

reach
down
and
help
somebody
else
up

Learning

from those who've gone before us



Dr. Jenerette talks with study participant Suzanne Epps. The qualitative data obtained in her study interviews help to highlight the self-care strategies, tribulations and triumphs accumulated over years of living with sickle cell disease.

Growing up, the little girl's mother taught her to take care of herself and to be mindful of the special needs that came as a result of her sickle cell disease. Diagnosed as a toddler, today Suzanne Epps is a 56 year-old African-American woman living with sickle cell disease, a medical condition that may result in poor health and quality of life (see box opposite page).

She credits her mother for teaching her to be self-reliant, to understand the details of her medical history, what she could do to keep herself healthy and what worked best to treat her symptoms when they did flare up. From a very young age, Suzanne's mother helped her develop a level of self awareness that has made day-to-day life with sickle cell disease manageable.

"I don't feel bad about having sickle cell," Suzanne says simply. "My mother taught me to understand my condition and to set my own pace in life, to know what I can and can't do. I have been through a lot, but maybe because I understand sickle cell more than others, I have made it through." She adds, "So I don't feel sorry for myself for having this condition, I just think 'What can I do to help someone else who has it?'"

Now, as part of a study being conducted by investigators from Yale and Howard Universities, Suzanne is doing just that. The study, titled, "Successful Aging with

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—CORETTA JENERETTE

Sickle Cell Disease,” includes surveys and interviews that will enable participants to impart knowledge they have gathered over a lifetime of living with the daily challenges posed by sickle cell disease to newly diagnosed patients and their families.

YSN post-doctoral fellow and principal investigator, Coretta Jenerette, PhD, RN, explains: “From my previous work examining factors that influence health status and quality of life in adults with sickle cell disease, I found that several factors influence patient outcomes. These factors include social support, coping behaviors and self-care management activities.”

Along with Dr. Gloria Lauderdale at Howard University, who is collecting data from adults with sickle cell in Washington, DC, Dr. Jenerette is looking at how older adults with the disease in the New Haven area have aged successfully. This information will help shape interventions and training approaches, as well as influence the way the care of patients with sickle cell disease is managed in the future.

“By learning what has helped individuals currently living with sickle cell better manage the disease, we hope to assist younger patients to take that same well-traveled route,” says Dr. Jenerette. “We hope they will benefit from the life experiences of those who’ve gone before them,” she says.

In conducting this study, and in advancing her career as a nurse researcher, Dr. Jenerette has drawn on her own life experience, as well as on the advice of faculty mentors from YSN and the University of South Carolina where she completed her doctoral studies. She describes her career path and how she came to Yale: “While I was a doctoral student, a post-doctoral position at Yale was not one of the things I had considered. I was quite content to just complete my PhD.”

However, Dr. Jenerette’s mentor and dissertation chair at USC, Dr. Carolyn Murdaugh, along with Dr. Faye Gary, the Executive Consultant for the Minority Fellowship Program, which funded Dr. Jenerette’s doctoral studies, encouraged her and other doctoral students in the

program to pursue post-doctoral fellowships. At the time, Dr. Gary was collaborating with former YSN Dean Catherine Gilliss with whom she shared an interest in reducing health disparities. It was through Dr. Gary that Dr. Jenerette met former Dean Gilliss, Dean Margaret Grey ’76, (who at the time was Associate Dean for Research Affairs at YSN) and other YSN faculty whose work was advancing how individuals and families from vulnerable populations manage chronic conditions.

And so, as she was wrapping up her doctoral studies, a new and unexpected chapter in Dr. Jenerette’s career was just beginning. She recalls, “On the same day that I defended my dissertation I flew to New Haven. There I attended meetings of the Yale-Howard Partnership Center and listened to the 2004 Yale-Howard Scholars’ presentations of work that they and their Yale and Howard mentors were doing to minimize health disparities. I was very impressed.” The YSN faculty and Dean were equally impressed with Dr. Jenerette. Soon after that visit, she was offered a position as a project



Sickle cell disease is an inherited disorder that primarily affects people of African descent and Hispanics of Caribbean ancestry. It is also found with less prevalence among those with Middle Eastern, Indian, Latin American, Native American and Mediterranean heritage. The genetic mutation that causes sickle cell disease originated in areas of the world where malaria was common, and is thought to have been a natural adaptation to protect the body from the parasite that causes malaria. It has been estimated that over 72,000 people in the United States and millions worldwide are affected by the disease.

Sickle cell disease impairs red blood cells and their ability to carry oxygen. Normal red blood cells are smooth, round and flexible so they can move through blood vessels easily. However, in sickle cell disease they form into the shape of a sickle and are less flexible, tending to cluster together so they cannot easily move through blood vessels. Such blockage is what causes the painful and damaging complications of sickle cell disease. Although it cannot be cured, effective treatment to manage symptoms is available.



As a single parent and working mother, Dr. Jenerette is mindful of maintaining a healthy work-life balance. Her daughter, Jamison, age 7, identifies with her mother's role modeling — she enjoys playing teacher to her doll collection and is eager to visit mom at work. Dr. Jenerette comments, "The opportunity to enrich my daughter's life experiences was an important factor for me as I considered my own career advancement. Coming to Yale has enabled me to show her another part of the world."

director for the Yale-Howard Partnership Center. She accepted and serves in that role today.

During her first year at YSN, in addition to coordinating the summer seminar series for the Yale-Howard Scholars program, Dr. Jenerette also lectured in a master's level nursing research methods course.

One of Dr. Jenerette's mentors, professor Marge Funk '76, encouraged her to apply for NIH funded post-doctoral training at YSN. She applied and was accepted in September 2005. According to Dr. Jenerette, this educational extension gave her time to take additional courses and disseminate her dissertation findings, as well as further develop her skills as a research scientist.

"I had no idea, prior to arriving here, what to expect—other than that Yale was a place I never expected to be. My whole background, from grade school through college, graduate school and my doctorate, was with public institutions. I never thought I would end up at a private institution, let alone an Ivy League university," she says. She describes an initial feeling of being overwhelmed; as she made the leap from public to private university and moving from her southern roots in rural South Carolina to a much more urban, New England

environment. This was a tremendous life change for Dr. Jenerette.

"But I think that's one of the great things about being here at an institution like Yale," she says. "Your mentors work with you to create a unique experience that matches your professional goals, draws on your background and accommodates your personal needs."

For Dr. Jenerette, a single parent of a young child, the balance of flexibility and structure in her work schedule was especially important. "The time you spend as a post-doctoral fellow is limited—it is very precious," she explains. "It may also



be the end of your structured time to develop as a research scientist. The rest of the time you will have on-the-job training."

According to Dr. Jenerette, one of the things that make the Yale pre- and post-doctoral training program special is the close relationship between students and their faculty mentors. She describes the environment at the school as empowering. "YSN has offered me many opportunities and enabled me to find for myself the best way to develop as an academician and nurse scientist," she says.

For students just beginning their journey in nursing, Dr. Jenerette has some advice. "They should remember that the possibilities for them are endless. You have to reach higher than you expect; and then you will find the pathway to achieve more than you thought possible." She also has advice for those pursuing a doctoral degree or a post-doctoral experience. "Step outside of your box," she says, "and see what you have to offer, what different institutions have to offer, and search for the commonalities. You will find your fit."

Here there are parallels with the research Dr. Jenerette is conducting in her study of "Successful Aging with Sickle Cell Disease." She says, "Especially being a minority, people who have gotten to a certain point can often look back and, as the saying goes, 'Reach down and help pull somebody else up.'"

She continues, "So just as I am interviewing older adults with sickle cell in the hope that they can impart knowledge to younger people who are struggling with the disease, if other people can see this little southern girl at Yale—that I can be here in a place I never thought I could be and make a difference with my research, then perhaps they will also believe that they can achieve more, in their own way."

Dr. Jenerette smiles as she considers this. "The older adults in my study are a light to help illuminate the path for their younger counterparts," she says. "I hope that in a similar way, my experience can be a light for others who are contemplating pursuing a career in nursing research."