



Bethesda Newsletter



June 2017

About James Stuurman?

James is a 35 year old single male who was admitted to Bethesda's Intermediate Care Facility on 29 December 2016. He was diagnosed with **Motor Neurone Disease** on 29 December 2014.

Motor Neurone disease is a rare condition that progressively damages parts of the nervous system. This leads to muscle weakness, often with visible wasting of the affected muscles. **Motor neurone disease**, also known as amyotrophic lateral sclerosis (ALS), occurs when specialist nerve cells in the brain and spinal cord called motor neurones stop working properly. This is known as neurodegeneration. Motor neurones control important muscle activity, such as: 1) gripping; 2) walking; 3) speaking; 4) swallowing; 5) breathing



As the condition progresses, people with Motor Neurone disease will find some or all of these activities increasingly difficult. Eventually, the activities may become impossible. Many of you might be familiar with this disease as experienced by the late **Joost van Westhuizen**.

James is originally from **Avontuur**, near Uniondale (South Africa). He was previously a **General Worker** on a farm and also enjoyed playing rugby. James enjoyed his job and playing sports very much. Till this day, although he cannot physically take part in any sport, interests or hobbies, James loves to watch sport like Rugby, Cricket, and Motor Racing. One of his other hobbies was gardening; a pastime he could indulge in whilst living on a farm. Like anyone James has specific South African **Heroes** and **Roll Models**: Scalk Burger (who is one of the South African Celebs he wishes he could meet), AB de Villiers and Shaun Pollock to name a few. To our surprise James even has a **bucket list** and number one on his bucket list **IS TO FLY**. There is probably so much James still wishes to do and achieve; but unfortunately due to this disease his options are very limited.

Whilst in our Intermediate Care Facility our team started looking at various options for James; to make **his life** a bit **easier** and **more comfortable**. Our first plan was to try and integrate James back home into his Community. However, **CHALLENGES** involved in sending James home proved very big. We had to consider the following: The need for a full time Carer, accessibility of his home as well as surrounding areas and the possibility of an Electric Wheelchair that would allow James to still have some independence. After many discussions, a visit to his former home and an Application to the J9 Foundation it seemed that our vision to re-integrate James into his previous home environment might not be viable.

The Interdisciplinary Team then thought it best to keep James in our care and prioritise **the needs** that would make James more comfortable at Bethesda. James's disease will steadily progress and decrease his ability to do even the most basic of activities. We at Bethesda are committed to ensure **quality of life** for James in all stages of his disease. Together with James we feel the most appropriate place for him to undertake these challenging stages of his journey, is in our Intermediate Care Facility. We are **so impressed** with the **positivity** and **dignity** in which James handles his disease and impairment; and the active part he plays in his care planning.

To ensure **comfort** and **quality of life** for James, we will need some **assistance** from **FRIENDS** and **DONORS** in terms of the following:

Mobility

New/Second hand (in working condition) Electric Wheelchair. James cannot propel a manual wheelchair.

Communication

A Notebook or Tablet
James is not able to speak due to throat muscle weakness and thus needs a means of independent Communication.

Nutrition

A Nutri Bullet (this is a device used to purify food)
James cannot swallow effectively and thus his food needs to be purified.

Comfort and Care

Egg Box Matrass
James cannot turn himself in bed to relief pressure and he has no control over his bodily functions.
Adult Nappies and Toiletries

Leisure

A small television – To occupy the lonely hours James spends in bed

OUR DETAILS

If you wish to **assist** please contact Marzanne Cillié (projects@bethesdagorge.org.za) or Mandy Lucas (projectsassist@bethesdagorge.org.za) or phone 044 – 875 8088

NEDBANK (Branch Code: 109 114)

Acc Names: Bethesda Medical & Relief Services - **Hospice** (Acc No.: 1091 128 499) or Bethesda Medical & Relief Services - **Child & Youth Care Centre (CYCC)** (Acc No.: 1091 128 510)