Editorial
By Tim de Villiers

Stress and subconscious stress are major role players with seizures and we can help ourselves by managing our stress and subconscious stress better. I admit it is not easy managing stress as a student studying or in a career, but by changing one’s perspective in life to acceptance, loving and believing in oneself and by maintaining a positive mind, and by managing your condition you will put yourself in a good position to step completely out of the imaginary box that sets people back. I speak from experience and most of the time I forget that I have a condition. I live by these principles resulting in seizures only occurring on very rare occasions – due to my ignorance. Believe in yourself and you will be okay.

To our co-editor, Lesley Donnelly, in Ireland, thank you once again for your valued support in editing articles – just shows you can assist from anywhere in the world, and to Marina Clarke, National Director for her role in sourcing and support.

We trust you find this publication inspiring and we encourage you to share your life story, achievements, research, etc. in our future editions of this publication. You do not need to be a writer to share your experience.

Remember – Sharing is Caring
Feel free to contact us via Epilepsy South Africa National Office on 0860EPILEPSY or email info@epilepsy.org.za.

Epinews is a biannual newsletter compiled by people with epilepsy, for people with epilepsy and offers a platform to share their experiences. The dedication of Epilepsy South Africa staff, volunteers and youth ambassadors, has played a significant role in educating and inspiring others, and connecting those who can help, with those who are seeking help and advice.

I am encouraged by the articles highlighting achievements against the odds of having epilepsy. I often note the concern of having to leave home to study or work and the stress surrounding the what if’s and why can’t I be like a normal person, etc. What is a normal person? We are all different beings, with differing conditions, temperaments, metabolisms, stress, and so the list goes on. Though, we are unique having a condition called epilepsy, which is our deal in life.
Never confuse a single defeat with a final defeat.
F. Scott Fitzgerald
The ghost in me

By Ntombifuthi Priscar Mamiane

Every day when I wake up, I talk to myself about my dreams, telling myself good or bad things but I would talk. Most of all I talk about my dreams and plans about my life, i.e. how I would like to live it.

My mother always told me a women should have dreams; don’t be afraid of the world. I never knew what she meant, but as I grew older the challenges began. I would ask myself is it me or all women that go through this, observing. No, they don’t so what is different about me? Because I look like all of them and I have what all women have.

Then as I grew older my parents sat down with me and asked whether I saw any difference in myself or my life. I said ‘no, are we not all the same? But we are all the same, right?’ I replied. They asked a lot of questions about my feelings, how I handle anger, how I feel right now that they are talking to me and asking all the questions. I told my mom, irritated, angry and mostly confused about their questions, I said ‘fine!’

My mom said, ‘be calm let me tell you a story’. I said ‘okay, but it better be fast because I have to watch my favourite show’. She asked, ‘what show because you always spend time watching the television’. I said ‘Oprah’ at which she smiled. My dad said ‘you always have favourite shows’; he laughed. I smile and said ‘okay you got me; I just hate long talks. They said, ‘these won’t take time’.

My mother explained in this world we are born different, at which I said ‘sure, my sister is lighter than me in complexion and I am the darkest in the family’. I laughed! ‘No’ she said. ‘Each person has their own special character and each person in this world is different and special, which makes them their own character. She explained that one day I would understand it. She told me that as I had epilepsy, I always did these things. I asked what things she was referring to, and she said ‘these weird things. I just looked at them and smiled but shocked.

What was this ‘epilepsy?’ I guess she could not explain it, but she just cried and said, “If I could change and take it away I would but I can’t.” Confused I cried too because I thought this epilepsy meant I would soon die. I just stood up and went to watch the television. I watched cartoons as old as I was; 17 years then. I liked the characters and their behaviours and how each day they changed.

Amazing hey!

One day my mom came in my room, asking what I wanted to study when finishing high school. I told them that I always wanted to be a teacher. She thought maybe I had changed my mind. I told her I had, and I wanted to be a lawyer firstly, then teaching would be my second choice. She said I would make a great teacher, but it was my choice. I thanked her, with the attitude that I was able to choose what I want.

Years went by and I reached grade twelve with all the weird happenings in my life. I fell during the assembly in the mornings at school; each time this got worse. I woke up to people staring at me as if they had seen a ghost, other learners called me weird names, and others were taught that never let a person who suffers from epilepsy touch you or share food because you will get infected. It hurt when they called me the ‘demon girl’. My mom tried to teach me how to be calm and ignore them. OH! Yes, I did but it was never easy, and I felt trapped. I don’t know how many times I tried to commit suicide, but I was always interrupted. Then I said to myself ‘don’t ruin your life’. Today I’m thankful that I was always interrupted of all these scary things.

I remember finishing high school. I applied to many universities and applied for bursaries but was rejected because I always indicated that I had epilepsy. Some said I did not qualify. As my mother worked as a domestic worker, she managed to send me to one of our local colleges where I studied administration and computer studies; I obtained certificates in the process. I told myself it would be better to attend college than to stay at home.

I did many jobs; my first job was a domestic worker which my mother helped me to get. I have worked as a waiter, promoter, and did many jobs, still trying to get admission at the University. I registered a diploma in teaching with UNISA and whilst working I paid for my studies. I could not complete it due to financial constraints and finding out that the Diploma was phased out. All that effort, my money went to waste, I felt like a failure, and asked myself why do bad things happen to me, what have I done, people were treating me badly all of my life, and even now there was still people who did not like the fact that I had epilepsy.

Sometimes, I told myself that because most people in our culture do not understand that one can lead a normal life with epilepsy, they believe that people with epilepsy are mentally unstable and crazy, and trying to convince, teach, explain to people made me tired. Can you believe this is not the life I dreamed of? The resentment and the pain. Remembering my mother’s words, I wish I could change them all but that’s life. It’s amazing our people still believe that people with epilepsy are crazy.

After all my hard work, I got a job at Zamangwane Water Technology in Nelspruit. Though still difficult to adjust, I am trying together with my colleagues to learn about the condition so they can be able to help me when I have a seizure at work and teach them that I am not crazy; it’s only epilepsy and epilepsy doesn’t define me. I am happy and enjoy my work, the employees and management are understanding, and some try to stay with me. The management is good because they give me time off to go for my Doctor’s appointments and to collect my medication. Every day I wake with a dream that I want to change my life for the better. Every day is a challenge when I go to work because there are still people who continue to call me names and laugh at me.

To other people with epilepsy, live your life to its fullest, and never be intimidated by outside factors. You were granted this life by God so enjoy it and live your dreams every day when you wake up, have a purpose in life, then live it.

A ‘Big Up’ to companies like Zamangwane Water Technology who do not only think about making money, but also accept people with a condition like mine. People with epilepsy and other disabilities are human so treat them with respect together with the other employees in your company, not only to achieve the 2%+ that is needed by the Government.
Q & A

Q: I recently had seizures during a family crisis and don’t know if I have epilepsy?

A: Seizures triggered by stress look similar to epileptic seizures because these can have the same symptoms (e.g. numbness, confusion, convulsions, etc.). However, there are differences in the electrical activity in the brain between the two types. In fact, research suggests that between 5 and 20% of people with epilepsy may be misdiagnosed due to seizures provoked by anxiety or underlying trauma. It would be important for you to discuss your concerns with your doctor who may opt to refer you for diagnostic tests or to see a neurologist.

Q: Can a seizure be triggered by certain things?

A: Yes, many people are able to manage their seizure better because they recognise their personal triggers. Remember that because people are not the same their seizure triggers will also differ. What may trigger a seizure in one person will have no effect for another person.

The most common seizure trigger is not taking your medication as prescribed. However, people have also reported other common seizure triggers including not getting enough sleep, being ill, experiencing high levels of stress and temperature fluctuations (heat or cold).

During a research study 400 people with epilepsy were asked to identify seizure triggers. 61% were able to identify at least one thing that could trigger their seizure. Stress (30%) led the field as the most frequently cited trigger, followed by lack of sleep (18%), sleep itself (14%), fever or illness (14%) and fatigue (10%). Stress, lack of sleep and fatigue were often cited together. Women (especially women with temporal lobe epilepsy) identified menstrual effects. Fewer than 10% of respondents cited heat, humidity, caffeine and fasting as triggers with only 2% citing alcohol.

By keeping a seizure diary you will be able to identify your personal seizure triggers. You can download your own seizure diary from the Epilepsy South Africa website (https://epilepsy.org.za/new/uploads/files/Epilepsy-information-2017/My%20Epilepsy%20Diary.pdf). As a person with epilepsy it is better to avoid your personal seizure triggers. By adjusting your lifestyle you may be able to achieve better seizure control.

Q: Are there any foods I can eat to prevent seizures?

A: No single food or vitamin has been found to prevent seizures. Be careful when claims are made that a supplement or food item can cure epilepsy. It is best to ensure that you eat a healthy and balanced diet. If you are unsure about this, ask your doctor to refer you to a qualified dietician.

Q: Will I experience side effects if I take epilepsy medication?

A: All medication has side effects which may or may not be acceptable. Side effects may result from the specific medication or the dosage. Discuss possible side effects with your doctor when you get a prescription while you can also obtain information from your pharmacist and the information sheet included in the packaging of your medication.

Balancing side effects and benefits can be a challenging process. Some people are lucky and don’t experience any side effects (especially with some of the newer drugs). Even if one experiences side effects, these may be fairly minor, occur at the start of treatment and settle down after a few weeks.

The most common short-term effect you may experience is sleepiness. Lucky this often passes as your body adjusts to the drug. Sometimes the drugs may make you feel unsteady and ‘woozy’. This is usually a sign that the dose is too high and needs to be altered. Always talk to your doctor about adjusting your dosage. Some people are allergic to certain drugs and develop an itchy skin rash or other symptoms. In this case the doctor may take you off the offending medication and try something else.

More troublesome side effects can occur when certain drugs are taken for a long time. They may include poor memory and concentration, irritability and overactivity in children, swollen gums, acne and weight gain.

Q: Can I take other medication while taking anti-epileptic medication?

A: Most “over-the-counter” medication (i.e. those which you can buy without a prescription) are quite safe taken with anti-epileptic medication, provided that you follow the recommended dose. Possible exceptions are antihistamines (which may have a slight convulsive effect) and sedative drugs (the effects of which may be exaggerated by anti-epileptic therapy). Most other drugs prescribed by doctors can also be taken safely without any drug interaction provided that you inform the doctor about all medication you are taking. Remember that anti-epileptic drugs

continue on next page
make some medication less effective than usual as they can speed up their breakdown by your liver. This is especially true about oral contraception. You may experience breakthrough bleeding and lower contraceptive protection unless the oestrogen content of the pill is increased. This is why the higher dose oestrogen pill is given to women with epilepsy.

**Q:** What if I miss a dose?

**A:** If you miss a single dose take it as soon as you realise, but do not take double doses. If you miss your treatment over a longer period (e.g. a few days) do not try to catch up, but simply restart and continue on the prescribed dosage as soon as possible.

**Q:** How do I know if I’m having side effects from my anti-epilepsy medication?

**A:** All medication can cause side effects. However, most people tolerate their medications very well. The best way to tell if you are having side effects is to notice any symptoms you feel when you first take a medication or when the dosage is changed. Some side effects of seizure medication are related to your dosage. If you are taking more medication than you can tolerate, you may feel goggy, dizzy or sick to your stomach. You may have poor balance or double vision. The dose at which these symptoms occur varies and some people can tolerate higher doses than others.

**Q:** What kinds of side effects could I experience from my epilepsy medication?

**A:** In addition to side effects caused by the dosage, some people may experience symptoms such as weight gain (unrelated to calories eaten) on certain medications. Valproate (Depakote) may be the most common drug to have this side effect, but it has been noted with carbamazepine (Tegretol, Carbatrol) and gabapentin (Neurontin) as well. Felbamate (Felbatol), topiramate (Topomax) and zonisamide (Zonegram) can cause weight loss. Phenytoin (Dilantin) may cause undesirable cosmetic side effects (e.g. excessive hair growth, including facial hair) and coarsening of the features. Again, this does not happen to everyone and is more likely to occur after prolonged use. Mood changes seem to be more common with phenobarbital (Luminal) or primidone (Mysoline), but any seizure medication can make some people feel depressed or irritable. Obviously these symptoms may be caused by something other than epilepsy medicine (e.g. illness or stress). Give your doctor as much information as possible to help determine the underlying cause. Your ability to think clearly or to concentrate can be affected by several epilepsy drugs, including phenytoin (Dilantin), carbamazepine (Tegretol, Carbatrol), topiramate (Topomax), phenobarbital (Luminal) and primidone (Mysoline).

Some epilepsy medication may cause bone loss and increase the risk for osteoporosis. It is important to make certain that you are receiving adequate calcium (1,200mg/day if you are menstruating and 1,500mg/day if you are post-menopausal).

Other epilepsy medications are associated with changes in the menstrual cycle. If you notice a change in the duration or regularity of your periods, inform your doctor. There are some rare, dangerous side effects (including liver failure and blood disorders) that may initially show up only in a blood test. This is one of the reasons your doctor may order more frequent laboratory work when you first start new medication. Most of these serious side effects show up in the first few months, are not dose-related and are unlikely to occur later.

**Q:** What does it mean when my doctor orders a ‘blood level’ on my seizure medication?

**A:** When you take medication for epilepsy only a portion of it enters your bloodstream and goes to the brain cells for seizure control. Some of it is metabolised in the liver to a substance that is not effective against seizures; some of it may be eliminated from the body by the kidneys or the intestine. The amount in the bloodstream (the ‘blood level’) is measured by a laboratory test to determine how much medication is available to control seizures. This gives your doctor a practical range to make judgements about your dosage. This information together with information you share about seizure control and possible side effects helps determine the dose you should be taking.

**Q:** What should I do if I experience side effects?

**A:** It is vital to report any side effect to your doctor to enable him/her to make the right decision about your treatment. If the side effects are mild you should mention these to your doctor during your next visit. However, if the side effects are severe contact your doctor immediately. Never simply stop taking a drug without medical advice as you could have more frequent or severe seizures.

The range of safe, reliable drugs means that your doctor can change your medication to avoid unacceptable effects (i.e. finding a drug that suits you better). Even so you may be faced with a difficult choice between effective seizure control and side effects. Remember that some over-the-counter
medicines (especially cold cures, antacids and some preparations used to treat hayfever) interact with epilepsy medication.

Discuss this with your pharmacist or doctor before taking such medicine. Don’t feel bad about mentioning your side-effects to your doctor. If you don’t, they may presume that you are right as rain. Whatever the side-effect maybe they will have heard it before. These are significant things that can impact your quality of life, so don’t be afraid to tell your doctor.

Q: Where can I find out about the side-effects of my particular medicine?

A: Each box of medicine includes the information leaflet, which lists the possible side effects. Unfortunately, this can sometimes be unhelpful as it does not give a context to the side-effects. The symptoms listed are those that were mentioned by people in clinical trials. They need to be compared to those people in the trials who took the dummy pills without the beneficial effect (known as placebo). Therefore, many of the symptoms listed are just those that people with epilepsy will report day-to-day, such as coughs, colds, tiredness and aches and pains. Your doctor, nurse or pharmacist should be able to tell you whether they think you are at particular risk of specific side-effects, particularly those that might worry you.

Q: Is it normal to get side-effects?

A: Yes! Particularly when starting a new medicine or increasing a dose. Many side-effects will get better over a few weeks (such as tiredness). You will be warned by your doctor about those that need immediate help, such as the nasty pink itchy rash associated with some medicines. There are also symptoms where it’s not always obvious that they are a side-effect of the medicine such as irritability and snappiness with some medicines.

Q: Does anything make side-effects more likely or worse?

A: It’s very important to take medicines as they are prescribed by your doctor. Not taking them at the right time or changing things yourself can make side-effects worse (as well as possibly worsening seizures). Accidentally missing or doubling doses can make the amount of the medicine in your blood (and brain!) vary a great deal. Similarly, mixing the stronger medicines with lots of alcohol or street drugs can make people feel pretty poorly. Doctors tend to ‘start low and go slow’ when starting and increasing the medicines. This is in part to help the body adjust to the new medicines and help avoid side-effects as much as possible.

Q: What can my doctor do if my medicine is controlling my seizures but I’m getting bad side-effects?

A: Sometimes it can be possible to take the edge off the side effects by going for a smaller dose and hoping this is equally good at controlling the seizures. It can be possible to find different forms of the medicine – such as slow release capsules. These can help keep the level of the medicine in the blood steady rather than peaking just after the medicine is taken.

On occasion, your doctor can find a way of lumping or splitting the doses, or changing the time of day when they are taken. Finally, some medicines are in rough ‘families’ and it may be possible to swap to another medicine in the same family and hope that the side-effects are less with the new one.
Failure is only the opportunity to begin again, this time more intelligently.

Henry Ford
I have had epilepsy since I was six (6), was going for tests at Red Cross and my epilepsy treatment started at the age of nine (9). My Mom and teachers told me I was a clever child at school. My Mom also explained epilepsy to me, but I was very confused as a child. I had sudden unexpected seizures together with memory loss.

When I was twelve (12), I had a better understanding of my seizures as my peers and teachers would explain what happened to me. They would take me to the ‘sick room’ when I had a seizure. One time they forgot about me being in the room; I woke up and found the whole school locked. I managed to telephone the Police from the payphone, they contacted my father who then contacted the Principal who came to open for me.

I started High School in 2003 which was when my seizures were most frequent. I was part of the Student Christian Organisation and was very involved. When I had seizures at school, my peers would mock me and my faith by asking, “Where is my God now?” I also began to experience auras and could then anticipate my seizures.

I always dreamed of becoming a Civil Engineer and took Mathematics and Physical Science, but my seizures occurred every week, so I struggled in school. My teachers were very supportive and even though I never finished my Matric examinations, I will never forget their help.

I have struggled a lot with mental health as I questioned my future; I felt that epilepsy was taking control of my life.

After many changes to my medication, I now only have one seizure per month; occasionally every second month. I have completed many learnerships and have since been employed.

Both my family and I have learnt so much along the way and have a better understanding of epilepsy now.

Today I dream of being able to write a book about my experience. I want to share my story and encourage other people with epilepsy; they may be experiencing the same things I went through.

I hope to one day be a motivational speaker showing people that ‘This is Me, and epilepsy can be overcome!’
I decided to start recording lectures so I can revise and go over lecture slides at my own pace. This has helped tremendously but makes studying take longer which is not nice during test/exam season.

Even on my walk to class (10-15 minutes) I stress about what could happen especially because I walk on my own a lot. I am at Stellenbosch which is always hot; the heat gives me headaches which leads to not working.

Sometimes because I am so busy and have a lot on my mind other than my health, I forget to take my medication at the correct times which is not good either. Due to my age I cannot depend on my parents for certain things, i.e. medical aid. I must get my own membership which is stressful because I am not with my parents fulltime, so if anything happens it's an added stress factor.

In conclusion, being a 21-year-old 4th year student is tough...with epilepsy in the mix it is tougher but pushes me to try my best. I do not let it dictate my future and performance.

I am getting closer and closer now to wearing the robe and getting the sash, graduation hat and certificate which I have worked for since I started Grade 1, 15 years ago!
I was first diagnosed with Juvenile Myoclonic Epilepsy (JME) at the age of 12. JME is a common genetic disorder common in teenagers which I had inherited from my grandmother. I would experience irregular movements in both of my arms daily. I was unable to hold anything in my hand without having it fall to the ground. This had occurred approximately 1 to 2 hours before I woke up in the mornings and largely influenced whether I would be able to eat without the help of my parents.

Before I was diagnosed with JME, the continuous muscle jerks I had encountered each morning were not a primary concern as my family was unaware of the overall existence of JME. The minor jerks I had were not intense and did not result in anything drastic yet. It was not until one morning where I had undergone a seizure that left me unconscious for more than 15 minutes, was I immediately rushed to Constantia Medi-Clinic. I was there to stay until they could discharge me with the contentment of my stability.

The following day consisted of the diagnosis of the overall cause of my constant irregular muscle movements. This was done by Dr. John Gardiner who declared that I had JME as a result of genetic characteristics I had possessed by my grandmother. My JME was not well controlled over the past 5 years, as the lifestyle I encountered during high school and the first few years of university were not advantageous to my health and mental well-being.

I would describe the past few months as extremely satisfactory. I had finally passed my license after 8 attempts throughout the past 3 years and I was fortunate enough to land myself an internship at Anchor Environmental Consultants.

Driving to university each morning was very stressful for both my parents and me. The concern for encountering a seizure whilst on the road subsided once I adjusted my sleeping pattern and adapted to the long hours I spent at university and work every day.

Balancing both my studies and work has become a challenge that I am grateful for. It has educated me on many aspects of both time management and self-discipline. I have learnt how to better cope in challenging situations that require strategical thinking and critical analysis.

My JME is relatively under control as I haven’t experienced any major seizures within the past year. I am however still assigned to take 300mg of Epitoc each night in order to reduce the risk of any occurrence of a seizure the following morning.

I am very grateful to my peers, friends and family members who are supportive in assisting me in the daily challenges I encounter in life, in order to allow me the equitable opportunity to live in a normal society.

It is important to create awareness of the diagnostic traits of epilepsy as it can prevent further damage of an individual and their well-being.

This will result in the early treatment of it and the overall goal to adapt and adjust an individual’s lifestyle of living with epilepsy.
As I look back on my life, I realize that every time I thought I was being rejected from something good, I was actually being redirected to something better.

Dr. Steve Maraboli
The Rise of My Episodes

By Zanele Lusenga

I had my very first seizure in 2008 at the age of 12, in primary school and with absolutely no understanding of what epilepsy was. I woke up not knowing how long, and with no idea of what happened. I had never been so scared or confused in my life.

My second seizure was in 2010, when I was in a different school; this was the first time I realized that I had no recollection of any activities that took place prior to the seizure, or even any answers to questions like: “Who should we call?” I had to think long and hard and the most frequent question of all would be “What happened?”

My answer would consistently and honestly be, “I don’t know”.

This was the first time that I was officially diagnosed with epilepsy. I think it was the lack of frequency of my episodes that made me not take the condition as seriously as I should have. I was on medication from 2010 until 2013 which I stopped taking without any doctor’s orders because I would always just go to the GP and tell them I was on Epilim; they would give me a repeat prescription with no questions asked. It was only one doctor who told me I needed to see a Neurologist so he/she couldn’t give the prescription.

I had always wanted to do medicine. In 2015 I started my first year at Wits University to do a BSc Degree in Biological Sciences (majoring in biochemistry and human physiology), as I was not accepted for medicine. 2017 was my third and final year of my BSc undergraduate degree, which I still believe was the most academically hardest year of my life in university.

I had a seizure the morning of my first biochemistry test after spending the previous night preparing for it.

My epilepsy episodes arose from 20th February 2017; this seizure was the most severe that I have ever experienced in the history of all to date.

I still have very faint memories of what happened after I woke up from the seizure. I remember myself screaming, crying, being carried to the car by a man I did not know, being rushed into the emergency room, where I woke up later surrounded by my friends and family.

My head felt too heavy for my weak body to carry, my entire body was in pain and I was unable to move. During this time, I was allocated a Neurologist, Professor Girish Modi; my first neurologist. After one week in hospital I was finally discharged. I persistently had short-term memory loss, as well as a feeling of disorientation occasionally, so my neurologist put me on medication to improve my attention span and memory.

Six months later I had another seizure (August) and stayed a week in hospital, thus missing out on school work. My marks were badly affected, which meant at this point I had lost another chance of making it into medicine; my fear was that I would not get accepted in for honors in pharmacology. However, I got accepted for pharmacology, still at Wits University, and found comfort at the fact that I was doing something that I developed a love for in my years of biochemistry. I had the choice of either finding employment after this degree or trying harder for medicine, so I decided to keep both my options open.

On 29th January 2018, I had a seizure which left me with bad injuries on my face; I’d fallen down the stairs. From this point I started losing count of my seizures as they were no longer intense enough to put me in hospital; despite all the minor seizures I tried as hard as possible to keep them under control and do as best as I could. In January 2019, I got in for medicine and started from third year (GEMP1).

After all these years and the hard work and seizures, I finally got accepted for what I had originally come to Wits for. My recurring seizures in such a short space of time for the past two years, and my experiences from 11 years’ ago until today in terms of how far I had come with the condition, have motivated and fueled my drive. They have made me realize how there are probably many other children like myself in townships and villages, who will be diagnosed without any history of epilepsy in their families, together with a lot of other parents like mine, who need more education and counseling about the condition and the importance of visits to a neurologist and having scans done.

I want to be that Doctor, that individual who makes a kind of difference in the lives of people with epilepsy and those who live with and around them.

I still suffer from migraines and occasional dizziness; my seizures have been under control since my neurologist added medication to my usual treatment. I try to make it work, I sleep when my brain is sending signals, and I’ve learned it helps more to listen to my body, than to keep pushing it.

I learned from a very close friend of mine that when you want something so bad and set your mind to getting it, your plan B is always your plan A. I think it’s important that people with epilepsy are taught from a young age that like other individuals without epilepsy, we too can become whoever we want to be!
Thabu du Randt was admitted to Epilepsy South Africa in 1980; he is currently the longest staying resident at Epilepsy South Africa, Geduld Centre.

Thabu is a passionate cricket player and is involved with numerous Cricket Associations. He is doing extremely valued work for Special Needs Schools in terms of Cricket Tournaments.

In 2011, Thabu received a merit award from the Namibian Sports Commission for his dedication and loyal support to Namibian Special Cricket on and off the field. This also opened doorways to international cricket matches between the two countries’ LSEN high school cricket teams.

In 2011, Thabo du Randt was also honoured in March 2014 by the Western Province Cricket association for the sterling work he has done for LSEN.

Longest Staying Resident

By Thabu du Randt

Acetazolamide

Acetazolamide is effective for focal, tonic clonic and absence seizures. It’s also used for menstrual-related seizures, certain episodic disorders and to enhance other AEDs.

Most common possible side effects include: Severe reactions (e.g. skin rash), nausea, vomiting, diarrhoea, taste disturbance, loss of appetite, pins and needles, flushing, headache, dizziness, fatigue, irritability, excitement, unsteadiness, depression, thirst, increased urination, and reduced libido. Tolerance may develop.

Aptiom (Eslicarbazepine Acetate)

Aptiom is an antiepileptic drug indicated as adjunctive treatment of partial-onset seizures. Common side-effects of Aptiom include dizziness, drowsiness, nausea, headache, double vision, vomiting, fatigue, vertigo, loss of coordination and balance, blurred vision, tremor, diarrhoea, constipation, abdominal pain, weakness, swelling of the extremities, urinary tract infection, difficulty speaking, memory problems, involuntary eye movements, depression, insomnia, cough, rash, high blood pressure, and the increased risk of suicidal thoughts or behaviour.

Ativan (lorazepam)

Ativan is similar to Clonazepam in dosage and action, but it is not as long acting. It is usually used as a ‘rescue medication’ for people who frequently have clusters of seizures. It works reasonably quickly when taken orally and the anti-seizure effect lasts for 2-6 hours. An Ativan concentrate, 2 mg per ml, can be taken as 1 ml liquid under the tongue in urgent situations.

Banzel (Rufinamide Inovelon)

Banzel is approved as an add-on treatment for children age 4 and older and adults with the Lennox Gastaut Syndrome. This syndrome can include seizure types such as atonic (drop) seizures, tonic (stiffening) seizures, myoclonic (brief jerking) seizures, or staring (absence) seizures, as well as partial seizures.

Common side-effects include headache, dizziness, fatigue and sleepiness, double vision and trembling. People who have a heart rhythm irregularity, should not take Banzel.

Side effects of anti-epilepsy drugs (AEDs)

By Thabu du Randt
Briviact (Brivaracetam)

Briviact has been approved for the adjunctive treatment of partial-onset seizures in patients 16 years and older. Briviact is the first antiepileptic drug for partial seizures, approved by the FDA since the 2013 approval of eslicarbazepine (Aptiom).

Common side-effects of Briviact include drowsiness, sedation, dizziness, fatigue, nausea, vomiting, loss of balance or coordination, irritability, and constipation. It may increase the risk of suicidal thoughts or behaviour.

Depakote (Depakene, Valproate, Valproic Acid)

Depakote is considered one of the most effective medications for treating generalized seizure types such as partial, absence, and generalized tonic-clonic seizures. Some of the common side-effects include dizziness, nausea, vomiting, tremor, hair loss, weight gain, depression in adults, irritability in children, reduced attention, and a decrease in thinking speed. Over the long term, the drug can cause bone thinning, swelling of the ankles, irregular menstrual periods. More rare and dangerous effects include hearing loss, liver damage, decreased platelets (clotting cells), and pancreas problems.

Dilantin (Phenytoin)

Dilantin is the most prescribed AED by general physicians in the US but less so among epilepsy doctors, because of its side-effects.

Common side-effects are unsteadiness and moderate cognitive problems, dizziness, fatigue and slurred speech. There is also long-term potential cosmetic (body/face hair growth, skin problems), and bone problems (osteoporosis). Phenytoin can also cause a rare and dangerous rash called Stevens-Johnson syndrome.

Epilim (Sodium Valproate)

Effective for all types of seizures. Most common possible side-effects include severe reactions, such as a skin rash (which should be immediately reported to your doctor), hair loss (not usually severe and usually reversible if the dose is reduced), nausea, stomach upset, diarrhoea, weight gain (due to increased appetite), increased levels of ammonia in the blood and reduced platelets in the blood. It has been associated with polycystic ovaries and menstrual problems. Sodium valproate carries a higher risk than other AEDs of causing developmental problems in unborn babies if taken during pregnancy. Having pre-conceptual counselling is recommended.

Felbatol

Felbatol treats partial and some generalized seizures. Side-effects include decreased appetite, weight loss, inability to sleep, headache, and depression. In rare cases, the drug can cause bone marrow loss or liver failure. Therefore, use of the drug is limited. If you are taking it, you must have blood cell counts and liver tests regularly.

Fycompa (Perampanel)

This is an anticonvulsant used to treat seizures in adults and children who are at least 12 years old. This AED is used to treat partial-onset seizures with or without secondarily generalized seizures, and for use with other medications to treat primary generalized tonic-clonic (PSTC) seizures.

Side-effects include abnormal gait, aggressive behaviour, dizziness, drowsiness, equilibrium disturbance, falling, hostility, ataxia, fatigue, and irritability. Other side-effects include anxiety, back pain, blurred vision, vertigo, and weight gain.

Gabitril

Gabitril is used with other epilepsy drugs to treat partial and some generalized seizures.

Common side-effects include dizziness, fatigue, weakness, irritability, anxiety, and confusion.

Keppra (Levetiracetam)

Keppra is one of the more used medicines in seizure clinics because it’s usually effective for a broad-spectrum of seizures types. It has a relatively low incidence of causing thinking/memory problems and has no drug interactions. The most common side-effects are dizziness, fatigue and insomnia, but the more troublesome problem can be irritability and mood changes. This may occur to some degree in up to a third of those taking the medicine.

Lyrica (Pregabalin)

Lyrica is used to treat partial seizures and chronic pain of certain types. A relative of gabapentin, it may work better, and can be given twice a day. Some believe that it is more effective against seizures than gabapentin. The good news is that it has no drug interactions.

Side-effects include dizziness, sleepiness, dry mouth, peripheral oedema, blurred vision, weight gain, and mild cognitive impairment. In rare cases, it can cause Stevens-Johnson syndrome which poses a dangerous risk if not treated immediately. Doses should be increased slowly to avoid any complications. Lamictal is also used for mood stabilization.

Klonopin (Clonazepam)

Klonopin is in the same family as Valium (Diazepam), Ativan (Lorazepam), Tranxene (Clorazepate), Xanax (Alprazolam). They are often used in the emergency room to stop a seizure and are effective in short-term treatment of all seizures. Tolerance usually develops within a few weeks, so the same dose has less influence over time. Klonopin appears to be more long-acting against seizures than Valium or Ativan.

Side-effects of Klonopin include tiredness, unsteady walking, nausea, mood changes, loss of appetite and addiction.

Lamictal (lamotrigine)

Lamictal treats partial and some generalized seizures, but it may not be as effective for myoclonic seizures. Its side-effects include dizziness, fatigue, insomnia and mild cognitive (thinking) impairment. In rare cases, it can cause Stevens-Johnson syndrome which poses a dangerous risk if not treated immediately. Lamictal is also used for mood stabilization.

Lyrica is used to treat partial seizures and chronic pain of certain types. A relative of gabapentin, it may work better, and can be given twice a day. Some believe that it is more effective against seizures than gabapentin. The good news is that it has no drug interactions.

Side-effects include dizziness, sleepiness, dry mouth, peripheral oedema, blurred vision, weight gain,
and difficulty with concentration and attention.

**Neurontin (Gabapentin)**

Neurontin is used with other epilepsy drugs to treat partial and some generalized seizures. It has the reputation of being a safe but not particularly powerful AED. The effectiveness criticism probably is because it’s often prescribed at too low a dose. Side-effects include unsteadiness, weight gain, fatigue and dizziness, but are rarely lasting. Neurontin is also often used for chronic pains of certain types.

**Onfi (Clobazam)**

This medication is used with other medications to help control seizures. It belongs to a class of medications called benzodiazepines, which act on the brain and central nervous system to produce a calming effect. This drug works by enhancing the effects of a certain natural chemical in the body (GABA). Drowsiness, dizziness, tiredness, headache, constipation, weight gain, fever, cough, drooling, trouble sleeping, or nausea may occur. If any of these effects persist or worsen, tell your doctor promptly.

**Phenobarbital (Luminal)**

This old-timer is very inexpensive and effective in a single daily dose. Unfortunately, side-effects include sedation, thinking/memory problems and depression. Phenobarbital can also cause long-term bone problems. It’s mildly addictive and requires slow withdrawal. It is not suitable for pregnant mothers because there is a significant rate of birth defects.

**Sabril (Vigabatrin)**

Sabril has been used for over a decade in many countries, and it is effective for partial seizures. It also may be very effective for infantile spasms, a serious type of seizures in young children. Release in the US was delayed because the drug is toxic to the retina of the eye in up to 30% of people who take it long-term. This toxicity can result in permanent loss of peripheral vision. Regular vision testing is recommended for all people on this drug.

**Tegretol (Carbamazepine or Carbatrol)**

Tegretol is the first choice for partial, generalized tonic-clonic and mixed seizures. Long-acting forms can be given once a day. Potential side-effects include nausea, dizziness, fatigue, weight gain, blurred vision, low blood counts and low blood sodium. In a few percent of people, Tegretol can cause a rash, sometimes even the dangerous Stevens-Johnson syndrome. People of Asian descent with HLA-B*1502 antigen are more at risk.

**Topamax (Topiramate)**

Topamax can be used as a general AED to suppress seizures or in combination with other drugs to treat partial or generalized tonic-clonic seizures. Side-effects include sleepiness, dizziness, speech problems, nervousness, memory problems, vision problems and weight loss.

**Trileptal (Oxcarbazepine)**

Trileptal is slightly different from Tegretol, however it is at least as effective in treating partial seizures and may have fewer side-effects, except for more risk of low blood sodium, fatigue, dizziness, headache and blurred vision.

**Vimpat (Lacosamide)**

Vimpat is a new entry into the AED arena, first introduced in 2009. It's effective for partial and secondarily generalized seizures. Side-effects include dizziness, headache, nausea or vomiting, double vision, fatigue, memory or mood problems. In rare cases, Vimpat may affect internal organs, blood counts or heart rhythm, but these potentially serious side-effects are infrequent.

**Zarontin (ethosuximide)**

Zarontin is used to treat absence seizures. Adverse effects include nausea, vomiting, decreased appetite, and weight loss.

**Zonegran (zonisamide)**

Zonegran is used in combination with other drugs to treat partial seizures. It’s similar in its coverage to Topamax with side-effects including drowsiness, dizziness, unsteady gait, kidney stones, abdominal discomfort, headache, and rash.
Success is the sum of small efforts, repeated day in and day out.

Robert Collier
My Student Life with Epilepsy

By By Ellé Axel

Another year has passed with a plethora of memories made.

As I reflect on my life as a student with Epilepsy I can only smile. Why? Because I am proud of my achievements and mistakes. I am proud of myself for not living in fear and overcoming obstacles I thought were immovable.

I decided to change things this year and made a picture collage instead of just inserting a few pictures here and there. I decided to do it this way because I have experienced life this past year in one big flurry of events, successes and failures; as you can see, there were many.

The NWU-PUK Choir and my hostel have been absolute anchors and lights in my life this past year. I have made life-long friends, learned so much about my abilities, been accepted and loved despite my Epilepsy and have gained even more respect because of it. I have tried to change the perspective/prejudice of people with Epilepsy wherever I go and am astonished to say that it has worked. A lot of people have asked me how I "deal" with everything on my plate and the answer is simple: I just keep trying every day and always give my best.

I have learned how to manage my time better, keep calm and improve my mental and physical health, as well as accepting and trying to overcome my limitations. My parents have come to terms with my diagnosis and restrictions and supported me through the good and bad times. This has also encouraged me to fight every day to reach my goals of becoming an Educator and a parent.

I am proud to say that I am in the top 5 of my year/group for English (one of my main subjects); the most challenging teaching subject that you can study at the NWU-Potchefstroom. I learned the value of collaborative learning and discovered the beauty in language and its history.

The achievement I am most proud of (one of my main goals for 2018), is achieving recognition and an invitation from The International Golden Key Society due to my academic performance in my first year (top 15% of my faculty) to become a lifelong member. This has long been a dream of mine and it is a true honour to have been recognised.

Unfortunately, one’s life is not merely a highlight reel. I experienced quite a few setbacks and “bloopers”. A reality I had to come to terms with, first and foremost, is things do not work out according to your plans. They work out according to God’s (and often not always in ways that we enjoy, but in ways that are necessary). Secondly: you WILL drown if you try to swim through life alone and keep all your doubts and negative thoughts to yourself.

Lastly, I realised just a few weeks’ ago that I still need to work on how I process trauma. There was an incident in a store where my mother and I were shopping. A man (one of the store’s staff members) whom I was talking to, had a grand mal seizure right in front of me. I just reacted on impulse, went down on my knees and tended to him, whilst giving out orders to anyone and everyone around me while trying to keep calm for his sake. I was in such a state I hadn’t even realised that my mother had been next to me the entire time helping me keep the man on his left side. It was the worst seizure I had ever seen.

Once I stepped back and a woman with a medical background took over, the shock started to set in; I felt my own attack was on the way. Luckily, my medication prevented it, but I ran out of the store as fast as I could to get fresh air. Only when I was outside, I realised that my face was already moist from tears. My mother found me shortly, thereafter, calmed me down and took me home.

When I reflected on the entire incident afterwards, I realised two things:

•  We NEED to work on the general public’s knowledge of, and medical response systems, to epilepsy or any other serious medical conditions.

•  I still need to learn how to process trauma and improve my knowledge on basic medical procedures for incidents such as these, to be the best possible teacher for my future learners and keep a level head in crisis situations.

However, I would never have been able to overcome my obstacles, reach my goals and have so much fun this past year without my friends’, parents’ and ESA’s support and most importantly, God’s grace!

Emma Watson said: “I’ve probably earned the right to screw up a few times. I don’t want the fear of failure to stop me from doing what I really care about.”

I think we should all never let the fear of failure, of not being good, strong, intelligent or privileged enough from stopping us reach our goals and make our dreams come true. Learn from your mistakes and never stop moving forward, even if you must lean on others occasionally to do so.

Thank you once again ESA for helping me to be and make the difference I want to see in the world!
Being a mother is a great calling from above.

I am Cynthia Masombuka from Siyabuswa. I stay with my son Sello Masombuka who is 16 years old; he attends Masinakane Special School, near Siyabuswa.

When I was seven (7) months pregnant my husband passed away, I couldn’t cope and was in and out of hospitals because of stress and depression. The Doctors advised me not to stress because that would affect my unborn child.

When Sello was born they told me he has epilepsy and asthma and was having short breath and seizures at the same time. It was not nice at all to know that your child had such a condition, as well as losing his father before he saw him. It is very tough for me to accept but with time, I lived with it and care for my son.

I attended the educational talks and met other people who are affected at the Hospital.

He grew in front of me and I was happy with him. When he was five (5) he started schooling, he was getting lots of seizures, the teachers & Principal phoned me because he was not coping, and the other learners were teasing him.

The school arranged an appointment with the School Psychologist for his assessment, it was done, and he was transferred to Masinakane Special School. He has been there since 2014, he’s in level 4, and he is enjoying it and happy there. He loves cooking and is assisting the kitchen staff; he is also playing rugby at school.

I am very happy with his progress; he is growing to be a man now.

My advice to other parents is to learn to accept the condition of your child, learn, talk and encourage others; you will be so much more at ease.

Embrace your gift from God and cherish every moment of life with him.

I LOVE MY SON!

A Positive Mindset

By Slindile Magwaza

God being the Glory, I haven’t had many challenges yet except for not being able to see clearly from the board. If I’m not sitting in a front row sometimes, I feel as if I’ll have a seizure which ends up being a false alarm.

Whenever I get this feeling, I take a deep breath, try to calm down, and drink water. If I’m wearing a jersey, I take it off, I take my Epilim medication, and remain in a safe place with the people who are aware of my condition.

I was so concerned at the point that I almost quit, but all those negative thoughts were overthrown by the words of Olivia Tomchick which I found in the Students who Live with Epilepsy Group. Olivia said then ‘If you are living with epilepsy, the condition should not define the person you are. To persevere in life, you need to kick your fears to the curb end and pursue your dreams!’ These wise words helped me so much and reminded me that having epilepsy does not make you any less human.

It faded away all the negative thoughts and brought back the spark and excitement in my life. I then went to the College with a positive mindset, I made friends on my first day and on the second day all four friends of mine brought chocolate, which they wanted to share. I then told them about my condition; luckily for me one of them has a younger brother who suffers from epilepsy too, so it was easy explaining why I do not eat sweet things because of Mbali’s assistance.

I relate when I’m in class, I try to listen critically, analytically and am open-minded. I stop the lecture as soon as I get confused and ask the lecturer to explain right up until I fully understand. In class I always try to take a front seat so I will be able to see clearly on the board. Sometimes, if I cannot get the front seat and cannot see clearly from the board my friend, Ovuyo, will let me take notes from her book or she will ask the people in front to make the space for me without making it obvious that I have a small problem. My friends have been very helpful; I occasionally feel like I’m a burden to them however Ovuyo does great work to make that negativity fade away.

When I get home, I take a ‘nap’ which assists me to relax and regain energy; once wakened I do everything that we did in class which helps me not to forget easily; I even got ‘A’s’ in all my assignments!

I have not had any seizures yet, am perfectly healthy, try not to overwork myself and avoid unnecessary stress, stay calm, get enough sleep and exercise for one hour a day!