

Jenna Lowe's powerful legacy for South Africans lives on

More than a decade ago, it took over 18-months to correctly diagnose 17 year old Capetonian, Jenna Lowe with rare and severe Pulmonary Hypertension (PH).



Source: Supplied. The late Jenna Lowe with her oxygen concentrator.

Little was known about this devastating and deadly disease before Jenna set her mind to raising awareness of how the sudden, unexplained onset of PH completely changed the course of her bright and happy life.

PH is different from hypertension in that it is dangerously high blood pressure that occurs only in the lungs impacting not only breathing but heart health. Research into the condition is scarce, and according to Dr Gerald Maarman, from the Centre for Cardio-Metabolic Research in Africa at Stellenbosch University, the prevalence of PH in Africa, which mostly impacts low and middle-income countries, can range from 10% to 68%.

It is estimated that 75 million people worldwide suffer from PH, however that could be higher in reality as PH is frequently

mis- or undiagnosed.

Thanks to the Jenna Lowe Trust - set up as the legacy of the trailblazing, luminous teen - today Cape Town boasts a twice-monthly specialised PH Clinic at Groote Schuur Hospital. The Pulmonary Hypertension Association of South Africa (PHA SA) is also providing an array of essential support for PH patients, and the disease is slowly but surely garnering more support.

World Pulmonary Hypertension Day

The Jenna Lowe Trust and the PHA SA are coming together with around 80 organisations worldwide on 5 May 2022 to raise awareness on World PH Day.

Unfortunately, this debilitating, progressive condition remains a life-threatening challenge for patients. There is still no cure beyond organ transplants; and many of the necessary medications and equipment to prolong and improve quality of life are prohibitively expensive and unavailable in South Africa. However, probably the greatest reason for the need for PH awareness, is that it is often still misdiagnosed as it is not yet widely understood and recognised by most primary healthcare professionals.

Many of the symptoms of PH, which is marked by breathlessness, are shared by other more common lung conditions, including asthma. This is why it is so important for South Africans to be aware of the condition so that they can request the tests for PH should they suspect they might have it.

Gabi Lowe, mother of Jenna and director of The Jenna Lowe Trust says: “We started the clinic in 2015 as a place of hope for patients and their families. Jenna’s heart-breaking journey with this cruel disease was made harder because we struggled to access the expertise and help she needed. It is her powerful legacy and wish that it shouldn’t be this way for other South Africans suffering with PH.”

Jenna Lowe tragically passed away in 2015, three months before her 21st birthday, after launching the successful social-media campaign *Get Me to 21*, which highlighted the plight of PH patients and advocated for research, improved care and organ donation.

Jenna Lowe documentary

Jenna Lowe’s story is the subject of an upcoming documentary, which the family hope will bring international attention to the disease.

The Jenna Lowe Clinic, which currently serves approximately 500 patients in South Africa is also a hub of training and international engagement for the medical profession. The Jenna Lowe Trust provides the clinic with the services of Nurse Hilary Barlow, and it is overseen by Dr Greg Symons.

Nurse Barlow says: “With fundraising support from the public we are able to help patients who would otherwise not be able to afford high-cost equipment such as oxygen concentrators and mobility support in order to give them better quality of life.”



Honouring Jenna Lowe in pulmonary hypertension awareness month

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It is important to note that PH can strike anyone, at any age, even those who have previously enjoyed good health. According to the Jenna Lowe Trust, early diagnosis is vital as it can have a significant impact on your health, quality of life and length of life. It is important not to ignore the following symptoms:

- Breathlessness or shortness of breath, especially during physical activity
- Chest pain known as angina pectoris, especially during physical activity
- Dizziness or light-headedness, especially when climbing stairs or standing up
- Fainting
- Swollen ankles, legs, or abdomen, which is also called oedema
- Loss of energy and feeling tired all the time
- Dry cough
- Raynaud's phenomenon: chalky white or blue fingers; can be painful and provoked by the cold

In advanced stages of pulmonary hypertension, minimal activity may produce some or all of these symptoms. Patients in advanced stages may experience irregular heartbeat, a racing pulse, passing out and difficulty breathing at rest. Sometimes these symptoms mean you have another condition, but sometimes, they may mean you have Pulmonary Hypertension, and it may be important to ask your doctor for a test.

Support the important work of The Jenna Lowe Trust [here](#)

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