



September 2008

Dear Valued Subscriber

This time of year is a very busy period for Epilepsy South Africa. We have celebrated National Epilepsy Week in June and are happy to say that we are still receiving phone calls, e-mails, referrals and other enquiries due to the increased marketing and exposure during the month of June. This week assisted to increase awareness about epilepsy and Epilepsy South Africa and we are therefore glad to say that this in return helped to decrease discrimination toward people with epilepsy.

We are now focussing on Casual Day which is taking place on 5 September 2008, you might even receive this letter on Casual Day! So if you have not bought a sticker yet - do so before the sun sets. We know that it will be a brilliant day and would like to inspire all South Africans to "Wake Up" for the rights and needs of people with disabilities. Thereafter we only have two months left before the holiday and Christmas season starts. This leaves us with very little time to achieve all our goals before 2009. That is if summer actually arrives in Cape Town?

As National Office our focus for the next four months will include the following:

- Celebrating Casual Day on 5 September 2008
- Hosting the National Directors meeting from 10 – 12 September 2008
- Hosting the Mick Leary Trust AGM on 12 September 2008
- Hosting the Epilepsy South Africa AGM on 13 September 2008
- Hosting the Epilepsy South Africa National Board meeting on 13 September 2008
- Appointment of the new National Social Development Manager
- Finalization of constitutional changes for adoption in April 2009
- Finalization of our long term marketing and fund development strategy
- Continuation of our skills development and economic empowerment programmes

In 2009 we will give additional attention to our advocacy programme. This leads me to challenge persons with epilepsy in South Africa, who are willing to speak out on the rights of people with epilepsy. Become involved with Epilepsy South Africa and to contact us. Together we can make a difference!

Our promise remains: "Turning obstacles into true potential!"

Warm Regards : Noeline de Goede (National Director, Epilepsy South Africa)

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Dr Potgieter visits the South Cape/Karoo Branch!

Dr Anton Potgieter, a retired medical doctor who specialized in the treatment of epilepsy while on the staff of the Tygerberg Hospital will again visit the South Cape/Karoo region during October 2008. This is a service facilitated by the Epilepsy SA branch in Knysna. The project aims to promote access to specialized medical care, especially for people in marginalized communities.

Dr Potgieter will consult with patients at various clinics and people interested in an appointment with him should contact their local clinics. The service will be available in the following towns:

- Monday 6th October 2008 , Heidelberg Brandwag
- Tuesday 7th October 2008 , Mossel Bay – Eyethu Clinic - Alma Clinic
- Wednesday 8th October 2008 Friemersheim, Touwsrante (Hoekwil)
- Thursday 9th October 2008, Plettenberg Bay Day Hospital, Kranshoek
- Friday 10th October 2008, Epilepsy SA Centre residents Outpatients
- Monday 13th October 2008, Sedgfield George – Conville Day Hospital
- Tuesday 14th October 2008, Oudtshoorn Day Hospital
- Wednesday 15th October 2008, Oudtshoorn – Day Hospital, - Bongolethu
- Thursday 16th October 2008, Beaufort West Day Hospital
- Friday 17th October 2008, Murraysburg

Please phone us for more information : 044 3822155

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News from the Western Cape Branch...



Epilepsy South Africa, Western Cape Branch invites you to our AGM as well as to join us at the launch of our Youth Development Programme. Our guest speaker is Kai Fitch, a young man with epilepsy. Kai will be climbing Mount Kilimanjaro in early January and would like to take the opportunity to raise awareness about epilepsy and to change perceptions by using the mountain as a metaphor to overcome obstacles.

Date: 17 September 2008

Venue: Epilepsy South Africa, Lansdowne Road, Wetton

Time: 14h00 – 16h00

Theme: Turning obstacles into true Potential

For further information, contact Berenice Berry @ 021 703 9420

Kai's Story :

The reason why I am climbing Mt Kilimanjaro is because I am passionate about mountaineering and because, before I started out on this journey I had very low self esteem due to epilepsy. I want to raise awareness about epilepsy and how it can be defeated mentally – by putting one foot in front of the other. Epilepsy is a bit like a huge mountain, when you are standing at the foot of it, you cannot imagine how you can begin to climb it. But once you start to discover other people's experiences and successes about climbing huge mountains, then their challenges and adventures become your dreams.

My dream is to successfully summit 'The Seven Summits' and Kilimanjaro is the highest point in Africa and is the highest free standing mountain in the world. It is an extinct volcano but there are no records of when the volcano erupted. One of the most incredible features of Kilimanjaro is that it is a snow covered peak in East Africa., very near the Equator. When hiking to the summit, your journey takes you through four different eco systems. It is rather like hiking from the Amazon Jungle to the North Pole in seven days.

The walk up to the summit is not technically difficult, but the altitude makes the climb extremely dangerous and many people succumb to altitude sickness and serial edema, which can kill you. The success of climbing this mountain is to go POLE –POLE, meaning SLOWLY-SLOWLY in Swahili. Respect that nature is stronger than we are and value the moment. Many people in their lives have never even glimpsed at the physical greatness of a mountain such as Kilimanjaro, but due to disabilities, lack of self esteem and feelings of hopelessness, they face mountains as huge as Kilimanjaro, every day. If I can share my experience, regardless of whether I make it to the summit or not and encourage other youth who face insecurities and challenges, and I can inspire them to dream, like me, then I feel

we can face challenges that Life throw at us together.

Not only do I want to use 'Kai's Kili Climb' to raise awareness about Epilepsy in particular, but I hope to encourage as many kids as possible to find their passion and overcome whatever physical challenge they face. I have several key people who have inspired me – Natalie Du Toit, who will be SA flag bearer at the 2008 Olympics, Jonty Rhodes our brilliant Springbok cricketer and Erik Weißenmayer, the first blind person to have successfully accomplished 'THE SEVEN SUMMITS.' These are just a few of my heroes who like me, started off with A DREAM.

Please support me and pledge your donations to EPILEPSY SA. I fly to Tanzania on the 3rd January 2009 and begin my climb on the 5th of January 2009.

Notices:

- We will be hosting our third annual Epilepsy Seminar on the 25 October 2008 to be held at Red Cross War Memorial Children's Hospital. Guest speakers, amongst others include Dr. James Butler, Prof. Roland Eastman and Prof. Jo Wilmshurst. Further notices will be communicated closer to the time.
- Our Golf Day will be taking place on the 31 October 2008. For further information on how you can support, please contact Melody @ 021 7039420

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Children and disability



Empower your child:

Casual Day is a day to think of people with disability as well as to take part in contributing toward organisations involved in disability - in a fun way (to Wake Up!-Theme of Casual Day). The National Office therefore approached pre schools around Western Cape to present puppet shows on this national day in South Africa. These shows would explain disability in a child's language and prepare the little ones psychologically for accepting those with disability. People look different to start with, but that does not mean you are more able

if you look a certain way. We aim to teach young ones that people with a disability are also able to do a lot of things although they seem different. We also teach them that you aren't your condition if one has flue - other's do not call you "Flue!" like they often call people with epilepsy an Epileptic?

Somehow we can all learn from children and take back the childhood simplicity that did not see difference. We hope that these children will in turn educate others, even adults by what they learnt on Casual Day.

Pictures of the puppet show will be submitted in the next month's letter.

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SIYB TRAINING OF TRAINERS (TOT) SEMINAR 2008



Epilepsy South Africa hosted an SIYB TOT seminar for a group of 7 participants in Cape Town from 17 to 29 August 2008.

The seminar was attended by:

1. Joyce Mbanjwa, Social Auxiliary Worker in the KZN Midlands Branch of Epilepsy SA;
2. Selina Radebe, Social Auxiliary Worker in the Gauteng Branch of Epilepsy SA;
3. Hans Tjege, Social Auxiliary Worker in the Gauteng Branch of Epilepsy SA;
4. Thandile Gladile, Eastern Cape Development Worker with the SA National Council for the Blind;
5. Michael Mashinini, Mpumalanga Development Worker with the SA National Council for the Blind;
6. Elvis Mhlahlo, a community volunteer with the Free State & North West Branch of Epilepsy SA; and
7. Bongani Ntshingile, a community volunteer with the Free State & North West Branch of Epilepsy SA.

Despite long hours (often exceeding 10 hours per day) participants successfully completed the course and presented programme designs for implementation on the final day. Each participant will discuss these plans with their respective management for approval prior to implementation during the period September 2008 to August 2009. Each participant will be assessed on their progress with a view to accreditation as an SIYB Trainer with the International Labour Organisation in Geneva. Participants expressed their appreciation through a formal evaluation of the seminar on the final day, resulting in a score of 96,7%.

Picture : Back row from left to right: Elvis Mhlahlo, Bongani Ntshingile, Joyce Mbanjwa and Hans Tjege
Front row from left to right: Marina Clarke, Thandile Gladile, Michael Mashinini and Selina Radebe

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Algoa FM - Pick 'n Pay Woman of Inspiration for 2008



We are very proud of our latest achiever in the social field of epilepsy, Lynn Jansen van Rensburg who some of you know as the editor and founder – frankly everything of Y.A.N.A (You are not alone). Lynn had epilepsy and can witness of a dramatic change in her life after an operation by Dr. James Butler. She continues however to work very hard to encourage people with epilepsy and their families. The obstacle was turned into something beautiful and great. It is a pity that she came second, but in our books Lynn deserves an award. Please take some time to visit her site and see what she does.

We leave you with her motto of 'The more we know the more we can pass to others...'

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Remember to buy your Casual Day Sticker!



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Visit our website or to contact any of our Branches or National Office.
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