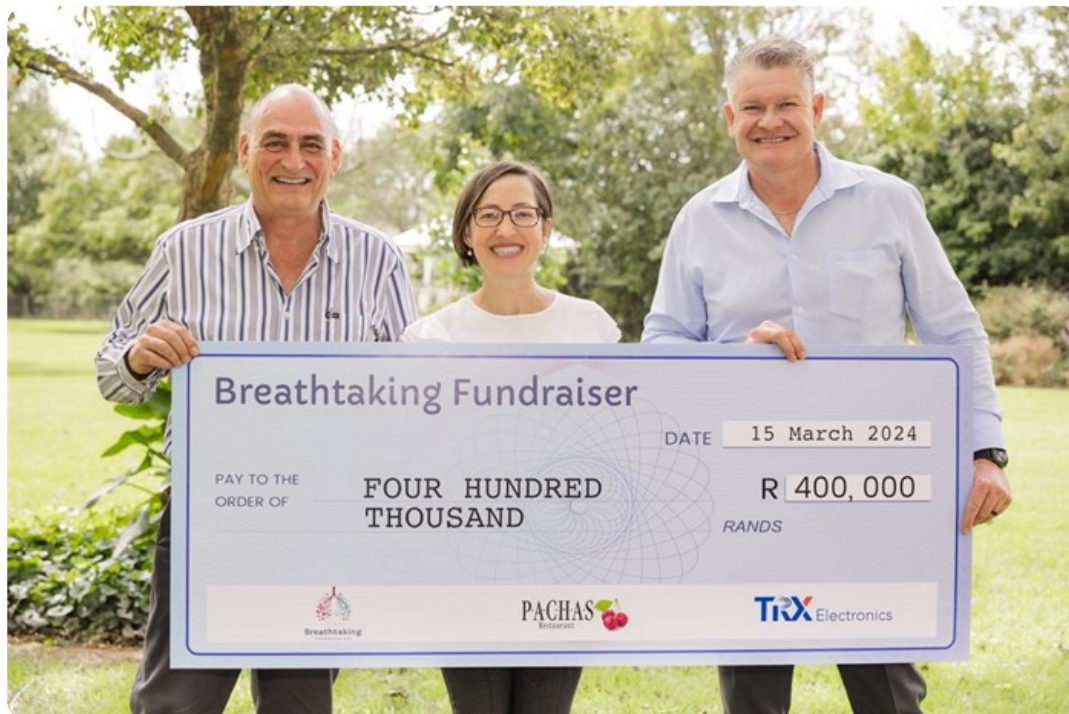


R400k boost for cystic fibrosis fighters

Breathtaking Fundraising, a non-profit that supports individuals with cystic fibrosis (CF) in South Africa, has received a R400,000 donation to address the significant challenge of medication accessibility.



Supplied image (L-R): Jan Willem Pont from Pachas Restaurant Pretoria, Maré Smit, Director of Breathtaking Fundraising NPC and Hannes Taute from TRX Electronics.

Breathtaking Fundraising assists those suffering from CF with access to medication, and raises awareness about this debilitating condition. The NPC received the donation through a golf day event at Wingate Golf Course in Pretoria by done TRX Electronics and Pachas Restaurant on 15 March 2024.

The funds will go towards much-needed support for individuals living with CF who can only access life-changing medication from Argentina to help manage the disease.

CF is an inherited genetic disorder that thickens mucus in the body causing blockages in vital organs such as the lungs and pancreas. It can lead to recurrent lung infections, irreversible damage and hamper digestion and nutrient absorption.

Symptoms and health issues due to CF are wide-ranging and may include frequent sinus infections, diabetes, osteoporosis, arthritis, infertility and liver problems.

Around 600 patients have been diagnosed with CF in SA however due to the complex nature of the disease and a high rate of misdiagnosis, it is estimated that at least 4,700 people may be living with the disease. It is a lifelong condition for which there is no cure, with an average life expectancy of under 21 years.



MEDICAL RESEARCH

New approach to treating cystic fibrosis

3 Dec 2019

Until 2019, doctors were only able to treat the symptoms of the disease. Given the life-shortening and debilitating health effects, treatments such as CFTR modulator therapies were developed by US-based company, Vertex Pharmaceuticals

which drastically improved and extended the lives of patients; however, these therapies are not registered in SA.

A lawsuit is underway in SA against Vertex to allow medication access to patients at an affordable cost. A recent announcement by the South Africa Cystic Fibrosis Association (Sacfa) reveals that the modulator drug Trifakta is now available to Discovery Medical Aid members. Unfortunately, this still leaves a significant portion of South Africans without access to treatment.

Managing director of Breathtaking Fundraising NPC Maré Smit, who lives with CF said, “We deeply appreciate the support from companies like TRX Electronics and Pachas who are instrumental in advancing our mission to improve the lives of those impacted by cystic fibrosis. We believe that everyone should have access to this life-saving treatment for improved quality of life and extended life expectancy.”

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