

Health system
teams up

TURNING LAUGHS

with the
Bernie Mac
Foundation
to search for
a cure for
sarcoidosis



INTO LIFE SAVERS

BERNIE MAC WAS a beloved entertainer and a Chicago native whose knack for generating laughter stood in poignant contrast to his concurrent suffering from a mystifying chronic disease. More than three years after his death from complications of sarcoidosis, a foundation named for him is partnering with the University of Illinois Hospital & Health Sciences System to demystify that disease and lend some star quality to the system's efforts to discover a cure.

Details of the public partnership were announced in April, which was Sarcoidosis Awareness Month, says Nadera Sweiss, MD, lead researcher in the sarcoidosis program at the University of Illinois. It's the culmination of nearly two years of talks with top executives of the Bernie Mac Foundation, who were drawn to the campus collaboration by both expertise and inspiration.

Sweiss, a specialist in rheumatology, had developed a practice in Chicago centered on treating people with sarcoidosis, a disease of unknown etiology that attacks multiple organs but most often the lungs and lymph nodes. It disproportionately affects African-Americans, who constitute more than 90 percent of her patients. So there was a lot for those patients to identify with as Bernie Mac fought the disease from onset in 1983 until his death at age 50 in 2008.

"His death was devastating to a lot of my patients," says Sweiss. "They would come to me and say, 'Am I going to die the same way Bernie Mac died? Why did Bernie Mac die?'"

In 2010 Sweiss called the Bernie Mac Foundation's executive director, Mary Ann Grossett, the older sister of the comedian's wife of 30 years, Rhonda McCullough. They discussed how they were engaged in the same push for both awareness of the disease and a clear plan to unlock its mystery and thus point the way to

productive treatment.

Sweiss unveiled the imagery of a "star center" at the University of Illinois, which would incorporate Bernie Mac's star quality as well as an acronymic identity: Sarcoidosis Translational Advanced Research. For Grossett, it wasn't just what Sweiss said but the way she said it. A like-minded relationship "started immediately when I picked up the phone," she says.

"What stuck out in my mind about Dr. Sweiss was her pure honesty and her being connected personally to what she does. I immediately saw and felt from her a sincerity that was beyond her being a doctor—I saw a real compassion and truthfulness in her," Grossett remembers. "We began to communicate like we had known each other all of our lives."

That warm inspiration spread quickly to McCullough. "When the opportunity came up that we would be able to work with the University of Illinois, for me it was like a dream come true," she says. "I always wanted to partner with a world-renowned facility—they had the means, they had the pulmonologists in place, it was just wonderful. And, to me, their focus just kind of mirrored mine."

Star power for the STAR program

ESTABLISHING THE RESEARCH program also was a dream come true for Sweiss, who follows 400 sarcoidosis patients in her practice along with 200 living with scleroderma, another disease of unknown origin that attacks healthy tissue. Before coming to the University of Illinois from the University of Chicago, she had initiated three interrelated studies into sarcoidosis, including the use of drugs to inhibit tumor necrosis, which plays a role in the disease. She developed a reputation as an expert in these disorders that drew patients regionally and nationally.

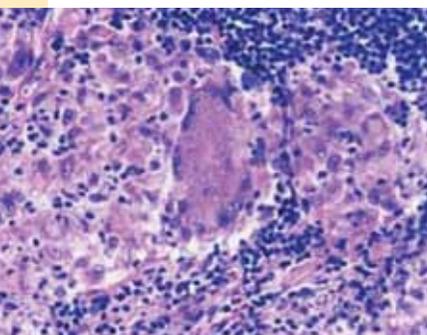


PHOTO: DONALD BARGE

Rhonda McCullough (from left), who was married to Bernie Mac for 30 years before his death, at the premiere of the documentary with Nadera Sweiss and Skip Garcia, VP for Health Affairs

Working with the University of Illinois is "like a dream come true."

— RHONDA MCCULLOUGH



The image above shows the inflammation commonly found in the lungs and other organs of sarcoidosis patients. In sarcoidosis, immune cells cluster to form a granuloma — inflamed cells that have replaced normal tissue.

In the Bernie Mac Foundation, the STAR program gains a powerful source of funding and visibility that first became apparent amid the tragic news of the entertainer’s declining health in 2008. Bernie Mac had established the foundation himself a year earlier, intending to make it a priority alongside his acting career. Donations started pouring in as news of his ultimately unsuccessful battle with pneumonia played out, says McCullough.

More money came in after his death, “but I really wasn’t ready to do anything with it just yet, because it took me awhile to grieve,” she says. Nearly two years went by. “At first I thought about not continuing the foundation, and then I realized that this was the last thing he was working on and this is a great way to continue his legacy. So that’s when I took over the reins.”

Attaching the foundation’s goals to a celebrity’s name “allows us to reach a wider audience,” says Grossett, “and people are just more naturally curious because it’s the *Bernie Mac* Foundation.”

Family involvement

GROWING UP as Bernard Jeffrey McCullough, the man who would become Bernie Mac met Rhonda at Chicago Vocational High School on the city’s South Side. “We met him when he was 16 years old,” says Grossett. “And so when you know someone that long, he becomes your brother.”

The legacy issue is not just a cliché. All of Mac’s family is involved in the foundation, and Chicago is their home. The foundation “was truly where his head was; he wanted to leave the world with something that he felt would make a difference. I know he felt like he had made a difference in the entertainment world, and he had done all that he could do in that arena,” Grossett says. “But for sarcoidosis he wanted to leave his mark there, something that could be carried on, even in his passing.”

As the foundation found out more about the approach and aims of the STAR program, it latched onto the underlying theme of personalized care. The personalization includes both the clinical and humanistic needs of each patient and the family that gathers around. For patients stricken with a chronic disease, says Grossett, there’s a toll on the person physically, financially and mentally, as the McCullough family lived through for years. “The medical team is interested in treating the patient holistically.”

It’s also a medical and research theme, says Sweiss. “As a disease, sarcoidosis affects almost every single system in the body; it most commonly affects the lungs, so it’s most commonly taken care of by lung specialists, but the patient may end up in the eye clinic, or in the gastrointestinal clinic, because of the nature of the disease.” Sweiss, still rare in the field as a specialist in inflammatory diseases, is taking a multidisciplinary approach to evaluating the disease in a systemic way. Each patient, with individualized aspects of sarcoidosis, will provide a piece of the puzzle and a bit of the solution as bedside clinicians work with lab researchers and geneticists to combine expertise and move more quickly to treatment options.

A day at the university

FOUNDATION MEMBERS spent a day at the hospital and its research facilities to get a tour and learn about the history of the disease and the STAR team assembled to target it—including Vice President for Health Affairs Joe G.N. “Skip” Garcia, MD, with his eminent background in translational research, and Rick Kittles, PhD, with a track record of discovering the role of genetics in disease, especially in racial minorities.

Among Garcia’s contributions to sarcoidosis research is a collaborative effort to establish a biobank to enable studies of genomic associations between DNA and diseases. Sweiss, a clinician and teacher as well as a researcher, has leveraged her experience to create



guidelines to plug the gap in available clinical trial data, including algorithms to manage bone issues and rheumatic manifestations of sarcoidosis.

Impressed with the science as well as alignment with the foundation's own mission statement, "I think it's safe to say that after that first meeting, we were signed, sealed and delivered," says Grossett. "There was a sense of comfort, a sense of trust on both parts. We were in the right place, at the right time, talking to the right people."

"They're going to help us to keep up awareness of the disease sarcoidosis with the public," says McCullough, "and it will also help to allow treatment for patients and their families, because families need an understanding of the disease, too, for their loved ones."

Driven by the continuing need for medical discovery—the Food and Drug Administration still has no approved treatments—the University of Illinois is grateful for the foundation partnership, says Sweiss. "Sarcoidosis patients really need a star in their lives; we live

in the darkness with this disease, as physicians, because we don't know what is the best way to treat this disease."

Gaining the star quality of Bernie Mac will help accelerate the process. Even before the official inking of the partnership, the foundation held a fundraising gala in January to coincide with the red-carpet premiere screening of a tribute to the entertainer's life, titled, "I Ain't Scared of You," that later aired on Comedy Central. Garcia and Sweiss made short speeches about the program as part of ceremonies at the Showplace Icon Theater in Chicago's South Loop neighborhood prior to the screening.

Associating the Bernie Mac name with a program destined to have a worldwide reach is the ultimate tribute to the man, says his wife. "Bernie was an international star, and the health system will welcome patients from around the world. So to me that makes them an international star.

"I actually believe this was Bernie's dream, and I do believe it exceeds what he thought could be accomplished." 🏥

Nadera Sweiss
(above): "As a disease, sarcoidosis affects almost every single system in the body."