



A Disease That Creates Other Diseases: Regina Gordon & Her Unpredictable Sarcoidosis

Right on time, April is Sarcoidosis Awareness Month

For Regina Gordon, March's difficult advance began on the fourth day when she woke up, in pain and for a lack of a better one-word description...blind. Technically, she could see, her vision wasn't opaque, but everything was blurry and light appeared only in the form of huge starbursts. And you know it's bad when your trusted doctor is like...I don't know what this is.

The next day, she was driven by her mother, Bea Williams-Tevis, to an emergency appointment in Cleveland, to the closet clinic that treats the inflammatory disease, sarcoidosis; it attacks the immune system, leaving the body super vulnerable. "It attacks every part of your body, and you never know when it's going to come out," Gordon said.

It's a disease that opens the door to other diseases. Gordon was soon diagnosed with sarcoid in the eye...the steroids she was given to treat it raised her blood sugars and opened the door straight to Type 2 diabetes.

The "blindness" was corrected; her eye doctor said she's doing well. For the diabetes, Gordon injects herself with insulin five times a day. She's been adapting with sarcoidosis since her hospital visit in 1994. She has Stage 2 of the disease. Sarcoidosis is detected in the lungs; she has it in her lymph nodes (head and neck region), her skin, the eyes, and a form of it inside of her mouth. In her throat, she has a digestive disorder called GERD (Gastroesophageal reflux disease). There are four stages.

Comedian Bernie Mac died from it; actress Tisha Campbell has it. "Sarcoid is very prominent in the African-American community," Gordon said, "but a lot of people don't know they have it" because it looks like cancer (but isn't cancerous). That's exactly what happened to Gordon; her first diagnosis was non-Hodgkin lymphoma, but the doctors kept probing.

The impetus for the hospital visit was a case of pneumonia so life-threatening that she



Gordon pinning Garrett Serstad, a staff aide for Governor Jim Banks, with a Sarcoidosis awareness pin. One of her duties as ambassador included pitching officials in Indianapolis about the disease.



The 95 Foundation for Sarcoidosis Research nationwide ambassadors, including Gordon.

called her parents to say she thought she was dying. When the nurse looked at her chest x-ray, she told Gordon, full-stop, they're keeping her overnight. "I will never forget the look on her face," she said.

The disease can either be hereditary or can stem from the environment. Gordon surmises that hers is the latter, pinpointing the moment in 1992 when she breathed contagious agents while working at the Salvation Army during their construction phase. The work had unearthed asbestos for a prolonged period; two years later, she was diagnosed.

Gordon's sarcoidosis went into remission in 2017, but "came back with a blast [this year]," she said. Wanting to start a Sarcoid support group

in Fort Wayne, she discovered the Foundation for Sarcoidosis

Research organization in 2016. She was recently made

ambassador by the nonprofit, one of 95 across the country and one of two from Indiana; Hawaii is the only state (knock on wood) that doesn't have any.

April is Sarcoidosis Awareness Month. To sound the trumpets in Fort Wayne, Ambassador Gordon has partnered with local groups for the worldwide event "Lighting Up the City." On April 13, the Ashe Plaza, History Center and the MLK Bridge will be lit up in disease-branded purple. At 7:30 p.m., the night will culminate with a speech and a proclamation at the MLK Bridge, on the skate-park side.

This is Gordon's first event as ambassador; she was finalizing details on her hospital bed. She's hoping the Mayor will swing through, but she wants numbers, a crowd to educate and hype to start something passionate.

She hasn't let Sarcoidosis slow her roll, by any stretch. You ever met somebody who makes you feel lazy? That'd be Gordon. "My motto is: I have Sarcoidosis, but it doesn't have me," she said. The ambassador with a mission works a full-time job and is going to school for her second master's degree, this time in communications because it's a skill she's going to need down the road. And by down the road, I mean now.

To contact Sarcoidosis Fort Wayne, visit their Facebook page: SarcoidosisFortWayne or call: 260.232.3641.

The What What What: Editorial Notices & Shout-Outs

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The Past Is Not Through With Us

Corrections:
In our FWVO Page 6 section, cremes was misspelled as creams. Phyllis Bragg's last name was misspelled.

From The Editor

Our Business issue was kind of a mixed bag, with a lot of stories that didn't fall into the category but were still relevant. Welcome (again) to the world of newspaper publishing.

WBR



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