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Wayne State University student's story of hope, courage

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Tarek Ghani, left, chats with Victor Chukwueke at a fund-raiser Thursday to help bring Chukwueke's family from Nigeria to his commencement address at Wayne State University. / KATHLEEN GALLIGAN/Detroit Free Press

BY DAVID JESSE
DETROIT FREE PRESS
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Victor Chukwueke falls into silence, the Nigerian student's smile chased away by a painful memory. His one good eye clamps shut, trying to block the tears.

"My mother tell me, it will be well with me," Chukwueke says of their good-bye when she sent him away to America for medical treatment. "God is in control."

Chukwueke hasn't seen his parents or siblings for 10 years.

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They haven't seen the results of six surgeries that cut his head and face open to remove large deforming tumors.

Overcoming a genetic disorder

Victor Chukwueke came to Michigan from Nigeria in 2001 for surgery to remove benign facial tumors. In the past 10 years, besides receiving medical care, he has earned a degree in biochemistry and chemical biology from Wayne State University and will give the commencement address to his graduating class May 5.



Victor's commencement photo, 2011

THE DISORDER

Neurofibromatosis (NF) causes tumors to grow on nerves throughout the body. Here are some facts about the condition:

Who can get it?

It is a genetic disorder than can occur in any race or gender in 1 out of 3,000 children born — more common than cystic fibrosis, Duchenne muscular dystrophy and Huntington's disease combined.

What are the complications?

Deafness, blindness, bone deformities, cardiovascular problems and cancer may accompany the condition. About 60% of people with NF have learning disabilities.

What are the early symptoms?

Six or more skin markings called café au lait spots and nodules on the eye are indications. In the most common form, NF is typically diagnosed in young children and adolescents. Symptoms may increase during puberty.

How is it treated?

There are different types of tumors; some may be removed. Victor had six major surgeries to date to improve his condition.

Is it fatal?

Complications from NF may shorten the lives of some people with the disorder.

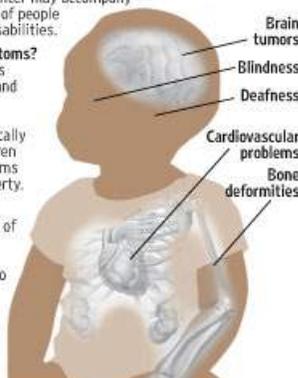
For more information: Children's Tumor Foundation, www.ctf.org, or the National Institute of Neurological Disorders and Stroke, www.ninds.nih.gov/disorders/neurofibromatosis/neurofibromatosis.htm

Sources: Wayne State University, Children's Tumor Foundation, National Institute of Neurological Disorders and Stroke

MARTHA THRENTON



Victor, at 15 years old, in 2001



Overcoming a genetic disorder

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They haven't seen the house where he lived with nuns, or the lab where he works as a biochemistry student at Wayne State University.

They haven't seen the inspiration he's become to others.

Chukwueke will speak at Wayne State's graduation on May 5 -- a slot usually reserved for the class valedictorian.

School officials are trying to raise money to fly his mother and sister from Nigeria, as they also navigate an ocean of U.S. government red tape. The U.S. government is way of potential terrorist elements in Nigeria, so quickly approved visas are difficult to obtain.

Chukwueke doesn't know whether he'll see his family sitting in the audience. But that won't change his message: "I want to tell everyone that they should not let their challenges hold them down."

Wayne State University student who once lost all hope now inspires others

Victor Chukwueke wouldn't venture outside his house to play, the way children should.

He didn't want to face the taunts, jokes, stares -- the hurt.

"I didn't have any hope," Chukwueke says of his childhood in rural Nigeria.

His parents couldn't afford medical treatment for large tumors growing from the top of his head and side of his face. And even if they did, Nigerian doctors didn't know what to do. They, too, gave up on him.

A decade later, Chukwueke, now 25, is to graduate with honors from Wayne State University on May 5. He'll give the

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Sources: Wayne State University, Children's Tumor Foundation, National Institute of Neurological Disorders and Stroke



Victor Chukwueke, from left, Brian Towns and Rob Neda play football at a fund-raiser Thursday held to bring Chukwueke's family from Nigeria to his commencement at Wayne State University. Chukwueke left Nigeria a decade ago for surgeries in the U.S. and has not seen his family since. / Photos by KATHLEEN GALLIGAN/Detroit Free Press



Fatima Ismail, 22, of Livonia, left, and Linda Fakhour, 23, of Dearborn work for donations at the fund-raiser held by their student organization.

How you can help

Donations for the travel expenses can be made at any Fifth Third Bank. Checks should be made payable to: Benefit Account for Victor Chukwueke. Write account

commencement address, and talk about having hope again after six operations and of his dream of returning to Nigeria as a surgeon.

There's a chance his mom will be in the front row. He hasn't seen her in 10 years, not since he left Nigeria with a nun heading to America and its skilled surgeons.

Wayne State officials are trying to raise money to fly his family to the graduation. The school is also working to secure last-minute visas.

Growing up

Chukwueke can't remember a life without tumors.

"I wouldn't go outside. I felt so ashamed. Everywhere I went, people were making jokes. All the kids would just stare at me. I couldn't face it."

He has neurofibromatosis, a genetic disorder that causes tumor growth in the nervous system. Experts say they believe mutations in genes that suppress cell growth are to blame. An estimated 100,000 in the U.S. have it, according to the National Institutes of Health.

His case is extreme.

Despite little money, his mother took him to physicians all over Nigeria. Nobody could help, including a doctor at a large teaching hospital.

The doctor "touched my face and told me there was nothing they could do. I begged him and cried. ... I was so tired of the humiliation."

Then in 2001, he met the Rev. Mother Mary Paul Offiah of the Daughters of Mary Mother of Mercy. The nun, on an African mission, arranged for a Southfield plastic surgeon to operate for free.

That meant major changes. He left Nigeria and his family -- an emotional good-bye.



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If Chukwueke's family is unable to attend the commencement, the travel funds will be applied toward his continuing education.

The mirror

Chukwueke arrived in Michigan a decade ago to begin a long process of six major surgeries.

Surgeons cut into the top of his head, leaving a scar visible today from ear to ear. They operated on his face, removing tumors and his right eye.

After the first surgery, doctors wrapped his face in bandages. He's not sure how long it took, but they eventually removed the dressing and brought him a mirror.

"It was like a new person was looking at me," Chukwueke said. "I was dreaming of this all my life."

Schooling

As he recovered, living in a home with nuns, Chukwueke completed his GED. He enrolled at Oakland Community College. Then Wayne State. His education was paid for by a man he met through the sisters.

He excelled, diving into chemistry. He's been on the dean's list every semester. He's been researching the causes of tumors.

Kenneth Honn, a WSU professor of pathology, nominated Chukwueke to be a commencement speaker.

"Victor has braved situations and challenges that would humble many and that could have instilled self-doubt or insecurity," Honn wrote in his nomination letter. "However, he created goals for his personal and academic life that he has systematically achieved with self-possession beyond his years. ... The personal example set by this genteel young man with a wicked sweet tooth is an inspiration to all who meet him."

In the speech, Chukwueke will tell his classmates they can overcome anything. He'll thank the surgeons who changed his life, the country that gave him opportunity and the nuns who rescued him.

He'll describe his dream of medical school and of becoming a surgeon to one day help others like him in the Third World.

"I know where I came from," he said.

The reunion

It's thousands of dollars for a last-minute flight from Nigeria. But money isn't the only obstacle. Riots have engulfed the country, and the U.S. State Department has listed it on travel warnings.

WSU officials asked U.S. Sen. Carl Levin for help, but his office said it is unsure it can expedite the visas.

Chukwueke imagines standing in the airport to greet his mom.

"It will be a magic moment," he says, fighting tears. "It will be a moment I won't ever forget."

Contact David Jesse: 313-222-8851 or djesse@freepress.com

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