

# Living to the fullest



## Kuisel says hemophilia will not change his 'options in life'

staff writer | Kat Kollegger

As school nurse Lisa Kuisel watches on varsity boys' lacrosse team playing, her mind isn't just on the score of the game.

Her mind isn't just on the performance of her son, midfielder, John Kuisel.

Instead, it drifts between awareness of the score and worry for her son's safety.

She glances at the cooler housing the possibly life-saving medication that must travel to every lacrosse game and must be kept refrigerated.

Sometimes thoughts of the worst clutter her mind.

"If he got a concussion..." she said. "He's very lucky he never has, but that would be the scariest thing..."

John has type B hemophilia, a blood disorder that affects the patient's ability to clot normally. He was born with the disorder, although the Kuisel family didn't know until John was older. Hemophilia most often is hereditary, but it can occur because of a genetic mutation.

"I found out when I was 10 years old. I got two of my baby teeth removed, and a week after I got them removed, every night I woke up and there would just be like a pool of blood on my pillow," John said. "I finally went to the doctors at MUSC and they tested my blood, and that's when they found out."

Severe hemophiliacs may have no ability to clot and will actively bleed until death occurs or medication is given to aid clotting. John, however, has a mild form of hemophilia that allows clotting to occur, but not in the normal way. John's case affects mostly internal bleeding issues, such as bone breaks, ligament tears or sprains.

When an internal "bleed" occurs with these injuries, the patient suffers severe pain and the injury takes longer to heal than in a person without hemophilia.

The Kuisel family faced a new obstacle when their son was diagnosed: there was a pos-

sibility that their extremely active son wouldn't be able to participate in the sports he loved anymore.

"I was shocked. Because he was 10 years old and playing football," Mrs. Kuisel said. "I mean he was extremely active and we had not had any big incidents.

"Things changed dramatically. He had to quit football, so he was 10 and he was probably someone who would be playing Wando football right now, and being a running back and be really good," she continued. "They really wanted him to stop lacrosse, and we had to really make agreements with the doctors for him to be able to play."

John and his hematologist -- a blood specialist -- created a contract stating that if a bleed ever occurred, John would be required to go on medication.

"He has a great doctor at MUSC, and they made a contract. So when we started at Wando, she wasn't sure she was going to let him [play sports] because you know as a high school player you have to have a physical signed," Mrs. Kuisel said. "So she made a contract with John, if he got a bleed and if he still wanted to play, he was going to have to start giving the medicine. And she held him to it."

Despite the high risk involved with playing lacrosse and having hemophilia, John is in his eighth year in the sport, including four years and two state championships with Wando.

Mrs. Kuisel said she was worried about the risk involved in remaining in sports.

"I wanted him to stop," she said. "It was a family argument that went on for a long time."

However, sports had become a big part of who John was. It's what he loved. The family didn't want to take that love away from him. She is more at peace now and proud of her son's success.

"If you go on to the hemophilia society website, they'll list the sports and they're in categories of what they consider dangerous and not dangerous," she said. "I mean lacrosse is up there with football."

But John went his entire high school career with no incidents regarding his hemophilia.

Until last December.

John sustained an ankle sprain that led to a bleed. The irony, John said, is he wasn't even

playing sports when the injury happened.

"I'd really never had a problem with it before this ankle thing," he said. "We never even thought it [severe pain in his ankle] was that in the first place, so we went to a doctor and they were like 'you have internal bleeding there' and then they gave me the medicine, and it kind of got better."

Since then, he has been working to fully recover from the injury that occurred two months ago. Originally returning to the field, John had to once again step aside when the injury was aggravated.

Part of the issue is that having hemophilia slows down the healing process due to the difficulty with clotting in internal bleeds, like the one that occurred in John's ankle.

"It's been hard," Mrs. Kuisel said. "Hemophiliacs don't heal quickly like you and I do."

Having a potentially life-threatening condition didn't prevent Kuisel from being a Division I lacrosse commit at Virginia Military Institute. But Kuisel made the decision to decommit, since hemophilia would keep him from serving in the military -- his original plans.

"John wanted to go into the military, and that was out. The rule with the military is if you have a condition that requires a medication you cannot be accepted," Mrs. Kuisel said. "It changed his path of life."

Having hemophilia also affects John's future as he prepares to move to college in the fall. He now has to take over the responsibility for administering his medicine. Currently, his mother administers an IV infusion of hemophilia medication every 14 days. The family hopes, though, to be able to stop the medicine before he leaves for college.

In case of a bleed, John or one of his parents would have to inject the emergency medication. The medicine would prevent any serious internal bleeding from happening in the future.

"The new drug he's on is Alprolix, and that actually is the drug that he's on every 14 days and this is also the emergency drug," Kuisel said.

John is learning to inject the drug himself, but it is no small task. The medication has to be mixed, loaded into a syringe and injected over a three-minute period. During the lacrosse season, the responsibility for the medication falls almost entirely on the Kuisel family. Athletic trainers are not trained to administer the medication, nor is Coach Lance Renes.

"We always had to be the parent that went," Mrs. Kuisel said, explaining that one of John's

parents has to be present at every game in case the medicine needs to be administered.

John's teammates also know about his condition and are there to look after him making sure he stays safe.

John said he will not let hemophilia change his options in life.

"It's not as bad as it sounds," he said. "When you're on the field it doesn't really cross your mind."

(Above) John Kuisel's mother, nurse Lisa Kuisel, keeps medicine handy at all times in case he suffers an injury. (Below) Kuisel walks off field after game on Feb. 22.

When you're on the field it doesn't really cross your mind.

John Kuisel

