Epilepsy South Africa 2010
Turning obstacles into “SCORES”
for People with Epilepsy!

From the Director’s pen, by National Director: Mrs. Noëline de Goede

Epinews is a very special instrument of Epilepsy South Africa that is made possible by the kind financial support of Sanofi Aventis. It is a mouthpiece for people with epilepsy to share their stories, experiences, difficulties and achievements with others. I find that this publication provides hands on information to all those with epilepsy, those affected by the condition and society in general. This assists everyone to deal more positively with epilepsy.

We have used most of 2009 to redesign and restructure the Epinews panel and publication to meet the identified needs of people with epilepsy. Our new panel consists of a positive group of people with epilepsy and it is the panel’s responsibility to source relevant stories and information for this publication to educate, inform and educate all others with epilepsy. This also provides direction to Epilepsy South Africa’s services in terms of the problems that those with epilepsy are struggling with.

Please take the time to read this edition that is brought to you by our new panel for 2010.

Epinews is a publication providing people with epilepsy the opportunity to speak out about matters affecting them, share their information and support each other. Epilepsy South Africa renders services to all those affected by the condition, as well as all sectors of society. Its aim is to promote equal opportunities and social justice; and to turn obstacles into true potential. As such, it is my privilege to share some information about the work that we are involved in.

The six Branches of Epilepsy South Africa achieved so much during the year- and- a- half gone by that it is very difficult to single any one thing out. I will however mention the things that I find are clear examples of successful practice in living our mission.

For more information on the organisation visit www.epilepsy.org.za
In Gauteng

Ekurhuleni Municipality’s Social Development afforded the Gauteng Branch the opportunity to lease an office at the Multi Purpose Centre in Kwa Thema, thus expanding services to under-serviced areas.

The Director provided support and advocacy services to a client suffering from epilepsy, who was unfairly dismissed from his work. The client, a qualified chartered accountant, was accompanied by the Director of the Gauteng Branch at the CCMA and the matter was then referred to the Labour Court.

The Branch received funding from DG Murray to expand their Hydroponics tunnel, thus enlarging their economic empowerment programme.

In Mpumalanga/Limpopo

Mr Matlala of Special Olympics SA visited the Branch office and their residential care centre. The purpose of this meeting was to establish a partnership with his department and to involve the Branch in future Special Olympics events. Mr Matlala attended the Branch’s annual sports day in Moutse in October 2009, where it was agreed that the Branch would participate in the planned games in 2010. Thirty eight athletes from the Branch participated in the regional games on 22nd April, 2010, in Moutse and fourteen selected athletes participated in the Provincial games which will were on 13th/14th May, 2010, in Pretoria.

The Branch celebrated its 30th anniversary and a donor breakfast was held, where a glass flame trophy was awarded to each donor for their support in either funds or donations in kind. The 50 glass trophies were donated by Mr Jeze Prettejohn, a local businessman in Dullstroom.

OSDP – Premiers Office joined the Branch in radio talks and visited the Branch. This formed part of their awareness and advocacy campaign, which resulted in an invitation to the branch to participate in the Mpumalanga Disability Parliament which was held in Nelspruit on 12th and 13th November. Five people with epilepsy, one volunteer with epilepsy and one staff member attended the parliament and gave valuable input during the discussions.

A roadblock was held at a four-way stop in Dullstroom where motorists received information packs about epilepsy, thus increasing awareness; within half an hour R1200 was also raised.

A fundraising dinner dance was held on the 19/8/2009. This was well attended and the National Fundraiser who also attended was in awe at the support that this Branch receives from the local community.

Annually this Branch hosts a Chef’s Cookout fundraising event. This is huge fun and is enjoyed by the whole community. As this event has been so successful, Epilepsy South Africa is now planning to turn this into a national event.

In the Southern Cape/ Karoo

Knysna Oyster Festival. For the first time in 30 years the festival made provision for the participation of people with disabilities in the festival programme. Thirty residents of the Epilepsy SA Residential Centre in Knysna participated in this inaugural event and The Epilepsy South Africa pancake stall raised more than R10.000 at this festival.

Thanks to financial assistance from the National Lottery the branch has been able to appoint two more staff members in its Social Development department, thus enabling it to reach out to more rural and previously under-serviced areas.

The support of the GCIS enabled us to raise our awareness campaigns to a new level at relatively low cost as the printing of information material was done free of charge.

The Golden Games which promotes healthy living and active ageing amongst older persons was a definite highlight and the 2010 event is eagerly anticipated.

In the Western Cape

The social work department has increased its capacity to five social workers and one social auxiliary worker. As a consequence they have extended their services in the Cape Metropol and services were extended to include areas such as Ocean View, Hout bay, Kommetjie, De Noon and the broader northern suburbs.

The social developmental programmes have also expanded and the following new programmes were piloted and implemented during 2009:

Please contact any of our EPILEPSY SOUTH AFRICA Branches on 0860 EPILEP (0860374537)
National Office on 021 595 4900. / visit www.epilepsy.org.za / email info@epilepsy.org.za
Disability sensitisation programmes with the youth in mainstream schools.
Disability sensitisation programmes in the workplace for the promotion of inclusion and acceptance.
Disability and human rights.
Programmes celebrating Childrens’ Day, Youth Day, Epilepsy Week, Womens’ Day, 16 days of activism and the international day of the disabled.
The branch Annual Epilepsy Seminar for the community and professionals has grown from strength to strength. The seminar provides participants with an opportunity to engage directly with renowned neurologists who are based in Cape Town, together with other experts in the disability field.
The three protective workshops and income generation groups in Khayelitsha and Cross Roads continue to employ people with epilepsy. Care Craft Mitchell’s Plain Workshop and the Business Place in Philippi were acknowledged by the International Labour Organisation due to an award received for the best social enterprise business. A prize to the value of R10, 000 was received; this was to be utilised for the expansion of the workshop.
Funding was also received from the National Lottery Distribution Trust Fund for the expansion of the Regional Office. This is to include a training centre; show room for the products, manufactured offices and five business hives, and will be completed during 2010/2011.

In the National Office:

In the National Office, Syfin house, Parow in Cape Town.
The National Office of Epilepsy South Africa has never owned its own building. The staff number and services rendered by the National Office has more than tripled since 2004 and our rented office space became far too small to accommodate us any longer. We were introduced to fantastic premises called Syfin House, of which the ground floor is available for purchase. We have moved offices on 15 February 2010 and will at first rent the office space. We have until June 2010 to raise the money needed to purchase the ground floor of Syfin House. These premises will accommodate all our services and will also allow us to open our training wing. This will offer relevant and affordable training to the NPO and Corporate sector as well as Civil Society. This will not only strengthen the NPO sector but will also provide us with some income toward being financially sustainable.

In the Free State

We were able to reach out and give assistance to other community structures, i.e. crèches. Fifty blankets and food to the value of over R75000.00 has been distributed.
Thanks to financial assistance from DG Murray the Branch was able to purchase a double cab/bakkie, together with Vuka Scooters, which is certainly making service delivery to rural areas more accessible and affordable.
A business hub has now been established which will provide new entrepreneurs with a venue for joint marketing of products to our tourists. This will form part of their SMME and entrepreneurial development programme.

Social Development services
- Counselling, advice, information and referrals

Economic empowerment services
- Income generation training
- Income generation project formation
- Entrepreneurial development training
- Entrepreneurship development
- Advice, information and referrals

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National Office on 021 595 4900. / visit www.epilepsy.org.za / email info@epilepsy.org.za
Food gardening project formation

**Advocacy**
- Training and information to people with epilepsy
- Advocating on behalf of people with epilepsy when discrimination is experienced, e.g.
  - Schooling
  - Employment
  - Social security
- Empowering individuals with epilepsy to become self-advocates

**Awareness and information**
- Distributing pamphlets, booklets and information pages
- Doing talks and exhibitions
- Writing and publishing articles

Epilepsy South Africa National Office would like to express gratitude to the Discovery Foundation for awarding us the necessary funding to establish the first direct Epilepsy South Africa service point within the Eastern Cape. We would also like to thank DEC Letsema Sizwe, DEC Putco and DEC Big 5 for their financial contribution towards direct service programme delivery in the Eastern Cape. Lastly we extend a big thank you to our NPO partners: REHAB East London for allowing us to rent an office in their building, for assisting us in setting up our direct services and for assisting us with direct services towards people with epilepsy, as well as to Utho Ngathi who assists us in service delivery towards people with epilepsy.

For more information on our Eastern Cape Development programme please contact James Mkalipi +27 043 722 1811(ext 205) or email at development.ec@epilepsy.org.za

During 2010 the National Office will focus on the following programmes and services:
- Continued and increased marketing of Epilepsy South Africa, our services, projects and programmes.
- To increase our funds through developing and implementing new fundraising initiatives.
- Further development of services in under-serviced provinces and opening our new direct service point in the Eastern Cape.
- A critical focal area of our social development programme will be advocacy and we aim to empower people with epilepsy to act as self-advocates within South Africa.

The social development programme will also focus on increased epilepsy awareness, youth development, and the formation of a youth forum, counselling, advice, information and appropriate referrals.

Continued implementation of our very successful entrepreneurial development programme, as well as our income generation training and SMME development. This forms part of our economic empowerment programme.

Our vision is to ensure economic independence for all people with epilepsy and we make this a reality for a small percentage of people with epilepsy and / or other disabilities through our economic empowerment programme.

We aim to increase the percentage of beneficiaries through the implementation of our Training-of-Trainees programmes, which allows information and skills to be cascaded to more beneficiaries at community level.

We will also implement a youth-focused economic empowerment programme and focus on employment equity for people with disabilities within the open labour market and government departments.

Through our skills development programme we ensure that all personnel and volunteers are adequately skilled to ensure quality service delivery. We fully comply with skills development legislation.

We will continue implementation of our Good Governance programme, which includes:
- revision of our policies, procedures, constitution and regulations;
- training, monitoring and evaluation of good governance practices, and
- recruitment, selection and training of Board members.

Lastly I invite you to subscribe to our monthly electronic newsletter if you have access to the web. This will provide you with news from Epilepsy South Africa as it happens. It is quite easy to subscribe when you visit www.epilepsy.org.za just complete the detail in the box provided.

Let’s talk Epilepsy

*Noëline de Goede*
(National Director Epilepsy South Africa)
Section B
My Story: by Juanita Fourie

I was diagnosed with epilepsy at age 16 after having two seizures. I went for the necessary tests which were traumatic in themselves as there was nothing wrong: no tumor or head injury. When the condition was confirmed, I started on Tegretol; an anti-convulsant to help control my seizures. At that stage my epilepsy was diagnosed as Grand-mal. I think over the years it sounded too harsh to some people so they changed the name of the condition to tonic-clonic epilepsy.

I went through high school with only having a few seizures. Being exposed to other patients, I was very thankful for only having a few seizures and could focus on my studies. I had dreams of studying further and being successful in my career whilst starting a family.

After high school, I got my diploma in Public Relations and started to work. I got married to a wonderful man who proved to be understanding and later in life was to prove a Godsend. We planned to have a baby and I gave birth on the 1st January 2000: a Millennium baby. We called her Lindi and we were very happy. Our Lindi was born with Spina Bafida and only lived for 4 months and 19 days.

Although, during my pregnancy, I went for all my sonar scans and “everything proved to be normal”, I naturally felt that I was to blame for Lindi’s condition because of being on anti-convulsant medication. After Lindi and the trauma experienced of losing our first baby, I’ve decided NEVER to have a child again. I could not believe that God could do such a thing to us. I was very angry with Him and had lots of questions that had no answers.

My epilepsy started to become worse, so my medication was changed to Epilim, Lamicton and later Urbanol was added. As time passed, it healed our wounds and four years after Lindi was born, we decided to try for another baby. I prayed during the entire 9 months for this baby to be normal. We didn’t care for a boy or girl, as long as the baby was healthy. We learnt to appreciate life. My husband is such a blessing. He understood me and loved me even during my seizures. That surely is love, because a seizure is not a beautiful sight. He knew what to do in each case and stood by me every time.

Our baby was born. It was a girl and she was healthy! We named her Stephani. Our Stephani is now 5 years old and we know how to cherish our child, after what we’ve been through with Lindi.

Some personal lessons that I have learnt:

I cannot remember if my medication was changed before or after my second child, but it is VERY important to know everything about your medication during pregnancy.

I am now diagnosed with ‘Generalised tonic clonic’ and Mioclonic seizures. After all these years, I still sometimes have no clue what the doctors are talking about. I believe that they know best and I am happy as long as I’m standing and not “kissing” the floor. I still think the strangest thing is the “weird” feeling one has after having a seizure; not knowing what happened and not being able to recognise people.
The Impact of Epilepsy on Individuals and their Families

- Epilepsy cannot be treated with medication alone.
- Impact of living with epilepsy often goes unacknowledged, without much assistance.
- Every individual and their family are affected in their own unique way.
- Diagnosis of epilepsy is a process that may involve several visits to hospitals, doctors, specialists and other professionals.
- Take an active role in learning seizure management and teaching it to others around you.

Epilepsy and Pregnancy

Women who have epilepsy and become pregnant have a higher risk for pregnancy-related complications than pregnant women who don’t have epilepsy. These complications include:

- Vaginal bleeding
- The possibility that your seizures may occur more often
- Preeclampsia (a condition during pregnancy that is a combination of high blood pressure and the presence of protein in the urine after 20 weeks of pregnancy)
- Separation of the placenta (the organ that provides nourishment for the baby during pregnancy) from the uterus (womb)
- Pregnancy affects each woman who has epilepsy differently. More than 90% of women who have epilepsy deliver normal, healthy babies but there are some risks.

It’s very important that you take your anti-seizure medicine just as your doctor tells you.

As with all pregnant women, it’s also very important for you to take prenatal vitamin supplements and folic acid, which can help prevent certain kinds of birth defects. Eating a healthy diet, getting enough sleep and exercising regularly are other things you can do to have a safe and healthy pregnancy. During your pregnancy, you will see your doctor often. Your doctor will perform frequent blood tests to be sure that you’re getting enough anti-seizure medicine.

Professional advice on lessons learnt by Juanita:

My short swimming career:

By Lesley Donnelly

At the age of 13 and 14, I was a champion swimmer and springboard diver and entered several competitions. I loved being in a swimming pool and out in the open with my friends. Unfortunately, during a major diving event, I hit a diving board and was stopped from diving for a while.

My epilepsy started at the age of 16 and after having a few seizures in swimming pools and almost drowning, I was also stopped from swimming and diving. Both were favourite sports of mine along with hockey and netball, but I had to finally acknowledge the fact that it was now time to stop being in a pool. I also rode a bicycle to school regularly and had to have the strength inside me to follow the road, and not think what would happen should I lose control.

My parents were always concerned when I left home early in the morning maybe not to return and wanted to transport me to school, but I had to show my independence and carried on. Their joy showed when I arrived home safely each time. It was only a year since then that I managed to get my driving licence. I found that understanding the diagnosis of epilepsy and some of its restrictions was an extremely difficult process.

After walking and cycling to school for months and going for various other bicycle rides on the road, my life became hazardous and at the age of 17, I had a car accident. Luckily, I wasn’t injured but the epilepsy had played a part during my trip. My parents explained to me that it was my choice if I wanted to risk my life, as well as others’ whilst driving, but asked which was more important? I chose not to drive.

I am now 52 and haven’t driven since. One has to be strong-willed to accept the fact that one eventually has to make a decision for one’s own safety. I also find that you have to be independent, not to rely on others permanently, and live with the decision made. Acceptance is the first step to managing your life with epilepsy.

- I am a happily married and competent woman. I plan my life carefully and enjoy the normal things that life has to offer. Epilepsy remains an interesting condition and I learn on a daily basis, but I am a joyful person willing to encourage others – you are not alone!
Some personal lessons learnt:

During our school years we meet many friends, parents, families and teachers. Schooling can be a wonderful environment, which creates a feeling of closeness to them all. From my past experience other children do not understand what is involved when one has a medical condition or what it entails. It is natural to be careful in sharing or to know others problems.

Those who are affected for health reasons eventually get left out of a friendship. This leaves a child feeling alone in an emotional, miserable and difficult time. Teasing by other children or/and fellow learners may lead to social isolation, behaviour changes (depression, anxiety, anger, frustration) and add to a lack of achievement by children with epilepsy. On the other hand, the child with epilepsy can flourish if possible discrimination is immediately addressed and eradicated.

It is advisable that parents inform the child’s school, teacher and friends about epilepsy to prevent any misconceptions or stigmatisation. Parents have the right to be directly involved in the planning of their child’s education and related needs.

The following guidelines should assist parents, teachers, family members and friends to support the child with epilepsy:

- Emphasise what the child can do rather than what he/she cannot do while taking sensible precautions.
- Treat the child like all other children but there are certain issues and options for people when it comes to understanding their safety.
- Help the child integrate into as many social activities which will help him/her to develop and enjoy the required social skills like all other children.
- Do not overprotect the child, make the child’s condition the centre of attention, or blame the child or his/her epilepsy if the family experiences difficulties.
- The focus should remain on ensuring that the child lives a happy and integrated life where having epilepsy becomes a secondary focal point.

Professional advice on lessons learnt by Lesley

- Having the opportunity to participate in sport and recreational activities is important
- A lack of understanding about epilepsy can mean people with epilepsy are cautioned against taking part in some activities where this is not necessary. With qualified supervision where appropriate and applying the necessary safety precautions there are little that you should avoid if you have epilepsy.
- Active recreational activities can improve both mental and physical health
- Most sports can be safely pursued by individuals whose seizures are not fully controlled.
- Recreational activities are very important for socialising and happiness. Achieving the balance between a safe and active life is possible by just making a few adjustments in sports activities.

Safety tips:

Water sports:
- They should never be done alone.
- At least one person participating in the activity or observing it should be aware of the possibility of seizures and know basic life-saving techniques.
- Always wear a high-quality, properly fitted life vest when near the water to help prevent drowning.
- Always wear a medic alert bracelet or necklace!

Contact Sports:
- Contact sports such as football, rugby, basketball, soccer, and ice-hockey are generally safe for people with seizures.
- Most individuals with epilepsy can safely exercise in a gym and use exercise equipment.
- For those who have uncontrolled seizures, a buddy system may be needed.
- Activities like scuba-diving, rock-climbing, sky-diving, hang-gliding, and mountain-climbing should be avoided by individuals with uncontrolled seizures.

Recreation safety tips:
- Always have a “buddy” for activities that require considerable exertions that are likely to cause injury.
- Take frequent breaks and drink plenty of water.
- Wear protective clothing (elbow or knee pads, helmet, protective eyeglasses or goggles) whenever possible.
- When bike riding, avoid busy streets; ride on bike paths or side streets.

Obituary: Audrey de Villiers

(23-11-1920 – 25-01-2010) by Tim de Villiers - National Chairperson

Audrey de Villiers, a long term member (approx 25 years) of SANEL/Epilepsy SA Western Cape, passed away on 25th January 2010 aged 89.

Audrey was a strong, down to earth loving and caring lady who never wanted a fuss made over her and always put others needs ahead of her own. She was very supportive of all my interests and sports, especially with Epicare Cape Town, which I initiated 23 years ago. She assisted with enveloping Epicare’s monthly Brainstorm newsletters and with serving teas at most of the Epicare meetings over these years.

Thank you mom for your love and support, especially through all ups and downs during my earlier years with epilepsy. **Rest in Peace!**
Member/Prospective Member of Epilepsy South Africa:

In order to become a member at your local branch of Epilepsy South Africa phone 0860374537

Epilepsy South Africa continues to assist people with epilepsy to live to their maximum and true potential. We therefore aim to be of service to people with epilepsy and people affected by the condition. In the recent year a lot has happened which includes our National Strategic Plan where we specifically looked at the future of the organisation and how we can improve our service delivery to the community at large. We will definitely focus on the rights of people with epilepsy again this year, with an emphasis on inclusion issues to build up toward a National Campaign in June when we celebrate National Epilepsy Day on 21 June.

We also aim to build the capacity of families, community members and even companies to support people with epilepsy. We would really like our members to become more involved in our programmes. We will therefore keep you updated on the activities within the organisation throughout the year if you should choose an appropriate communication channel to reach you.

Activities we suggest your involvement in/which you can benefit from:

- Epinews compilation (A bi-annual newsletter by people with epilepsy, for people with epilepsy)
- Casual Day (A national Fundraising event that benefits a broad spectrum of people with disability)
- Online newsletter sent monthly to the email address of your choice
- National Epilepsy Week
- International Day Disabled People
  - Annual General Meetings
  - Epilepsy South Africa and Epilepsy South Africa Educational Trust

We want to thank you for your ongoing support. You have the choice to become a member of the National Office or a member of the Branch closest to you.

Please contact them for information on the latest membership renewals. We will continue our bi-annual Epinews publication and communication through our electronic newsletters. To subscribe to this go to www.epilepsy.org.za, it is free and released on a monthly basis.

You are a very important part of our team and we would therefore like to stay in contact with you. We value your interest and regular feedback!

Payment information: Epilepsy South Africa, FNB, Cheque Account # 50120006868 Branch # 200309

Please complete and return to:
Epilepsy South Africa National Office, PO Box 12100, N1 City, 7463, or fax to 021 595 4901

Date: __________________________
I have a close friend or family member that has epilepsy
I have epilepsy
YES I would like to renew my membership.
Yes I would like to apply for membership
I enclose proof of payment for my 2010 membership of R30
I enclose proof of payment for a voluntary donation of R............
Total amount of which proof of payment enclosed R............
Name & Surname: ................................................................................................................
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A Women’s Entrepreneurial Development Capacity Building seminar will be hosted at the National Office from 16 – 20 August 2010.

The programme will focus on:
- Gender and Enterprise
- Markets and market access for Women Entrepreneurs
- Business Development Services for Women’s Entrepreneurial Development
- The enabling environment for Women’s Entrepreneurial Development
- Building associations and strategic alliances
- Access to finance for Women Entrepreneurs
- Assessing impact
- Social entrepreneurship as a gender issue
- Management training for Women Entrepreneurs.

Target audience:
- Disability organisations with an entrepreneurial or women’s programme
- Women’s organisations with a disability component.

For more information contact Marina Clarke on (021) 585-4900 or economicdev.no@epilepsy.org.za.
MOUNTAINS, EPILEPSY, AND OTHER INTERESTING CHALLENGES.

by Kai Fitchen

On the 10th of January 2009 at 7.15 am, I summited Mt. Kilimanjaro. I was standing at Uhuru Peak 5895 meters above sea level, which is the highest point in Africa. It was one of the most challenging experiences of my life and one of the toughest things I have ever put my body through. Not only was it mentally and physically challenging, but I had to stay focused, dig deep and really believe in myself.

Living with a disability is similar. Every day we need to dig deep and understand that we need to overcome many obstacles, so we can live wholesome and productive lives. My metaphor for epilepsy is like a mountain, you need to take it on one step at a time.

I was diagnosed with epilepsy when I was nine, and I sort of fell apart. I did not want to sleepover with friends, or tell anyone that I was now ‘different.’ I was lucky as my family were very supportive, and they told me that I can still do all the things I wanted to do. We all had to get our heads around understanding epilepsy. I introduced myself to Wendy Neft who is director of Epilepsy in the Western Cape, and said I wanted to do something that would help the youth understand more about epilepsy. She was great and so I started meeting other people who had lived with epilepsy and were getting on with their lives.

I can’t exactly remember why I decided that I needed to climb Mt Kilimanjaro, but once I made the commitment I threw myself into the project. I started training with a group of people, of whom many were scouts, who were planning to do it in January 2009. We started hiking in earnest in April 2008. Everything I did revolved around Kilimanjaro. I started talking about my dream to anyone who was prepared to listen. Even though I was only 14 at the time, I managed to get a Saturday job with Seven Summits; the owner Dave Davis is an internationally acclaimed climber. I had to watch my diet and I had discussions with my neurologist Dr James Butler, who gave me unequivocal thumbs up.

The great thing about my preparation was meeting new friends and everyone was aware that I was not just doing it for myself, but I wanted to use the opportunity to share my adventure with people who experienced seizures. Epilepsy Western Cape invited me to speak at schools and I became a youth ambassador using the mountain as a metaphor.

When I got back I was so stoked at having just DONE IT! Everyone was thrilled for me and I had the picture of me holding the Epilepsy SA banner on the highest point in Africa!

Whilst we were climbing, my friend Josh Stehr (now a Springbok Scout) and I decided we wanted to do all 7 Summits – and most importantly, to try as far as possible to work towards doing Mt Aconcagua in South America using zero emissions. (This we plan to do in 2012). We realised we needed more ice climbing experience, so on the 9th of July 2010, I fly to Russia, where Josh and I will meet to travel to Mt Elbrus in the Caucasus’s which is the highest peak in Europe. We are attempting to do the North face, and if I succeed I will be the youngest South African to have done it.

We have managed to get many people and organisations supporting our bid. Cape Storm, Mountain Club of South Africa, SA Mountain Sport magazine, Outward Adventures and 7 Summits/Mountain Mail Order are assisting us either with gear or publicity. I am currently in Grade 11 at Rondebosch Boys’ High School and they understand and support me. I want to use the opportunity to talk about epilepsy in particular and create an opportunity for Epilepsy Western Cape to make some money, by setting up a pledge line, be it telephonically or following us on line and see what we are attempting to do.

I am utterly committed to this adventure and am currently setting up networks and resources, so by the time I leave not only will South Africans be full of football, but many people will be aware of what I am attempting to do. If you would like to participate in our adventure please send your contact details to wcape@epilepsy.org.za and we will put you on the data base.
**Adults with epilepsy have the right to employment.**

The South African constitution guarantees people with epilepsy the right to work and to choose their profession. In addition, the Employment Equity Act (No. 55 of 1998) offers protection to people with epilepsy in terms of employment as epilepsy meets the requirements of the term “disability” in terms of this Act.

People with epilepsy have the same range of abilities and intelligence as the rest of the population. While no job categories are closed to those with epilepsy, a thorough assessment will ensure their safety and successful placement in a particular job. Each person must be assessed individually to determine potential risks; however a risk assessment shouldn’t form the basis for deciding whether to employ him/her.

**Steps and Tips for finding employment**

- Ensure that your seizures are optimally controlled. The level of seizure control is critical to the successful employment of a person with epilepsy.
- Identify a potential career path through an individual assessment.

**Our heroes of 2010!**

By Wynand du Toit, Epilepsy South Africa National Office Fundraiser

With 2010 kicking off as a fantastic year for all sporting codes in South Africa, it is with excited expectation that we look forward to an opportunity to showcase South Africans as positive ambassadors, not only to the Soccer World Cup, but also as really diverse people filled with heroes of positive endurance.

At Epilepsy South Africa, one of the greatest privileges of working with people with epilepsy and other disabilities is to regularly discover the hidden heroes within our communities. People facing enormous challenges every day and still living positively, working hard to make life just that little bit easier for others in need. We all know of the celebrities that proved this possible, but we often do not realise the heroes are also among us.

Epilepsy South Africa aims to partner with these individuals that live their lives to the full, many of them diagnosed with epilepsy themselves. With the Pick ’n Pay Cape Argus cycle tour we identified the opportunity presented to us by one of our local heroes, Steven Densum.

Steven lives in Welkom and is a person with Epilepsy that overcame every obstacle in his way since he was diagnosed. More cyclists are supporting our cause and we would especially like to thank our chairman, Tim de Villiers and his wife Caroline, as well as Charl van Rooyen for making themselves available on the Backabuddy system.

The weather forecast for the 2010 Pick and Pay Argus Cycle Tour did not favour the participating cyclist this year. On the actual day Cape Town experienced a cool but windy day. Wind is however always on the list of things to be prepared for when you are cycling this prestigious race.

Epilepsy South Africa’s four Champions took part and wore their branded Novartis and Epilepsy South Africa shirts with pride. We could share in the excitement in seeing Steven Densum’s dream come true and are still convinced that obstacles can be turned into potential. He motivates that his epilepsy is a condition that pushes him to achieve more as a person. In partnership with Novartis we could support Steven to complete the Argus. He did this in 4h35min.

Draw up a Curriculum Vitae (CV). A well-prepared and updated curriculum vitae (CV) will assist those seeking employment to match their own knowledge, skills and abilities to vacancies.

- Ensure that you are ready to take on the responsibility of a job and career. If necessary, seek counselling advice. The nearest Branch of Epilepsy South Africa will be able to provide information and advice in terms of employment (including counselling, job seeking, job-readiness, placement and follow-up).

- Upgrade your interviewing skills, as these are a key in finding appropriate employment.

- Identify and review available vacancies and match your knowledge, skills and abilities to these vacancies.

- People with epilepsy must know their rights and responsibilities as a job-seeker/employee.

Should you have any queries regarding employment or other issues, please feel free to contact Epilepsy South Africa by dialling 0860 374 537 to automatically connect to your nearest Branch or contact the National Office telephonically on (021) 595 4900. You can also email economicdev.no@epilepsy.org.za and information is available on our website (www.epilepsy.org.za).

Remember that we are here to support you regardless of your circumstance.

Congratulations Steven and thank you for doing us proud! The other three fellow cyclists joined in for additional exposure to Epilepsy and South Africa as well as opened the opportunity to raise funds through the Backabuddy site. This is important as Epilepsy South Africa depends on donations to maintain and improve services to people with epilepsy and other disabilities.

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Champions:

- Steven Densum (Argus time 4h35min)
- Muneerah Humzah (Novartis representative)
- Caroline de Villiers (Argus time 5h30min), Tim de Villiers (National Chairperson - Argus time 4h56min), Karen Robinson (National Social Development Manager), Ruth Gabier (National Office Administrator)

Visit Backabuddy Website: [www.backabuddy.co.za](http://www.backabuddy.co.za) and make a donation by sponsoring either or all of our cyclists.
Join in our daily chatter!

If you have access to social media tools, you are welcome to drop us a line and talk epilepsy!

We are currently featured on Facebook, Twitter and have a regular Blog that is updated with relevant news.

Interested in becoming part of our group to receive sms text only messages - please send an email with SMS EPINEWS in the subject line or send a request sms to 400012011002.

In both cases include your name, surname and cell phone number in the body.

You are welcome to unsubscribe from this service at any time, and are charged normal cell phone rates for replies, but none for receiving our messages. The email can be sent to marketing.no@epilepsy.org.za

Advocates needed
2010-2011
Karen Robinson–National Social Development Manager

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It is time for youth living with epilepsy to reclaim it’s place and by telling their stories on different levels to create awareness of their felt needs, issues and also of the stigma’s and discrimination that they are experiencing. It is time that we should stop being complacent, take control of our lives and do something positive about the issues that are affecting us.

Epilepsy South Africa National Office objective is to do 3 training sessions, each of which will consist of approximately 15-20 youth living with epilepsy.

If you want to make a difference by being an advocate on all levels, collaborate with other youth living with epilepsy and mobilise yourself as a national youth epilepsy forum then JOIN OUR ADVOCACY CAMPAIGN or TRAINING 2-4 August.

Please contact us:
086 037 4537 or 021 5954900

Opening of new offices, by Epilepsy South Africa Free State Branch

During the year our services have become more and more in demand by the community of Tumahole. The problem with service delivery started as the offices in Parys were not so accessible especially when it comes to home based care. The people that we serve are poor and far away from the offices in Parys.

Thanks to the Thabang Society that started with a community centre within the old Mmabatho Primary School Building we are now able to have an office in Tumahole. The offices in Tumahole have 2 permanent staff members, 9 Volunteer Lay Counsellors and 29 Volunteer Home Based Carers.

The following services are being delivered from this satellite office:
- Home Based Care
- Community Development
- Mental Health
- Education and Advocacy
- Volunteer Management
- Food Security
- Victim Empowerment
- Entrepreneur Development

With this new and exciting expansion we are now able to reach more people in a cost effective manner from our office, which is accessible to the people from the Tumahole community.

For more information about the office please contact Sr. Nellian van Niekerk at our Branch Offices in Parys (056) 811 5959.

The first five entries that are received will receive a 2011 Epilepsy South Africa Calendar.
(No relatives of any board members, personnel or residents of residential care facilities may enter)

To order a calendar at R50 please send a request email to marketing.no@epilepsy.org.za

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<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Venue/Project</th>
<th>Branch contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 June – 6 June</td>
<td>Epilepsy Week</td>
<td>Communities of Dullstroom &amp; Elandsdoorn</td>
<td>Limpopo and Mpumalanga</td>
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<tr>
<td>9 June</td>
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<td>Dullstroom / All Staff</td>
<td>Limpopo and Mpumalanga</td>
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<td>World Cup Soccer</td>
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<tr>
<td>16 June</td>
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<td>21 June</td>
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<tr>
<td>21-27 June</td>
<td>Epilepsy Week</td>
<td>South Cape Karoo Region</td>
<td>South Cape Karoo Province</td>
</tr>
<tr>
<td>21-27 June</td>
<td>National Epilepsy Week</td>
<td>Distribution of information, special talks,</td>
<td>Western Cape Branch</td>
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<tr>
<td></td>
<td></td>
<td>corporate HR challenge</td>
<td></td>
</tr>
<tr>
<td>21-27 June</td>
<td>Epilepsy Week</td>
<td>National and Provincial</td>
<td>National Office 021 595 4900 or 0860374537 for a branch</td>
</tr>
<tr>
<td>21 June</td>
<td>Epilepsy Day/ Candle Lighting</td>
<td>Elandsdoorn &amp; Dullstroom Centre</td>
<td>Limpopo and Mpumalanga</td>
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<tr>
<td>21 June</td>
<td>Door to door</td>
<td>Chiawelo</td>
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<tr>
<td>23 June</td>
<td>Info Campaign at Taxi Rank</td>
<td>Chiawelo and Dlamini</td>
<td>Gauteng Province</td>
</tr>
<tr>
<td>23 June</td>
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<tr>
<td>25 June</td>
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<tr>
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<tr>
<td>6 July</td>
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<tr>
<td>7 July</td>
<td>Talk on epilepsy</td>
<td>Afa Park Clinic</td>
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<tr>
<td>9-10 July</td>
<td>Pancake Stall at Knysna Oyster Festival</td>
<td>Loorie Park Sportsfield Knysna</td>
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<td>Radio Talk Show</td>
<td>Tembisa Community Radio</td>
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<tr>
<td>August/Sept</td>
<td>Teaspoon dinner</td>
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<tr>
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<td>National Office</td>
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<td>4 August</td>
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<tr>
<td>7 August</td>
<td>Epilepsy Poker Challenge</td>
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<td>10 August</td>
<td>Gauteng AGM</td>
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<tr>
<td>5/10 August</td>
<td>Women’s Day (9 August)</td>
<td>Pamper day for women with disabilities</td>
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<tr>
<td>14 August</td>
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<td>Dullstroom</td>
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<tr>
<td>16-20 August</td>
<td>Women’s Entrepreneur Development Capacity</td>
<td>National Office, Parow</td>
<td>National Office</td>
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<tr>
<td></td>
<td>Building Seminar</td>
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<tr>
<td>18 August</td>
<td>Dinner Dance</td>
<td>Dullstroom</td>
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<tr>
<td>18 August</td>
<td>Talk on Epilepsy</td>
<td>Kalafong Hospital</td>
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<td>28 August</td>
<td>Staff Braai</td>
<td>All Staff</td>
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<td>Epilepsy SA South Cape/Karoo AGM</td>
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<td>3 September</td>
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<td>Casual Day</td>
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<tr>
<td>3 September</td>
<td>Casual Day Street Parade</td>
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<tr>
<td>6-17 September</td>
<td>Access to Health Care for Persons with epilepsy</td>
<td>South Cape Karoo Region</td>
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<tr>
<td>23 September</td>
<td>Braai Fest</td>
<td>The Grill</td>
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<tr>
<td>October</td>
<td>Epilepsy Seminar</td>
<td>Neurologists educate the public about epilepsy</td>
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<tr>
<td>8 October</td>
<td>Annual Golf Day</td>
<td>Parys Golf and Country Estates</td>
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<tr>
<td>9 October</td>
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<td>Highland gate Golf course</td>
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<td>10 October</td>
<td>Enduro Cycle Tour</td>
<td>Commence from London</td>
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<td>Chef Cookout</td>
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<td>26 November</td>
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<tr>
<td>1 December</td>
<td>World Aids Day</td>
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<tr>
<td>3 December</td>
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</tr>
<tr>
<td>3 December</td>
<td>International Day for Persons with Disability</td>
<td>Poster Campaign, WC Network, IPD Event</td>
<td>Western Cape Branch</td>
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<tr>
<td>3 December</td>
<td>Staff Function</td>
<td>All Staff</td>
<td>Free State North West</td>
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<tr>
<td>4/5 December</td>
<td>Residents closing function</td>
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<tr>
<td>8 December</td>
<td>Open Day Concert</td>
<td>Epilepsy SA Residential Centre</td>
<td>South Cape Karoo Province</td>
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**National Epilepsy Week 2010: 21 to 27 June 2010**

Epilepsy South Africa celebrates this day and week as at least 1% of the South African population has epilepsy. Join the activities by contacting 0860374537

**Please contact any of our EPILEPSY SOUTH AFRICA Branches on 0860 EPILEPSY (0860374537)**

National Office on 021 595 4900. visit [www.epilepsy.org.za](http://www.epilepsy.org.za) / email info@epilepsy.org.za

**Epilepsy Week 2010: Sharing Epilepsy**

National Epilepsy Week is the annual awareness raising campaign of Epilepsy South Africa. The aim of this week is to draw the South African public’s attention to the condition of epilepsy. The 21st of June is National Epilepsy Day.

**Epilepsy Week Campaign 2010: Poster Campaign**

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