

People, events and culture in the Lake Region

LAKE MARTIN *Living*

OVERCOMING OBSTACLES

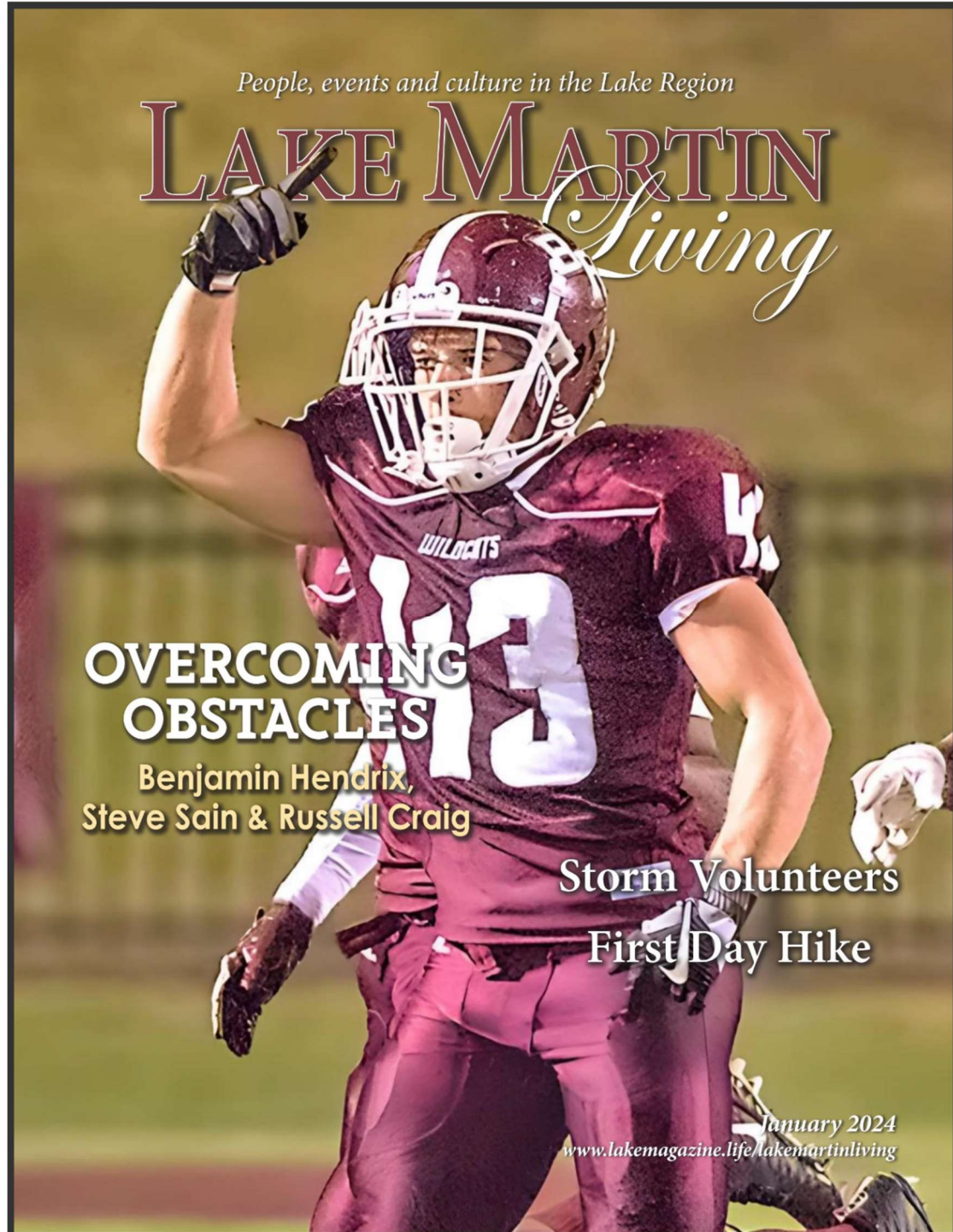
Benjamin Hendrix,
Steve Sain & Russell Craig

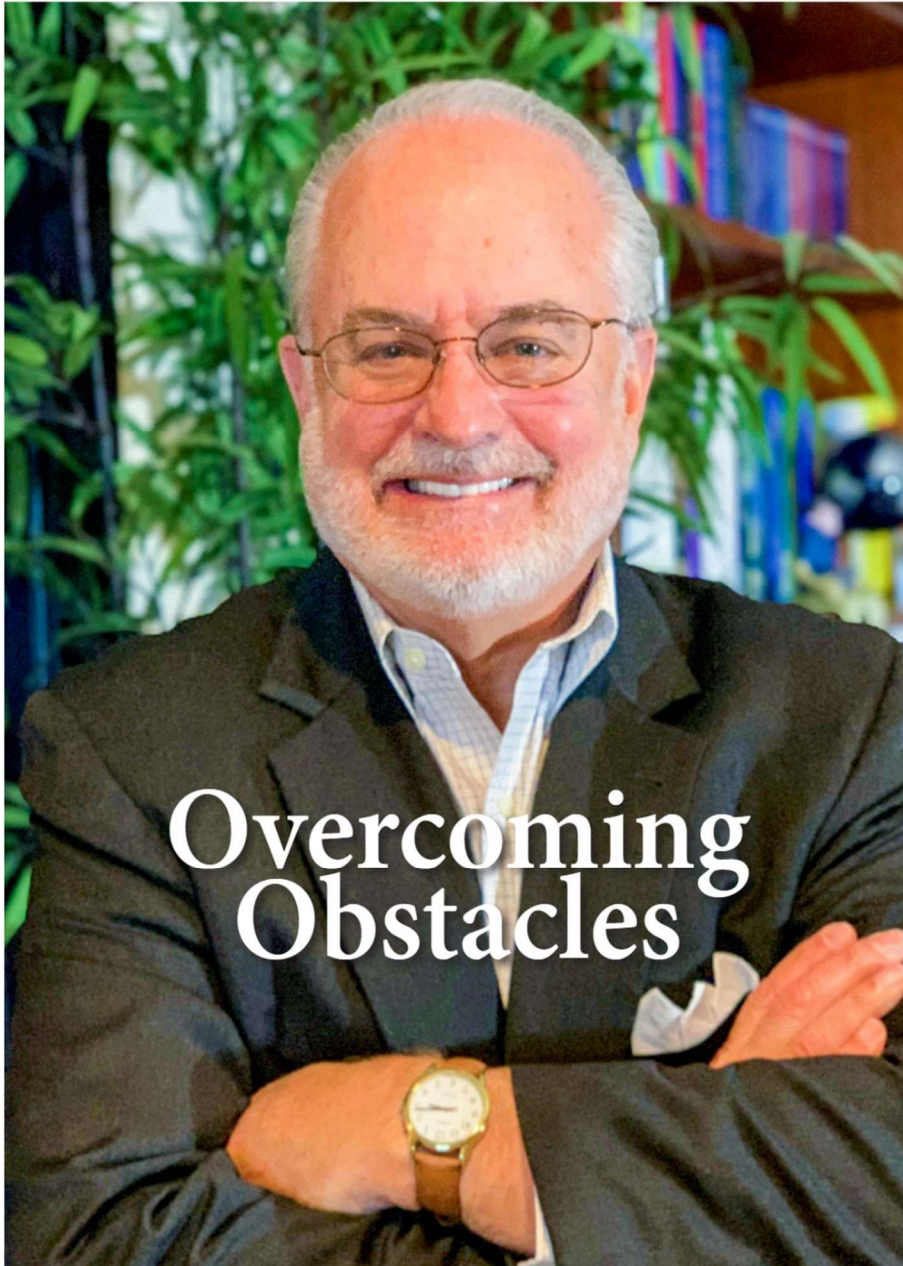
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January 2024

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Overcoming Obstacles

STORY BY BEN SMITH

One of the first things Steve Sain did after being diagnosed with Parkinson's was buy a motorcycle; a Triumph TR6 Trophy, the same model Steve McQueen drove across the German countryside in the Great Escape. As a child, Sain told himself that one day, when he was older, he would buy one just like it.

Sain picked up drumming again, a long-forgotten passion from his high school days. He was told by doctors that Parkinson's is a disease that devours the fine motor skills of a person first, and that drumming involves so many concurrent signals heading to so many different areas of the body that playing drums would be impossible.

"When I first started to play, my left hand just wasn't having it," said Sain. "I shed a few tears out of frustration.

Facing Challenges

Facing Page: Steve Sain is giving Parkinson's the Heisman stiff arm, as he says. Below: Russell Craig performs on stage at The Warehouse in downtown Eclectic.

But I kept at it, and I got better and better. And now, I'm not as good as I once was, but I'm not too far from it."

Sain took his daughter on a snorkeling trip to the Maldives, and when it was time to go back, he took the long road home, flying around the entire planet. They

had so much fun, they did it again. This time, the other way around.

Sain attends studies for Parkinson's research. He has been involved in a Sylacauga support group since he was first diagnosed in 2018, and he is organizing a new group in Alexander City. He's the president of the Regional Board of Advisors for the Parkinson's Foundation.

Sain is familiar with his disease. He knows how it progresses, and he knows what it looks like in its final months.

Despite all this, Steve Sain is living in the moment, marking items off his bucket list with a toothy grin.

"I've realized that most of us don't know how our life is going to end," said Sain. "And I don't either, but I can take a pretty good guess on what it's going to be like, as it progresses. And it's incumbent upon me to do certain things now. My mantra . . . is 'do it while you still can.'"

Ginny Archer, a licensed professional counselor of 33 years, said living in the moment and enjoying experiences as they come, are exercises in gratitude.

"Don't focus on the past, don't focus on the future, but what do I have grateful for now?" said Archer. "What do I have today that I can be present and involved in?"

Sain's philosophy is to keep moving. He likens Parkinson's to molten lava – if you stop trying to outrun it, eventually, it will get you. And it will destroy



everything it touches. Sain has seen it happen to other members of his support group; a negative attitude seems to breed negative outcomes, and the disease progresses faster.

But Sain keeps on running with his arm extended outward, keeping the disease at bay. Giving Parkinson's the Heisman stiff arm, as he calls it. Exercise is key, he said. But also, keeping his mind sharp through reading or socializing is important. And although he isn't giving himself too much credit, his tactics seem to be working.

For the past five years, Sain has been involved in a research study focused on declining cognition in Parkinson's patients. In four of the five memory exams he's taken, he's shown no cognitive decline. Remarkably, he's shown cognitive improvement.

"They said you're getting better, and we're fascinated with that," said Sain. "Yeah, so that's kind of reassuring. Maybe what I'm doing is working."

By the time Russel Craig was 15, he could no longer read. He was born legally blind, with a rare group of degenerative eye diseases called Retinitis Pigmentosa. In his younger years, he could still play video games, read books and safely navigate his environment. But slowly, those abilities began to slip away.

Craig walked the hallways of his high school with sunglasses and a cane, feeling out of place and different, always distant from his peers. His parents read him his class notes at home, but Craig was somewhere else. He had stopped caring about his schoolwork. It all seemed meaningless when he could no longer read on his own.

"I literally just sat in class and like went into dreamland," said Craig. "I would just skate by on intelligence and no effort at all. And it was tough for a while. It honestly took me several years to take

accountability and get back on track."

Slowly, through the help of others, and through the clarity of maturity, Craig came to understand that no matter how hard he shook his fist at the heavens, he would continue to lose his vision.

"I've just come to terms with it," said Craig. "I don't think you really can do that when you're a kid, because you don't really understand abstract thinking. I think you have to become an adult to realize certain things are permanent."

Although he could not read or watch TV without assistance, he was still able to play his guitar.

"What people don't understand is that all those years in high school, everybody else played sports, everybody went to parties and socialized. Everybody had a girlfriend or boyfriend, and I had none of that," said Craig. "When I got home from school, I sat in my room, and I played guitar. That's what I did. I did it for hours every day. And that was the only thing that kept me from going completely off the tracks."

Today, Craig has opened for acts such as the Charlie Daniels Band and Glen Templeton. He plays guitar and sings in bars, at parties and festivals across Alabama. Whether it is Metallica, Otis Redding or Eric Church, he's loving every second of it.

During the day, Craig works at the Alabama Institute for Deaf and Blind in Talladega. Many times, he's helping people to accept a loss of vision, and a loss of all the capabilities, beauty and experiences that go along with it.

"I still want to inspire other people and be a resource for them," said Craig. "Because I really think you get more out of helping others than helping yourself. Helping yourself, at least in my life, doesn't really help you much at all."

There's truth to that, said Archer. A focus on others is a healthy way to deal with loss of vision and independence.



Success After Struggle

Top: Benjamin Hendrix receives the Alabama "A" club's achievement and scholar athlete scholarship award.

"You're getting outside yourself, and you're not wallowing in your own pain," said Archer. "And that's the best thing someone can do to get outside of their own situation, is to reach out and do something for another human being."

Benjamin Hendrix was diagnosed with Burkitt's Lymphoma as a 13-year-old, an extremely aggressive form of cancer that caused his stomach to swell. The symptoms first presented during football practice, when he noticed himself tiring unusually quickly. He remembers some of the worst nights, lying in his bed in agony.

"My stomach was grown out like a basketball, just from the tumor growing so fast," said Hendrix. "I remember, crying that night, feeling like my stomach was going to rip open."

Soon after, Hendrix found himself in the hospital, being told by Dr. Billy "B.B." Sellers that he had cancer. The doctor approached him first, looked him in the eye and told him he needed to be strong for his parents. He said the cancer was curable, but it would not be without its battles.

"It was just as hard on them emotionally as it was on me physically," said Hendrix.

The young teen went through five rounds of chemotherapy, each round administered much more frequently than standard treatments. Whereas, an adult

might undergo treatment for a day, then take a week off, Hendrix's youth meant that he could withstand higher doses. He received chemotherapy for a week straight, hooked up to the IV the entire time.

Hendrix's goal was to be in shape for the next season of football. While in the hospital, he kept his body moving, walking the length of the floor for exercise. Other times, he did push-ups and sit-ups, sometimes with the IV still stuck in his vein.

Three months later, Hendrix's treatments concluded. Soon after, he was cancer free.

"My experience with cancer showed me how precious life is, and how it could be gone in an instant," said Hendrix. "A lot of people that age freak out or get upset at trivial things. For me, it was just like man, look at where I am now. Look where the Lord has led me now, compared to where I was then. I mean, I have yet to experience a thing worse than being hooked up to three IVs, chemotherapy running through my veins, not being allowed to leave the hospital for weeks on end."

"People who have been through struggles and gotten on the other side, are typically much more resilient people than the general population. They've done it," said Archer.

Hendrix said the experience has given him a defining moment, something that has produced a greater purpose. He credits his faith for getting him through it, and he credits his cancer for strengthening his faith.



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