

Access to Innovative Care Foundation marks 10 years & access for over 2000 patients in need

The Access to Innovative Care Foundation marked 10 years this June, having assisted over 2000 patients in need to access treatments they would not otherwise not have been able to afford.

A non-profit organisation set up to support patient access to innovative care, the AICF's aims are two-fold:

1. to provide access to innovative medicines; and
2. to improve oncology nursing skills in the private and state sectors.

Chairperson of the AICF is Dr Bianca Rowe-Potgieter, a Paediatric Oncologist who heads up the Paediatric Unit at Chris Hani Baragwanath Hospital: "As a clinician working in both the public and private sectors, a researcher and teacher, I am proud to be associated with the Foundation and am excited about its vision for the future."

Research and development pharmaceutical companies (which produce branded products) invest huge sums of money to discover innovative treatments for highly specialised diseases. When a new molecule or drug goes to market, it comes with a high price tag placing it out of reach for many. Medical schemes are often unwilling to re-imburse these medicines in part or in full so the Foundation was set up to provide access funding support for defined periods, and support patient access to innovative care.

When the Foundation embarked on its journey, it was focused on oncology. Founding member, Dr Shane Cullis, an oncologist based in Kwa-Zulu Natal, says: "I joined the Innovative Cancer Care Foundation Board 10 years ago as I felt strongly about a large group of oncology patients on lower (and middle) tier medical aids who were unable to access innovative drugs because of their cost and unaffordable co-payments. It has been extremely gratifying to see how the now AICF has been able to bridge this gap for so many patients; initially in the Oncology sphere but now in many other medical disciplines."

The change of name to the AICF has allowed the inclusion of other therapeutic areas of haematology, immunology, gastroenterology, dermatology, rheumatology, ophthalmology and endocrinology.

"One of the challenges the AICF has faced has been getting international pharma companies who would partner with the AICF on patient access programs, to understand the South African legislation because the law is so different here than to other countries. In other countries, pharmaceutical products can be donated," says Schwegman.

Rowe-Potgieter says: "The Foundation builds upon its enormous success in establishing patient access programs that spans several clinical disciplines."

"The greatest success of the AICF has been the number of patient access programs, the inclusion of multiple disease areas and the number of patients assisted." says the AICF CEO, Jeanette

Schwegman. "In the past, patients who have needed life-saving or life-altering medication have been willing to go to just about anything to access funding. Some mortgaged houses, others harnessed crowd-funding, or accepted or sought donations from churches, sold cars, used their pension funds or borrowed money from friends and family. There is less of a need for this as a result of the AICF programs."

John Malan, a lung cancer patient who has benefited from one of the AICF programs, says: "A cancer diagnosis together with an estimate of remaining life, confronts one with all sorts of uninvited questions. In South Africa, we have outstanding medical professionals who assist a great deal, but one challenge they cannot resolve is the astronomical cost of medication. I was diagnosed with lung cancer and a particular gene mutation that can be treated with a medication the cost makes one gasp for breath and grapple with "well how long can I afford to keep myself alive?" The AICF and a wonderful medical aid have assisted substantially and removed the huge financial stress of cancer treatment."

"I am extremely grateful to the AICF program making ongoing treatment a reality for our patients." says Dr Irene Hitchin, Mr Malan's oncologist. "My patient, John Malan, has been symptom free and living a full life now for two years following a diagnosis of metastatic lung cancer. Without the support of the AICF we would not have been able to continue with treatment."

The support of the AICF to patients on lower tier medical aid is amazing and allows access to innovative new drugs that would have otherwise have been unaffordable.

I would like to congratulate the AICF on achieving the milestone of 10 years and thank you for your continuing support of our patients."

Suzan Santo, the mother of a young 16 year old boy, expressed her heartfelt gratitude to the AICF for the support provided to them. Suzan's son has Crohn's Disease and Ulcerative Colitis. The doctor couldn't complete the colonoscopy as his colon had so many lacerations and there was a risk of perforations. After several treatments didn't work, the doctor prescribed a product which was unaffordable to the family with them being on a lower medical aid option. After the doctor applied to the AICF and Suzan's son was approved for AICF support and started his treatment, Suzan said: "He feels like himself again, laughing, getting his energy back, no pain and most importantly there is no diarrhoea, and no bleeding. He is not anxious and depressed anymore. I will never be able to express in words how the AICF has changed my son's (and our) lives by contributing to his treatment."

Having built a strong reputation of good governance, trust and reliability over the past 10 years, a proliferation of programs and a growing number of doctors accessing the AICF on behalf of their patients, the impact of the Foundation is expanding. "We've helped by lessening the financial burden and allowing the patient to be treated with the most clinically suitable option," says Schwegman.

"Equitable distribution is a priority for the AICF as illustrated by the Adcetris-program that recently became accessible to state oncology patients with work being done to ensure more innovative drugs are made available to all sectors of the community." says Rowe-Potgieter.

The second aim of the AICF is to improve oncology nursing skills. The AICF Oncology Nursing Programme aims to facilitate the development of specialist knowledge and professionalism within oncology nursing in South Africa, and ultimately Sub-Saharan Africa.

Rowe-Potgieter, speaking from first-hand experience as a clinician, says "The AICF acknowledges the immense value of quality nursing and are proud to collaborate with international experts to expand our Oncology Nurse training program and empower South African nurses through furthering their education and skills set."

The AICF have two paper-based programs that have been available since 2017. These are a Three Month Induction to Oncology Nursing and ChemoSAfety for Oncology Nurses. Over 500 nurses around SA both in private and state have passed these courses and wear their AICF badges to reflect these trainings with pride.

Our aim has been to move to an on-line platform and to provide a curriculum for Oncology Nurses. We've partnered with an incredible US NGO organisation, Nurses International, to develop a comprehensive peer-reviewed curriculum for oncology nurses. The primary goal of the course is to provide on-demand, science-based information that facilitates safe nursing care and treatment of oncology patients.

The course will be housed in-the-cloud on a Learning Management System. This allows for the flexibility of having nursing oncology information available 24/7.

Two on-line options will be available. One for learners (nurses or any other medical professional) to quickly access information (reading resources, lesson slide decks, lesson quizzes, case study activities, clinical nursing checklists and associated videos as well as an open access Nursing Skills textbook. No tests are required for this section.

Should learners wish to gain a Skills Certification, the curriculum will follow a specific path with paced learning, knowledge tests, practical nursing assessments and a final exam at the end. The course is currently being assessed for CPD (continuous professional development) points in the USA.

We intend to pilot the course locally in the near future.

As the AICF Chairperson, Rowe-Potgieter concludes by saying: "The AICF will strive to continuously be associated with transparency, equality, integrity and compassion and believe that the work of our Foundation will undoubtedly influence the landscape of South African Healthcare in a positive way. "