhD ScM’91 MD’98, turned her research attention to the study of progeria after her young son was diagnosed with the disease. The advocacy group she founded with her husband demonstrates the power of grass roots efforts to focus research attention in given areas through pilot studies, conferences, workshops, and yes, lobbying.

The importance of the aforementioned work and the recognition it receives are a boon to us all. These critical research efforts enhance the visibility and reputation of academic medicine and of the multifaceted biomedical endeavor that is thriving in our midst.

As I begin my last semester as dean of the Division of Biology and Medicine, I am pleased by the recognition that we have laid a strong foundation upon which our future will be built. Further, I am honored to join the ranks of esteemed emeriti leaders who remain committed and involved long after leaving the Dean’s suite.

The students, alumni, faculty, and staff who proudly represent Alpert Medical School, the Program in Public Health, and the Program in Biology are the heart of this great institution. On their behalf, I ask for your continued support and involvement as we move ever onward and upward.

Sincerely,

LUCAS FOGLIA
“The use of war metaphors to describe any illness, including cancer, does such a disservice. What does that say about the people who didn’t live? It’s not about courage.”

—Ruhan Nagra ’10 MD’14

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Thinking Out Loud

As we finalize another issue of Brown Medicine, I am struck even more than usual by the many voices contained in its pages: everywhere there are people talking, people listening, people responding. There are the voices of patients and their families as they advocate before lawmakers and scientists, becoming decision-makers in the allocation of research dollars. There is the voice of an undergraduate who survived cancer but who shuns the very term “survivor.” There is the voice of a pediatrician describing the symbiosis inherent in the doctor-patient relationship—the patient cared for by the doctor, the doctor learning from the patient. And there is the pragmatic urgency in the voice of a medical student explaining why she favors action over words and has faith in the wisdom of the people she wants to help.

Especially gratifying are the voices of the doctors and soon-to-be doctors who are also reflective and elegant writers, and who have contributed to this issue. Writerly physicians are in no short supply around here, of course. Take frequent contributor Christine Montross, whose book we excerpted last fall, or “resident” columnist Micaela Hayes, whose essay each issue focuses on a particular point of her learning curve, always described with intimacy and clarity. This winter two articles, “Safekeeping” and “Shanghai Underground,” came in over the transom. The former is a psychiatrist’s thoughtful exploration of the blurry boundary between his responsibility to ensure his patient’s well being and his patient’s freedom to decline his care. Two other pieces, “It’s Simple, Really” and “Ana and Mia Are Not Your Friends,” have already received the distinction of being published—the former, written by a current medical student, in the prestigious Journal of the American Medical Association.

I trust you will enjoy hearing these voices, and I hope you will talk back.
WINTER 2008 | BROWN MEDICINE

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would have hoped that she commend these students for their mission rather than criticize their appearance. Rather than being "shocked" by the term Queer Med, I would appreciate her assistance in helping them develop a curriculum to “better train physicians to care for the LGBT population, a community widely recognized as medically underserved.” It was not that long ago that any physician other than a white man wearing a shirt and tie was, as she stated, “off-putting to the average patient”; fortunately, appearances became secondary to qualifications.

Jason [Lambrese '06 MD'10] and Andrea [Dean MD'10] should be applauded for joining a long list of cultural pioneers that risked ridicule and discrimination to advance a worthwhile cause that has come a long way, but clearly has a long way to go.

Bernie Lambrese
Bristol, RI

NOTE FROM THE EDITOR

The sidebar of that article addresses the critically important topic of palliative care, and the Fall 2002 issue of Brown Medicine dedicated a feature story to it, titled "How We Die." Copies of the article are available on request.
What’s the Matter with Kids Today?

New study will follow subjects from birth to twenty-one.

Big problems, Steve Buka notes, call for big science.

Health statistics reveal some major challenges for America’s kids. Over the past three decades, the obesity rate in the United States has more than doubled for preschool children aged two to five and has more than tripled for children aged six to eleven. Children are getting asthma at more than twice the rate they were just twenty years ago. Unintentional injuries remain the biggest killer of children aged fourteen and under. These health problems along with autism, schizophrenia, and diabetes cost America $642 billion each year.

Enter the National Children’s Study, the largest long-term study of children’s health and development ever conducted. Brown is now one of twenty-two new study centers taking part in this landmark research project, hailed the five-year, $14.1 million contract awarded to Brown and lead partner Women & Infants Hospital of Rhode Island.

“This is viewed nationally as a signature award,” according to Adashi. “It really is one of those awards that you cannot do without if you want to be at the leading edge.”

And the study is, indeed, groundbreaking. National Children’s Study centers will enroll a representative sample of 100,000 infants and follow them from before birth to age twenty-one. In Rhode Island, investigators will enroll 1,000 children in Providence County. The researchers, led by Buka, a professor in the Department of Community Health and the director of the Center for Population Health and Clinical Epidemiology, will collect biological samples from children and their parents, as well as air, water, soil, and dust from the child’s environment. Additional information—from details of a child’s diet to his or her access to parks—will also be gathered.

The aim is to identify the root causes of diseases such as asthma and diabetes, as well as to gain a better understanding of injuries, birth defects, and learning, behavioral, and

Health problems such as asthma, autism, schizophrenia, and diabetes cost $642 billion a year.
mental health disorders. Findings will provide the basis for new prevention strategies, health and safety guidelines, and potential treatments and cures for disease.

“We’ve seen another major initiative of this type with the Human Genome Project, which sought to sequence the entire human genome,” Buka said at the press conference. “This has led to major scientific, medical, and economic advances. The National Children’s Study seeks to answer questions of a similar scale, but focuses on how the environment impacts on children’s health, disease, and well being. It is a critical and valuable next step, with dramatic implications for disease prevention and health promotion.”

Maureen Phipps, associate professor of obstetrics and gynecology and director of the Brown University/Women & Infants Hospital National Center of Excellence in Women’s Health, is co-principal investigator on the project.

From behind the press conference podium, Phipps said results from the study will influence prenatal care in Rhode Island—and the rest of the nation.

“We can understand how diet and weight gain during pregnancy might affect both a mother and her child’s risk for obesity after birth, for example, and understand how infections in the reproductive tract and in other parts of the body may increase the risk for having a preterm delivery,” Phipps said. “These new insights will improve the health of children, women, and families.”

Carcieri’s ear-to-ear grin gave away an emotional reaction: “I’m up here beaming,” he said. “[F]or two reasons. One is for Brown, my alma mater. But I’m also beaming for the state of Rhode Island.” —Wendy Y. Lawton

Findings will provide the basis for new prevention strategies, health and safety guidelines, and potential treatments and cures for disease.
Meet Biohybrid Man
Forum explores melding of humans and technology.

If you are in good health and possess all your limbs, you might be surprised to hear yourself referred to as “TAB,” or “Temporarily Able-Bodied.” As Jerry White ’86 said in his keynote speech at the November 29 forum sponsored by the Brown/VA Center for Restorative and Regenerative Medicine (CRRM), the term “TAB” reminds us of the vicissitudes of fate and increases our consciousness of disability culture.

The prevalence of those requiring medical attention for limb loss is responsible in part for this growing consciousness. Thousands of soldiers have suffered traumatic amputations, often at proximal levels where restoration of function is difficult. They join more than 1.6 million Americans currently living with limb loss—a common result of diabetes and circulatory disease. Internationally, millions of buried land mines continue to be a cause of limb loss for thousands of civilians every year, many of them children.

CRRM’s mission is to restore limb function after injury by pioneering technologically advanced approaches in regenerative medicine, neurotechnology, robotic prosthetics, and rehabilitation. This year’s forum united nationally and internationally recognized speakers, including White, the co-founder and executive director of the Landmine Survivors Network and co-recipient of the 1997 Nobel Peace Prize.

Other speakers included CRRM investigator and Brain Science Program Director John Donoghue, who discussed achievements in decoding neural activity to enable individuals with motor loss to control rehabilitative devices, including prosthetic limbs; MIT professor Hugh Herr, who explained the principles involved in constructing the world’s first powered biomimetic lower extremity prosthesis (see Brown Medicine, Fall 2007); William Warren, chair of Cognitive and Linguistic Sciences, who described how virtual reality and motion tracking could be used to assess limb disability and treatment; and Jeffrey Morgan of the Department of Molecular Pharmacology, Physiology, and Biotechnology, who explained how osseointegrated percutaneous devices offer a novel method of attaching prosthetic limbs directly to bone.

These advances have obvious military applications. COL. Roman Hayda, MD, chief of orthopedic trauma at Brooke Army Medical Center, discussed therapeutic challenges faced by soldiers in Iraq and Afghanistan. Dr. Richard M. Satava, special assistant in advanced surgical technologies at the U.S. Army Medical Research and Material Command, updated the audience on current and potential advances in robotic medicine. As CRRM Director Roy Aaron noted, continuing research in biohybridity could ultimately enable us “to envision solutions that transcend the limitations of biological tissue or prosthetic materials alone.”

—Margaret Case

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CRRM’s mission is to restore limb function after injury by pioneering technologically advanced approaches in regenerative medicine, neurotechnology, robotic prosthesis...
JOINT EFFORT

Last October, officials from Brown’s medical school and Lifespan joined lawmakers and elected officials to celebrate a five-year, $11.1 million grant to establish the Center of Biomedical Research Excellence (COBRE) for Skeletal Health and Repair at Rhode Island Hospital and create a multidisciplinary team of scientists with the Medical School. The grant will focus on cartilage and joint health, disease mechanisms, and repair strategies, according to center director and principal investigator Qian Chen, the Michael G. Ehrlich, MD, Professor in Orthopaedic Research.

“The aging of the baby boom generation and soaring obesity rates mean we can expect to see a sharp increase in the number of patients with osteoarthritis and other joint diseases,” said Chen, whose multidisciplinary team includes researchers from orthopaedics, emergency medicine, pediatrics, medicine, and bioengineering.

COBRE, ROBIN D. BLOSSOM; COURTESY MARRERO; LUCAS FOGLIA

Left to right, Louise Ramm of the NIH, Dean Eli Adashi, Governor Donald Carcieri, Dr. Chen, Dr. Michael Ehrlich, Rep. James Langevin, Lifespan CEO George Vecchione, Rep. Patrick Kennedy, Sen. Jack Reed, and Mayor David Cicilline

She’s a Gem

Student starts a program to help peers help peers.

At age fifteen, prompted by the Columbine school shootings and the threat of violence, substance abuse, suicide, low self-esteem, and other behavioral issues faced by peers, Jessica Marrero ’07 MD ’11 wrote a grant proposal that received $100,000 to start a community-based program aimed at reducing school violence and substance abuse among students in her Gainesville, FL, community. What emerged was Partners in Adolescent Lifestyle Support (PALS), a school- and hospital-based program that provides peer support and therapeutic intervention to troubled students and enhances leadership skills for teens.

Marrero recently represented PALS in receiving the $100,000 Sapphire Award from the Blue Foundation for a Healthy Florida, the philanthropic arm of Blue Cross Blue Shield of Florida. This is the first time a student-sponsored program has won the award.

—Susan Lew

Public Health, Mastered

Young program accredited once again.

In October 2007, Brown’s Master of Public Health Program received a seven-year reaccreditation by the Council on Education for Public Health (CEPH).

“In the seven short years since its creation, in 2000, our MPH program has grown from one student to sixty, with a broad array of course options,” says Associate Dean of Medicine for Public Health and Public Policy Terrie “Fox” Wetle.

“Our excellent students and the high quality of our applicant pool are signs of the program’s national reputation.”

These are exciting times for public health education at Brown, which now offers two five-year combined degree programs: an AB/MPH program for undergraduates, and an MD/MPH program for medical students.

“We received extremely positive feedback on the MPH program,” says its director, Patrick M. Vivier, PhD ’85 MD ’89. “In less than a decade the MPH at Brown has grown from an idea to an established, well-respected educational program that is contributing to the public’s health in Rhode Island and beyond.”

—Beth Sundstrom

GOOD NEWS

Bill Rakowski teaches a course in the MPH program.
Stop the Violence

Do batterer intervention programs get to the root of the problem?

Over the past twenty years, awareness of intimate partner violence (IPV) has increased, in part due to some high profile and tragic cases. Who can forget the sounds of Nicole Brown Simpson’s 911 calls or images of her bruised face? Society responded with mandatory arrest laws for batterers and sentences that include participation in batterer intervention programs. These were major steps forward, but how well are they working?

Last summer Associate Professor of Psychiatry and Human Behavior Gregory L. Stuart, PhD, and colleagues Jeff R. Temple, PhD, and Todd Moore, PhD, both former postdoctoral research fellows at Brown, suggested means for improving batterer intervention programs in a Commentary piece in the Journal of the American Medical Association. After years of studying the impact of substance use and abuse on family violence, Stuart believes one reason batterer intervention programs are not more successful is because they fail to adequately address a major contributor to violence: addictions.

Brown Medicine asked Stuart, who is director of family violence research at Butler Hospital, for his thoughts on why change is needed.

The Centers for Disease Control and Prevention says 1.3 million women are abused annually in the U.S. How accurate is that statistic?

I believe that statistic dramatically underestimates the incidence of intimate partner violence in the general population. A fair estimate of prevalence is perhaps 20 percent of women (and men) have been victimized by an act of violence in the last year. IPV is a major concern, even if it is not severe aggression, because violence has the potential to escalate. I should mention that psychological abuse, which is also detrimental to women’s health, occurs at an even more alarming rate.

How do addictions and family violence interface?

Substance abuse mediates the relationship between impulsivity and psychological abuse, which in turn predicts physical abuse. That said, there are plenty of people who perpetrate violence who have never touched a drop of alcohol, and people who have substance abuse issues who have never perpetrated any family violence. Even though there is an extremely strong relationship between certain substances, particularly alcohol, and violence perpetration and even victimization, I don’t want to suggest that alcohol use is an excuse or justification for violence. The perpetrator is always responsible for his or her actions. But we certainly know that some substances increase the risk. Part of my research plan is to make people aware of the connection.

On what aspect of the problem does your research focus?

We started by doing a study to see what happened to violence in terms of frequency, prevalence, and severity when one partner came to Butler Hospital for substance abuse treatment. IPV is overrepresented in substance abusers of both genders relative to the general population. Our study showed that over time, there tends to be a decrease in violence after either partner gets treated for an addiction. We also compared folks whose alcohol problem relapsed to those who remitted. People whose alcohol problems were in remission had lower levels of perpetration and victimization than those who relapsed. Not surprising, but an important finding because it shows that if there is physical violence going on it might be ameliorated if the person obtains substance abuse treatment.

Do court-ordered batterer intervention programs decrease violence?
Batterers are typically court-referred to this intervention. They are going to these programs to avoid being incarcerated. So, they often may lack the motivation to change. If you forced a substance abuser, for instance, into treatment when they have little motivation to stop, or their only motivation is a hang-up with the police, it's doubtful that [they] will make a change. With that said, some people certainly do benefit considerably from batterer intervention programs. However, as highlighted in the JAMA article, we believe that there are some things that the programs can do to increase their effectiveness.

And how many people in these programs have substance abuse issues?
Substance use is extremely common among men and women who are court-referred to batterer intervention programs. Over two-thirds of the men have alcohol or drug issues and about half of the women. Although batterer intervention programs often dedicate one session to substance misuse, one of the potential reasons these programs are not as efficacious as they could be is that there's a lot of untreated substance use that we could address. For many in these programs, more intensive addiction treatment could be helpful.

What is the physician’s role in stopping family violence?
Intimate partner violence is prevalent and it directly impacts physical and mental health. An important message for clinicians is that it is absolutely happening in their practices relatively frequently. Just because a physician doesn’t ask about it doesn’t mean it is not happening. Research has shown that women are not bothered about being screened for partner violence and are generally forthcoming when asked about it. I would like to see physicians directly asking about relationship aggression along with the other routine screenings that they conduct and for them to have pamphlets available in their offices with local resource information. —Kris Cambra

Researchers at Rhode Island Hospital’s Injury Prevention Center have reported impressive results from a program called Reducing Youthful Dangerous Driving (RYDD), earning themselves a $2 million grant renewal from the National Institutes of Health. RYDD is a court-mandated, three-week motivational intervention program followed by twelve months of monitoring for teen traffic offenders. In the state with the second-highest percentage of alcohol-related traffic fatalities in the U.S., “our program has shown excellent promise in helping local teens identify their risky actions and make subsequent changes in their driving behavior,” says Ted Nirenberg, PhD, director of RYDD and associate professor of psychiatry and human behavior (research). “This new funding will help us refine what strategies work best, with the intent of RYDD becoming a national model...to reduce risky teen driving.” —S.L.
The Miriam Hospital’s Weight Management Program, which last fall marked its twentieth anniversary. Founded and directed by Clinical Assistant Professor of Medicine Vincent Pera, the program has helped approximately 10,000 people over the years, with patients routinely achieving weight loss in the range of 100, 150, even 200 pounds. “With patients losing an average of at least fifty pounds apiece,” Pera says, “we’re confident that in twenty years we’ve lost 500,000 pounds.”

The key, says Pera, is a coordinated approach that combines weight loss, behavior modification therapy, nutrition, exercise, and group support in a customized program tailored to individual needs. Led by specially trained psychologists, groups meet once a week for one-hour sessions in either twenty- or twenty-eight-week programs, where patients learn to identify triggers that cause overeating, and to practice behavioral strategies to manage stress without eating and handle everyday situations like restaurants, social gatherings, and holidays. Participants spend another hour undergoing a weigh-in, blood pressure check, and medical monitoring by a physician. The weight loss regimen typically involves one of three versions of a liquid diet, tied to how much an individual needs to lose. The didactic component of the program covers weekly topics of nutrition, medical factors, and lifestyle issues, and an on-site gym provides opportunities to work with exercise physiologists.

The success of the program also depends on its understanding of obesity as a chronic
disease that, like diabetes, for instance, requires life-long treatment. “Losing weight is a much easier proposition,” Pera says, “than successful long-term weight maintenance.” To aid in that, Pera’s team also offers a master’s program, a year-long undertaking for individuals who have completed the weight loss program that offers ongoing group support, with the focus on relapse prevention, nutrition, and exercise but with a more self-directed approach. Despite accomplishments that number in the tens of thousands (of people helped) to half-million (pounds lost), what Pera is most proud of is his exceptional staff. His team, he says, has first-rate clinical skills, and works hard and well together and with their unique clientele. Obesity is a difficult illness, Pera explains, because of its associated biases and stigma. His team “is extremely careful to create an environment where patients are comfortable and a place they look forward to coming to each week.”

—L.R.

For the ninth annual Ceremony of Commitment to Medicine, which took place on October 27, friends, family, and faculty filled the First Unitarian Church to applaud the MD Class of 2011 (above) as they received their white coats. Student speaker Sybil G. Dessie ’04 MD’08 told the class, “Medicine is hierarchical. My short white coat gave me a place on the totem pole—albeit at the very bottom—but at least I was on it.”

—Lisa Rowley

Old News

Brown receives $10 million to study care for elders.

Last October, the National Institute on Aging awarded Brown a major grant to create the first research database aimed at improving the nation’s long-term care system—and the lives of the elderly who rely on that system to eat, take medications, and carry out other tasks of daily living. Vincent Mor, chair of the Department of Community Health and a member of the Center for Gerontology and Health Care Research, is principal investigator on the five-year, $10 million grant.

Mor and his team will combine existing federal data on Medicare reimbursement claims, patient hospitalization rates, and other data with new information the team will collect on the health status of residents, reimbursement rates for long-term care services, the organization of those services, and other topics from a random sample of 2,600 nursing homes across the country. The goal is to trace a clear relationship among state policies, local market forces, and the quality of long-term care. The information can be used to craft state and local guidelines that promote high-quality, cost-effective, equitable care for older Americans.

—W.Y.L.

The team creates a place patients look forward to coming to each week.
BARBIE GIRL, MEET GI JOE

The Barbie doll and the microchip debuted in 1959. Both would go on to revolutionize their respective industries. Both would make a few ripples in Carol Del Pico’s life, too.

Del Pico, the Office of Admission’s resident software specialist, works closely with Computer and Information Services to ensure students can manage the application and financial aid processes online with minimal psychic injury. She is also responsible for testing upgrades to make systems run better. Here in particular she excels: she’s part of the team that received the University’s 2007 Excellence Award for Innovation.

Del Pico has always been a forward thinker. While some of her childhood playmates abandoned Barbie, Del Pico carefully preserved all of her dolls. Today, she’s an avid collector and owns more than 150 mint-condition Barbie dolls of every era and edition.

“I got my first doll in 1961,” she says. “I remember standing in front of the big glass display case at Sears. [My parents] would let me pick one doll and one outfit.” Barbie retailed for just $2.98 back then; these days, early editions are worth thousands.

Del Pico began her collection after attending a doll convention fifteen years ago. “I loved the camaraderie among the collectors, the sense of nostalgia,” she says. Though once a regular on the convention circuit, today Del Pico does most of her Barbie buying and selling and general ogling on eBay.

Barbie isn’t the only industry icon living under Del Pico’s roof. Her husband, Stephen, collects G.I. Joe action figures. “He always says I dragged him to all those doll shows,” Del Pico explains. “He had to do something. So he got into the act.”

—Jumoke Akinrolabu

WHO KNEW?

TEENS IN PAIN

Intentionally cutting or burning oneself and other forms of non-suicidal self-injury (NSSI) are actually more prevalent among high school students than once thought, according to a new study in the August 2007 issue of Psychological Medicine. Of 633 high school students surveyed, nearly 46 percent reported intentionally injuring themselves in the past year on multiple occasions. Of those, 60 percent engaged in moderate/severe forms of NSSI, which may be predictive of more serious outcomes such as suicide. The findings are “essentially a wake-up call to take better notice of these behaviors in the community and learn how to help teens manage stress without harming themselves,” says lead author Elizabeth Lloyd-Richardson, PhD, assistant professor of psychiatry and human behavior. “Understanding the specific motivations behind an adolescent’s behavior...allows for the development of an individual treatment plan that could help prevent future episodes,” she says.

PETRI IN 3-D

Brown scientists have taken the Petri dish to a new dimension—literally. In the September issue of Tissue Engineering, Associate Professor of Medical Science Jeffrey Morgan and Anthony Napolitano, PhD candidate in biomedical engineering, describe their 3-D Petri dish, an innovative design that allows cells to culture into bits of three-dimensional microtissue. Napolitano spent two years perfecting the design and received a $15,000 award from the National Collegiate Inventors and Innovators Alliance to develop the patent-pending technology. Their Petri dish differs from a traditional one in that it contains 820 tiny recesses or wells in the agarose jelly. When cells are added to the dish—about one million at a time—roughly 1,000 sink to the bottom of each well and form a pile. These piles allow cells to form the natural cell-to-cell connections required for tissue development.

According to Morgan, “these microtissues...can be used to test new cancer compounds and other drugs. And they can be transplanted into the body to regenerate tissue, such as pancreatic cells for diabetics...Our 3-D technology is fast, easy, and inexpensive.”

DON’T WORRY, EAT HAPPY

Good news for dieters: overeating at a holiday party or two won’t affect long-term weight loss. According to a study published in the October 2007 issue of Obesity, dieters who have the tendency to eat in response to external factors, such as festive celebrations, have fewer problems losing weight over time than those who tend to eat in response to internal emotions. In contrast, emotional overeating, or “internal disinhibition,” was a strong and more accurate predictor of weight change than other psychological issues such as depression, binge eating, and per-
Recent faculty titles.

**THE SCENT OF DESIRE: Discovering Our Enigmatic Sense of Smell**

*By Rachel Herz, PhD* | *WILLIAM MORROW, 2007* | *$24.95*

**DISABILITY IN TWENTIETH-CENTURY GERMAN CULTURE**

*By Carol Poore* | *UNIVERSITY OF MICHIGAN PRESS, 2007* | *$70.00*

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**BOUND**

Recent faculty titles.

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**Researcher at Rhode Island Hospital. In the October 4 issue of *Cell*, Chin and his team identified yet another critical requirement for signal transduction: acetylation, another chemical process that modifies amino acids. The researchers found that acetylation plays a central role in activating interferon receptors.**

The discovery marks a milestone in the study of signal transduction. Many diseases, such as diabetes, cancer, and heart disease, occur when signal transduction goes awry. Chin’s findings may explain why some drugs that target phosphorylation do not work for everyone. The work provides an important new target for therapies for cancer and other diseases.

**CU @ THE Y 4 HIV TEST**

Brown-led researchers have found that teens are motivated differently than adults are when it comes to getting tested for HIV. The study, in the December issue of *the Journal of Adolescent Health*, is the first to take a prospective look at the factors associated with HIV testing among adolescents. Lead by Marina Tolou-Shams, assistant professor of psychiatry and human behavior (research), the team found that teens were more likely to seek an HIV test if they had already been tested before. “These findings were a bit surprising, since we thought teens would be more likely to get an HIV test if they engaged in risky behaviors...or attended an HIV prevention workshop,” says senior author Larry K. Brown of the Bradley Hasbro Children’s Research Center and a professor of psychiatry and human behavior. The authors suggest that “implementing testing throughout various nontraditional adolescent venues, such as schools and community settings (e.g., Boys and Girls Clubs, YMCA) could increase future testing thereby... reducing future HIV transmission among youth.”

**DROSOPHILA DOZEN**

Brown biologists have made a major contribution to a groundbreaking genome sequencing project—single-handedly assembling the mitochondrial DNA sequences of seven species of fruit fly. The work, which appeared in *Nature* in November, is part of the international Drosophila 12 Genomes Consortium, a group of about 150 scientists who came together to sequence the genomes of twelve different species of *Drosophila*. David Rand, a professor in the Department of Ecology and Evolutionary Biology, along with postdoctoral research associate Kristi Montooth and laboratory technician Dawn Abt, were the only scientists in the consortium to assemble mitochondrial DNA, or mtDNA, sequences.

The potential impact of their findings is far-reaching. Says Montooth, “mtDNA can teach us about metabolic performance and how it can be disrupted through mutation, giving insight into possible mechanisms for mitochondrial diseases and conditions such as diabetes, deafness, and nerve damage that can result in vision loss or dementia.”

*S.L. and W.Y.L.*
NIGHT TO REMEMBER
New professorship honors cancer pioneer.

Administrators, faculty, friends, and family gathered on October 30 to celebrate the dedication of the Paul Calabresi, MD, Professorship in Oncology. Peter J. Quesenberry, MD, director of hematology/oncology at Rhode Island Hospital and The Miriam Hospital and professor of medicine, is the inaugural incumbent.

Dean Eli Y. Adashi presided over the ceremonies, which honored Calabresi’s legacy as both an early luminary at Brown’s medical school and a brilliant researcher and clinician who contributed to the development of the first treatments for cancer. He became internationally renowned as a leader in the development and testing of anti-cancer agents and established what was likely the first medical school-based division of medical oncology in the U.S., at Yale. At Brown, he was chair of the Department of Medicine and started the interdisciplinary Cancer Center, of which he served as director for twenty years. He died in 2003.

In his current role, Peter Quesenberry oversees the cancer program at both hospitals as well as within Brown’s Medical School fellowship program in hematology and oncology. With more than four decades of dedication to cancer treatment and research, Quesenberry is nationally renowned for his research on stem cells, and has also maintained a focus on mentoring junior investigators throughout his career. He is the author of more than 250 articles in peer-reviewed journals and other publications and is the author of nearly 100 books or book chapters with a focus on cancer, chemotherapy, bone marrow transplant, and stem cell research.

Calabresi’s widow, Celia, and his three children were in attendance. His son, Peter A. Calabresi MD’88, an associate professor of neurology and director of the Multiple Sclerosis Center at Johns Hopkins, offered remarks during the ceremony. He presented Brown with a gift—a beautiful portrait of his father—and noted that his father would have been thrilled to see how Brown has grown and that construction of a medical education building was slated for the near future.

—Kris Cambra

A GIFT WITH VISION
Unrestricted giving bolsters Campaign total.

An unrestricted gift is like a holiday gift card: you can use it for anything you would like, be it a pressing necessity or a special treat. Brown’s medical school received a generous “gift card” from Bank of America—$100,000 for unrestricted purposes.

Such gifts are the cornerstone of the Campaign for Academic Enrichment, which places an unusually high percentage of its $1.4 billion goal on such current-use funding. President Simmons often describes unrestricted support as key to the Campaign’s success. It provides support for operating expenses, offsetting the day-to-day costs of everything from faculty salaries to new electronic journals for the library, from stipends for student travel to professional conferences. And it makes possible some of the new initiatives—faculty-inspired curriculum innovations or new research projects—that are part of the Plan for Academic Enrichment but not yet part of the School’s budget.

The Bank of America gift represents a major vote of confidence in Alpert Medical School from one of the region’s most important corporate entities. Bank of America has a long history of philanthropic giving, including previous support of the Medical School. From 2001 to 2006 its Community Fellows program offset the educational loans of forty-two medical alumni working in underserved communities. The Bank’s latest gift speaks to its unusual vision in offering operating support to what it calls “anchor institutions”—the local arts groups, universities, and hospitals that as economic drivers and catalysts of growth help develop the intellectual, human, and physical capital that make healthy and vibrant communities. This contribution also reflects the Bank’s commitment to the mission of the Medical School and the way it has changed the health care environment in Rhode Island and southern New England.

—K.C.

MEMORIAL GIFTS

Longtime Brown Medical Annual Fund supporter Frank Scott ’50, P’75MD’86, ’79, GP’05MD’09, ’09MD’13, died November 13. Scott was the father of Medical School alumnus Mark Scott ’75 MD’86, and grandfather of current Program in Liberal Medical Education students, Mark Scott II ’05 MD’09 and Dana Scott ’09 MD’13.

He was a registered landscape architect and was involved in building and developing numerous residential and commercial properties throughout Rhode Island, Massachusetts, and Connecticut. He served thirty years as chair of the Cranston School Buildings Committee, overseeing the development, expansion, and improvement of public schools in that city.

Gifts in his memory can be made to the Brown Medical Annual Fund, The Warren Alpert Medical School of Brown University, Box 1893, Providence, RI, 02912.

—K.C.
Death Becomes Her
A doctor finds her greatest strength at her patients’ darkest hour.

“Doctor, are you sure? Is there no chance at all?” Leaving the room, the woman turned back for a moment to catch my eye, pleading one last time for a sliver of hope, for a way out of this nightmare. I couldn’t give it to her. “No, there is no chance,” I said. “This is the right thing to do.”

As physicians we are taught to heal and give hope. Yet sometimes healing requires us to take that hope away, to remove any last doubts and allow families to move on. This woman’s husband—the father of her three children—had just suffered a massive heart attack and cardiac arrest. The lack of oxygen killed most of his brain; only the part that controlled heart rate, blood pressure, and breathing remained. His kidneys, liver, and heart were damaged, probably beyond repair. If we removed life support he might continue to breathe, but he would never be the father, husband, brother, and teacher he had been just forty-eight hours before. Certain he would never want to “live” on life support, his wife and children asked us to remove the ventilator and keep him comfortable. They remained at his side until he died a few hours later.

I have cared for many memorable patients during my training. For one reason or another their stories have stayed with me, becoming part of my medical gestalt. Some stories are intensely positive—the stroke reversed with clot-busting medicines, the heart attack aborted with balloons and stents, the pneumonia held at bay with powerful antibiotics.

Surprisingly, other stories stay with me because they revolve around death, dying, and grief and their potential connections with healing. Odd though it may seem, end-of-life care provides a deep satisfaction I have yet to experience elsewhere in medicine. While at other clinical junctures one’s diagnostic and therapeutic expertise reign supreme, when death is imminent the humanistic skills matter most. A kind voice, clear explanations, an acknowledgment of suffering, and a supportive shoulder transform a sterile, senseless tragedy into a shared human experience that contains the seeds of meaning and healing. The ability and desire to effect this change makes the difference between a good clinician and a great physician.

I did not always feel this way. As an intern, I shied away from end-of-life discussions. The requisite prognostication felt awkward and somehow dishonest. Who knows for sure whether, when, and how a person will die? Medicine is imprecise, and death is so very final! To be wrong is to rob weeks, months, or years from a patient’s life. Overly fearful of stealing life, I presented clinical facts and treatment options but offered little real guidance. As I cared for more and more patients, I began to accept clinical uncertainty as an unavoidable evil and to appreciate the critical role of physician as counselor.

In this era of patient autonomy, I was trained to minimize the weight of my personality and beliefs lest I overwhelm the patient’s true desires. Indeed, in our increasingly consumer-driven health care system, physicians have become purveyors of evidence-based choices rather than advisors on complex biopsychosocial decisions. The intentional nullification of physicians’ personality, beliefs, and experiences limits our ability to provide empathic, meaningful guidance at an incredibly vulnerable time.

Although my experiences may yet be meager and my personality strong, I would rather perform a difficult balancing act than neglect such a valuable asset. So I have intentionally inserted myself back into the equation, sharing my past experiences, future predictions, and current recommendations, always with a soft voice and Kleenex box in hand.

Micaela Hayes is a resident in Brown’s general internal medicine residency program.
At the start of the summer of 2005, Caitlin Cohen ’08 MD’12, a recipient of a prestigious Royce Fellowship, left the comforts of campus to conduct AIDS vaccine research in Bamako, Mali. She arrived eager to work, but soon came to something of an epiphany: She wasn’t that into research.

“I just don’t enjoy it. I think there’s a ton of research in this world and not a lot of action coming out of it,” she explains. “Ultimately, I was much more interested in doing something. Not to say that research is a bad thing—but public health research without the action component is a waste.”

By 2007, Cohen had turned what was supposed to be a summer vacation into an extended leave of absence from Brown. Her efforts culminated in the founding of the Mali Health Organizing Project (MHOP), an initiative aimed at addressing the most critical health issues in Mali’s densely populated slum areas. Having decided on early retirement from research, the development studies concentrator traded in her survey instruments for 501(c) tax forms, grant proposals, and all the “bureaucratic hoo-haa” that goes into starting a non-profit organization from the ground up.

MHOP is headquartered in Sikoro, Mali, a town of 60,000 where citizens have limited access to drinking water and electricity, where 90 percent of the population lives on less than two dollars a day, and...
where nearly one-quarter of the children will die of malaria or malnutrition before reaching age five.

According to Cohen, these are the statistics with which Malians are most concerned and are the reason why MHOP has eschewed an “expressly AIDS-based activist agenda.”

“No that AIDS is not important,” she says. “Malians I spoke with said it didn’t concern them because their children were dying of malaria, starvation, or other issues. It’s ineffective to address AIDS [exclusively] if you’re not addressing the fact that people don’t have enough food to eat.”

MHOP’s signature project, Sigida Keneyali (Bambara for “Health in Our Homes), is similar to many humanitarian initiatives in its emphasis on improving infrastructure and health care access. The defining difference between Sigida and other programs is its approach. Every program is implemented in a three-way partnership with the town and the government to jumpstart mutual investment in the health infrastructure of slums. Rather than working from an external agenda, Sigida projects are prioritized by those most knowledgeable about how they might be effective—the Malian people.

Cohen’s view is that if you want to know how to triage African hardships, then you’d better ask the Africans.

“Malians have a lot to say about what they want to do with the development aid that comes into the country, but they don’t get [to do] much of it,” she says. “So addressing the priorities of the community in the order they want them addressed was very important to me.”

Sigida is run by a committee of local citizens charged with planning projects that focus on education and resource acquisition to benefit public health and infrastructure. In just a year, the committee has launched a network of health advocacy programs in which lifesaving medical practices are shared. Cohen, now back in the U.S., is currently organizing a fundraising campaign for Sigida to catalyze the construction of a clinic for 28,000 people and a badly needed trash disposal system.

Cohen’s long-term plan is to adapt the MHOP model to benefit other African populations living in similar conditions. “A simple idea [like Sigida] can be radically redrawn as appropriate for the community in question,” she says.

For more information on Sigida Keneyali, visit www.malihealth.org.

Cohen’s address in Sikoro is “Pig Corner, ask for the white girl.”
Ana and Mia Are Not Your Friends

The Internet proves to be fertile ground for sites that promote eating disorders.

BY CARLY D. LEVY MD’07

Anorexia nervosa kills. This common eating disorder, largely affecting females from twelve to twenty-five, often poses a mortal threat. Knowing this, how could anyone promote anorexia?

An underground movement doing precisely this lives and thrives on the Internet. A query for “anorexia” on popular search engines promptly yields many pro-disordered-eating websites. Pro-anorexia—“pro-ana”—redefines, usually subtly, anorexia as a lifestyle choice rather than as a disease requiring treatment. Many of these sites are interactive forums where extreme weight loss is applauded, starvation is equated with willpower, and female perfection is based on body appearance. A media-savvy appeal to the doctrine of free speech may be linked to a message that “Ana,” a female name, is a member of a persecuted, misunderstood minority group. A parallel pro-bulimia—pro-“Mia”—network exists.

As many as 75 percent of twelve- to seventeen-year-olds now have a home Internet connection. More than 400 pro-ana websites existed in 2003, some claiming more than 350,000 visits. A 2006 Stanford University survey indicated that 40 percent of adolescent girls with eating disorders had visited pro-disorder eating sites; yet almost half of parents were unaware of these sites. The number of sites changes daily, as some are removed by free service providers while others are re-started under new names or move underground into private chat rooms, blogs, password-protected sites or hidden group e-mails. These sites proclaim that successful, extreme weight loss helps control one’s body and life, demonstrates strength and transforms “fat and ugly” to “thin and beautiful.” Many offer the three T's: Thinspiration, tips, and tricks on losing weight and concealing it; the Thinspiration photo gallery exalts cachectic models. Website viewers are given tips on weight-loss strategies, including dieting and purging techniques. They also provide tricks to conceal weight loss, “wear baggy clothes” and “drink a quart of water and don’t urinate before doctor’s visits.” Message boards and interactive chat rooms typically feature inspirational messages such as “Nothing tastes as good as thin feels.”

Many wonder why anyone would support this philosophy. Proponents claim that these sites provide a forum for divergent views that otherwise might be isolating or stigmatizing. Some believe that these sites provide a judgment-free community where members, feeling rejected by the health system or not ready for treatment, may express themselves in the anonymous, disinhibiting setting created by the Internet. Moreover, using such names as “Ana” or “Mia” avoids the impersonal or medical connotation associated with the terms “anorexia” or “bulimia.” These female names personalize the ideology, as if it were a friend rather than a philosophy or morbid lifestyle. A chat room posting might be, “Are there any Anas in Cleveland for me to write to?”

As it survives online and increasingly underground, this movement poses serious public health challenges. As many as 70 percent of adolescent girls seek health information online. Of adolescent girls viewing pro-ana sites, 96 percent reported learning new weight loss or purging techniques. As many as 70 percent of adolescent girls seek health information online. Of adolescent girls viewing pro-ana sites, 96 percent reported learning new weight loss or purging techniques.
behaviors from parents, peers, teachers, and health professionals is dangerous. The pro-ana movement thrives, as public criticism intensifies.

Consequently, some pro-ana website creators have developed strategies to escape detection and censure, by migrating from one free website to another; avoiding free portals such as Yahoo and MSN that may actively censor sites; requiring passwords to enter or to escape surveillance; encouraging text messaging, instant messaging and private, undetectable e-mailing; organizing private chatrooms and social networking sites; using disclaimers and minimum-age warnings to circumvent site removal; or backing up pro-ana sites on hard drives so they may be relocated rapidly.

What can be done? Interventions are challenging because of the accessibility and anonymity of the Internet. For some, censorship is a legitimate approach. Common search engines such as MSN and Yahoo that host free sites have specific terms and conditions to which all websites using their services must adhere. These portals and organizations such as Anorexia Nervosa and Associated Disorders (ANAD) actively scrutinize pro-ana sites to find any breach of terms and conditions, in order to legitimately close sites. This enforcement process is laborious.

Another strategy involves electronic security and filtering systems that can be installed on computers to monitor or block access to specific websites or content. Data indicate that as few as 50 percent of parents have installed filters on their children’s computers. Parents should consider establishing rules for Internet use, checking which sites their children visit, and having home computers in open family spaces. Media literacy programs may help equip teenagers to critically assess media content. Evidence indicates that interactive, school-based efforts may reduce internalization of pervasive media messages about body image and weight concerns. The community health clerkship at Brown’s medical school has produced a pamphlet on dangers of the pro-anorexia movement for pediatric providers, schools, and parents.

A pro-anorexia movement exists and thrives on the Internet. These websites commonly advocate unhealthy practices with potentially devastating consequences.

**Brown’s community health clerkship has produced a pamphlet on dangers of the pro-anorexia movement for pediatric providers, schools, and parents.**

Carly Levy is an intern in pediatrics at Thomas Jefferson University, in Philadelphia. Edward Feller, MD, a clinical professor of medicine and co-director of the community health clerkship at Alpert Medical School, and Suzanne Riggs, MD, a professor of pediatrics at Alpert Medical School and director of adolescent medicine at Hasbro Children’s Hospital, collaborated on this article. The article first appeared in the Providence Journal.
It’s Simple, Really
A patient stirs painful memories.

BY SARAH ELIZABETH WAKEMAN ’05 MD’09

Even before I entered Mr. D’s room, I knew what to expect. Mr. D was a long-term alcoholic in end-stage liver failure, laying all his hopes on a transplant that he would almost certainly never receive. He was here to rule out spontaneous bacterial peritonitis, an infection of the fluid that had been building in his belly over the past four years as his liver gave out. The case was told to me briefly, with even more than the usual dose of hospital cynicism. As I would come to learn, Mr. D was an archetype of sorts; liver failure patients were far from a rare occurrence here. As I heard the details I could already picture him, the jaundiced skin sprinkled with burst capillaries, the swollen belly rising like a perfect half dome beneath the sheets, and the sad, watery, yellowed eyes. He would look just like my father did the last time I saw him.

* * *

I often wondered how my father seemed to his doctors. Did they view him as the brilliant academic, the book author and international historian that he tried always to present to the outside world? Or would they take one look at his medical history, see the chart labeled with cirrhosis and chronic pancreatitis, and write him off as one more of “those” patients? I wonder if he recounted for them the fictionalized accounts of his children’s lives that he spun for friends, the details of birthday parties he’d never attended, the reports of school and friends he’d heard third hand. He was nothing if not a storyteller, and he seemed to believe, or at least hope, that he could rewrite his own history in the telling.

As a child, I grew up believing in his words. It was easier to assume he meant it when he told me how much he loved me, to trust him when he called to say he was sick again and wouldn’t be coming that weekend. Even as I got older and it became clear that words and actions were not two things that went hand in hand for Dad, I still grew hopeful every time he promised he would call or show up. I carefully sketched out plans for the bedroom he said would be all mine in his new apartment, told my friends about the swimming pool we would use, and then sat and waited as the months ticked by. Years later, at one of our biannual dinners, I stood and looked out the windows of the extra room Dad used as a study at the blue waters of the pool that seemed miles away.

* * *

With his bright tattoos and missing front teeth, Mr. D looked nothing like my professorial father, clad always in blue button-downs. Yet as I’d envisioned, the stigmata were all the same. The stories also had common threads: the wife who finally had enough and left, the son and daughter he claimed he saw every weekend. As he flipped open his wallet to show me their school photos, I flashed on the framed photos in Dad’s office and wondered if he had kept photos of us with him during those final hospital stays.

Mr. D told me he relapsed five days before his admission. After three years sober and finally getting on the liver transplant list, with one swallow he threw it all away. I wanted to understand why, I guess that’s always been my problem. I asked him if he’d been depressed recently or if something awful had happened. He looked me in the eye and said, “It’s simple, really. I just picked up.” Out in the hallway, I told my resident Mr. D seemed like a nice guy. “They all do,” she said.

In rounds, I presented Mr. D’s case. “Forty-eight-year-old male with a history of cirrhosis due to alcohol abuse, hypertension, and depression who presents with abdominal pain status post a paracentesis showing 212 nucleated cells and many bacteria.” Technically Mr. D didn’t meet the criteria for spontaneous bacterial peritonitis, and we debated whether we should start treatment. The consulting GI doctor advised against treatment. “If there’s still a hope he might remain on the transplant list being labeled with SBP might jeopardize his spot. Besides, it will mean he has to get weekly prophylaxis until…” The timeline hung in the air. “Until he dies” is what the doctor meant. We continued to discuss back and forth until the senior resident asked the standard ethical question meant to remind callous medical professionals of the humanity of our patients.

“How would you treat him if he were your father?” he asked. I turned away.

Sarah Elizabeth Wakeman is in her third year of medical school.
local doctors from the Shanghai Center for Disease Control and the Chinese Academy of Sciences. Shanghai has the highest incidence of sexually transmitted infections in China, with a population even larger than Beijing. In published surveys, 8 to 10 percent of Chinese men admitted to having had a prostitution experience at some time in their lives. This is alarming.

We therefore organized this project with the hypothesis that migrant women in Shanghai are at very high risk for acquiring and transmitting HIV as well as other infections. This marginalized population has been little studied in China because of their illegal status and traditional discrimination against their occupation, as well as widespread denial of the extent of commercial sex work and HIV. The project would also allow us—having just completed the first year of medical school—to put our newly acquired medical knowledge and interviewing skills to use in our childhood homeland; we were both born in China and raised in Cantonese-speaking families here in the U.S. We would be able to hone our Mandarin-speaking skills as we interviewed more than 500 women using oral surveys with the help of local doctors.

Although the Chinese government has declared HIV a national public health problem, sexually transmitted infections remain a taboo topic—even for many health care professionals. On our site visits to community health centers, many local health workers strongly insisted that HIV was not a local public health threat; many insisted that homosexuality, teen pregnancy, and drug abuse did not exist in their communities. One explained that while the government had written policy directives supporting action to prevent an HIV epidemic, these
FIELDNOTES

policies did not elucidate specific interventions: “If you do nothing, you cannot go wrong because you are not associated with it,” she said.

We found little consistency among the strategies employed by different public health districts. We were told that district health chairmen are typically appointed by the Communist Party and have considerable autonomy. They will approve or reject a project on the basis of personal connections and their relationship with the project’s primary investigators, as well as the impression of their districts they wish to give their political bosses. And it was natural to want to give the impression to the Central Government that public health in their districts was excellent.

For this reason, organizing and conducting our research was much harder than we had anticipated. We discovered that forging personal connections with local collaborators was crucial to obtaining official support for our study. Fortunately, Dr. Alphon Amitai, a teaching fellow in emergency medicine, helped us tremendously with this networking process.

Born in Africa, Dr. Amitai earned a degree in Asian studies from Berkeley, attended medical school at Tel Aviv University in Israel, and is now a fellow in international medicine at Rhode Island Hospital Department of Emergency Medicine. He is fluent in Chinese and knowledgeable about the history of its many dynasties. (Did we mention that he also speaks Hebrew, Spanish, and French?) He has impressed not only his Chinese-American students but also our collaborators in China. During a preliminary winter visit to Shanghai, Dr. Amitai acquired a powerful local ally for our project, a People’s Liberation Army General with an interest in epidemiology and many contacts with local researchers. In turn, during our time in Shanghai, we were able to meet with liberal and dedicated epidemiologists as well as community physicians, all of whom were interested in learning American approaches to HIV research and prevention.

SETTING UP SHOP

In the spring of 2007, with the guidance of Dr. Amitai, we were able to define a comprehensive plan for our project. It involved hiring community outreach workers and doctors to facilitate our surveying migrant women (in a range of occupations) and their managers. We would collect demographic data (age, education, place of origin, family status), HIV/STI knowledge, and information about access to health care. We were especially concerned about women’s mental health, a topic under-addressed by contemporary public health specialists in China. More than 95 percent of our study population comes from economically underdeveloped parts of rural China, where higher education is unavailable. Arriving in the big urban setting of Shanghai, these women virtually do not know anyone, and “work” twelve to fifteen hours at their salons and massage places serving customers (either with or without clothes), usually six to seven days per week. They therefore did not have opportunities to pursue normal social activities with the outside world, nor did they possess additional professional skills for a career change.

We arrived in Shanghai in June, and Dr. Amitai was with us for several weeks to help us get started. We based ourselves in an industrial, working-class district on the north side of town, near Shanghai’s ports, which is home to many migrant workers, sailors, and prostitutes. With an estimated population of 1.26 million, more than all of Rhode Island, the district was the perfect location for our study. We rented a cheap apartment near the steel factories. At night, most of the local hair salons lit up red lights and transformed into brothels.

When we began our survey, we were surprised by how enthusiastically the migrant women and their managers welcomed us to their places of business. We visited typical sites of employment: restaurants, factories, hair salons, massage parlors, and saunas, and found a 70 to 80 percent willingness to complete our surveys. Many women were especially happy that visiting researchers were taking an interest in their well being. They were grateful that we offered them advice and condoms. Some criticized the free condoms given out by previous community health workers as being too thick and rubbery. One might think this silly, but now we understand that condom use rate might easily be improved if we simply “improve the quality of condoms.” Some community doctors gave out their personal cell phone numbers so that the migrant workers could call them to discuss their health needs privately.

PERPLEXITY IN THE WORKPLACE

We also made other poignant observations: sex workers usually are employed in cover businesses, such as hair salons or foot massage centers. One line of our survey asked respondents to define the nature of their place of work. Some weren’t even sure what type of business they were pretending to be employed in. Our survey also asked whether respondents found their jobs and daily activities to be meaningful. While this was a validated component of the CHQ-12 mental health screen, sex workers occasionally commented that it seemed odd to be asked those questions. Still, we were glad we had asked—data analysis showed 45 percent of respondents were at risk for depression, more than double the rate of the general population in China. Future studies should conduct more detailed mental health screens for depression, suicidal ideation, bipolar disorder, and schizophrenia in this population. In addition to the stress of having to provide sexual services to strangers, there are many other
reasons why this group of women may develop psychiatric illnesses, such as lack of self-esteem, pessimistic view of the future, and potential for substance abuse.

During our surveys, business went on as usual. Customers walked in and interacted with our subjects without appearing to mind or even notice our presence. Typically, they would enter, point at a woman, then disappear with her into the back of the hair salon, without obvious price negotiation. On one occasion, a customer was told that the woman he had requested was not being “marketed,” but would he care for someone else? He accepted the alternative offer. Another time a nervous-looking man in his fifties was refused service by a very young-looking twenty-year-old.

Police occasionally walk into hair salons to “check” licenses and arrest suspicious-looking women. (Given the nearly ubiquitous presence of brothels in Shanghai, we suspect some district police receive “protection” payments.) Police suppression efforts in general appeared to us to be sporadic and ineffectual and support by the local public health workers for the police presence lacking. One epidemiologist mentioned that in a study of several months when police actively suppressed commercial sex work in a nearby district, the rates of sexual assault and rape went up.

On one occasion, Lily was inspected and photographed by the police, who took her for a prostitute. She was initially horrified. Her first thought was “I am not like one of them.” She was embarrassed by this reaction and realized, for the first time, how much prejudice she also held against them. Sharing in the prostitutes’ experience of police humiliation, if only briefly, let [Lily] understand the stigmatization these women have to face every day.

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Brown sophomore Ruhan Nagra in her dormitory room on campus

10 Million Saved

*Cancer survivors are a growing breed.

But what is life really like after cancer?

BY KRIS CAMBRA
PHOTOGRAPHY BY RICHARD HOWARD

Three years ago, Ruhan Nagra ’10 MD’14 was a typical, hard-charging high school junior with her sights set on getting into a good college. When she began experiencing flu-like aches and fatigue, she dismissed them as stress, and even a relentless, racking cough and shortness of breath could not
The report acknowledged, however, that “the lack of clear evidence for what constitutes best practices contributes to a wide variation in care.”

Most of what is known about the physical consequences of cancer treatment has been learned through the Childhood Cancer Survivor Study (CCSS), a retrospective cohort study of children diagnosed with cancer between 1970 and 1986. The study uses the patients’ siblings as controls. Last year, researchers published an article in the New England Journal of Medicine analyzing the incidence and severity of chronic health conditions in the adult survivors of childhood cancer. Astonishingly, nearly two-thirds had at least one chronic condition, and among thirty-year survivors, the incidence was 73 percent.

Professor of Pediatrics Cindy L. Schwartz MD’79 is director of Hematology/Oncology at Hasbro Children’s Hospital and a member of the CCSS Scientific Advisory Board. She has spent much of her career building and shaping the study of cancer survivorship and establishing some of the first hospital-based survivorship clinics in the country, including the one at Johns Hopkins. One year ago, she began work on Hasbro’s clinic.

“Overall, anyone who has survived cancer is considered a survivor from the day they are diagnosed. But for most of the formal studies that we’ve done we use the five-year mark as the start of long-term survivorship. That doesn’t mean you don’t think about risks before five years, but at that point you’re no longer worrying that the disease is going to come back,” Schwartz says.

For young survivors, those who will live for decades after treatment, figuring out what after-effects they might experience is especially important. The world of adult oncology has been slower to think about and address late effects (the side effects of chemotherapy, surgery, and radiation that only become apparent with long-term monitoring of the patient over a period of years). Schwartz thinks that might be because some of the risks involved, such as infertility and cardiac or lung disease, get mixed up as part of normal aging, “whereas when a child has a cardiac problem, it’s not supposed to be. In addition, therapy affects the growth and development that marks childhood. [Pediatricians] became attuned to late effects much earlier.”

At the Hasbro survivorship clinic, Schwartz and June Bjerregaard, a nurse practitioner, first review each patient’s treatment history, to understand exactly what types of therapies the person was exposed to. They calculate the patient’s risks and then interact with whatever specialties he or she needs. Neuropsychologists are available because people who have had radiation to the brain or certain chemotherapies have to be monitored for school functioning or learning disabilities. An endocrinologist is available to help with thyroid or fertility complications, and a social worker to address psychosocial issues.

Nearly two-thirds of childhood cancer survivors have at least one chronic condition.
The effects of treatment depend on the tumor, how it was treated, and the age at treatment. “One major concern of the survivors,” Schwartz says, “are secondary malignancies. We know radiation therapy can increase the risk of tumors in any area that’s irradiated. Chemotherapy can cause secondary leukemias.”

An expert in Hodgkin disease and chair of the Hodgkin Disease Committee for the Children’s Oncology Group, Schwartz says that one of the after-effects that has received the most press is the high rate of breast cancer in Hodgkin disease survivors. “It can be as high as 20 to 30 percent in women after twenty to thirty years.”

Before she began treatment, Ruhan Nagra’s doctors did discuss the potential side effects, but she doesn’t believe they would have had the discussion if her father, an anesthesiologist, hadn’t asked. While Hodgkin’s is one of the most curable cancers, with a 93 percent cure rate, the CCSS showed that its survivors have the highest risk of second cancers and heart disease.

“I am more prone to leukemia because of chemo. I am more prone to breast cancer because of the radiation. I have to start getting mammograms when I’m twenty-five instead of forty. That’s very alarming,” Nagra says. Still, she tries not to worry too much. “Treatments are always advancing and who knows what will be available. Every year things are changing in the medical field. I try to be logical about it.”

Schwartz is quick to point out that treatments have changed radically over the past twenty years; doses of chemotherapy and radiation have been ratcheted down.

“From 1986 on children got twenty to twenty-five gray [units of absorbed radiation] compared to thirty-five or forty gray previously. It’s not as clear that the risk of breast cancer is that significant when you get down to the doses we’re doing now,” she explains.

That’s why survivorship clinics are learning experiences on both ends—physicians learn from patients what the effects are and then adjust the treatments accordingly. And it’s a balancing act. For every drug they stop using or for which they decrease the dose, they need to find an alternative that can achieve the same success.

“Late effects feed back into what you do up front,” Schwartz says. “It’s fine to cure the disease but you have to cure the person. We now try to plan treatments that will eradicate the cancer with minimal risk of long-term injury.”

What’s also become clear is the need for survivors of childhood or young adult cancers to be followed closely by physicians who understand late effects and know what types of complications to look for in the future. While the survivorship clinics can provide some of that follow-through, it may not be feasible for every survivor to be seen in such a clinic just yet. Patients also need to know the complete history of their treatment. Saying “I was treated for cancer” is not enough, since the specific drugs and doses can result in very different complications.

The transition from pediatric care to adult internal medicine can be tricky for survivors, too. Even when the transfer of medical records and history is done well, patients can fall through the cracks. Schwartz says, “The optimal people to follow these childhood cancer survivors will be family practitioners or physicians trained in both internal medicine and pediatrics.” That continuity of care can ensure that survivors are followed appropriately across the lifespan.

**SOUND MIND AND BODY**

Human service providers and cancer survivors themselves are lobbying for a true...
“whole person” approach to treatment. Another IOM report, just released in November, tackled the psychosocial health care needs of cancer patients. Brown’s Associate Dean for Public Health Terrie Fox Wetle served on that panel.

Despite evidence that caring for patients’ psychosocial health clearly reduces their suffering, helps them adhere to treatment, and facilitates their return to health, the panel concluded that “attention to patients’ psychosocial health needs is the exception rather than the rule in cancer care today.”

Clinical Associate Professor of Family Medicine Margaret S. Wool, PhD, is a clinical social worker who specializes in psychosocial oncology, counseling survivors and their loved ones.

Her patients, she says, have a wide range of experiences both during and after treatment. One man is concerned about communication with and among all of his doctors. Another is coping with total impotence after prostatectomy. Many are dealing with scarcities of money, insurance, transportation—all of the classic barriers to care.

“I’ve had to sit with young people who...
are dying of cancer and help them decide who is going to have custody of their children following a contentious divorce when they believe the other parent is unfit,” Wool says. These are problems that are outside the scope of medical concerns so physicians may not get involved in them, and practitioners don’t always know what to look for.

“All the other problems of life don’t stop just because you have cancer. In addition to the emotional strain of cancer, sometimes there are other things, too. People get divorced, people have other issues.”

Families can feel very lost and confused about cancer treatments and their aftereffects. Wool describes a young man in his early thirties who started having cardiovascular and gastrointestinal problems due to cancer treatment he had received as a five- or six-year-old. It soon became clear that nothing could be done to resolve the complications, and he died.

“It helped him and his wife to be able to talk about the process with me even though we couldn’t change it,” Wool says. “Providing the support was very valuable. We addressed issues that were very meaningful for accepting his decline, and confronting her bereavement and future without guilt.”

In fact, she says, the role of support and contact is so strengthening that people can do things they wouldn’t have thought they could do.

“I have seen positive outcomes, where women who have been in unsatisfying and even abusive marriages say ‘I got through cancer treatment and I’m stronger than I knew, and I’m not putting up with that anymore.’”

For the most part, people emerge from cancer as much the same person they were before. Wool says some do reevaluate their lives, and take on a “don’t sweat the small stuff” attitude, as if now that they’ve survived a major illness every other obstacle in life is trivial. Typically that change is fleeting. “If you’re a crank before, you’re going to be a crank after. If you are optimistic and nice before, you still will be. Your basic character doesn’t change.”

There’s also some expectation put upon people in cancer treatment that the greatest factor affecting their survival is their own state of mind, that remaining positive and upbeat results in faster and fuller recovery.

Nagra debunks that myth. “People always talk about your good attitude, and that that will help you. And that’s not true. I met a lot of people who had a horrible attitude about it, but that was just their way of dealing with it. Some people with horrible attitudes are going to be cured. And some people with good attitudes are going to pass away. It’s all luck of the draw. It’s nothing you have control over.”

Some patients do experience significant anxiety and depression, and require more concentrated attention. Wool works with a radiation therapy practice and many of its patients are referred to her. She believes, however, that she is not seeing all of the patients that could use professional counseling, and one reason is some remain tightlipped about their emotional status. She hopes to begin using a screening instrument with all patients in the practice to help identify those at risk for severe emotional strain.

And, she says, there are certain objective things that doctors ought to look out for, even when a patient won’t admit they are having difficulty. “Being the parent of a young child, or having anyone dependent on you, such as an elderly parent, is one. Recent bereavement, other chronic illnesses, and any history of psychiatric illness … a history of depression makes one more vulnerable to depression in response to cancer.” These are the people who should be referred for psychological services.

“There’s more distance to go in having a clear profile of the people that need help, but we know what some of the psychosocial characteristics are and we can put mechanisms in place to reach out to them.”

**LIVE STRONG**

**Psychosocial stresses** are particularly devastating for young adults dealing with cancer, people who in general believe they are immortal, who have their first taste of...
freedom from their parents and feel they have their whole lives in front of them.

Doug Ulman ’99 was nineteen years old and just about to start his sophomore year at Brown when he was diagnosed with chondrosarcoma, a tumor growing on the cartilage of his rib cage.

Leaving the hospital after surgery, he and his family were given pamphlets and brochures about support services, but none were for people his age. When they contacted the organizations, “some even said ‘Young adults don’t get cancer.’ We knew the issues young adults were facing were different than they were for children and older adults,” Ulman says.

“Young adults have a sense of invincibility. It’s an awkward time without having cancer and then you add cancer in and it becomes a very complex maze of physical, psychosocial, and emotional issues. Then you add in life insurance, regular health insurance, fertility, dating, social life—it’s not your typical college experience.”

Part of the problem is that the medical establishment is not set up to treat adolescents and young adults. Hospitals are geared more toward the very young or to adults, and that can make it awkward for teens and twenty- or thirty-somethings.

“I wasn’t treated at a pediatric facility. I was treated at the adult facility,” says Nagra. “There were periods when the hardest thing was looking around and seeing all these middle-aged and older people who were really sick. And I was like, Wow, I’m seventeen years old and I have this illness that all these old people have. What’s wrong with me? I felt so out of place. I just wanted to be normal again.”

To fill the gap in support services, Ulman and his family established the Ulman Cancer Fund for Young Adults. They offer a patient navigator program to help young adults make their way through the health care system, a program that matches survivors with someone else who has the same diagnosis, and support groups in several cities. Since cancer treatment leaves many young adults in debt or bankrupt, the Fund offers a higher education scholarship program for those who cannot afford college or trade/technical school as a result of their health care bills.

By day Ulman is president of the Lance Armstrong Foundation. The LAF is singularly focused on helping people survive cancer, facing the reality that it is unlikely cancer will ever be “cured,” but better treatments and ways to detect it early will yield more and more cancer survivors in the future.

“We realized that Lance, for the rest of his life, will be a survivor,” Ulman explains. “When he won the Tour de France, people started to forget his survivorship story, and it’s a very powerful one. He had to bank sperm so he’d be able to have kids, he was dropped by his cycling team which meant he had no insurance, he wasn’t sure he’d be able to go back to his job again.

“All these psychosocial and practical issues, sometimes they get lost and people see him standing on the Champs-Élysées and they think, ‘Oh, he’s lucky, he’s a famous person,’ but he went through all these survivorship issues himself. And that’s one of the reasons we decided to focus on it.”

LARGER THAN LIFE
Margaret Wool calls people like Doug, who returned to the soccer field after his cancer surgery to help Brown to three Ivy League Championships in four years and has since participated in a dozen marathons, including a 100-mile race in the Himalayan Mountains, “supersurvivors.” But, she says, she understands that while many are inspired, other survivors resent that because it implies “if you’re not achieving outstanding physical or personal accomplishments that somehow you’re not really doing it well.”

Some, like Ruhan Nagra, prefer not to be called a survivor at all.

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...[P]eople see [Lance Armstrong] and they think he’s lucky...he’s famous...but he went through survivorship issues himself.”

“I take so much issue with the word ‘survivor,’” she says. “The use of war metaphors to describe any illness, including cancer, does such a disservice. What does that say about the people who didn’t live? It’s not about courage. It’s about people doing what they need to do to get well. And we all want to be healthy.”
Nevertheless the experience was life-changing for her. Before cancer she had envisioned a career in international relations. She enrolled in the Program in Liberal Medical Education instead, because being sick made her realize she could help others more directly.

“I used to think, Those are other people's problems. It’s like you’re hearing someone else’s story, but then it’s your own and you realize that and it changes everything. The one lasting thing [cancer] gave me was direction in my life and a sense of purpose. It gave me passion for this.”

While she says it feels “pretentious” to say she knows what kind of medicine she wants to practice, as she is only a sophomore, Nagra feels that as an oncologist, she will be able to relate to patients in a way other doctors cannot. Though it will not always be appropriate to reveal to patients that she, too, had cancer, she believes she can convey that empathy without saying a word.

“It’s an unspoken understanding. And patients can sense that, it doesn’t need to be verbalized. It will help me connect with them better and they would also feel that connection.”

Even the “supersurvivors” like Ulman and Lance Armstrong believe each person has to live his or her own version of survival.

Doug Ulman and colleagues at the Lance Armstrong Foundation were sitting around the office one day when they stumbled across a disturbing statistic buried in a National Cancer Institute (NCI) report. Over the past thirty years, survival rates for young adults with cancer have not increased at all. If you are thirty years old today and diagnosed with cancer, no matter what type of cancer, your chances of surviving are less than what they were in 1975.

Ulman picked up the phone and called the director of the NCI. The conversation led to a progress review group, or PRG, on young adult oncology to find out why there was this lack of survival. PRGs are considered the “gold standard” for scientific strategic planning at the federal level, and in the past had only been done for individual cancer sites, like breast, prostate, and colon.

The Lance Armstrong Foundation put up a quarter of a million dollars for the PRG, and was matched by $250,000 from the NCI. “It was the first ever private-public partnership” of this type, says Ulman.

The findings revealed a perfect storm of factors, from the scientific to the psychosocial: biological differences in the cancers that manifest in adolescents and young adults; a dearth of research on young adult cancers; delayed diagnosis; too few young adults enrolled in clinical trials; lack of psychosocial support; and lack of health insurance.

The PRG resulted in five recommendations with the goals of increasing young adult survivorship, improving quality of life, providing advocacy and support, and improving health care delivery across the continuum, from earlier diagnosis to better end-of-life care. With the PRG’s recommendations as a guide, the LIVESTRONG Young Adult Alliance was established, bringing together nonprofit organizations and medical institutions, and in late 2007 the Alliance issued its strategic plan. “We believe if we can implement these strategies we can change the curve,” says Ulman.

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Even the “supersurvivors” like Ulman and Lance Armstrong believe each person has to live his or her own version of survival.

Ulman has this take on it: “Cancer should not control someone’s life. Anybody who is diagnosed with cancer should have the opportunity to live and live well. To go back to work and to see their kids graduate from school and to be around their family and to do all the things, if not more, that they had planned on prior to having cancer.”
FOR Ourselves AND Others
Patient advocacy groups push their agenda:
FIND A CURE.

BY
SHARON TREGASKIS

PHOTOGRAPH
BY SCOTT KINGSLEY

Richard Siravo, with a photograph of his son, Matty
Matthew Siravo died on May 11, 2003. The cause: cardiac arrest and massive brain damage induced by a grand mal epileptic seizure lasting ninety minutes two days earlier. Matty’s death certificate was signed on Mother’s Day. He was five.

Within a month, Matty’s parents, Richard and Debra Siravo, had parlayed their grief into the first of what would become a trio of annual fundraising events—a golf tournament, a 5K road race, and a winter ball—all intended to increase epilepsy awareness, support families coping with the diagnosis, educate physicians and school personnel, and fund basic research. To date, the family’s Matthew Siravo Memorial Foundation, based in Wakefield, Rhode Island, has raised more than $600,000, established a visiting professorship in pediatric neurology at Hasbro Children’s Hospital, and awarded $50,000 to support a pilot study of the biochemical pathways affected by anti-seizure medications.

In late November 2007, the foundation hosted a symposium for Brown physician-scientists as part of an effort to cultivate local scholarship on epilepsy and expedite the search for a cure. “When Matty was first diagnosed, we felt as though here in Rhode Island there were very limited resources for parents and families struggling with epilepsy,” says Richard Siravo, who now serves as the foundation’s full-time executive director and staffs the state’s only resource center for families dealing with diagnosis and treatment. “We surround ourselves with folks who have children with epilepsy, so we have a lot of pressure on us and a great burden on our shoulders to commit our funds to research.” The Siravos aren’t alone. Nationwide, as the Internet makes it possible for families faced with rare and tragic diagnoses to find one another and share the stories of the poorly understood diseases that afflict their loved ones, patient advocacy groups are forming at a record pace. To date, most groups struggled to share information on symptoms, treatments, and coping. Now they’re drumming up interest among researchers and facilitating the search for cures, in the process delving into the genetic roots of disease and funding investigations of biomedical fundamentals.

There’s no doubt that without these independent funding agencies and advocacy groups, there are niche research programs that would never see the light of day or never even be initiated,” says Dr. Tom Tracy, vice chair of the Department of Surgery at Alpert Medical School and pediatric surgeon-in-chief of the division of pediatric surgery at Hasbro Children’s Hospital, who serves on the Matthew Siravo Memorial Foundation’s Professional Advisory Board. “They’re essential to this kind of work.”

A LITTLE HELP FROM OUR FRIENDS

The grants from such groups aren’t huge, often just $100,000, spread over two years—but it’s enough to get a scientist interested, launch a pilot study, and collect preliminary data to support a more ambitious grant application to a federal agency, says Professor of Medicine Sharon Rounds, the chief of pulmonary/critical care and of the Medical Service at the Providence VA Medical Center and former president of the American Thoracic Society. “It’s a small portion of total biomedical funding,” says Rounds, who serves as co-chair of the Scientific Advisory Committee that reviews all grant applications considered by the ATS,
which collaborates with patient interest organizations to fund a wide range of inquiry. “But for a young person starting out, it’s seed money to get them off the ground and running. For the patient interest organization it’s a way to attract investigators into research that’s relevant to their disease.”

Perhaps even more important than attracting new researchers is the continuity patient interest organizations provide in the face of shifting federal priorities. “There’s always a political, cultural impact on where public dollars go. That’s inevitable,” says Director of Child Neurology at Rhode Island and Hasbro Children’s hospitals David Mandelbaum, who received funding from the National Alliance for Autism Research. “Now autism is very prominent, but there was a time it wasn’t and the only way to get money was through NAAR and some of these other organizations. These are the kinds of agencies that not only generate investigations in areas that might not be getting the focus, they can also provide bridge money for the lean years.”

As with autism, funding for AIDS research has ebbed and flowed, with patient advocacy groups such as ACT-UP and the Gay Men’s Health Crisis working to keep the disease in the public spotlight for two decades. Ditto for myriad breast cancer groups and the families of kids with juvenile diabetes.

Often, says ethicist and Clinical Assistant Professor of Emergency Medicine Jay Baruch, patient advocacy groups address inequities in public funding. “From a justice perspective, there are maladies that will be left out of the fray,” says Baruch, who serves as director of Brown’s medical ethics curriculum. “How many people do you know who have muscular dystrophy? But Jerry Lewis has been doing his telethon for years and raising money for MD.” The trick, he and Rounds agree, is balancing the need for investigation of orphan diseases that afflict small numbers of patients with the imperative to achieve the greatest good with the limited research dollars in the federal budget.

“The little ones get a disproportionate share of the pie?” asks Rounds. “Sure they do. But because of the work that’s done in understanding the mechanisms of the disease, they provide scientific insight that’s relevant to other diseases.”

Molecular biologist Walter Atwood investigates the JC virus, a human polyomavirus that can precipitate the fatal demyelinating disease Progressive Multifocal Leuкоencephalopathy in AIDS patients. Recently, the disease PML occurred in two multiple sclerosis patients and in one Crohn’s disease patient being treated with immunosuppressive drugs and a new medication known as Tysabri. This prompted Atwood to apply for a small pilot project grant from the National Multiple Sclerosis Society. The application was funded, making Atwood the first Brown researcher to receive funding from the Society. The application focuses on developing a novel stem cell model to understand how the virus attacks oligodendrocytes, the neural cells affected both by PML and MS.

“In the lab, the research is expensive,” says Atwood, “and the money provided by the pilot project grant will allow us to bring this technology into the laboratory.” If all goes well, says Atwood, whose primary support comes from two longstanding National Institutes of Health awards, the relationship could yield further funding. “Potentially, if this pilot project goes forward and we make good progress, we would be in a position to apply for a larger chunk of money.”

“Can these families dictate what constitutes good science? Are the studies being done in an objective, scientific way?”

When it comes to patient advocacy groups, money is only part of the equation, says Rounds, who spent five years in the nineties working on cystic fibrosis after the CF Foundation awarded her a small, two-year grant to extend her research in that
serves as chairman of the board and heads Gordon serves as medical director; Berns, MD, MPH, founded the Progeria Research Foundation at their kitchen table. Berns, who highlights the possibilities for gaining a better understanding of the healthy aging process through PRF-funded investigations. “Certainly there’s a lot of basic science that’s essential to building toward a clinical trial or finding the gene for your syndrome, but the mission itself is medically based.”

“In the eight years since its inception, PRF has distributed $1.5 million in research grants, established a cell and tissue bank, organized and run five scientific workshops on progeria, all of which were co-funded by the NIH, and conducted lobbying that resulted in language in the Children’s Health Act of 2000 supporting progeria research. In May 2007, PRF began funding a clinical drug trial at Boston Children’s Hospital, a two-and-a-half year, $2 million effort, for which Gordon serves as a co-investigator. “Everything we fund is funded with an eye toward...finding a cure for progeria,” says Gordon, who, who helped isolate the progeria gene in October 2002, co-authored an April 2003 Nature article detailing the mutation behind the disease, and in early 2006 co-authored two reports in the Proceedings of the National Academy of Sciences describing a mutant form of protein that damages blood vessel cells (see Brown Medicine, Spring 2006). The finding may shed light on the progression of progeria and atherosclerosis, a leading cause of heart attacks and strokes. “Living with a child who has progeria certainly makes [the work] more directed and more time-sensitive.”

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Rigorous peer review has been critical for PRF, says Gordon, because the quality of the data her group funds propels the research to the next level. “We seek to partner with the NIH, complement the NIH, work with the NIH,” she says. “We wanted to give laboratories a chance to get start-up data to garner larger grants from the NIH. Where a lab might have been doing nothing on progeria, now they can go to the NIH and say ‘Here’s what we’ve got, will you fund us?’”

Mandelbaum sees an added benefit in peer review—allowing scientists to do their best, most objective work, while patient interest organizations deploy the passion and dedication that makes them incredibly effective advocates. “You need that dispassionate jury to allocate the funds, but to get the money obviously you want the passion of the advocate,” he says. “It’s a good combination if they’re kept separate.”

But even with dispassionate peer review, advocate-funded research isn’t without its challenges. Grants from the NIH include close to 50 percent funding for overhead—expenses associated with actually running a lab. Unlike many interest group-funded grants which preclude coverage for overhead, Atwood’s MS Society award includes a 10 percent overhead account, which he credits with having facilitated Brown’s willingness to accept the funds. “Most societies are like that,” says Atwood. “They want their money to be used for research. They don’t want the money to be used for the light bulbs and electricity we use in the building to actually do the work.”

Many smaller foundations also explicitly preclude salary support for clinicians whose research endeavors compete with responsibilities to generate revenue through patient visits. “Time is the most important commodity,” says Mandelbaum, whose NAAR grant allowed him to hire a statistician and a research assistant, and dedicate some of his own attention to a languishing dataset accumulated through an NIH-funded project. “You’re often asking people to spend their nights and weekends to do the work that is made possible by the non-salary support money.”

MAKING IT PERSONAL

Meanwhile, Baruch credits patient interest organizations with an ability physician-scientists simply don’t have—putting a name and face to the diseases legislators crafting federal budgets might otherwise fail to recognize.

“If there’s an identifiable face to a person who needs a certain treatment, people are more apt to do everything, or go to more extreme measures and make more of a financial commitment,” says Baruch, citing Michael J. Fox’s work on behalf of Parkinson’s awareness and funding. Rounds, who takes vacation time from her appointment at the VA Hospital to lobby for funding for the NIH and VA on behalf of the ATS, says nothing compares with the power of a patient to bolster a scientist’s message about the need for research funding.

“When a doc goes and lobbies for funding from the NIH, there’s a lot of self-interest involved and the legislators and their assistants say, ‘Sure, they’re lobbying for themselves,’” says Rounds. “When you go with a patient who’s wearing oxygen, who has to catch his breath before finishing a sentence, it has a visceral impact and the message from the professional comes through much more effectively.”

While the Siravo Foundation hasn’t yet launched a lobbying effort, the Progeria Research Foundation has seen a significant rise in awareness of its cause during the past eight years. From 1950 through 2002, only 104 peer-reviewed articles tackled the topic of progeria. From 2003 to 2005, there were fifty-two.

“One of the most amazing things I’ve experienced is the number of volunteers, researchers, and physicians who just want to help these children,” says Gordon. “That’s been a privilege for me and given me a lot of hope over the years.”

Ithaca, NY-based freelance writer Sharon Tregaskis reports on health care, the environment, and higher education.
Safekeeping

By Paul Christopher, MD

Even at ten p.m., she looked just dressed for work. Her dark suit was pressed, her makeup was perfectly applied and her jewelry carefully selected. In a soft, dispassionate voice she told me that birthdays were difficult for her. When she turned thirty-eight, her husband confessed to having an affair and divorce followed. She soon fell into a profound depression. Her family doctor prescribed an anti-depressant which she took faithfully for a year and stopped once she felt better. For the next few years she “was fine,” except for the weeks leading up to her birthday when she cried “for no reason,” slept poorly and lost weight. Then, on her last birthday, she put her children to bed, drank half a bottle of scotch, and tried to hang herself from a wooden rafter in her basement.

“I have no idea what happened,” she said. “The next thing I remembered was waking up on the floor with a broken cord around my neck.” Eventually she got up, untied the cord, threw it in the trash and went to sleep. Since then, she had sought no treatment and told no one what happened.

In the past three weeks her mood had darkened again. A feeling of worthlessness now enveloped her. Work was increasingly difficult; she couldn’t focus and had no energy. To get there on time, she’d been waking up an hour earlier than usual. She skipped meals—“I just don’t feel like eating”—and, as a result, had lost ten pounds. “Each night I lie awake dreading the next day,” she said. “I can’t face another birthday.”

When she finished her story I asked a few
A PSYCHIATRIST WONDERS

HOW TO PREVENT WHAT HE CANNOT PREDICT.
I did not want to argue with Hilary. Still, I felt hospitalization was the right option for her, so I went to speak with her again.

A different woman stood before me. Her voice now was edgy, insistent. “Listen,” she began, “I had no idea I wouldn’t be allowed to smoke. I would never have come here.”

I pulled up a chair and invited her to sit down. Then I explained our hospital’s smoking policy: after a short period of observation, if she was felt to be safe enough, she could go on scheduled smoke breaks with staff and other patients.

“I smoke two to three packs a day,” she said. “I can’t wait for a smoke break. How many are there anyway? Six? Eight?”

“There are four.”

“Then there’s no way I’m staying here!”

I took a slow, deep breath and fell back on a strategy that had proven helpful in situations like this in the past: I summarized her story. If she only heard again how bad things were she would remember that she desperately wanted and needed help.

“I know what you’re doing,” she interrupted me seconds later, “and I appreciate it. But I just can’t stay. I’m better off at home.” She smiled politely and moved to the edge of her chair.

I tried again, reminding her she wasn’t just here for herself but for her children, too. I pulled up a chair and invited her to sit down. Then I explained our hospital’s smoking policy: after a short period of observation, if she was felt to be safe enough, she could go on scheduled smoke breaks with staff and other patients.

“I smoke two to three packs a day,” she said. “I can’t wait for a smoke break. How many are there anyway? Six? Eight?”

“There are four.”

“Then there’s no way I’m staying here!”

I took a slow, deep breath and fell back on a strategy that had proven helpful in situations like this in the past: I summarized her story. If she only heard again how bad things were she would remember that she desperately wanted and needed help.

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I tried again, reminding her she wasn’t just here for herself but for her children, too. It was clear, I told her, how much she loved them. “If they were here, they would want you to stay,” I said. At this, her frame softened and she looked away for the first time since I’d come back into the room. We sat in silence for a few moments.

“Each night I lie awake dreading the next day,” she said.

“I can’t face another birthday.”

Besides her mood, she had many of the neurovegetative symptoms, things like loss of energy, appetite, and weight, trouble concentrating, and insomnia. Her prior response to medication was a good sign but she needed a safe place to resume treatment. I told her this and recommended hospitalization.

She agreed. Together, we walked to the waiting room where I left her before returning to the nurse’s station to complete the paperwork needed for her admission.

A few minutes later, a nurse approached. “Dr. Christopher? I just want to let you know Mrs. Asher changed her mind. She wants to leave.”

“Why?”

“She found out she can’t smoke.”

In 1993, the Joint Commission—the not-for-profit group tasked with evaluating and accrediting U.S. health care organizations based on quality and safety standards—prohibited smoking in hospitals. It was a policy most physicians supported, one already enacted at many facilities. Its unintended effect, though, was to make smoking the nemesis of emergency room staff and on-call residents everywhere.

Physicians respond to this issue in different ways. Some argue if patients want to smoke so badly, then they can’t be that concerned about their other problems. Barring a catastrophe, let them smoke. Others have a more paternalistic, “not under my watch” attitude. Patients can accept or refuse a nicotine prescription but they will not be allowed to expose themselves to further harm by smoking.

For psychiatric patients, the issue is more complex. Because so many are at risk of hurting themselves—not by the inevitable diseases of smoking, but more immediately—they cannot be left unattended. If they’re going to smoke, hospital staff must bring them somewhere they can be safely observed. In fact, this is what many hospitals do for psychiatric inpatients. But emergency rooms are not designed, manned, or obligated to accommodate this need. Thus staff are left arguing with patients over the issue while others wait to be seen.

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I tried again, reminding her she wasn’t just here for herself but for her children, too. It was clear, I told her, how much she loved them. “If they were here, they would want you to stay,” I said. At this, her frame softened and she looked away for the first time since I’d come back into the room. We sat in silence for a few moments.
silence and I ran through all the things I could say to her, looking for whatever might convince her to stay and settling, finally, on the truth.

“I’m really worried about you, Hilary.”

She nodded weakly and suddenly began to cry. “Me, too.”

I offered her a box of tissues. “Being here really is the right decision,” I told her. She cried softly for several minutes and I sat with her, saying nothing. When she finished, she dried her eyes, looked directly at me and said, “I can’t stay here, I won’t. I want to go home.”

What gives psychiatrists the right to lock people up? The very idea of forcing someone to be hospitalized breaks one of the basic principles of medical ethics: patient autonomy, the simple notion that doctors should respect their patients’ wishes.

Suppose, for example, a man goes to see a surgeon after his primary care physician finds a pulsating mass in his abdomen. The surgeon diagnoses a 7-centimeter aortic aneurysm. She knows that if it ruptures, this man has a 50 percent chance of dying, whereas if she repairs the aneurysm now, his risk of death drops to 5 percent or less. So she recommends surgery. The patient thinks over and says, “You know, doc, I hear everything you’re saying. But I’ve lived a good life and I think I’ll take my chances.” As long as the man understands his options and the risks of refusing care, he is free to do so. Why shouldn’t the same be true for patients with psychiatric problems?

Actually, in many ways, it is. The majority of decisions about mental health are made by patients, not doctors: whether to start a medication, whether to stay on the medication if a side effect develops, whether to have electroconvulsive therapy. Many psychiatric patients even have advanced directives, documents indicating how they want to be cared for if and when they can no longer make decisions for themselves. For sure, doctors play a part in helping patients make these choices—that is, after all, their job. Most often, patients agree with their physicians’ recommendations. But plenty of times they don’t.

When someone comes in with a problem with the heart, or liver, or spleen, the doctor listens, discusses the options, and prescribes a treatment on which they both agree. But what happens when the affected organ is the brain? What if the ability to appreciate a problem—to think about it clearly—is impaired? When judgment fails, what then?

This is where the controversy starts. Can anyone with a mental illness like depression be involuntarily hospitalized so long as they are shown to have impaired judgment? Historically, the answer has been a qualified yes. For a long time, psychiatrists could involuntarily hospitalize patients for any number of reasons: at the request of a weary family member, because a patient refused to adhere to outpatient treatment, or because the hospital was seen as the ideal place to quickly bring a patient’s symptoms under control. The extent to which a psychiatrist exercised this power depended on his or her professional judgment and the case in question.

In the 1960s and early 1970s, judges reigned in these broad powers. Their landmark rulings reflected what many patients and others had long felt: that the stigma associated with involuntary hospitalization outweighed the potential benefit gained by being there. Many psychiatrists, too, welcomed the change, having been uncomfortable with so much authority over their patients’ lives. By the end of this reform period, psychiatrists were left with only a handful of reasons to justify such a restriction of their patients’ freedom.

Today, mental health codes differ from state to state—for instance, in the number of days one can be held involuntarily before a court hearing (one in West Virginia, twenty or more in Georgia). What unifies them, though, is the theme of danger: to forcibly hospitalize mentally ill patients, a physician must believe they pose a danger to themselves or others, and the risk of this danger must be imminent.

If this sounds more like law enforcement than medicine, it’s because psychiatrists (and other professionals who treat the mentally ill) must serve and protect, not just their patients, but society as well. In that sense, we are agents of the law. And some
who hears voices commanding him to kill his wife, or someone who's swallowed a bottle of sleeping pills. The majority, unfortunately, remain stubbornly unpredictable.

Most psychiatrists go about their work doing little to resist the duties imposed on them by the law. They may concede the limits of our knowledge but, in deciding to hospitalize someone, they believe that patient care remains the primary focus. Of course, our patients may not see it that way.

“Why would you force me to be here?” Hilary asked. “I’m not going to kill myself, I swear. I promise.”

“But how do you know that?” I asked.

“Look,” she said, “I came here voluntarily—”

“—asking for help,” I added.

“Right, asking for help. And I know I need help. But this place isn’t what I need. I’m telling you, if you make me stay here, it won’t help. It will only make things worse.”

The more she talked, the more composed and rational she seemed. Where had the sad and desperate woman I’d just listened to gone? Could her feelings have evaporated so quickly? Was she really no longer suicidal? I went back to see Hilary again—for the last time—to inform her of my decision. She did not take it well. She pleaded with me, unsuccessfully, and then she cried for a long time.

The following morning I woke my wife and told her what had happened.

“‘You’d be even more worried about her if you’d let her leave,’ she said before returning to sleep.

That evening we met several residents at a restaurant for dinner. Inevitably, our conversation keyed on work and I told them the same story I had shared with my wife. Without exception, they all assured me they’d have done the same thing I had. Whether they were being honest or simply supportive of a fellow resident—and I do think they were telling me the truth—was, I later realized, beside the point. What troubled me was not the prospect that my decision to hospitalize Hilary might not meet their benchmark for patient care. Even if they had all disagreed with me—even if I was the one psychiatrist in a hundred who’d have chosen to hospitalize her—the appropriate time to make that mistake, if you could call it that, was during my residency. Medical training consists of hours and hours spent trying to avoid messing up. The irony is that the most powerful learning occurs in those rare moments when something goes wrong.

No, professional reassurance was not enough. I wanted to know that I’d made the right decision. I needed something to tell me she’d been before coming to the hospital.

There’s a saying among residents in all fields of medicine: never worry alone. With this in mind, I excused myself from the interview room and found Dr. O’Reilly, the senior resident on call with me that night. I’d worked with O’Reilly before and trusted his judgment.

I pulled him aside and presented my case. As I spoke, he listened with the same intensity he gave his patients. He nodded a few times when I’d finished, indicating he had all the information he needed.

“So, what do you want to do with her?” he asked.

“Well, I’d like to hospitalize her. But she doesn’t want to come in and I guess I’m not sure I can make her,” I said.

“Tell me something. If she leaves tonight, how sure are you that she won’t kill herself this weekend?”

“Not at all sure.”

“Then I think you have to hospitalize her.” There was no hesitation in his voice, no uncertainty.

Suddenly, I realized why the decision was so easy for him. While I had been worried about depriving her of her civil liberties, he was worried about saving her life.

Put that way, it made perfect sense. How could I let her go when just minutes before she was on the verge of ending it all? And though she seemed to be pulling herself together, who could say how long that would last? Maybe that was nothing more than her craving a cigarette. It had already been several hours since she’d last smoked. Later on, at home, would she find herself right where she’d been before coming to the hospital?

WHILE I HAD BEEN WORRIED ABOUT DEPRIVING HER OF HER CIVIL LIBERTIES, MY SENIOR RESIDENT HAD BEEN WORRIED ABOUT SAVING HER LIFE.

Hilary belonged in the hospital. What could possibly satisfy such a request?

There was a time when predicting heart attacks held the same enigmatic aura that surrounds suicides. In the first half of the twentieth century, doctors watched as the number of deaths from heart attacks rose to epidemic proportions. With little knowledge of what caused cardiovascular disease,
they could do little to save the lives it claimed. But over time, researchers identified the factors at play in the development of heart disease: smoking, diabetes, older age, male gender, and high blood pressure and cholesterol. By targeting the ones that can be treated, our country has witnessed a 50 percent reduction in the rate of heart disease-related deaths.

If we’re serious about predicting suicide—and thereby preventing it—we need to know as much as possible about what happens in the brains of people who carry it out. So far, we know that low levels of a breakdown product of serotonin—one of the brain’s neurotransmitters—are often found in the cerebrospinal fluid of those who die from violent suicides. Also, post-mortem studies indicate suicide victims may have more serotonin receptors in the prefrontal cortex. This area of the brain sits directly above the eyes and, when damaged, often leads to disinhibited behaviors and cognitions. We know, too, that people who inadequately suppress cortisol—a hormone released in response to stress—when stimulated to do so, have a higher risk of completing suicide later in life. However, most of the “weak suppressors” do not kill themselves, and many of the normal suppressors do. This is important to understand: that the result of any laboratory test correlates with a higher rate of suicide says nothing about whether it causes suicide. This is why we don’t test for serotonin or cortisol levels in our depressed patients. Even if we saw a particularly poor suppression of cortisol in a patient, that would be scant evidence on which to base a clinical decision. While we know these markers have something to do with suicide, what that something is remains elusive. We still need to understand the mechanisms—the pathophysiology—that cause suicides, as we do with heart attacks.

What about variables more easily discernable, such as family history, income, employment, and marital status? In the largest study of its kind, Danish researchers led by Dr. Ping Qin looked at socioeconomic and demographic data for the 21,000 people who completed suicide in Denmark over a seventeen-year period. They matched each individual with twenty control subjects of the same age and gender. Confirming what smaller U.S. studies had shown, the Danish suicide victims were more likely to be single, unemployed, and among the population’s lowest income quartile. Having a child was a protective factor—the younger in age, the better.

By a huge margin, though, the strongest risk factor for suicide was a recent psychiatric hospitalization, and the more recently one had been discharged, the greater the risk. On the one hand, this makes sense. People who die from suicide are more likely to have serious psychiatric illnesses, ones often requiring inpatient treatment. But this doesn’t explain why these victims were more likely to have died within days of leaving the hospital.

Were these patients discharged prematurely? Did their doctors decide to send them out before their suicidal thoughts and impulses had resolved? I doubt it. A more likely explanation is that the psychiatrists who treated these victims simply weren’t able to predict who remained at high risk of suicide.

In general, doctors don’t like being asked to make predictions. It’s a lot easier to order a few tests or give a diagnosis. But when we have no choice, when we’re backed into a corner, we tend to give the most conservative answer. That way, our patients may prepare for the worst but hope for the best. (At times, I’ve found myself doing the same. In the iffy business of suicide assessment, this has been especially true.) Yet prediction, with its shortcomings, is the bedrock of this work. For sure, my decision to keep Hilary in the hospital was based on a careful scrutiny of her symptoms and her history. But it was also based on my gut: it didn’t feel right to let her go. That’s not an explanation that any patient would find satisfying. I am not satisfied with it. But what I’ve learned about the practice of psychiatry is that often whom we keep and whom we let go says more about the doctor than the patient.

WHAT I’VE LEARNED ABOUT THE PRACTICE OF PSYCHIATRY
IS THAT OFTEN WHOM WE KEEP AND WHOM WE LET GO SAYS MORE ABOUT THE DOCTOR THAN THE PATIENT.
Remarks like these are at once comforting and disturbing. They mean no one is perfect; even the most experienced doctor may be unsure of what to do. They also offer a sobering appraisal of how little we really know.

One afternoon after seeing patients in the emergency room, I sat in with an attending to review the day’s cases. I’d finished presenting a patient and waited as he wrote a note that would eventually accompany mine into the chart. When he finished I asked him how he felt about having kept so many people in the hospital who didn’t want to be there—so many of whom probably didn’t need to be—over the years he’d been in practice. He set down his pen and rubbed his forehead for a few moments.

“It’s an awful dilemma. And it’s worse than you think,” he said.

I looked at him blankly, unable to think of what could make it worse.

“Yes, we’re terrible at figuring out who’d really hurt themselves or someone else. But even if we could, many of the patients we hospitalize will end up doing it anyway. If someone really wants to end it all, eventually they will.”

I flipped open the chart and found my evaluation. Reading it over, everything was there: the details of her history, my description of her mental state, my formulation of her case—including a statement about why I felt she needed hospitalization—and a plan for treating her. The next page, a nursing note written when she first arrived to the floor, was perfunctory: “Patient oriented to unit, all questions answered. Slept overnight without incident.”

There was only one other note, just a few lines scrawled by the psychiatrist who saw her on Saturday. A couple of sentences summarized her history. Nothing new. Skipping down to the bottom, I read the attending’s assessment and plan: “No longer suicidal. Discharge home. Agrees to return if feeling unsafe. Mother to pick her up.”

Just below this—as if a postscript—were the words, “Patient thankful for being kept safe on her birthday.”

The following Monday, I finished my shift and walked to the inpatient floors to check on Hilary. I wondered how she was adjusting to being in the hospital. Had she changed her mind and decided it was the right place to be? Would she say something to alleviate my uncertainty—my guilt—for having hospitalized her?

When I entered the unit most of the patients were on a smoke break. Looking around, I noticed she wasn’t among the few who remained inside. I figured she’d been given smoking privileges. I walked into the nurse’s station and stopped before the large dry-erase board on which was written the entire twenty-one-bed census for this particular unit. Next to each patient’s name were the names of the attending and resident assigned to that case. I didn’t see Hilary’s name. Had I remembered it wrong? I looked again, giving each name the chance to jog my memory. Still nothing.

“Are you lost, Dr. Christopher?” it was the charge nurse.

“Hi, Donna. I think I might be. Do you know what happened to Mrs. Asher? I admitted her on Friday night. Was she transferred to another unit?”

“Nope. Discharged. She left on Saturday morning.”

I blushed. Why would she be discharged on her birthday, the day she’d tried to hang herself a year ago? Unfortunately, there was no one on the unit to ask. The psychiatrist who’d seen her—and let her go—had only covered for the weekend. Besides me, no one else had evaluated her.

I left the unit and went to the one place where I thought I might find an answer: medical records. A receptionist typed Hilary’s name into the computer. “Looks like it just came down from the unit,” she said, and pulled a chart from the pile next to her and handed it to me. It was thin. Since she’d just left, the usual discharge summary was missing. Even if someone had already dictated it, it would be a week or more before the transcription service finished typing it, then it would be sent to the attending for a signature, and only then placed in her record.

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Paul Christopher is in his third year of Brown’s psychiatry residency training program.
CHECKING IN WITH BROWN MEDICAL ALUMNI

Enough About Us.

What Have YOU Been Up To?

Take a moment to contact us at med.brown.edu/alumni/ (click on “fill us in”) or send your updated contact information, including e-mail address, directly to us at Med_Alum@brown.edu.

1981

At last fall’s Alumni Awards Dinner, Seth F. Berkley ’78 received the William Rogers Award. Established by the Brown Alumni Association in 1984, this award recognizes an outstanding alumna or alumnus whose contribution and service to society is representative of the words of the Brown Charter: living a life “of usefulness and reputation.” President and founder of the International AIDS Vaccine Initiative, Seth is one of the world’s most prominent figures in the field of immune systems research focusing on preventive solutions to combating the AIDS epidemic.

1982

Richard Pieters has been inducted as a fellow in the American College of Radiology. Richard is a clinical associate professor of radiation oncology and pediatrics at the UMass Medical School, a consultant at Jordan and UMass Memorial HealthAlliance, and vice speaker of the Massachusetts Medical Society.

1977

Mark Haffenreffer ’73 is in practice at Needham Orthopedics, where he specializes in minimally invasive joint replacements. He was previously the president of the medical staff and chief of orthopedics at Beth Israel Deaconess Medical Center in Needham, MA. Because of his efforts, the hospital was honored for its contributions working with orthopedic companies on instrumentation of certain joint replacements. An orthopedist for Boston Symphony Orchestra string players, Mark is involved in their technical and conditioning protocols. He and his wife, Nona, have two kids, Hartford, 18, and Annie, 17, and live in Dedham, MA.

Mark can be reached at markhaff@comcast.net.

CLASSNOTES

1976

Bryant Toth P’08 writes, “All is well in San Francisco. I continue to do a lot of international medicine, having just gotten off the airplane from rural Brazil, where I was a guest speaker at the Brazilian Society of Plastic Surgery. My daughter, Alexandra S. Toth, will graduate from Brown this May and the entire Toth family is very excited. Ali spent her junior year in Bologna, Italy, as a part of the Brown Overseas Program. She is fluent in Italian and would like to follow in my footsteps and pursue a career in medicine. Bryant, Jr., is a sophomore at Cornell University and is loving his undergraduate experience.”

1977

Mark Haffenreffer ’73 is in practice at Needham Orthopedics, where he specializes in minimally invasive joint replacements. He was previously the president of the medical staff and chief of orthopedics at Beth Israel Deaconess Medical Center in Needham, MA. Because of his efforts, the hospital was honored for its contributions.
Lisa Shea Kennedy ‘80 writes, “Still in a thriving and rewarding solo family medicine practice, in the same location for eighteen years. I teach medical students from EVMS (Eastern Virginia Medical School), continue to chair various committees at my local hospital, and still find time to participate in state and local medical ‘politics.’ Over the past few years, Tom ’80 and I, with our teens, Jason, 19, and Krista, 16, have started exploring our own ‘50 places’ lists, and while we still think our area has a lot of the best of everything, as we approach ‘empty nesting’ age, Tom and I are starting to explore ‘sabbatical’ options. I’m also starting to search for someone to join my practice, so send me names of anyone who is interested in family medicine the way people imagine it ought to be!” Lisa can be contacted at Fischa01@ummhcc.org.

Frances Wu ’81 writes, “I am enjoying my work immensely as a Somerset family medicine residency faculty member in Somerville, NJ, and voluntary clinical assistant professor for UMDNJ-Robert Wood Johnson and Drexel med schools. My special projects this year have been leading a medical ethics curriculum, running a patient safety lecture and M and M series, spearheading an effort toward creating night float systems for the residents so no one will ever have to work twenty-four hours straight, and participating in a Doctors of the World program which provides medical exams for victims of torture. I also started a poetry club in my town, and am actively renewing friendships from the recent and distant past through alumni organizations for Brown as well as Bronx Science HS.”

Joel Kline ’83 recently became director of the University of Iowa Physician Scientist Training Pathway and urges anyone who is involved in MD/PhD programs to encourage their graduates to investigate the PSTP program for residency/fellowship training. Joel’s oldest son, Jacob, is a sophomore at Brown, Class of ’10.

1989

John Brooklyn is a family physician at the Community Health Center of Burlington, VT. He was recently recognized by the Vermont and New Hampshire Bi-State Primary Care Association for his efforts in the treatment of opiate addiction and his attempt to mainstream those treatments into primary care.

Christopher Breuer HS’97 has been awarded a five-year, $625,000 grant from the National Heart, Lung and Blood Institute for his research to develop tissue-engineered blood vessels for those suffering from serious cardiovascular diseases. He is an assistant professor of surgery and pediatrics at the Yale School of Medicine.

1991

Patty (Lim) Lee ’87 is an associate professor of medicine specializing in pulmonary and critical care medicine at the Yale School of Medicine in New Haven, CT. She has two children: Justin, 11, and Rebecca, 8.

Howie Kornstein ’89 and his wife, Natalia, welcomed an 8 lb., 12 oz. addition to the family on October 20, 2007. Benjamin Zev Kornstein joins big brother Samuel, 3, and big sister Orly, 2, in Scarsdale, NY. Howie is in private practice in ophthalmology in nearby White Plains and in Manhattan, specializing in corneal and refractive surgery. Beginning in 2008 he will be a clinical instructor in ophthalmology at Mount Sinai School of Medicine.

1993

Robert Li ’89 lives in Philadelphia with his wife, Bonnie, and son Christopher, 3. Robert is a clinical associate at the University of Massachusetts. Hologic Corporation licensed the patent and made its first sales this fall of the “Cellient Automated Cell Block System.” The technique should allow biopsies to become smaller and be a useful standard platform for molecular diagnostics.

Send me the names of anyone who is interested in family medicine the way people imagine it ought to be!
IT’S NOT ROCKET SCIENCE
But it is brain surgery.

It’s 10 o’clock Tuesday night at Children’s Hospital in Seattle. You’ve been at work since 7:30 that morning doing what you do every Tuesday: pediatric neurosurgery. You’ve performed five craniotomies, dealing with everything from brain tumors to brain malformations to spinal cord problems on young patients aged five months to sixteen years. The shortest operation took two hours; the longest took nearly seven. The surgeries went well, but there’s no guarantee that the outcomes in each case will be successful. Your thought at the end of this grueling day? “I can’t believe I get paid to do this!”

Richard Ellenbogen ’80 MD’83, P’11, chair of neurological surgery and Theodore S. Roberts Endowed Chair in Pediatric Neurosurgery at University of Washington School of Medicine, is no ordinary physician, let alone an ordinary human being. Tuesday is a long day for him, but it’s typical of this self-described “kid at heart.” On Mondays, he begins teaching conferences for residents at 6 a.m., seeing sixteen to twenty patients; on Wednesdays, he does grand rounds and leads lab meetings on grants for which he serves as principal investigator; on Thursdays he puts in another extraordinary sixteen-hour day performing surgeries (some elective, some emergency), this time at the Harborview Medical Center, where he is chief of neurosurgery; on Fridays, he works in the adult clinic and, as he puts it, “takes care of chairman stuff.” The tireless forty-nine-year-old also attends monthly faculty meetings and is on call one weekend a month.

“I want to know what the residents and interns are experiencing,” he explains. “Being on call keeps me in touch.”

“Why would any surgeon, no matter how talented, how dedicated, or how honored (he’s included in the “Best Doctors in Seattle” list) continue to push himself so hard every day of every week? “I have the opportunity to save lives,” he says simply. “What could be more rewarding than to have a parent thank you with, ‘You saved my little girl’s life?’ Or more gratifying than seeing a giraffe statue in the front of the hospital be dedicated to a girl who, though she had an incurable brain tumor, lived six additional years because of what you did?”

The work, to be sure, takes its toll. “When you do this,” he says, “you could be an atheist and find yourself praying to God. I have to deal with my own demons and depressions. ‘Did I do everything possible? ’ ‘Why wasn’t I able to save this little girl or that teenage boy?’ I want to save everybody, but that’s just not possible.”

Ellenbogen credits his wife, Sandy, for her unwavering support over the years. “When you do what I do, you need a spouse who is stronger than you are, and she totally gets it.” Though he’s derived great satisfaction from his work, Ellenbogen regrets the time he hasn’t been able to spend with his three children. “I missed their football games and fencing matches and I only saw one of my daughter Rachel’s crew races”—last spring, when she rowed with the winning crew at the national high school championships in Ohio. Rachel is now a freshman at Brown and rows on the University’s stellar team.

“Before she went to college,” says Ellenbogen, “I told her that she’d gain some weight and get some C’s. Instead, she’s lost weight and gotten A’s. She was supposed to make me look good, not bad!”

—David Treadwell

1995

Jayson Carr ’91 writes, “In August, I left my practice in RI to take a position on the staff of Beth-Israel Deaconess Medical Center in Boston. I inherited a busy internal medicine practice and enjoy teaching Harvard Medical School students sent to me by their clerkship director, my classmate, Sara Fazio ’91 MD’95. Jamie and I and the kids—Jackson, 10, Patrick, 7, and Maggie, 4—are adjusting nicely to our new neighborhood in Natick.”

Jayson can be reached at jcarri@bidmc.harvard.edu.

Jeremy Erdley ’91 works at Southeast Denver Pediatrics, a private practice in
No stranger to public policy or polemics, Satel speaks out in favor of incentives for organ donation.

Psychiatrist Sally Satel MD'84 splits her time between counseling patients at a methadone clinic in Northeast Washington, DC, and the conservative think tank American Enterprise Institute, where she writes, speaks, and testifies before Congress on issues of health-related public policy.

With book titles like PC, M.D.: How Political Correctness Is Corrupting Medicine and One Nation Under Therapy, Satel is no stranger to controversy. But even this veteran of contentious debate was taken aback by the news last spring that a Dutch television network planned on airing a reality show featuring a terminally ill, would-be organ donor choosing from among three potential recipients for her kidney.

Criticism of the show was loud, immediate, and widespread, and touched on morality, ethics, decency, and taste. Despite deep misgivings, Satel, who has written extensively on organ transplantation policy, came down as a reluctant endorser of the show, the effort to publicize the dire shortage of available transplant organs trumping her distaste. The idea for the Dutch series had emerged after the thirty-five-year-old network founder died from kidney disease while waiting for a transplant.

In 2006 in the U.S., according to Satel, only about a quarter of those in need of a kidney transplant—just under 18,000 individuals—received a donated organ. By year’s end, nearly 67,000 people were still on the waiting list, and during that year, another 5,000 had either died waiting or become too ill to tolerate a transplant operation.

Satel knows better than most that “uneasy questions of allocation arise in environments of scarcity.” A kidney transplant recipient herself, she knows first-hand about searching the Internet to find a donor. In the end, she got a kidney from a friend, but she understands the desperation that feeds an international black market for organs and growing transplant tourism industry abroad. Instead, Satel favors a regulated system of government-funded incentives to increase the supply of organs available for transplant. Donors, who would get extensive screening and medical follow-up, would be compensated by their choice of options—health coverage, long-term nursing care, tax credits, tuition vouchers, even 401(k) contributions.

Critics of the proposal, led by the United Network for Organ Sharing, the national entity that manages the list in the U.S., and the National Kidney Foundation, maintain that the system of organ donation is built on, and should remain solely based on, altruism.

“Altruism is a beautiful virtue,” Satel says, “but it is not enough. If we are able to reward those who donate to strangers, others will be encouraged to do the same.”

—Lisa Rowley

Sally Satel

Satel knows better than most that “uneasy questions of allocation arise in environments of scarcity.” She herself is a transplant recipient.
DO YOU HEAR WHAT I HEAR?

An ENT answers NOLA’s call.

In a case of “magical timing,” Moises Arriaga ’82 MD’85 relocated to his native New Orleans just eight weeks before Katrina devastated the area. He left a successful, fifteen-year practice in Pittsburgh to establish a Hearing and Balance Center in Louisiana and return full time to academic medicine as a professor of otolaryngology at Louisiana State University.

After the hurricane, with hospitals closed, basic services in shambles, and “nobody doing ear surgery at all,” Arriaga and his family returned to Pittsburgh, where he soon found a way to assist the hurricane recovery. With help from colleagues at Allegheny General Hospital and Pittsburgh Ear Associates, he established an otology rotation for LSU otolaryngology trainees left without a program. One at a time, residents work a month-long rotation in Pittsburgh with Arriaga, who also lectures weekly via teleconferencing to residents in Louisiana on topics in otology and neurotology. Arriaga in turn spends one week every month in New Orleans, performing surgeries, working with LSU residents, and overseeing the Hearing and Balance Center he has since established. The residency program recently won full accreditation. “It’s been remarkable,” Arriaga says, to see the residents’ performance improving and ear care in the region changing for the better.

Part of that improvement is a new Cochlear Implant program Arriaga started with Children’s Hospital in New Orleans. After the storm, the roughly 200 patients with devices already implanted had nowhere to go for the required routine monitoring and adjusting. So Arriaga marshaled resources and lined up a multi-sponsor collaboration, with the device manufacturer offering “tremendous” discounts, the hospital and LSU both participating at a loss, and a significant contribution from a local foundation. The program began seeing patients late last spring and performed its first new implant in October.

Besides providing vital care to patients in need, the Cochlear Implant program is a marquis service seen as evidence of high-tech medical capacity, Arriaga explains. “Its availability lets people think, ‘Okay, if I can get that kind of service here, I can move my family back home now.’”

That attention to the region’s broader recovery has become widespread among all kinds of redevelopment efforts.

While Arriaga is pleased with his involvement, he notes that “there is nothing exceptional about this. Lots of people all over the Gulf Coast are doing whatever needs doing to get this place back on its feet. The nation needs to know that South Louisiana has survived, that things are happening here. We’re coming back.” —L.R.
Dear Fellow Alumni,


Thanks to alumni feedback, Reunion Weekend 2007 was more family friendly. With your help, we can make this Reunion even more successful.

Do you wonder where your anatomy lab partner is now? Find out by encouraging your class members to come to Providence for an exciting Reunion weekend! We’re also eager to know which faculty members were most important to your class.

If you want to learn more about becoming a reunion volunteer, please feel free to contact me at Med_Ahum@brown.edu or Bethany Solomon, director of alumni programs, at Bethany_Solomon@brown.edu or 401-863-1635. We look forward to hearing from you.

Sincerely,
Daniel Medeiros MD’86
President, Brown Medical Alumni Association

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- Print Alumni Directory
- Annual Alumni and House Staff Family Festival
- Brown medical community events nationwide
- Educational Travel — China October 2008
- Reunion forums with CME credit

For information on any of the above programs, please contact the Office of Alumni Programming at 401-863-3231.

- Med.brown.edu/alumni
Evacuations and Peregrinations

A family medicine doc goes global with his family.

A fifty-three-year-old man from Luxembourg on assignment in Asia sustains injuries in a motorbike accident that require orthopedic expertise and hardware not available in his host country. A local physician recognizes that the patient’s needs surpass available resources and that he needs urgent evacuation by air to the nearest well-equipped medical facility. Arrangements are made for international aeromedical evacuation. This was the subject of a review article published in the January 18, 2007, issue of the New England Journal of Medicine. The article’s lead author, Peter G. Teichman HS’95, a graduate of Brown’s family medicine residency program, is qualified to write about the practice. As a physician working in an international health clinic in Ho Chi Minh City, with a passport that allows access to nations where such emergency transfers terminate, he has directed and performed a number of similar evacuations.

Before going to Vietnam, Teichman worked as an accident and casualty doctor in New Zealand, and before that, his wanderlust had taken him on locum tenens assignments in Alaska, Hawaii, Arizona, and Australia. He also spent five years as a faculty member of West Virginia University’s rural family medicine residency program, where he served as the director of its Eastern Division family medicine clerkship and leader of evidence-based medicine programs.

Teichman’s interest in international health began in medical school at Michigan State, where he completed an MD/MPA (Masters in Public Administration) program that emphasized international health development. His time at Brown further inspired him on his journey from “generalist” to “globalist.”

Accompanying Teichman on these adventures are his wife, Anne, a clinical pharmacist and sometime-chemistry teacher, and four sons, Soleil, 13, Quest, 11, Elan, 6, and Kenai, 4. The Teichmans have been living and working in Vietnam for nearly two years. According to the couple, “Being in a developing country is a good fit for our career goals—to help an emerging nation expand and enhance its health care programs.” They also find it an excellent place to raise children.

—Randall Rockney, MD
Associate Professor of Pediatrics and Family Medicine
ALUMNI ALBUM

happily married to Dr. Charles desBordes for seventeen months! Nana would love to hear from her classmates.

She can be reached at Nana_Tchabo@yahoo.com.

2001
Dorkina Myrick PhD’01 writes: “I completed a residency in anatomic pathology at the National Cancer Institute in Bethesda, MD, in June 2005. After residency, I accepted a position with the Cancer Training Branch of the National Cancer Institute, where I am currently employed. It’s a fantastic opportunity! I would not have been able to obtain this type of career experience anywhere else.”

Dorkina can be contacted at Dorkina_Myrick@yahoo.com.

2002
Deborah Archer ’95 and her husband, Shane McGregor, announce the birth of son Darius Malcolm on January 20, 2007, who joins his two older sisters, Imani Miriam, 8, and Nia Rose, 5. Deborah is a pediatrician at Salud Family Health Center in Fort Collins, CO.

She can be reached at Deborah_childoc@yahoo.com.

Terralon Cannon Knight is currently a physician with Unity Health Care, Inc., serving as medical director for Good Hope Road Health Center. Unity Health Care, Inc. is a nonprofit organization dedicated to providing quality health care to the medically underserved of Washington, DC.

Terralon can be reached at terralonknight@yahoo.com.

Radhika Varada Kuna ’98 is a fellow in cardiology at the University of Maryland Medical Center.

She can be reached at varadaradhika@yahoo.com.

Steve Liao ’97 is a cardiology fellow at the Mount Sinai Cardiovascular Institute.

Steve can be reached at sliao@alumni.brown.edu.

Sumayah Taliaferro ’98 currently works at Premiere Dermatology in Atlanta, GA.

Sumayah can be reached at sumayah_taliaferro@msn.com.

Eric Walsh currently works for Orthopedic Group, Inc., a private practice in Pawtucket, RI. He lives in Barrington, RI, with his wife, Caroline, and their kids, Emily and Ethan.

Amy Boutwell focuses on health care improvement at the Institute for Healthcare Improvement in Cambridge, MA. Amy and her partner, Christian, have two children: Myles, 3, and Lincoln, 1.

Amy can be reached at aboutwell@ihi.org.

John Kawaoka ’00 and his wife, Cristina Pacheco ’00 MD’04 HS’07, announce the August 18 birth of Madeleine Mae Kawaoka.

Tripler Pell lives in Toronto, where she is a PGY-1 (soon to be PGY-2 in February, after a six-month hiatus for maternity leave) in family medicine at the University of Toronto (Mount Sinai Hospital). She writes, “Our family has expanded to include Marina Hope Hammoud, born on April 17, 2007. Not much other news—just very busy and missing the RI ocean—lakes are not the same.”

Mark Bear and colleagues have corrected key symptoms of mental retardation and autism in mice.

Mark Bear and colleagues have corrected key symptoms of mental retardation and autism in mice. Their work, published in the December 20 issue of Neuron, indicates that a certain class of drugs could have the same effect in humans. These drugs are not yet approved by the FDA, but will soon be in clinical trials. Brown University graduate student Gül Dölen was a co-author of the paper.
There are some things in medicine you just can’t learn from a book. That’s why there’s doctoring.

"The doctoring course provided me with my first practical experiences as a medical student. My mentors this far have become some of my first role models professionally, and I am certain the lessons learned in their offices will serve both me and my future patients throughout my career. I am thankful that the opportunity to develop these strong relationships was provided at such a crucial, early point in my education."  - Ian Buchanan MD’10, pictured with his mentor, Assistant Professor of Medicine David M. Dosa

Your gift to the Brown Medical Annual Fund makes innovative educational experiences such as doctoring available to Brown medical students. Forty-five percent of the BMAF supports the medical curriculum, ensuring that as the practice of medicine changes and evolves, so do our methods of teaching. The remainder of the Fund supports students in another critical way: financial aid.

Every gift to the BMAF counts as a gift to the Campaign for Academic Enrichment. So be bold. Consider becoming a member of the Brown Medical Society with a gift of $1,000 or more. Your gift—at any level—will help us reach our goal of $760,000 by June 30. Return the enclosed envelope with your contribution or give online at www.gifts.brown.edu.

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These are just some of the stops on this extraordinary fourteen-day tour. If you have questions or would like more information, including a brochure, please visit the Brown Travelers website at http://alumni.brown.edu/learning/travel or call (401) 863-6322.