

THE PATIENT ADVOCATES

With an unwavering commitment to patients and protecting their rights, these forward-thinking individuals are advocating best practices for clinical-trial recruitment and education.



SPEAKING UP FOR THOSE IN NEED

Despite an often uphill battle to provide better facilities for patients who have mental health problems, Zane Wilson has made huge inroads as an advocate for patients in South Africa. Founder of The South African Depression and Anxiety Group (SADAG), Ms. Wilson established the organization in 1994 to benefit the welfare of people with mental health problems throughout South Africa

and its neighboring states and helped Zimbabwe, Namibia, and Botswana to establish their own advocacy groups.

She has worked extensively with major pharmaceutical companies for the past 12 years to remove the stigma from mental illness and to educate communities about depression as a real and treatable illness.

SADAG has inspired GlaxoSmithKline, Pfizer, Eli Lilly, and Aventis to fund rural workshops for home-based care workers in numerous provinces. Thanks to Ms. Wilson's tireless dedication, SADAG today supports more than 40,000 patients, has more than 180 support groups, and has a scientific and advisory board of 17 professionals who donate their time to ensure the organization's success.

The barriers to improving healthcare for such patients are enormous. There is always a battle to get funds for rural communities to access mental healthcare and often the infrastructure does not even exist. That means it can take rural patients four hours to get to a hospital, a huge expense for people with no jobs who are often turned away because of lack of knowledge about mental health problems.

Ms. Wilson has faced and overcome many challenges, including building large teams of outreach trainers; getting toll-free lines in place, without which it wouldn't be possible to talk to the many millions who cannot afford even a phone call; and motivating the medical schemes to pay for patients with bipolar disorder.

Since many HIV/AIDS sufferers are cared for by home-based care workers in South Africa, Ms. Wilson recognized that there was a need for tools to help these caregivers deal with the depression both they and their patients deal with. One of her most significant innovations is the Speaking Book, developed to enable low-literacy communities to receive vital healthcare messages. Launched in 2005, these books are informative and essential to primary-healthcare education.

Inspiring others through her willingness to do any work in the organization, Ms. Wilson is dedicated to helping rural communities, has a strong work ethic, and is tenacious in coming up with new ways of getting mental healthcare to isolated communities. She is inspired by people who never give up, even when others doubt that those goals can be accomplished.

Ms. Wilson has received numerous national and international awards in recognition of her work, including South African Woman of the Year for Health, 1998; the World Health Organization and Federation of Mental Health's Award; and World Bank Marketplace Winner for 2003. In 2006, she was a finalist for the Pan African Health Awards.

Zane Wilson is constantly on the look out for new business ideas that are adaptable to the organization's NGO and mental healthcare work. One of her most significant innovations is the Speaking Book, which allows low-literacy communities to receive vital healthcare messages.

ZANE WILSON

CURRENT POSITION

Founder and Director, The South African Depression and Anxiety Group

PLACE OF BIRTH

Skegness, England

EDUCATION

GCE O Levels, United Kingdom

ON HER READING LIST

Business magazines — American Forbes, Entrepreneur, Success, Business Week, PharmaVOICE, and South African business magazines and local papers

CAREER HIGHLIGHT

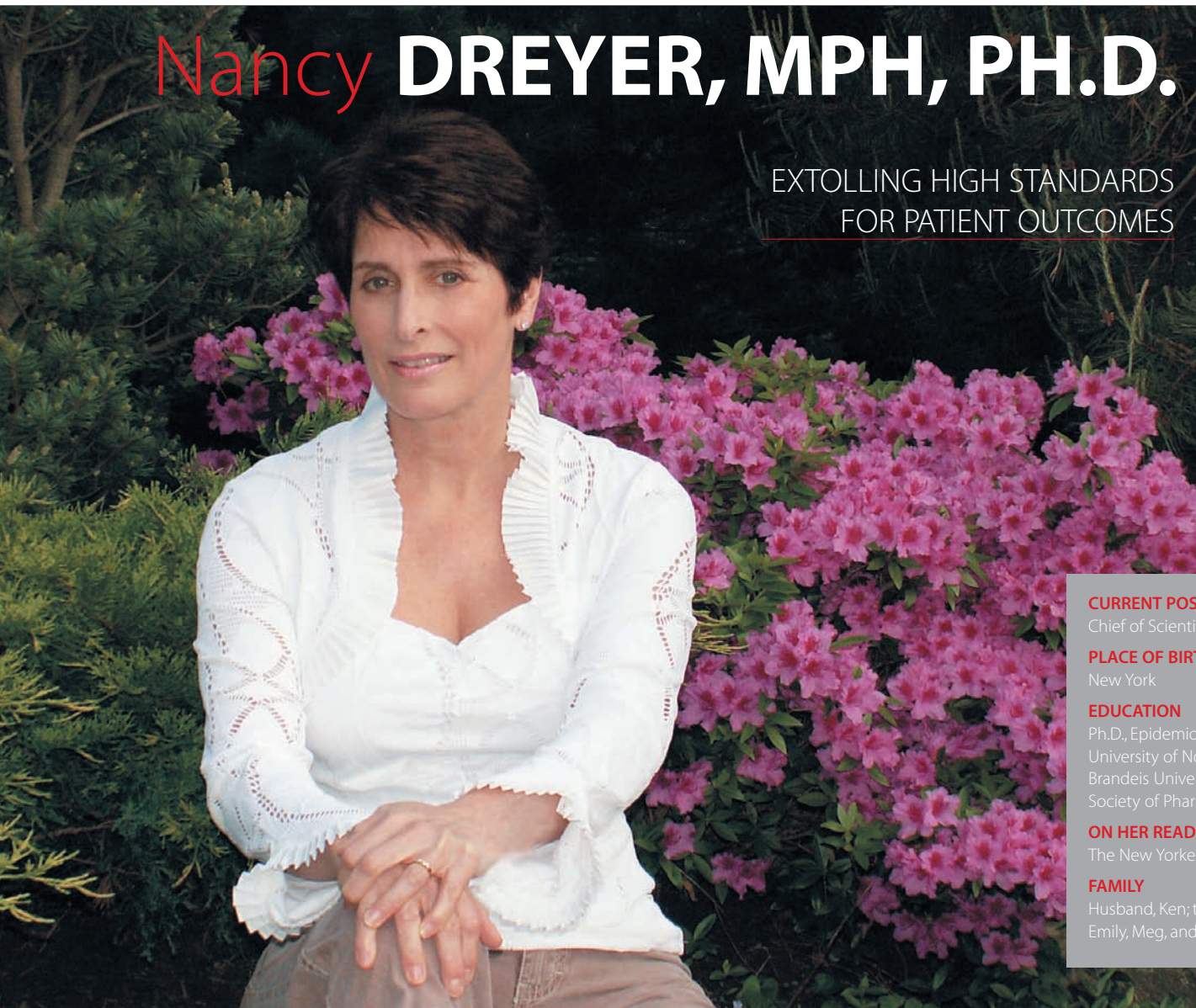
Witnessing the response to the first speaking books in Limpopo (the northernmost province of South Africa) that addressed how living with HIV and AIDS doesn't mean living with depression; this is a very poor community that couldn't read or write but could hear a celebrity voice talking to them

NEXT ON HER LIST TO ACCOMPLISH

Expand the speaking books to the rest of Africa to further increase healthcare information on other topics — diabetes, TB, malaria, glaucoma, Avian flu — and fight for parity for mental healthcare from medical schemes, which still discriminate against mental health patients

Nancy DREYER, MPH, PH.D.

EXTOLLING HIGH STANDARDS
FOR PATIENT OUTCOMES



CURRENT POSITION

Chief of Scientific Affairs, Outcome

PLACE OF BIRTH

New York

EDUCATION

Ph.D., Epidemiology, Master of Public Health, University of North Carolina at Chapel Hill; B.A., Brandeis University; Fellow of the International Society of Pharmacoepidemiology

ON HER READING LIST

The New Yorker magazine

FAMILY

Husband, Ken; three daughters — Emily, Meg, and Samantha Rothman

It's her ability to energize all those she comes into contact with and a passion for patient-focused science that makes Nancy Dreyer, MPH, Ph.D., one of a kind.

Always promoting and adhering to the adage, do the right thing, Dr. Dreyer is a thought leader in the postapproval world and provides vital knowledge to the industry as chief of scientific affairs at Outcome. She makes it very clear that if a device could cause harm then it needs to be monitored; if the affect of a drug on a population is studied, then the protocol parameters should have a study population that matches the affected population. Essentially, the message she delivers is that the industry should not skirt the rules that protect patients.

Drawing on a distinguished career as an epidemiologist, Dr. Dreyer has led a variety of research projects, including studies related to outcomes and the safety of prescription drugs, OTC consumer products, cellular telephones, and occupational and environmental contaminants, and she has had more than 50 articles published in peer-reviewed scientific journals.

She played a primary role in the development of the Agency for Healthcare Research and Quality's Registries for Evaluating Patient Outcomes handbook, essentially the bible for Phase IV registries.

She has a passion for public health, high standards, a positive outlook, and an appreciation for the contributions of others. She thrives on working

with smart thinkers, who demonstrate can-do attitudes and strong follow-through.

And she has expounded that go-getter attitude on a number of occasions. She founded a company that defined a niche, Epidemiology Resources Inc., a private epidemiology research institute, serving as the company's president and CEO for almost two decades. And in this role, she also created and directed the New England Epidemiology Institute, an international summer program that, in collaboration with Tufts University and Boston University, provided postgraduate training for 21 years. In addition, her company launched a peer-reviewed journal, *Epidemiology*, which became a leading publication in its field and was acquired by Lippincott in 1999.

Her ability to make all this happen can be attributed to her focus on setting standards for quality and service and then working every day to assure strong performance.

Dr. Nancy Dreyer inspires her peers and clients with her gusto for medicine and science, as well as patients. She energizes a room and encourages colleagues to help improve the registry process.



To access a FREE Podcast featuring Dr. Nancy Dreyer, go to pharmavoice.com/podcasts.

KEEPING HIS "SITES" ON PATIENTS AND RESEARCH

Throughout his career, Ken Getz has been instrumental in creating solutions and founding organizations that serve the drug-development enterprise and provide vital educational and information services.

As founder of CenterWatch, which was later acquired by Thomson Corp., Mr. Getz provided drug developers and investigative sites with the metrics as well as market intelligence to evaluate how they are doing, and information for patients on clinical research.

In his role as senior research fellow for Tufts CSDD, Mr. Getz offers insights into investigative sites, outsourcing, and study volunteer trends and policies.

In 2004, he founded the nonprofit organization CISCRP to raise public awareness and pride in clinical research and the important role it plays in advancing public health. To advance those goals, CISCRP has developed, produced, and implemented public outreach and educational materials and programs. CISCRP recently launched a "Got Milk" style national campaign in print, billboards, radio, and TV called "Medical Heroes can be Found in Everyday Places," which is designed to raise public recognition of the profound gift that clinical-trial volunteers give to everyone.

Even at the start of his working life, Mr. Getz was involved in creating solutions that brought industry and patients together. While working at a management consulting firm in the 1990s, one of his earliest assignments involved determining how to launch a breakthrough therapy for treatment-resistant schizophrenics that had a difficult side-effects profile. He and his colleagues created a bundled-offering — a first of its kind — that established a system permitting patients to have their prescriptions filled only after receiving satisfactory results from a blood-monitoring service. The drug went on to generate \$400 million a year in sales and made the cover of Time magazine.

In everything he does, Mr. Getz strives to be thoughtful, analytical, and strategic. Comfortable with taking risks and challenging convention, Mr. Getz brings enthusiasm, integrity, determination, and passion to everything he does, and he approaches problems creatively.

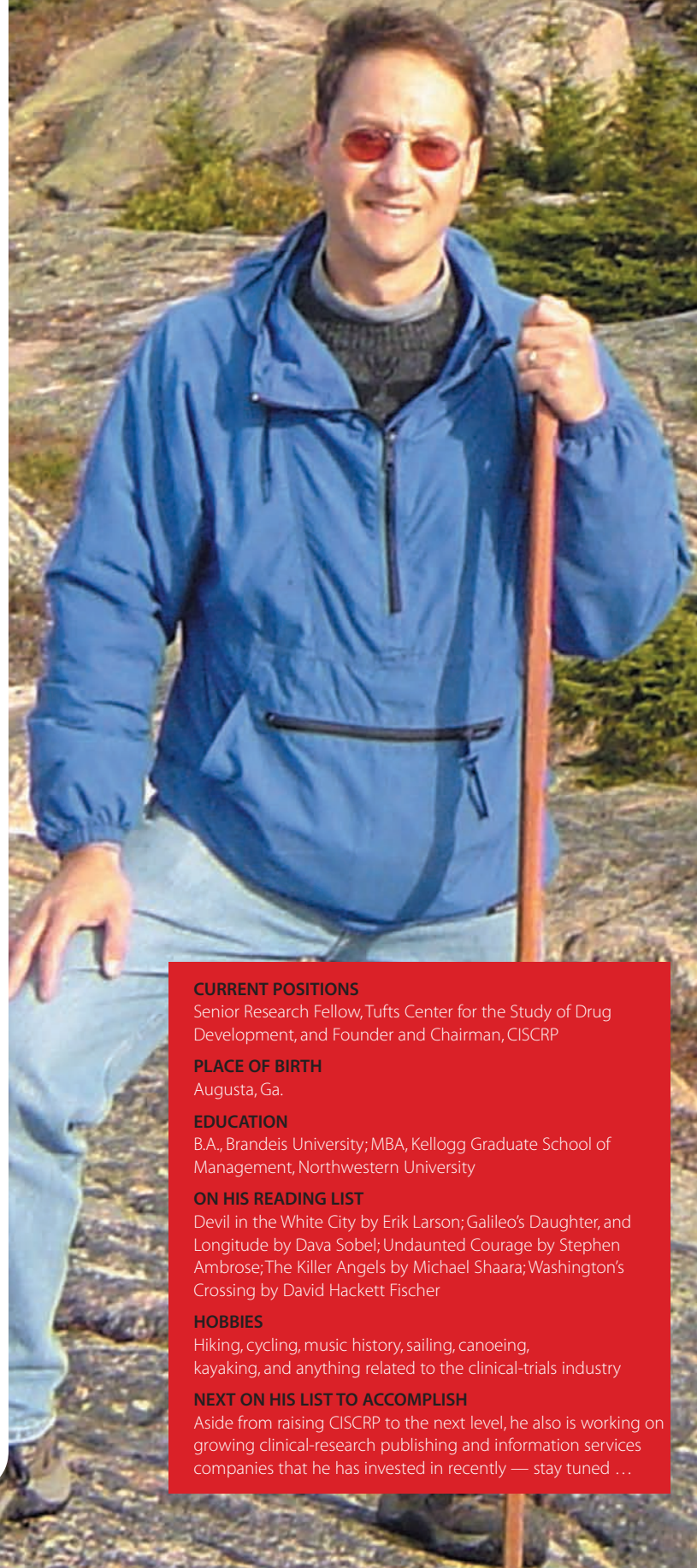
With a wealth of knowledge accumulated over his 20 years in the field, Mr. Getz has an ability to recall primary and secondary data on various aspects of the clinical-research enterprise, making him an invaluable resource and a sought-after speaker.

Taking a supportive approach to leadership, Mr. Getz is inspired by honesty, commitment, integrity, well-informed and practical thinking combined with creativity, independence, optimism, and calm and thoughtful responses to solutions.

Above all, he is inspired by all those involved in clinical research, from the patients who courageously choose to participate in clinical research to clinical-research professionals.

An expert in investigative sites and CRO markets, Mr. Getz's more than 150 articles and books, as well as his involvement in university symposia and conferences have been significant contributions to the body of knowledge in drug development.

Ken Getz has spent his career creating solutions that bring clinical-research professionals and patients together and that provide vital educational and information services.



CURRENT POSITIONS

Senior Research Fellow, Tufts Center for the Study of Drug Development, and Founder and Chairman, CISCRP

PLACE OF BIRTH

Augusta, Ga.

EDUCATION

B.A., Brandeis University; MBA, Kellogg Graduate School of Management, Northwestern University

ON HIS READING LIST

Devil in the White City by Erik Larson; Galileo's Daughter, and Longitude by Dava Sobel; Undaunted Courage by Stephen Ambrose; The Killer Angels by Michael Shaara; Washington's Crossing by David Hackett Fischer

HOBBIES

Hiking, cycling, music history, sailing, canoeing, kayaking, and anything related to the clinical-trials industry

NEXT ON HIS LIST TO ACCOMPLISH

Aside from raising CISCRP to the next level, he also is working on growing clinical-research publishing and information services companies that he has invested in recently — stay tuned ...

CURRENT POSITION

Senior Copywriter and Strategist, BBK Worldwide

PLACE OF BIRTH

Boston

EDUCATION

B.A., English, Oberlin College

ON HIS READING LIST

Reinventing Patient Recruitment by Joan Bachenheimer and Bonnie Brescia; Scientific Progress Goes "Boink" — A Calvin and Hobbes Collection by Bill Watterson; The Dharma Bums by Jack Kerouac; Thirteen Moons by Charles Frazier; and National Geographic

FIRST INDUSTRY-RELATED JOB

Temp job working as BBK's receptionist, 13 years ago

HOBBIES

Singing, songwriting

NEXT ON HIS LIST TO ACCOMPLISH

Build study sponsors' and CROs/SMOs' appreciation of the value of e-recruitment products

TURNING SCIENCE INTO RECRUITING POETRY

Mark Twain wrote, "The difference between the right word and the almost right word is the difference between lightning and a lightning bug." For Rob Laurens, this is a quote to live by. An exacting wordsmith with a passion for patient recruitment and 12 years in the field, Mr. Laurens weighs and measures protocol criteria, quantifying just the right concept, phrase, or word to fulfill the enrollment equation.

This attention to detail is the difference between success and failure when it comes to difficult-to-recruit studies. Making the right choices is indeed a science, but when Mr. Laurens is done, the final product has the sensitivity of poetry.

To Mr. Laurens, it's about turning ideas and concepts into language and materials that not only motivate people, but also challenge or change the way people think about clinical studies.

distinction between patients and healthcare consumers, coining the phrase, "consumers shop; patients make decisions." The BBK Worldwide senior copywriter and strategist helped to spearhead the now industry-wide standard of referring to study participants as patients rather than subjects. This distinction, he believes, was a turning point in the industry that elevated the understanding and discussion of both clinical-study participation and patient recruitment. This not-so-subtle change paved the way for patient recruitment to become an advertising discipline in its own right.

With an eye to the future, Mr. Laurens works to help structure and refine new technological solutions for patient recruitment, ensuring they get to the heart of key challenges.

Patient recruitment is a metrics-based discipline, but equally there is a need for the more artful side exemplified in the words and concepts of recruitment outreach materials. Rob Laurens is an inspiring example of how clinical-trial patient recruitment brings art and science together.



Rob **LAURENS**

In addition to setting the bar high for patient-recruitment outreach through his work on hundreds of clinical-study recruitment campaigns, Mr. Laurens has contributed significantly to the industry. He was a key player in defining the

AMBASSADOR FOR HOPE

Few people understand the challenges facing patients living with a chronic condition better than **Brenda Snow**. As someone who battles multiple sclerosis, Ms. Snow offers a unique perspective to connect with and inspire others on a level that transcends diagnosis and disease.

Ms. Snow founded Snow & Associates in 2001 with the goal of using authentic stories from patients to reach people with chronic medical conditions. Out of this was born the Patient Ambassador program, a unique direct-to-patient (DTP) partnership with the industry to educate and empower patients, helping end the stigma associated with chronic illnesses.

Ms. Snow works with companies to place regulatory compliant Patient Ambassadors — patients living with conditions such as MS, epilepsy, breast cancer, etc. — in community forums to convey their personal stories to urge patients to take charge of their own healthcare. From her own experience, Ms. Snow imparts her passion, sense of empowerment, and knowledge into useful strategies that inspire and motivate patients.

With the industry under scrutiny, Ms. Snow believes there is a need to focus on the real stories of those who have overcome life-long challenges and conditions with the help of pharmaceuticals and to help educate patients about the invaluable contributions the industry makes to society.

As direct-to-consumer and DTP advertising face growing scrutiny, it will

become important to focus more on the innovative aspects around these communications. From her experience with clients, Ms. Snow maintains companies are embracing a candid, fresh approach and understand that

the conversation is changing and they recognize the value of having authentic people inspire others to take action. She is both proud and humbled by the opportunity to have been involved in this process, in particular the fact that what started out as a good idea in the 1990s has become a viable business model that is still going strong. She still counts her first client among a growing clientele.

One of the lessons earned early in life, which has been a source of strength and inspiration for Ms. Snow, is that it is possible to inspire others to achieve their greatest potential by doing what one believes in without focusing on who gets the credit.

Ms. Snow plans to launch consumer programs for Asia in August 2007, after having developed similar programs for the EU last year. Her company also is in the final phase of launching a nonprofit organization to give back to patient communities. The

goal is for the organization to function as a philanthropic platform for clients as it continues to demonstrate its commitment to the patient communities it serves.

As the reach of her message expands, Brenda Snow hopes to dramatically change the face of how people live with chronic conditions and how they perceive the companies that make their medications.



CURRENT POSITION

Founder and CEO, Snow & Associates

PLACE OF BIRTH

California

EDUCATION

UCLA

Brenda **SNOW**

SCIENCE-SAWY MEDIA PLANNING

Among the first in the industry to recognize the need to apply a more structured approach to media planning for patient recruitment advertising, Lisa Fell applies direct-to-consumer media savvy to create campaigns that deliver results.

With more than 20 years of experience developing successful media campaigns for clients as diverse as McDonald's and Aetna US Healthcare, she breathes new life into anemic campaigns by using media analysis, forecasting, patient focus groups, census data, and historical metrics to create and deliver healthy patient-recruitment campaigns that generate response.

Often referred to by her staff as "Doctor Media," Ms. Fell considers media planning a science. She directs a team of media professionals that work closely with each pharmaceutical and biotech study manager to identify target populations and customize media campaigns to meet study needs.

With an acute awareness of all forms of media and how each works to produce results, Ms. Fell and her team thoroughly research the disease, patient population, and caregiver involvement to strategize the most effective patient recruitment and retention campaigns.

By taking a scientific approach to media planning and buying she eliminates the mystery of not knowing what to expect in terms of media response and cost. As a result, clients are assured that their dollars are spent much more effectively and efficiently.

Ms. Fell balances the science of media buying with an awareness of the experience of each patient population. She believes that knowing and understanding what each patient is feeling and how to communicate that in patient-recruitment advertising is an important factor in successful recruitment campaigns.

The next challenge is, in the wake of a growing emphasis on pediatric clinical trials, related to developing new and better marketing programs to reach prospective patients.

A smart, sophisticated, positive professional, she encourages her team to challenge media standards and develop new ideas to achieve clients' objectives; going the extra mile to provide support to the sponsor and the study site.

A warm, engaging personality combined with media expertise ensures that Lisa Fell, together with her team, successfully implements effective patient-recruitment and retention campaigns.



LISA FELL

CURRENT POSITION

Chief Operating Officer, MediciGroup

PLACE OF BIRTH

Trenton, N.J.

EDUCATION

B.A. in Communications, University of Massachusetts

QUALITIES THAT INSPIRE HER

Self confidence, creativity, people who are open to new ideas and new approaches to problem solving, a good sense of humor to get everyone through those hectic days "when everything is due at once"

ON HER READING LIST

My Sister's Keeper by Jodi Picoult; everything related to new and better marketing programs to reach prospective patients

FAMILY

Husband, Steve; daughter, Taylor, 13

FIRST JOB

Assistant media buyer for a Boston-based advertising agency

Abbey MEYERS

Patients with rare diseases have Abbey Meyers to thank for spurring action on all levels. One of the driving forces behind the Orphan Drug Act of 1983, Ms. Meyers has provided a vital link to connect patients and families, industry, regulatory agencies, and academic researchers. Without her intervention, countless life-saving therapies may otherwise not have been developed. The Orphan Drug legislation, for example, has led to about 1,400 orphan drugs entering the research pipeline and more than 360 brought to market.

Working tirelessly with scientists, physicians, and members of Congress, she has ensured that patients with rare diseases receive the recognition, treatment, and support they need. She urges support group leaders to rise above their individual concerns for their own organizations and work together with all rare disease support groups on the issues each group has in common. She encourages companies to develop unique medical breakthroughs for untreated diseases rather than focusing on drugs for common diseases.

Ms. Meyers is credited as the mainspring behind the organization of the National Organization for Rare Diseases (NORD), which speaks to all whose lives are touched by orphan disorders through education, research, and advocacy. The opportunity to lead NORD has been both rewarding and challenging, she says, since each day the organization touches thousands of lives, but at the same time it must raise enough funds to do the job right.

Other important landmarks in her career have been mandating the Website clinicaltrials.gov in PDUFA and requiring the publication of a list of drugs in short supply. She has served on the National Commission on Orphan Diseases, the NIH Human Gene Therapy Subcommittee, and the National Human Research Protections Advisory Committee. She has written extensively, given speeches around the world, and helped establish orphan drug programs in Europe and Asia. She is honorary president of EURORDIS, the European Rare Disease Organization. In 2005, she was the recipient of the Harvey W. Wiley Award and Lectureship of the FDA Alumni Association.

Companies working in the area of rare diseases have benefited from Ms. Meyers' mentorship, as she helps them understand patients' priorities. Leaders from advocacy organizations say it is hard to imagine where they would be without her, and they note that her imminent retirement from NORD will be felt for some time to come. Those she has worked with describe her as a life force.

Abbey Meyers has worked tirelessly with scientists, physicians, and members of Congress to ensure patients with rare diseases receive the help they need.

A LIFE FORCE
FOR PATIENTS**CURRENT POSITION**

President, National Organization for Rare Diseases Inc. (NORD)

QUALITIES THAT INSPIRE HER

People who can rise above their individual needs and work together to solve a universal problem

EDUCATION

Associate in Applied Sciences, New York City Technical College, 1962; Honorary Doctorate of Humane Letters, Alfred University, 1994

FAMILY

Three children and eight grandchildren

PEOPLE WHO INSPIRE HER

Dr. Craig Burrell, Former Executive VP of Sandoz, a humanitarian who wanted to assure healthcare access for every patient who needs it, and Marjorie Guthrie (the widow of Woody Guthrie and mother of Arlo) who wanted to solve the orphan drug problem so that treatments for Huntington's disease would become available

GOT INFO?



THE RESOURCE FOR LIFE SCIENCES

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contact Dan Limbach at dan.limbach@accessfyi.com

or 847-594-0157.