

Drikie Snyman

From: Epilepsy South Africa [info@epilepsy.org.za]
Sent: 10 July 2009 16:13
To: funddev.no@epilepsy.org.za
Subject: National Electronic Newsletter July 2009 - Preview



July 2009

Dear Subscriber

We have celebrated National Epilepsy Week during the week of 15-21 June 2009 and discussed a number of issues relevant to people with epilepsy during this week, as well as hosted some memorable events on Branch level. More information is available on our website (www.epilepsy.org.za) or can be requested by calling the nearest Branch (0860 EPILEPSY). We are passionate to assist people with epilepsy by helping to change obstacles into true potential.

View our seven articles by visiting our downloads and publications page at www.epilepsy.org.za

Some things to look forward to now:

- Bi Annual National Directors meeting to be held end July
- Casual Day 2009, to be held 5 September
- International Disability Day to be held 3 December

Please take the time to read what some of our Branches achieved during National Epilepsy Week!

Noeline de Goede

July E-news Contents:

- [People with epilepsy have rights!](#)
- [Epilepsy week, Free State and North West Branch](#)
- [Epilepsy Week, Gauteng Branch:](#)
- [Epilepsy Week, Western Cape Branch:](#)
- [A letter from a concerned individual](#)
- [A third great Wine Auction for the National Office and old friends:](#)

People with epilepsy have rights!

The National Office released a series of articles and videos for public review during National Epilepsy Week 2009. It was reported that the last article did not reach all the subscribers and decided to present it as an introduction to the reports for June 2009.

Here is the link to today's video
<http://www.youtube.com/watch?v=DcZ4fmd9Ye4>



People with epilepsy have rights!

The rights of people with epilepsy differ from those of people with other disabilities (e.g. special parking close to an entrance or wheelchair accessibility for mobility-impaired people). However, understanding such rights will help you to understand how to include people with epilepsy in day-to-day life. A small change can often make the world of difference to a person with epilepsy. These changes differ from issues such as architectural changes to buildings but ask people to change their attitude toward people with epilepsy.

A person with epilepsy needs to understand the condition, its causes, the triggers for seizures and coping mechanisms to be able to lead a good quality of life. They must consider many factors in terms of safety, time management and interaction with people as these can present barriers demanding specific attention.

People with epilepsy often experience discrimination in the following areas:

- Travelling,
- Employment,
- Protection in the workplace,
- Respect,
- Information of their diagnoses,
- Support,
- Treatment options.

Most people with epilepsy are diagnosed before age 20, but the onset can be at any age. Many children with epilepsy outgrow the condition and are able to live drug-free and seizure-free lives as adults. It is interesting to note that many people with epilepsy report the negative impact on their lives due to ignorance, stigmatisation, discrimination and lack of knowledge evident in society as more problematic than the actual seizures. Because people do not understand epilepsy as a condition and often fear it, they discriminate against people with epilepsy by excluding them from social events and the world of work.

It is important to know that people with epilepsy (both adults and children) can live active and normal lives as long as society is willing to accept them and learn more about epilepsy.

Ensure that you, your whole family and your friends receive adequate information about epilepsy, as well as counselling which can prevent any long term psychosocial impact.

The most important thing to remember is that every person's seizures are different and that every person experiences living with epilepsy differently from another person. Thus it is not possible to generalize when talking about epilepsy.

These simple guidelines should assist parents, teachers, family members and friend to support the person with epilepsy:

- Emphasise what the person can do, not what he or she cannot do while at the same time taking sensible precautions
 - Treat the person like all other people.
- Help the person to integrate into as many social activities as possible as this will help him/her to develop the required social skills like all other people.

- Do not overprotect the person with epilepsy.
- Do not make the person/child or his/her condition the centre of attention or every discussion.
 - Do not blame the child/person or his/her epilepsy if the family experiences difficulties.
- Should someone in your family or a friend experience a seizure consult a medical practitioner (preferably a neurologist) in order to obtain an accurate and specific diagnosis. Should the person be diagnosed with epilepsy you, all the friends and family members of that person and the person him/herself need to learn more about the condition. This will help you to accept the diagnosis and carry on with life.

You can call Epilepsy South Africa for information and support services. Epilepsy South Africa is a Non-Profit Human Services Organisation that renders services to persons with epilepsy and/or other disabilities as well as persons affected by the condition.

To contact your closest epilepsy South Africa branch please call:
0860 EPILEPSY/ 0860 374537

Your call will automatically be routed to the closest Epilepsy South Africa Branch.

You can also send an e-mail to: info@epilepsy.org.za

Or visit the web-site: www.epilepsy.org.za

Or contact the National Office at: Tel: 021 – 447 3014, Fax: 021 – 448 5053

What to do during a seizure

DO...

- Remain calm and note the time and duration of the seizure.
- Clear a space around the person and prevent others from crowding around.
 - Loosen tight clothing/neckwear and remove spectacles.
 - Cushion the person's head to prevent injury.
- Put the person into the shock recovery position (i.e. roll the person onto his/her side with the top leg bent and the bottom arm slightly extended).
 - Wipe away any excess saliva to facilitate breathing.
- Reassure and assist the person until he/she has recovered or become re-orientated.
 - Allow the person to rest/sleep if necessary, covering him/her with a blanket.
- Note the duration of the seizure and the time it took place. Provide this information to the person who had the seizure after he/she has recovered fully. This will allow him/her to record the information in his/her seizure diary.

DO NOT...

- Restrict or restrain the person's movements.
- Move the person unless the person might hurt him/herself or is in immediate danger (i.e. in a busy road).
 - Put anything between the person's teeth or in the person's mouth.
 - Give anything to eat or drink during the seizure.
 - Give extra anti-convulsants unless instructed to do so by a neurologist.
- Call a doctor or an ambulance unless the person has injured him/herself badly, the seizure lasts longer than 6 minutes or the person has repeated seizures without recovering!

[\[back to top\]](#)

Epilepsy week, Free State and North West Branch



The Free State Branch received so much media coverage that we had to extend our programs into the next week. We had radio interviews on Radio IFM (Vaal Triangle), Radio Overvaal (Viljoenskroon), Radio Rosestad (Bloemfontein) and Radio MEDFM (Bloemfontein). In the Northern Free State Gazette we had articles the week before, during and the week after about Epilepsy and the activities of our Branch.

Night March through Parys:

On Friday 19 March 2009 we took 25 of our stronger residents and went on a night march through the streets of Parys. Each resident and staff member carried a poster with an interesting epilepsy fact and some flyers. Once in town, Spur treated our residents to a friendly complimentary milk shake. This group walked back to the centre with a lit candle, which signifies the knowledge shared (a symbol for epilepsy internationally).

We had an epilepsy festival for the first time in the organisation's existence. The Dome Motor club exhibited their Vintage Cars which obviously attracted the public. The members from the club also surprised us with a donation of R 500 and some useful toiletries for our residents. The entrance was free and the public were treated to a warm cup of soup. The guests enjoyed the guided tours through the Centre and had the chance to buy some of the crafts made by residents and some clients.

Apart from this we had a white elephant table, a candle table and the public had a chance to test their knowledge on epilepsy by playing the famous epilepsy board game.

[\[back to top\]](#)

Epilepsy Week, Gauteng Branch:

It was decided that in June 2009 an accelerated effort would be made to create awareness about epilepsy and the services offered in Gauteng, with special emphasis during National Epilepsy Week. The theme was "People with Epilepsy have the Right to be Included"



Media Coverage was done by SABC TV News International, Community Radio Stations - Jose FM, VUT Radio, Radio Pretoria, Thetha FM, Radio Soshanguve, TNT Radio, Radio Impact, Spruitview Ekasie FM, Lesedi FM, East Rand Stereo, Alex FM, Kaya FM, Radio Islam – as well as by The Citizen and The Daily Sun newspapers.

Presentations were done at the National Department of Social Development (136 staff members) Gateway School x 3 sessions (80 Educators and Caregivers) National Department of Education x 2 sessions (73 staff members) Gateway Village x 2 sessions (35 staff members) Gauteng Department of Health (1 387 community members) National Department of Public Administration, Leadership and Management Academy (16 staff members) Chiawelo Clinic, Soweto (98 community members), Farranani Multi-purpose Centre, Brakpan (600 community members), NG Church, Springs and United Reform Church, Springs.

Other events that took place were exhibitions held at the Springs, Tsakane, Kwa-thema and Kempton Park Libraries to create awareness.

Staff at Wesbank was given contact details for the Gauteng Branch through their Human Resources department.

The Geduld Centre had their Candle Lighting/Thank You ceremony on 17th June and it was attended by the Residents, Sponsors, Staff of the Gauteng Branch and Day Workers from the East Rand and Johannesburg Workshops. Residents were given certificates in

recognition of their achievements and sponsors were given thank you letters for their support. Daggafontein Centre had their Candle Lighting ceremony on 18th June and their residents' achievements were recognized at this function.

There was a good response to the above events in the form of queries and requests for more information from members of various communities, schools, government departments and businesses. There were also a number of questions during live radio interviews. This was very encouraging and the small, but dedicated team that worked on this project must be congratulated on their enthusiasm and passion.

[\[back to top\]](#)

Epilepsy Week, Western Cape Branch:

"EPILEPSY AND HUMAN RIGHTS"

Epilepsy South Africa Western Cape launched Epilepsy Week 2009 with much excitement and enthusiasm. The week began with an awareness campaign at Canal Walk shopping mall where the shoppers were made aware of epilepsy and National Epilepsy Week. This year we decided to add a new dimension to our awareness campaign and embarked on the "Epilepsy Road Show".



This road show included awareness campaigns at 6 schools in the Mitchells Plain area as well as conducting talks at Children's Homes. The road show was received with much enthusiasm and there was great participation by both young and old audiences! This enthusiasm was particularly generated through the presence of our guest speaker, Kai Fitchen. Kai added a fantastic element to the awareness talks as many children and adults were asking him about his epilepsy and how he has overcome obstacles in his life.

Throughout the week general public education and training sessions were conducted at different government departments and education centres. There were also exhibitions at various Libraries and Community Health centres. Radio talks were also done.

The highlight of Epilepsy Week was the Disability Awareness Day Event held at Khayelitsha Special School. This was a day with a difference as school children from the neighbouring main stream schools were invited to join the children of Khayelitsha Special School as they discussed "Disability and Human rights " which was the theme for the event. The programme was jam packed and it began with an awareness raising march around the school by the children and educators from Khayelitsha Special School and the mainstream schools. A guest speaker from Khayelitsha Disability Forum spoke about the rights of people with disabilities and artistic performances were done by the children of Khayelitsha Special School all of which was well received.

The focus of the day was Epilepsy and Human Rights and the Disability Rights Charter Articles on Education and Non discrimination were discussed. A talk was conducted on the importance of education and a thought provoking group activity centred on discrimination and how the community feels they can change negative attitudes directed towards people with disabilities in the community. The feedback from the group activities showed a commitment by the community to raise awareness and dispel myths and encourage non discrimination towards people with disabilities. There was much singing and joyfulness on the day and the event was thoroughly enjoyed by all.

Epilepsy week ended with the Epilepsy staff taking to five shopping malls across the Cape metropole to raise awareness to the general public. Many questions were asked and answered and information about epilepsy was widely distributed. All in all the Western Cape office had a full and exciting week and are looking forward to taking this positive

Epilepsy Week energy through until next years Epilepsy Week!

[\[back to top\]](#)

A letter from a concerned individual

This letter was received from a concerned mother of a child with epilepsy. She is a proud advocate for the cause and supports the rights endorsed by the organisation during this week. (We apologise to the English speaking readers for not being able to translate this in time)



From Belinda O'Connor: Ek is die Moeder van 'n dogter wat Epilepsie het en wil graag my insette lewer hoe ek die Nasionale Epilepsie Week beleef het. Ek is siek en sat daarvoor dat die samelewing en veral Mediese Praktisyne hierdie mense verwerp. As niemand hul se sal se oor hierdie onderwerp nie dan sal ek 'n absolute kampvegter word aangesien Epilepsie mense TE veel diskriminasie moet verduur. Die dokters se spreekkamers is vol 'ryk' pasiente wat kom botox en allerhande onbenullighede terwyl 'n epilepsie lyer dringende aandag nodig het en dan is die kommentaar "Praat gou want jy mors my tyd, ek het pasiente wat wag". As 'n Pasient dit kan maak tot in die spreekkamer kan hy seker 1 minuut wag sodat die noodoproep net afgehandel kan word om die epilepsie lyer wat in 'n hospitaalbed le te help wat aanvalle kry minder as 2min uitmekaar.

Die 2e dokter (neuroloog) gaan nie uit na sy pasiente toe nie. Die ontvangsdame is so ongeskik maar sy vergeet die R750.00 wat ek elke keer betaal om die dokter te sien, (ons het nie medies nie) betaal haar salaris elke end van die maand en is deel van die kos wat sy elke aand op die tafel sit vir haar , let wel vir haar Epilepsie vry kinders.

Het enige persoon 'n idée hoe dit is om met hierdie mense saam te leef en elke keer as jou kind 'n aanval kry breek jou moederhart in stukke terwyl ander mense of selfs die wat deel is van jou ondersteuningsnetwerk ander pad kyk en se "Praat gou, ek het pasiente wat wag, jul mors my tyd". "n Alkoholis kan genees word, 'n Drug addict kan rehab toe gaan, maar waar klop ons Epilepsie lyers aan wat vir die res van hulle ewe hiermee moet saamleef en/ook met die ongeskikte samelewing moet deel. Het iemand al ooit gedink hoe voel hierdie mense as hul aanvalle in die openbaar kry, dis nie fun en games vir hierdie mense nie. Ja, Mnr die dokter, jy KON 'n verskil gemaak het as jy nie te besig is met jou ander pasient nie(gesond genoeg om voor jou te regop te sit.

Die Samelewing moet besef hierdie mense het ook regte.

Is ook geregtig op 'n normale beroep, stokperdjies, babas te he, geleerdheid ens, 'n lewe.....

Ek het gister genoeg gehad toe my dogter wat pas 'n babadogterjie gehad het in die kraamhospitaal le en aanvalle elke 2 minute kry en almal hul skouers optrek toe ek in tranes die gange op en af paradeer op soek na hulp. Ek, die Moeder met geen mediese kennis, moes sekere besluite maak en vinnig ook aangesien die Neuroloog wat nie 1km van die hospitaal af is, "Nie uitkom na sy pasiente toe nie" (dit was 'n noodgeval). Maar sit in 'n aircon kantoor en collect net die inloop pasient se fooie. (lekker leefstyl). WAT HET GEWORD VAN DIE EED WAT HUL AFGELE HET? Of is dit 'n kwessie van Memories are short lived.....

Besef hul in watter verwerpingstoestand het hul my gelaat?

Wat is die doel van NASIONALE EPILEPSIE WEEK as mense nie saamstaan en die Epilepsie Vereniging ondersteun nie en veral diegene wat werklik die mag in hul hande het om 'n verskil te KAN maak al is dit net vir een persoon wat dit dringend nodig het.

Ek vra – As daar buite een dokter is wat omgee en spesialiseer in hierdie toestand (ja, ek noem dit 'n toestand want hierdie mense is nie siek nie en Epilepsie is ook nie aansteeklik nie. Ons kan dit almal kry enige plek en enige tyd) en daar is wanneer sy pasient hom dringend nodig het en sy hart in sy werk is en nie in sy bankrekening is nie, Kontak my asb?

Ek en my dogter en alle ander Epilepsie lyers het JOU broodnodig.

[\[back to top\]](#)

A third great Wine Auction for the National Office and old friends:

With showers predicted for the evening of Epilepsy South Africa's annual Wine Auction, the non profit was glad when 200 guests, amongst others Jonty Rhodes, arrived dry and eager to participate. With a French theme and setting Daniele Pascal enchanted the audience whilst Soli Philander brought smiles to every face. What created the most attention were the 79 lots donated to benefit the organisation and the 18 cellars and wine makers that availed themselves to present a display of tasting opportunities. With the winery that stepped in as the main sponsor, Blaauwklippen 2006 Cabriolet 1, 3 l sold for R700. Other interesting numbers were a 2006 Springfield estate (Wild yeast Chardonnay) that sold for R1800 and a 2007 Newton Johnson vineyards Chardonnay that went for R1200.



The entertaining factors were of course the bid that got Jonty to loose his shirt but another bid that involved the cricket legend with epilepsy, is the Lourensford wine estate (Shiraz/Viognier) 6 l that sold for a staggering R2500. It was autographed and personally dedicated to the buyer by Jonty.

Other donations that drew attention was the 2001 Haute Carbiere sold at R250, 2004 and 2008 Under Oaks (Cabernet Sauvignon) 6x7 that sold for R2700. A 3 bottle KWV 1980/1970 lot sold for 1575 whilst an interesting single man brand Blank Bottle went for R750 for a moment of Silence.

Within the current economic climate the organisation was successful in obtaining R75,340 from willing guests that enjoyed the mid week and cold evening out definitely more than the thought they would.

[\[back to top\]](#)

Visit our website or to contact any of our Branches or National Office.
Website: www.epilepsy.org.za

EPILEPSY SOUTH AFRICA – National Office, Cape Town

PO Box 73
OBSERVATORY
7935
Tel: (021) 447-3014
info@epilepsy.org.za

EPILEPSY SOUTH AFRICA
South Cape/Karoo
PO Box 107
KNYSNA
6570
Tel: (044) 382-2155
southcape@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Western Cape
PO Box 24573,
LANDSDOWNE,
7779
Tel: (021) 703-9420
wcape@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Mpumalanga / Limpopo
PO Box 55,
DULLSTROOM,
1110
Tel: (013) 254-0161/2/3
mpumalanga@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Gauteng Branch
Regional office
PO Box 1070
SPRINGS
1560
Tel: (011) 816-2040/57
gauteng@epilepsy.org.za

EPILEPSY SOUTH AFRICA Free
State & North West
Branch
PO Box 167
PARYS
9585
Tel: (056) 811-5959
freestate@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Kwa Zulu Natal Midlands
Branch
PO Box 2165
PIETERMARITZBURG
3200
Tel: (033) 394-1041/8
kzn@epilepsy.org.za

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

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

Visit our Website

Unsubscribe from our newsletter