

ALPHA-1 ANTITRYPSIN DEFICIENCY IN SOUTH AFRICA

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From

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Reason for being here – my PI*ZZ husband

Find us on

- Alpha-1 Global: <http://alpha-1global.org/en/south-africa/>
 - Facebook:
<https://www.facebook.com/groups/218421731982317/>

Alpha-1 Antitrypsin Deficiency Support Group, South Africa

ALPHA-1 ANTITRYPSIN DEFICIENCY IN SOUTH AFRICA



- Current Population approximately 58.33 million (estimate for 2019)
- 2011 census
 - 79.2% (41 million) Black African
 - 8.9% (4.62 million) Coloured
 - 8.9% (4.59 million) White
 - 2.5% (1.29 million) Indian/Asian
 - 0.2% (280.4 thousand) Other

While it is believed that AAT deficiency is a disorder which mostly affects white people, a study by de Serres in 2002 showed that both PI*Z and PI*S has prevailed over racial and ethnic boundaries.

The large distances between towns and cities make patient's contact with each other logistically difficult.

South Africa – from the sublime to the ridiculous; and everything inbetween

- Extreme wealth enjoyed by the minority of people.
- Private health care which is world class.
- However, alpha-1 antitrypsin augmentation is not generally available through medical aid due to its extremely high cost.
- Section 21 conditions are available to import augmentation but private funding is required.



South Africa – from the sublime to the ridiculous; and everything inbetween

- The majority of the population lives in extreme poverty.
- They are obliged to use state hospitals and clinics.
- Limited resources.
- HIV/AIDS treatment is a priority and takes up much of the budget.
- Alpha-1 is not a priority.



South Africa

– challenges and achievements

- Patient register – all COPD patients should be tested for AATD as per WHO recommendations.
- Physician register - No alpha specialists per se; pulmonologists, hepatologists, paediatricians and paediatric hepatologists
- Patient and doctor participation in clinical trials
- Research on alpha-1 antitrypsin deficiency at places like The Lung Institute in Cape Town
- Alpha-1 antitrypsin deficiency is now listed with Rare Diseases, South Africa
- Awareness is slowly being raised
- Patient register in progress
 - Issues around ethics and logistics