

Honouring Jenna Lowe in pulmonary hypertension awareness month

The Groote Schuur Hospital Pulmonary Hypertension Clinic (GSH PHC) is a specialist clinic offering improved treatment for state and private patients suffering from the disease. It was set up in honour of Jenna Lowe, who died of the disease in 2015, is funded by the [Jenna Lowe Trust](#) (JLT), and operates in collaboration with pulmonologist, Dr Greg Symons and Dr Greg Calligaro.



PH Clinic specialist nurse, Helen Williams with patient, Bridget Nkonyeni

PH is a rare, life-threatening disease that is often misdiagnosed leading to a delay in diagnosis up to two to three years. Most patients have a severe form by the time clinicians identify it. An accurate early diagnosis is vital to develop a successful treatment plan to prolong the patient's life.

Despite having to cope with the symptoms of her rare disease, Jenna sought to make a positive difference for all PH patients, rallied her parents, their networks and resources to increase awareness of PH and improve patient diagnosis in the public domain as well as within the medical fraternity in South Africa. In doing so, she brought to light the enormous need for a specialist clinic or treatment centre for patients like her.

"It is incredibly rewarding to be a part of Jenna's legacy. She brought the critical need for a tertiary specialist clinic for PH into focus. With the support of the divisions of pulmonology, cardiology and the divisions of pharmacology, the GSH PHC has been running successfully for almost two years now. We provide hope, support and treatment to the patients we treat here in the Cape. And with the crucial financial and resource backing of the Jenna Lowe Trust, we have most certainly raised the level of PH health care in the country.", explains Symons.

Improving quality of life

The progressive nature of this disease means that an individual may experience only mild symptoms at first, but will eventually require treatment and medical care to maintain a normal lifestyle. Through regular engagement with medical specialists around the globe and support from the Jenna Lowe Trust, the GSH PHC is able to keep up-to-date with developments in patient treatment and carry out the costly diagnostic testing on patients and with the accurate diagnosis, the clinicians are able to improve the quality of life, exercise capacity and survival of these PH patients.

"Jenna's PH diagnosis was overwhelming, especially when we realised that so little is known about the disease. We were shocked, confused and frightened – we had to cope daily with whatever the disease threw at us. We vowed that after our experience with Jenna's disease that things had to change; PH patients, their families, their friends and healthcare professionals needed support to make this disease manageable and improve healthcare around it. We knew that driving awareness of this underdiagnosed disease for future patients was vital to change the landscape for other patients," says Gabi Lowe, Jenna's mother and co-founder of the JLT.

The GSH PHC undoubtedly provides relief for the PH patients that it currently treats, and its team plans to expand these clinic services to KwaZulu-Natal and Gauteng, also to start an African PH patient database to understand the disease better locally, as well as lobby pharmaceutical companies to make the medicine more affordable for all.

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