



The Torch



OUR STORY 1918- 2018

A Hundred years of service

St Dunstan's became so associated with blindness in the UK post WW1 that many came to believe that St Dunstan was the Patron saint of Blind People. This was unfortunately not the case; St Dunstan was the patron saint of Gold and Silversmiths. The name St Dunstan's came about some say by fault, the name was given to the organisation due to the simple fact that it was established in a House that held the name St Dunstan's, which itself was named after a very large clock which stood in the front garden

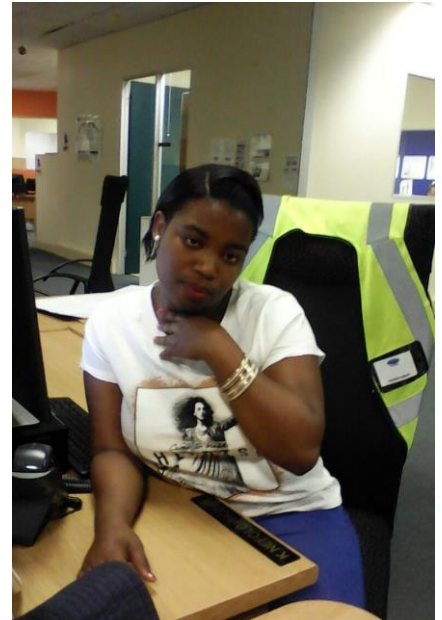
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Ian Fraser-new students 2018



Henry Herbst Henry loves reading, watching series and spending time with family. At the age of 25 he is already a Paralympic swimmer and hopes to win a gold medal soon. He studies Law at the University of Stellenbosch and would like to be an advocate one day. He believes that law has the ability to influence change and behaviour in society. Law will enable him to achieve his dreams and allow him to help others fight for their rights. He dislikes that people think that he is unable to reach his goals due to his disability. By achieving so much at this young age, he has proven many people wrong.

Elizabeth Maponya This 25 year old's goal is to become a successful psychologist. She absolutely loves listening to music and enjoys reading. Elizabeth is studying toward a Bachelor of Arts specializing in psychological counselling at Unisa. Her passion is to help people recognise their strengths and to equip them in order to deal with everyday problems. She is also busy with a learnership at Vodacom in the learnership and development Department. Elizabeth had great difficulties in school because she couldn't read what was on the board and was bullied because of her bad sight. With great support from her family and teachers she was referred to a school for the blind and visually impaired and now has nothing standing in her way when it comes to achieving her dreams.



Jean-Jacques Naudé Jean-Jacques (23) studies Law at the University of Stellenbosch. He feels the course he is doing suits his personality as he is a well-spoken systematic thinker.

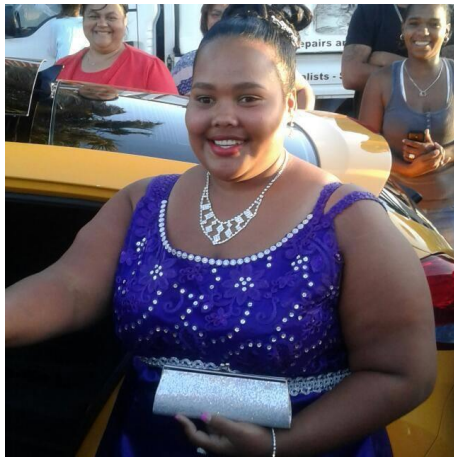
His involvement at Legal Aid Clinic in Stellenbosch already allows him to provide legal assistance to those who may need help. He enjoys this very much because he is making a difference in people's lives. He has his sights set on becoming a candidate attorney at a well-established law firm as early as 2019. In addition he would like to get more involved with the stock market as it sparks his interest. He wishes that people would realize that being disabled is not: "that person's fault."

Asanda Lengisi

Asanda has a passion for helping the community especially children with disabilities. She enjoys reading and doing research on topics that interest her.

She is 27 and is currently studying toward a Social Auxiliary Work Certificate at the Brooklyn Health Academy. The course she is doing will empower her to assist families suffering from domestic violence. She also wants to develop projects in communities to help in living standard upliftment.





Jody Oliver Jody is 21 and would like to become a public relations assistant in order to improve the lives of others. She is currently studying at Boston College toward a Certificate as a Public Relations Assistant. Through her degree she hopes to empower and help uplift those in need. She has a passion for motivating people, especially teenagers. She gives motivational talks at schools and churches and informs them of topics relevant to them and their immediate community. After completion of her independent training she realised that blindness was not a death penalty and that she is capable of many things just like any other individual.

Marike Naude

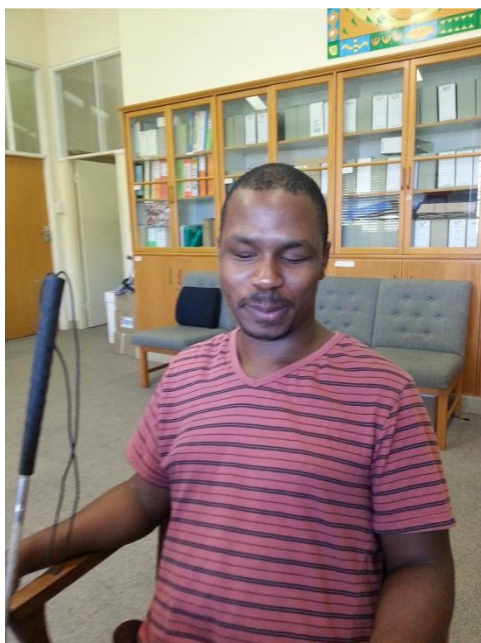
Marike is 23 and a complete animal lover. She studies Veterinary Science at the University of Pretoria. She has a passion for medicine and will soon work at the university hospital as part of her training. She believes in helping others to achieve their goals and one day would like to actively educate the public on animal welfare, zoonotic disease and how farms are affected by animal diseases. The use of specialized contact lenses makes it easier for her to follow lectures presented on an overhead projector. She feels that as a visually impaired person, she is motivated to go the extra mile to prove herself, as people often doubt her abilities. Looking at what she has achieved thus far, keeps her positive and motivated.





Tlangelani Mahori Tlangelani is 31 and has a great interest in sports and farming. Apart from hopefully one day owning a farm and growing crops, she wants to encourage youngsters to take part in sport and make a career from it. She is currently doing a short course in Sports Management at UNISA. She is involved in a soccer team and believes that sport keeps youngsters away from crime and substance abuse. She believes that this course will help her to manage her team correctly and in turn result in future stars being identified who may go on to bigger and better clubs. During her school years she was a victim of bullying due to her disability. She credits institutions such as Tape Aid for assisting her and is grateful for their contribution to her life.

Sergil January Sergil is 31 years old and is determined to inspire everyone to chase their dreams. He is studying at Boston College toward becoming a public relations assistant. Sergil works as a computer training facilitator at League of Friends of the Blind. He is also a blind cricketer, who has represented South Africa twice in the World Cup Tournaments. In addition to this, he loves spending time in the gym and researching information on how to improve the lives of blind persons through the use of tech. He believes that the course he is studying will assist him in growing awareness around those with disabilities.



Mbulelo Kaphetsu

Mbulelo is 38 and would one day like to set up his own school for the blind.

He is currently doing his Honours in Xhosa at the University of the Western Cape and would also like to be a translator for Parliament.

With his studies, he would like to expand the knowledge of politics and cultures through language. To pass the time, Mbulelo listens to music and spends time reading his text books. He believes that having respect for others is paramount to leading a good life. It was quite challenging to leave home for school, but Mbulelo soon familiarized himself with the new environment and the new people in his life and has adjusted well to his new surroundings.

Clementhia Xaba Clementhia (27) wants to be a successful business woman. She is doing a bachelor's in Business Administration at Rose Bank College. She thinks contributing to society is very important, whether it's through ideas, being a good citizen or volunteering. Her circumstances motivate her as she will become the first woman in her family studying at a tertiary institution. Clementhia has come to terms with her vision loss, the sadness, fear and anxiety. She realised that everybody has their own struggles, regardless of whether they know it or not. By surrounding herself with people who love her, she knows she is not alone. "My vision does not define me as a person, yes it would be lovely to have good vision, something that most take for granted, every experience in my life I take as a learning opportunity. My motto: "It doesn't matter how you get there, as long as you never stand still."



Johanna Pretorius

Johanna is 24 and currently training for the 2020 Paralympics. She is currently doing her Masters in Sport Physiology at the University of Stellenbosch.

She is coaching and tutoring part time at a primary and high school. She has a great passion for guiding the athletes she coaches to help reach their full potential.

She feels that her academic drive comes more from passion than ambition. "I love the Masters topic that I have and can't wait to find some answers to my research questions. I get really excited about sport physiology. This is also why I love being a tutor, because then I can share this passion with the younger students and help them understand the work."





Shani Little Shani is 37 and works as a Braille proof reader at Pioneer Printers. She is currently pursuing a BA degree in psychological counselling at Unisa.

In addition to this, she does extra work for SA library for the blind. She also holds a certificate in massage, reflexology and aroma therapy, and did part-time treatments at a life skills clinic for 16 years until 2016. Her dream is to become a psychologist with the hope of bringing something positive to the world. "Because of my disability I felt inferior, especially during my teens and early twenties. Challenges are opportunities to help you grow, and to give you life experience, I have been preparing for this my whole life."

Anoop Noratam Anoop is 29 and his goal is to become a medical doctor. He wants to inspire visually impaired and disabled individuals to follow their dreams. He enjoys working with people and try to live as actively as possible by running and swimming. He is studying at Wits University towards a Bachelor's degree in Medicine and Surgery. He is also a qualified physiotherapist and practise part-time. Many doctors told him that he won't make it in the medical profession and here he is in his final year. He believes that people should be themselves and that they should work hard to achieve their goals. By doing this people can beat the odds and achieve their goals. During his teen years Anoop had to deal with a lot of challenges due to his vision loss. As he grew older he realised that for every challenge, there is a way of overcoming it even if it takes a few years.



Congratualtions to **Liandri Steffens** who obtained her degree in BA International Studies at the University of Stellenbosch.

She is currently doing her BA honours in International Studies at the University of Stellenbosch.

Congratulations to **Joyce Maloka** who obtained her LLB Law degree at the North West University.

She currently works as a candidate attorney and will be attending Law School this year.



Charles Bonnet Syndrome



An Example of what people with CBS see

By Matthew Athey: Community Team Leader, London.

I first developed an interest in Charles Bonnet Syndrome (CBS) while I was working on the helpline at the RNIB. It was at the start of my time on a helpline talking to people who were losing their sight. I spoke to a woman who described seeing a young girl dressed in Victorian clothing who liked to come and sit on the sofa with her every afternoon. To say I was a little surprised by this was an understatement. I had never heard of Charles Bonnet Syndrome at the time and really didn't have much idea of what was happening for this person. However I was determined to find out more and that's where my interest in Charles Bonnet Syndrome started.

What do people see?

Charles Bonnet Syndrome causes people who have lost vision to see things that aren't there (hallucinate). There appear to be two broad types of hallucination that people see.

Repeated simple patterns and complicated pictures of people, animals and architecture.

The pattern like hallucinations are often seen 'on top' of whatever you are looking at. You might see brick or tile patterns, some people see branches and flowers growing across their vision, and some people may see colourful balls of light moving around in their vision.

The more complicated vision really can be of anything, people often see children in period costume or people wearing strange hats. It's also really common to see animals such as cats, dogs or more exotic creatures like tigers. Seeing people out of context is also common, seeing Bishops in their living rooms for example, or sometimes seeing things that make more sense, such as workmen in the garden. Sometimes people see small people that are a few inches tall stood on tables or chairs in their house. Other people may see distorted faces moving towards them or away. It's also possible to have a hallucination which changes the place where you are, some people say they see fences in their living rooms or they may see a large field or woods when they are in their living room.

There doesn't seem to be any obvious reason why someone sees what they do and the variation in what someone may see is as individual as the person experiencing the hallucination.

Why do they happen?

The relationship between the eye and the brain is a complicated one and no one is 100% sure why some people with sight loss develop CBS and others don't. It seems that losing a lot of vision can affect the way the eye and brain work together. It's as if the brain can't cope with the reduced visual information it receives from eyes affected by sight loss. The brain compensates for this lack of information by creating the Charles Bonnet Syndrome hallucinations.

Although many people with CBS have age related macular degeneration, CBS can be caused by any eye condition which causes loss of sight, so people with glaucoma or diabetic retinopathy may develop CBS. Most people with these conditions are older, but CBS can affect anyone at any age including children and people who lose their sight because of trauma.

People can be concerned when they start to see things which aren't there — it can be a frightening experience. We all know that conditions such as Alzheimer's, dementia, Parkinson's and serious mental health conditions can cause people to hallucinate. And the fear of one of these conditions can prevent people talking about their CBS. It's important to realise that having CBS doesn't make you more likely to develop any of

these other conditions and that in almost all cases CBS is caused by the loss of vision and nothing else.

The hallucinations that people experience with CBS are different to the ones caused by other conditions in a number of ways. CBS hallucinations don't involve any of the other senses. This means that people don't experience any sound, touch or taste when they experience their hallucinations. So the people or animals in the hallucination will not talk or make any noise.

People with CBS don't develop any complex explanations for the things they are seeing — sometimes known as a delusion. For example they don't become concerned that the people they are seeing want to hurt them. Most people with CBS are aware that what they are seeing isn't real. They are aware that they are having a hallucination and aren't too concerned about it.

What can be done about CBS?

At the moment there isn't a medicine which can be given to stop Charles Bonnet Syndrome. It is important if CBS starts that you talk to your GP or your ophthalmologist about it. They may want to rule out other causes of hallucinations like Alzheimer's, Parkinson's or mental health problems. But it's important to remember that someone who experiences CBS is not at more risk of developing any of these other conditions.

Coping with the hallucinations

As there isn't a medical treatment for the hallucinations there are some things that might help coping with the experience. The RNIB recommend the following things which may help:

If you experience your hallucinations while sitting quietly, try standing and moving around a little. If it's quiet put the radio or TV on. Sometimes just putting your attention into something else can stop the hallucination. Sometimes just blinking rapidly or looking directly at the hallucination can cause them to stop.

Moving your eyes from left to right while keeping your head still. A study showed that this exercise of moving your eyes from left to right while keeping your head still seemed to help some people to stop seeing their hallucination. If you imagine two points about three feet apart and move your eyes between those points keeping your head still for about 30 seconds it may stop the hallucination. Its worth trying this three times to see if it will work.

Changing the light levels, for some people certain light levels may cause them to experience hallucinations, so if you experience your CBS when the light is dim try putting more lights on and vice versa.

Getting enough sleep and trying to minimise stress. Some people may experience CBS more frequently when they are tired and stressed. Trying to get a good night's sleep can help.

Finally getting to know your hallucinations, what you see and when, can help you cope with them. Usually people experience CBS more frequently when their vision first deteriorates to a low level. With time most people notice that their hallucinations become less frequent and some will stop experiencing them. Other people may only get them now and again whereas some people may always be prone to the hallucinations. Knowing that the hallucination is caused by sight loss and nothing else can help coming to terms with them.

I am still interested in CBS to this day and I spoke to hundreds of people with the condition while I worked at RNIB. Almost everyone I spoke to was relieved to learn that their experiences were common and not a sign of anything to worry about.

What is Charles Bonnet Syndrome?

In current medical terms it is believed that the brain pathways attempt to fill in obscured areas of vision. The Royal College of Ophthalmologists say that it is thought that Charles Bonnet Syndrome occurs when visual images are no longer channelled into the brain, which goes on to replace real images with its own stored images. Or as one member was told by our consultant Ophthalmologist, it occurs when the brain becomes 'bored' so it creates these visual hallucinations.

When describing Charles Bonnet Syndrome, I liken the condition to phantom limb syndrome, where people with missing limbs experience sensations as though the body parts are still present. For example, an amputated leg where a patient still feels their toes.

Symptoms

The images are detailed and vivid but the person experiencing them knows that they are not real. They can vary from mild symptoms to the more severe.

Symptoms do vary and not everyone with a loss of sight experiences Charles Bonnet Syndrome.

The visions are very detailed, sometimes bizarre, and can last from a few seconds to several hours. They seem to come and go of their own accord.

Near misses have been reported by the British Medical Journal, in which patients were almost confined to mental health institutions. However, once asked about it, people generally say it is a great relief to be told of this condition and that they are not the only people who experience it. When some people tell me they see these visions their partners can be surprised as they are not aware this occurs. For instance, one member sees snakes descending from the ceiling, but did not tell his wife as he did not want to worry her.

It also happens the other way around, in that some individuals tell me that their vision impaired partner sees visions — cats seem to be a common one — and that they frequently tell the cat to get out of the way when there is not one in the house.

The mild symptoms vary from such visions as seeing lights that move across the field of vision, or balls of light, horseshoe shapes, lamps or sweets that float in the air and when

the person tries to grab them they disappointedly can't. Some people have told me that they enjoy these visions and even find them relaxing. The more moderate levels of vision are not too dramatic, but are more detailed than lights. Some of these present as common place objects, for example, surfaces covered in non-existent patterns, such as brickwork, mesh or tiles. One member I visit sees coloured plates on her ceiling, another lions' heads on her cushions, another geometric images and 'Eastern like', pierced screens of stone.

Then there are more complex visions which I have classed as high level. Again these are very detailed and 'real', usually involving people, gargoyles, or bright abstract shapes. The image can be life size or very small, scurrying across the floor.

Since Charles Bonnet's original recordings, there have been numerous cases diagnosed. It has long been regarded as a rare disease, but recent evidence suggests that it is much more widespread than previously believed. Charles Bonnet Syndrome is generally under-diagnosed by the medical profession, but is a rather common cause of complex visual hallucination.

The Royal College of Ophthalmic Surgeons feel that those with a sight loss have at least a 20% chance of developing visual hallucinations. They state that they think around 100,000 patients have Charles Bonnet Syndrome as a side effect of their macular disease. Some studies show its prevalence in patients with age related macular degeneration varies from 10% to 20%.

In the group of members that I visit I have found a much higher incidence, possibly 65%. This difference again could be due to medical under-diagnosis and recording, or the type of eye condition that our members experience.

Medical research tells us that most of those who experience Charles Bonnet Syndrome are people in the early stages of sight loss, and the hallucinations usually begin while their vision is still present but has diminished. The most common cause is macular degeneration. Other eye diseases such as glaucoma and cataracts can cause symptoms and in a few rare cases it has been diagnosed in people with no detectable vision problems.

In my research I have found that those who still have a fair amount of useful sight see less bizarre objects such as vases, shelves, books and lines. Whereas those with a more severe sight loss seem to see the more vivid images. There are members who tell me that they have seen images in the past but these have stopped after a couple of years, whereas some tell me they see images that seem to get more bizarre as their sight deteriorates. Medical research informs us that removal of a cataract or recovery of vision can lead to improvement. Some may find relief if the eye condition progresses to total blindness, although for some people the visions will stop over time.

Others are able to banish their phantoms by changing the environment in some way, such as closing their eyes, turning the lights on or off, increasing the lighting; if it happens when you are sitting down then try standing up. Trying to keep the brain active

can be helpful. Most visions seem to occur when you are relaxing. These recommendations do not banish the visions for everyone.

It helps if you can try and feel in control of their environment. Some people have tried befriending the apparitions, talking to them, but of course getting no answer. Sometimes talking over feelings with a counsellor or psychiatrist can help provide people with ways of coping with the visions.

At the moment there is no known cure for Charles Bonnet Syndrome. However, just knowing that it is poor vision and not mental illness that causes these problems often helps people come to terms with them. Generally these experiences will disappear after about a year or 18 months but this will not be the case for everyone.

Conclusion

Firm reassurance that Charles Bonnet Syndrome is not related to mental illness is in itself a major relief to a person already dealing with failing vision, and maybe other medical problems. Some sufferers consider them as 'one of those things you have to put up with'. I have found that once the symptoms of Charles Bonnet Syndrome are explained they feel immeasurable relief and can often tolerate the condition better.

Getting around

MyCiTi Services



Tactile paving and a talking traffic light

MyCiTi is designed to ensure that all special needs passengers can use the service. This includes the disabled, the elderly, young children, pregnant women, passengers travelling alone at night, and passengers with luggage including suitcases, surfboards, prams and bicycles.

MyCiTi's universal access facilities include tactile paving to help the visually impaired locate stations and platforms; induction loops at ticket kiosks for the hearing impaired and CCTV cameras, which are monitored by a control centre, on buses and at stations. There are also boarding bridges on buses serving residential and central city routes, which provide passengers with level access onto the buses from bus stops if required.

Uber Assist

What is uberASSIST?

UberASSIST is an extension of uberX designed to provide a more specialized service for anyone who needs an extra hand. Driver-partners are certified by third-party organizations on how to assist riders with different accessibility-related needs

How does it work?

As an uberASSIST qualified partner, you'll be providing your riders with a helping hand at the beginning and end of the trip. For example, people hard of seeing, people who use walking aids or wheelchairs.

This assistance does not extend beyond the door of their home. Drivers are not expected to lift or carry their passenger or act as a caregiver.



Boni's Matric Ball

Boni Ruiendo recently had his matric ball at The Horse Shoe Inn, in Kimberley.

Upcoming Events

Annual General Meeting - Friday, 14 September 2018 @ River Club

Project Gemini - 30 September 2018 until 7 October 2018 @ Lagoon Beach Hotel

Long Cane Rally - 13 October @ Muizenberg