

GIVING LUPUS A VOICE

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“It is the uninvited guest at a dinner party, the shadowy figure lurking over your shoulder for many years until one day it steps into the light for all to see...”

Young, beautiful and talented, Reeanna Harrilal does not strike you as someone who is ill. But some days, she can barely get out of bed. That is one of the biggest problems with her disease: the fact that it often cannot be seen by the naked eye. Harrilal is the President and Founder of The Voice of Lupus Foundation (VLF), a non-profit organisation established to foster greater awareness about Lupus in Trinidad and Tobago.

This role demands significant courage. In a 2012 Trinidad Newsday Women's Weekly article "Revealed", she discussed dealing with a morphine addiction, overcoming a nervous breakdown, and even multiple suicide attempts. "I was very scared as to how people would react, as there are things in my past I'm not proud of," she admitted. "But to be able to turn around my life and be a positive force giving lupus a face and a voice is essential."

 20% of people with lupus will have a parent or sibling who already has lupus or may develop lupus.

WHAT IS LUPUS?

Systemic Lupus Erythematosus (SLE) is a chronic auto-immune disease. It can be described as a type of self-allergy, whereby the patient's immune system creates antibodies which, instead of protecting the body from bacteria and viruses, attack the person's own body tissues.

There is no single blood test that can reveal lupus. If someone has four out of the eleven identified criteria, they should get tested for lupus. These criteria, established by the American College of Rheumatology, are:

1. Malar rash or "butterfly rash" on the face
2. Discoid rash on the body (red, scaly patches)
3. Serositis or pericarditis (inflammation of the membrane around the lung and heart, respectively)
4. Mouth ulcers
5. Arthritis, with tenderness, swelling or effusion
6. Photosensitivity (sensitivity to light)
7. Blood disorder – including low red blood cell count or low white blood cell count
8. Renal disorder
9. Positive antinuclear antibody test
10. Immunologic disorder
11. Neurologic disorder, including seizures or psychosis

These are not the only symptoms, and individual symptoms may vary, which makes the disease difficult to diagnose.

Lupus 'flares' are often exacerbated by stress, excessive sunlight, a viral infection, a drug allergy, and even one's diet. A major flare can attack a vital organ and cause death. It is a terminal disease, though many patients may appear to be in 'remission' for years.

LIVING WITH LUPUS

There is no known cure for lupus, and treatment may sometimes be worse than the disease itself. Common treatments for lupus include Cellcept, an immune suppressant drug that can be harsh to the body; prednisolone, a corticosteroid; and even chemotherapy

For Reeanna, it has been a long battle with various treatments. "Due to years of steroids, I gained a lot of weight and my stomach became severely damaged," she said. "I developed leaky gut syndrome – when I eat foods I am not supposed to eat, they leak into my bloodstream and make me sick."

Dissatisfied with medical treatments, she is now trying more alternative methods at the Eden Heights Clinic in Trincity, east Trinidad. Her current treatment includes prolozone therapy, a non-surgical ligament reconstruction involving injecting collagen to treat chronic pain; ozone therapy, which increases the amount of oxygen to the body; and, most recently, an experimental treatment called frequency-specific microcurrent, which treats nerve and muscle pain through micro amperage current.

These treatments go hand in hand with her daily cocktail of supplements, which includes a wide range of supplements – Super Bio-Curcumin, Super Booster B-12 Soft Gels, probiotics, sun chrollela, and Omega 3-6-9, just to name just a few. She also takes a daily dose of a vitamin we are all familiar with – Vitamin C.



FINDING HER OWN VOICE

Lupus can be a full-time job. The disease cost Reeanna her flourishing media career, which she tries not to dwell on. "I've stopped looking at it like 'what lupus has robbed me of', but rather what it has taught me," said Reeanna, who spent eleven years in the media industry working at television stations including CNMG and Gayelle, and radio stations Masala 101.1FM, Music Radio 97 FM, Sweet 100.1 FM, and Talkcity 91.1FM.

Though she had symptoms since she was 13, and was tentatively diagnosed since the age of 17; it wasn't until several years into her media career at the age of 24 that her disease truly reared its head, demanding to be noticed. Even then, she struggled to cope and balance her career, until finally her last media stint was swiftly cut short. "I had just started working at a media house, and within the first month, I picked up the flu from my boss. Because I have lupus, the flu is not the flu for me," she explained. "I ended up in the hospital with pneumonia for over three weeks. When I was finally discharged, I no longer had a job."

Looking back on it, Reeanna acknowledged that the media was just a stepping-stone to fulfill her purpose in life. "For about three days, I was really depressed. I didn't know how I would survive. But The Holy Spirit guided me to the Facebook page I had created about a year before, and told me to make this 'hobby' of mine a physical entity." Now, she uses her skills and experience in the media for the betterment of her Foundation.

THE VLF: A PILLAR OF STRENGTH

Founded in November 2011 by Reeanna along with Directors Dera Harrilal (Reeanna's mother), Reshma Cooke and Dianne Seepersad; The Voice of Lupus Foundation aims to provide hope, compassion, support, empowerment, independence and dignity to those living with lupus and to their families. Through programmes of education and advocacy, the VLF hopes to bring national attention and resources to elevate lupus to a place of prominence on the nation's health care agenda.

The VLF has embarked upon national awareness campaigns, a proactive media outreach, and has developed innovative online content through its website www.thevoiceoflupus.com and social networking sites Facebook, Twitter, and YouTube. The Foundation has been featured on CTV, and on


radio stations Talk City 91.1FM and Wack 90.1FM. They have partnered with the Chaguanas Lions Club and the Indian Women's Group of Trinidad and Tobago, and have visited schools to speak about the disease. The VLF also participates in health fairs almost every month.

In January 2012, the VLF filmed their infomercial "The Faces of Lupus Project" at San Fernando Hill in south Trinidad. Reeanna thanks film directors Oyetayo Raymond Ojoade and Steven Taylor for making this project possible. "I wanted to focus on local faces, persons who have the illness and have been living with it, so that we can show that anyone and everyone is at risk, regardless of the colour of their skin, texture of their hair or ethnic background," Reeanna said.

Currently, the VLF is working on setting up the "Gift of Hope" fund, which will help lupus patients that cannot afford medication by allowing a benefactor to 'sponsor' a patient for a period of time to assist with these expenses.

Needless to say, it is no easy task getting funding for a disease that few understand. Nevertheless, she does not let it discourage her. "One of our major accomplishments is that for the first time in T&T there is a website solely for lupus awareness," Reeanna said. "Our tagline, 'A Pillar of Strength', was chosen because this Foundation aims to be just that; a pillar of strength for someone who has lupus – and in today's world, being able to reach people through online means is crucial."

For Reeanna, it is heartening to see her efforts being realised. Looking back on the troubled past she revealed to the nation, she acknowledges the journey was necessary to get to where she is today.

"Coming from a place where you really gave up on life and gave up on yourself... to be able to propel yourself and reposition yourself to become an overcomer and to help others to cope – that is a blessing in itself," she said. "I've come too far to turn back now. I may have lupus but lupus does not have me." 

For more information and resources on lupus, visit www.thevoiceoflupus.com. You can also check out their Facebook page at www.facebook.com/thevoiceoflupus or contact the VLF directly at (868) 221-9677.