



Dear Subscriber

7 July 2008

You have recently signed up to receive our electronic newsletter and we hereby want to thank you for being able to talk "epilepsy" to you!

- 🔥 We hope that this is a welcome start to a great relationship, and that you will find the news letter encouraging as well as meeting your specific needs.
- 🔥 We will try our utmost to keep you updated and excited about Epilepsy South Africa, but at the same time value your time by presenting it in a short and sweet fashion.

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Please contact us for any questions regarding the information presented. You are also welcome to visit our website for additional information on our Branches and on epilepsy.

Your Electronic Newsletter editor

Driekie Snyman

National Marketing and Fund Development Officer, Epilepsy South Africa National Office

From the director's pen:(by our National Director : Noëline de Goede)

If you look at any country or organisation, the phases of growth and sometimes stagnation can easily be identified. In preparing the history of the organisation I realized that we achieved so many times, and that we can be proud of our active response to the pressures presented to charitable organisations at this day and age.

Please take the time to work through the history that follows my introduction, and note the hard work and the constant need for our services that forms the golden thread in the life cycle of Epilepsy South Africa.

We are very proud to announce that since 1967 Epilepsy South Africa has developed into a well recognized Non-Profit Organisation, priding ourselves on service excellence and our good internal governance. We have grown to render services throughout South Africa and even assist our neighboring countries.

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Our services are still in demand:

Despite the endeavors of the organisation, people with epilepsy are still discriminated against and still have to face a lot of obstacles in their daily lives. This general negative attitude towards epilepsy as a condition is also evident in the difficulty of the organisation to attract funding. People and companies seem to rather want to support a cause that they feel comfortable with and which tugs at the strings of their hearts.

People are often traumatized by epilepsy, especially when witnessing a seizure and they feel out of control, not knowing what to do or how to assist, thus shying away from being confronted by epilepsy and having to know more about it. What they do not realize is the epilepsy can affect anyone and that one in every hundred people in South Africa has epilepsy. It can also happen to children, adults, the elderly, the rich, the

poor and all animals. Anyone can develop epilepsy at any stage in their lives. This makes epilepsy a scary topic for most, but a relevant topic for all to be educated in.

In facing the difficulty that comes with the diagnoses of epilepsy and the life changing aspect it can be, Epilepsy South Africa decided to adopt a new tagline for our marketing and awareness campaign which was started in 2006, namely "Turning obstacles into true potential!" We are still seeing the truth of this tagline daily as we share in success stories and will use it for some time to come. We believe that every person with epilepsy can achieve their full and optimal potential and we believe that Epilepsy South Africa, through our services, assist people with epilepsy to achieve their true potential.

Thus watch out South Africa, you are going to hear and see more from people with epilepsy and from Epilepsy South Africa on an ongoing basis and we challenge you to learn more about epilepsy and to help us to eradicate the myths and stigma associated with epilepsy.

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The history of Epilepsy South Africa:

From a mere division:

Up until the 1960's the SA National Council for Mental Health delivered services to persons with epilepsy. Dr AV Bird from Johannesburg presented a "Blue Print on Epilepsy" to the National Council for Mental Health. This "Blue Print" led to the foundation of a "Division of Epilepsy" during October 1963.

It was clear, to everyone involved, that the "Division for Epilepsy" needs to function as an autonomous national council. The National Council for Mental Health gave its permission in October 1964. The "Division for Epilepsy" then became a steering committee.

From a steering committee to "SANEL":

The committee arranged a National conference on epilepsy, held in Pretoria September 1967 and SANEL (South African National Epilepsy League) was founded on 29 September 1967 at a meeting of representatives from the National Conference. An Executive Committee was elected with several sub

committees, namely, Education, Work Creation and Rehabilitation, Marketing and Fundraising and the Legal Constitutional Sub Committee.

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 **The founding objectives of SANEL were:**

1. To render a national service to epileptics (*we do not advocate calling people with epilepsy epileptics any more - please contact us for a document on language on epilepsy*), which would include the following:
 - a) the identification of persons with epilepsy and quick and efficient treatment;
 - b) the formulation of policy and promotion of methods for the treatment, care, education, training, work creation and general well being of persons with epilepsy;
 - c) investigation of the causes, treatment and prevention of epilepsy;
 - d) encouragement of research on epilepsy and related issues and the distribution of knowledge about epilepsy and related problems;
 - e) the promotion and training of staff for all related disciplines with the view to providing adequate care and treatment of people with epilepsy.
2. To co-ordinate the activities of all affiliated organisations and other interested bodies, which would contribute to the well being of people with epilepsy.
3. To give guidance on all aspects of epilepsy and to serve as a medium for the dissemination of information.
4. To act as the official channel of communication with government departments, provincial and other administrations on behalf of people with epilepsy.
5. To co-operate with international organisation with similar objectives in respect of people with epilepsy

A definite phase of growth:

SANEL then started to grow into the organisation it is today, with the formation of branches and structures throughout South Africa. This did not however happen without some setbacks as some of the structures, centers and workshops which were established had to close down due to financial problems.

In 1982 the organisation was totally reorganized as it changed from a national organisation with decentralized branches to a centralized national organisation. In 1987 the organisation was again restructured in that the Head office became the National Office and moved from Springs to Edenvale. The branches were decentralized geographically and received autonomy with regard to services and finances.

The following regional branches were formed: Gauteng, Western Cape, Knysna, Mpumalanga, Free State and Northern Province, Durban and Coastal areas, and Pietermaritzburg and Inlands areas

Another jump to a new phase:

In 1988 a new constitution and national structure was formed and a new National Office, with Ms K Pahl as National Director, opened during August in Cape Town.

Labeling the phase with a new logo:

The organisation entered a renewal phase in 2002 with the change of its name and logo on 20 April 2002, from SANEL to Epilepsy South Africa.



In 2004 the National Director, Ms Kathy Pahl wanted to further her studies overseas and Mrs. Noëline de Goede was appointed in this position.

In 2005 a national strategic planning workshop was conducted including all the Branches and the National Office. This strategic plan outlined the way forward and focal areas of service delivery for everyone involved. This document was based on direct needs of clients and consumers via input and feedback from the Branches.

A new focus:

From 2005 onwards the services of Epilepsy South Africa included and focused on the following:

1. Social development
 - Advice, information, counseling, individual work, group work, community development, referrals
2. Economic development
 - Protective workshops, SMME development, Entrepreneurial development, Income generation groups, open labour market employment, workshop transformation
3. Residential care
 - Physical and medical care; stimulation groups
4. Skills development
 - Skills development of personnel, volunteers and consumers
5. Governance and accountability
 - Constitution and regulations, policies and procedures, systems, structures and reporting
6. Advocacy
 - Rights of people with epilepsy and / or other disabilities; empowerment of people with epilepsy for self-advocacy
7. Awareness, training and information
 - Talks, presentations, exhibitions to educate people about epilepsy and to decrease discrimination towards people with epilepsy
8. Marketing
 - Marketing of Epilepsy South Africa and our services
9. Fund development
 - Events, proposals, etc to raise funds for the continued services delivery and sustainability of the organisation.
10. Research
 - Research based on the needs of consumers - formal and informal research

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

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Short reports on National Epilepsy Week:

From the National Office: A turn of a page in the turn of a week!

Epilepsy Week 2008 started at exactly 12:00 on the 16th of June for the National Office of the organisation. The anticipation of launching the newly designed website was answered when the site went live at the very start of the week. Invitations were sent to businesses and individuals to visit the website or to "Click and think of a person with epilepsy!"

The site presented a new look and feel of support and sense of family. A new quiz to test your knowledge of epilepsy can be played with immediate results displayed and ample information to verify what you have not previously known about epilepsy.

The challenge made during epilepsy week was to attract as many visitors to the website as there are people in South Arica with epilepsy. They have reached the 600 mark in 9 days and the 1000 mark in 21 days, now waiting anxiously to celebrate one for one!

The national director could be heard on four country wide radio stations and proudly presented a message of "discrimination toward people with epilepsy to be something of the past' and challenged listeners not to be ignorant any more.

Whilst others enjoyed along weekend we used the opportunity to bring epilepsy to the attention of shoppers at Canal Walk. They playfully informed people of what epilepsy is, and challengers could walk away with certificates and something sweet.

National Epilepsy day, the winter solstice, shortest daylight of the year also concluded the week on 21 June. The national office of Epilepsy South Africa had a cozy candle lighting ceremony where they launched the much anticipated: "Puzzle

of Potential". This is a wonderful opportunity for supporters to own shares of programmes or activities of the organisation. This means that the social community will start owning the good work being done for people with epilepsy, and become an intricate part of the hand that affects the people. They will share the responsibility in the easiest way possible and benefiting by knowing that your share is valued in much more than money.

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From the Gauteng Branch: Epilepsy Week 2008 calendar of events:

East Rand Stereo radio station advertised Epilepsy Week a few times a day, every day of the week from Monday 16th to Saturday 21st.

Radio interviews were conducted with the following Gauteng radio stations: (unfortunately the average numbers of listeners is not known)

Josi FM on Monday 16th

Vut FM on Tuesday 17th

Alex FM on Tuesday 17th

Ekasie FM on Wednesday 18th

Thetha FM on Wednesday 18th

TUT FM on Thursday 19th

Sosh FM on Thursday 19th

Wednesday saw our annual Epilepsy Week candle lighting ceremony/residents and supporters' awards ceremony/corporate challenge and luncheon held at the Geduld residential care centre. This event was attended by 152 invited guests, management and staff of Gauteng branch as well as 203 residents from both Daggafontein and Geduld centres and day workers from East Rand and Johannesburg workshops. The opening address was done by Mr Kgomotso Modise, chairperson of the Gauteng board and the welcoming speech was done by director, Magdaleen Kruger. Gifts and/or certificates were presented to donors, sponsors, supporters, volunteers, residents and day workers. A great time was had by all!

On Thursday 19th, assistant director, Kandas Kandawire and social workers held a very successful epilepsy awareness event at the Pimville clinic, Soweto for 250 people with epilepsy as well as their families. Refreshments and lunch were served thanks to sponsorship obtained.

On Friday 20th, René Jarman and Kandas Kandawire did a presentation on epilepsy at the SA Police Services Disability Management branch in Pretoria. This event was attended by 50 SAPS employees.

Information on epilepsy and the services offered by Epilepsy South Africa were displayed at the following libraries during Epilepsy Week: Kempton Park, Springs, Kwa-Thema, Bakerton, Thembisa, Ivory Park, Westonaria and Randfontein

11 000 Epilepsy Week flyers, with the theme 'Turning Obstacles into True Potential' were printed and distributed by management and staff of Gauteng branch to local school children and adult members of the public during the week.

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From KZN MIDLANDS: Awareness for Epilepsy and Epilepsy South Africa!

Our epilepsy week campaign focused on creating awareness both for the organisation and the neurological condition of epilepsy. Our activities were divided amongst 3 very dedicated staff members who each took responsibility for a portfolio:

1. Awareness/Educational Talks and Candle Lighting:

This activities were co-ordinated by our Auxiliary Worker Miss J Mbanjwa. She focused on the rural areas, at each of the areas she provided educational talks as means of creating awareness of epilepsy and of the organisation and she also conducted Candle Lighting linking the outcomes of the educational talks with the purpose of Candle Lighting. The following communities were addressed:

- Mpumelelo - 31 Community members
- Emaqelein - 15 Community Members
- Unit 1 Imbali - 12 Community Members
- Vumain - 62 Community Members
- Masiphile - 120 Community Members
- Nansidlela - +/- 300 School Children + 12 Teachers

2. Information Table and Display at the Liberty Midlands Mall

Our capable secretary Miss P Fenner, tackled this task and arranged to have a display at the local Mall and also she was in attendance of an Information table at the Mall. She distributed pamphlets, newsletters and information regarding epilepsy and about the organisation. We found that this activity to be very successful with many shoppers requesting information.

3. Media Campaign

The branch director handled this task. Local community newspapers, which are distributed throughout Pietermaritzburg, printed information articles both on epilepsy and the organisation. Articles appeared in the Mirror and the Mall Talk. The Natal Witness, which is distributed extensively throughout Kwa Zulu Natal, published a feature article on Epilepsy SA KZN and an article on Epilepsy, which was written by a local GP Dr C Lee. This feature article was sponsored by the following supporters of Epilepsy SA KZN: Dr S Pillay, CCA Contractors C.C. Duzimed Medicine Depot, DR Z Sacoor, Roshan Morar & Associates and PO Renovators. The response received from these articles has been very positive, with both queries from the community and donations made to the organisation. Many well wishes have contacted the organisation to congratulate the organisation on a job well done.

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From the South Cape Karoo Branch: KNYSNA ROCKS!

AWARENESS WEEK WITH THE JO ELLIS BAND!

We have previously published an article in our bi-annual publication, Epinews, starring the drummer of the Jo Ellis band - Zaan Ellis, who has epilepsy. She started having seizures while she was doing a chef's course. This was due to injuries incurred in a motorcar accident. How she found it difficult to come to terms with this condition until she started as the drummer in her brother's band? In the article she offered assistance to other youngsters who are similarly afflicted.

Well, the phone rang one day at our office in Knysna and the following conversation ensued: "Hi, this is Zaan! Our band members just had a meeting and would like to give something back to Epilepsy South Africa. We would like to assist with your awareness program involving high school learners. Find a week where the principals can accommodate us and we shall schedule our performances accordingly.

This was the beginning of a truly WOW-experience. We decided to target one school per day during 19-23 May 2008. Permission was granted by the various principals with times ranging from 8.00 to 13.55 and normally the slots lasted between 30-45 minutes. For the 8.00 o' clock slot we had to be at the school at 6.15 to set up and do the sound testing.

The band consists of:

- Jo Ellis, electric guitarist, song writer, lead singer and leader of the band
- Zaan Ellis, his sister, the drummer
- Panna Bekker, the bass guitarist who also has an excellent background in classical music.

Simone Ellis, Jo's wife, is their sound engineer and general handy"man". Petite, but dynamic, which once again proves that dynamite comes in small packages. She also acts as stage manager - sees to Zaan's needs and basically keeps the show rolling.

What impressed me most was their punctuality, professionalism and high quality performances which included excellent rapport with the audiences. By the time they conveyed the information on epilepsy, the audience was totally in awe of their performance and really listened to what they had to say.

Even the sound testing created such energy that one could sense the excitement long before the show started. For me to be part of this was sheer magic - this was so the right approach to reach this age group!

What an impressive sight it was to watch a sea of 1300 excited faces swaying, jumping and waving to the beat of the pulsing music! After a few catching songs, Jo explained that they perform on behalf of Epilepsy SA as Zaan had seizures and that does not stand in her way to fulfill her dreams. By this time everyone cheered Zaan on and was duly impressed that she was so great.

Following this announcement, Jo supplied some basic facts on epilepsy and the base guitarist, Panna, would motivate the learners to complete and submit the quiz which we supplied to win a R100 prize.

Information sheets on epilepsy were supplied and a quiz was included to motivate the learners to study the facts and supply the correct answers. If more than 200 quizzes per school are going to be submitted, we shall have a prize of R100 per school.

During these 5 days 4300 learners were reached. The principals were most supportive and commented that the learners will never forget the information supplied in this manner.

At one of the schools the band members spent more time to hand out autographs, and free CD's were tossed into the audience at all schools. Incidentally, they don't sell their CD's and invite everyone to download their music from their website: joellis.co.za. They would like to continue with similar performances throughout the country, so click on joellis@telkomsa.net to meet this amazing group.

Knysna rocks - what about you?

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From the Mpumalanga Branch:

Epilepsy Week in Mpumalanga - Limpopo started off on Friday 12 June 2008 with a bang and tourists passing through or visiting Dullstroom or Moutse. The obliging motorists became aware of us when they were met with a "**Road Block for Epilepsy**"

Police and Traffic officials in the two areas conducted routine road blocks and involved our Branch in the process. We were given the opportunity to hand out information, epilepsy games and a quick chat with people, making them aware of Epilepsy and our services

On Youth Day, Monday 16 June the communities in both areas joined Epilepsy SA Mpumalanga-Limpopo in a joint Prayer meeting, followed by a **Street Parade for Epilepsy** in which residents, day workers and the youth of local schools participated.

SAPS, youth, people with epilepsy, people with disabilities, school children and community members joined hands on this day, and prayed to combat discrimination, exclusion and misunderstanding of the condition of Epilepsy.

Tuesday and Wednesday was **"thank you"** day in the two regions when the Branch used the opportunity to show our appreciation towards two "great" communities for their support and kindness. During a morning tea it was our chance to treat them!

The director's challenge on Thursday illustrated the team work in which management, staff and consumers conduct the task of delivering the services to our target group. The team tackled the task together of upgrading the bathrooms in the residential care centre in Dullstroom

Achievers Awards were handed out to residents and day workers who showed outstanding improvement and development of life skills during the year on Friday. This was followed by a **"candle lighting ceremony"**

Epilepsy Week ended on Sunday 22 June with several devotional services in different denominations in the communities situated in the Branch to praise our Heavenly Father for His grace and love

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**PLEASE CONTACT 0860 EPILEPSY (0860 374537)
TO GET IN CONTACT WITH YOUR CLOSEST BRANCH OF EPILEPSY SOUTH
AFRICA**

This is the electronic newsletter of the Epilepsy South Africa, compiled by the National Office.

If you are an assistive software user, please read this newsletter as if it is a web page and use the hyperlinks to navigate the page. If you are a Jaws user you can also use the following shortcut keys: Insert + F7 will take you to a links list and Insert + F1 will take you to a help page