

Media Contact: Debbie Bolles
214-648-3404
debbie.bolles@utsouthwestern.edu

Ex-Dallas Maverick, rising musician survives rare form of leukemia thanks to experimental drug treatment at UT Southwestern

DALLAS – May 19, 2011 – Ray Johnston’s goal in three years is for his band to sell out at the 1,600-seat House of Blues in Dallas. In eight years, he wants to pack the 6,400-seat Verizon Theatre in Grand Prairie, and by 2030, to play to tens of thousands of fans at Cowboys Stadium in Arlington.

Mr. Johnston’s unmentioned goal, though, is to live another year after battling leukemia for the past seven. Despite four relapses, the former Dallas Mavericks basketball player is enjoying life as a rising musician in The Ray Johnston Band.

Although he credits God for his recovery, Mr. Johnston also gives thanks to Dr. Robert Collins, director of the Bone Marrow Transplantation/Hematologic Malignancies Program at UT Southwestern Medical Center, and the experimental drug that has killed his rare, stubborn form of cancer called acute promyelocytic leukemia.

“It’s got to be inspiring to Dr. Collins to see that I’m alive because I’m supposed to be done by now,” Mr. Johnston said of his painful yet rewarding journey, which was chronicled last year in an HDNet series called “Ray Johnston Band: Road Diaries.”

Today, Mr. Johnston’s self-described “happy rock” Dallas band is working on its second CD and booking about 100 shows a year. “My primary goal is to keep playing,” Mr. Johnston said.

Tamibarotene, the drug that’s kept the 32-year-old musician alive, is a retinoid drug that induces cancer cells to differentiate into mature cells and eventually die. Available only in clinical trials in the U.S., tamibarotene was sought for Mr. Johnston under a compassionate use protocol since he did not qualify for those studies and other treatments had been exhausted. The drug, approved only in Japan for cancer treatment, is being developed domestically by CytRx.

“It’s amazing that he’s still doing so well,” said Dr. Collins, professor of internal medicine and senior author of a report on this case published online April 11 in the *Journal of Clinical Oncology*. “This drug happens to be just right for him.”

Mr. Johnston’s treatment with tamibarotene, which is considered 10 times more potent than all-trans retinoic acid, another retinoid commonly used to treat this type of leukemia, began in December 2009. He took the drug twice daily for 56 days, followed by a two-week break. Since then, Mr. Johnston has been taking the drug 28 days on, 28 off.

On April 18, he returned to UT Southwestern for a positron emission tomography (PET) scan,
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which showed his cancer had not relapsed for the fifth time.

“The type of acute leukemia he has is very rare. It’s usually curable with current therapies, but as it relapses it becomes more resistant and harder to treat,” said Dr. Collins.

Gambling on life, and success as a musician, doesn’t scare the Alabama native who once dreamed of a professional basketball career. But cancer ended his NBA stint, which began when he won a spot on the Dallas Mavericks summer league roster during a Hoop It Up tournament in 2004.

Mr. Johnston didn’t even know he had leukemia until that August, when he injured his leg in a pick-up game. He was diagnosed with compartment syndrome, a condition in which pressure in the muscle builds to dangerous levels. Following surgery, doctors were unable to control bleeding. They soon discovered that Mr. Johnston’s body was riddled with advanced leukemia.

His treatment included chemotherapy, surgery and a bone marrow transplant. Mr. Johnston’s type of leukemia, which affects soft tissues rather than blood and bone marrow, represents just 5 percent to 8 percent of acute myelogenous leukemia, the most common form of the disease.

Discouraged by failing treatments and the thought of his first bone marrow transplant, he nearly gave up hope. In 2006, a recommendation from a friend led him to Dr. Collins and UT Southwestern.

“When you achieve a life milestone that you’re not supposed to, when you hug it out, you can see and feel Dr. Collins drop a tear on your shoulder. That’s life. That’s real,” said Mr. Johnston.

Reality for this cancer survivor also means getting serious about music. Mr. Johnston has a lot of work ahead after launching the six-member band in September 2009. Some of the band’s performances raise money for The Ryan Gibson Foundation, a Dallas-based nonprofit dedicated to leukemia research.

One of the songs on the band’s first CD, “Sweet Tooth,” is Rise & Go, based on a verse in the Bible, Luke 17:19. Mr. Johnston said it sums up “my last seven years.”

“Wake up and I go outside, I see my blue sky, I’m happy to be alive ... I got a tough upper lip, but a bottom little broken heart. When I look into the sky, I see my Maker’s eyes. That’s when I know my Plan B for eternity is strong as gold, so I rise and go.”

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