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Sent: 03 June 2010 15:00

To: Drikie

Subject: Electronic Newsletter June 2010



June 2010

Dear Reader

June is always a very special month to Epilepsy South Africa, as we celebrate National Epilepsy Day on 21 June each year and National Epilepsy Week during the week of the 21st June. This year we are celebrating National Epilepsy Week from 21 – 27 June 2010.

You will find a lot of information about our National Epilepsy Week Campaign, events and information in this newsletter and we invite all of you to assist us in Sharing Epilepsy with all South Africans. It is pertinent that we increase correct knowledge about epilepsy to decrease the unnecessary discrimination that people with epilepsy still experience. Let's adopt a spirit of "can do" and ensure that people with epilepsy are recognised and respected.

You will also read more about our new satellite service in the Eastern Cape that is growing from strength to strength. We congratulate Mr. James Mkalipi for his excellent achievements in such a short time. We are very excited about our new Women Entrepreneurial Development Training Course that is being planned. Read more about this exciting development and contact Marina Clarke for bookings or more information.

It truly seems that June 2010 is a month for celebration. Epilepsy South Africa will celebrate National Epilepsy Day and Week, the country will celebrate the kick-off of the 2010 Fifa World Cup ("Go Bafana Bafana!") on 11 June 2010 and during 2010 we also commemorate South Africa's centenary as a country.

Despite the winter cold I hope that you will celebrate National Epilepsy Day and Week with us, focussing on the abilities of people with epilepsy, spreading correct information and changing mindsets towards the positive inclusion of people with epilepsy in all spheres of life.

Regards
Noëline de Goede

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National Epilepsy Week 21-27 June - The theme and purpose

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 epilepsy as a condition. The 21st of June is National Epilepsy Day. Epilepsy South Africa celebrates this day and week as at least 1% of the South African population has epilepsy.



The theme for National Epilepsy Week 2010 is "Sharing Epilepsy". The aim of this campaign is to educate the general public of the human rights of people with epilepsy. This will assist in dispelling the myths and social stigma associated with epilepsy.

- By sharing epilepsy, you need to know that it is not contagious. However, people with epilepsy still get ostracized, stigmatized and struggle to find employment. The biggest challenge for people with epilepsy is social stigma which is prevalent because of the misunderstanding of what the condition entails.
- By sharing epilepsy, it will become a condition that is easily recognised and treated by general health services.
- By sharing epilepsy, we fight the negative attitudes towards the condition and people with epilepsy
 - By sharing epilepsy, we shed a positive light on the benefit of good seizure management and improve the quality of life for people with epilepsy who often choose to withdraw socially to cope with discrimination and stigma.
 - By sharing epilepsy, we make the nation aware that they can develop epilepsy at any stage of their life.
 - By sharing epilepsy, we make each person aware that their positive attitude and willingness to learn about epilepsy will have a tremendous positive impact for many individuals with epilepsy in South Africa

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Refresher: What is epilepsy?

It is...

- A physical condition which is characterised by unusual electrical activity in the brain.
 - The tendency to have recurrent, unprovoked seizures which is caused by a temporary change in the way the brain cells work.
- A disorder; not a disease, illness or psychiatric disorder, nor mental illness - epilepsy is not contagious.



- A condition that affects people of all ages and levels of intelligence and from all social backgrounds.
- It is one of the most common and serious neurological conditions and it affects at least one in every 100 people in South Africa.

There are several types of epilepsy which are generally divided into two main categories; namely generalised seizures and partial seizures

- Generalised seizures occur when the excessive electrical activity in the brain encompasses the entire organ, during which there may be loss of consciousness. There are several seizure types in this generalized category.
- Partial seizures occur when the excessive electrical activity is limited to one area in the brain, which causes either simple partial seizures or complex partial seizures.

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SMS Campaign to "Share Epilepsy"

"Share Epilepsy" by supporting our SMS Campaign this week. To receive inspirational and educational text messages for free send your name and "SHARING EPILEPSY" to 4000 120 11 002. Normal SMS rates apply and there are no costs for receiving our messages. You are welcome to unsubscribe from this service at any time. You can also subscribe via email by sending your cell phone number to marketing.no@epilepsy.org.za.



Contact 0860 374537 (0860EPILEPSY) for more information about epilepsy or Epilepsy South Africa.

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Living and overcoming, with epilepsy!

Although epilepsy is one of the most common neurological conditions, it is also one of the most misunderstood. A delay in obtaining the correct information because of misunderstandings about the condition prevents a better quality of life for the person with epilepsy, their families and those around them.



Some of these misunderstandings include:

- People with epilepsy can't do certain things like sport, or excel at other things that contain physical or even intellectual work.
 - People with epilepsy should be treated differently than able-bodied people.
 - People have epilepsy because someone did something wrong.
- A very small percentage of people with epilepsy (especially in rural areas) are fully aware of what the condition entails. Doctors, neurologists and social workers specializing in epilepsy are able to explain the condition to the person with epilepsy and their family, friends, colleagues and community members. This understanding should effectively assist the person with epilepsy to live a full life, making use of

different treatments to control the condition. However, despite information about epilepsy being readily available; society continues erecting barriers in the way of people with epilepsy.

For a person with epilepsy co-operation with their doctor is essential in establishing optimum control of the condition. About 80% of people with epilepsy can effectively control their seizures with medication or diets. If appropriate support services are readily available, more people will experience an improved quality of life.

People with epilepsy are often demotivated and prohibited from reaching their true potential due to myths and societal stigma surrounding the condition. If society in general accepts the truth about epilepsy and stops disseminating misinformation and frightening “stories” about the condition, the quality of life of people with epilepsy will improve dramatically, thus enabling them to live healthier and happier lives.

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. As such, people with disabilities (including epilepsy) are included in affirmative action legislation.

Employment options for people with epilepsy include open labour market employment, supported employment, protective employment and self-employment (either in individually or group-owned ventures). People with epilepsy have the same range of abilities and intelligence as the rest of the population.

Isolating people with epilepsy and other disabilities contributes to the alienation that the person feels and hinders that person in his/her attempts to overcome obstacles. We know that recreational activities are very important for socialising and general happiness. This is also true for a person with epilepsy. Achieving balance between a safe and an active life is possible by simply making a few adjustments to activities.

Active recreational activities improve both mental and physical health and should be encouraged for people with epilepsy. Most sports can be safely pursued by people with epilepsy and (with some adjustments) they can enjoy activities which may be considered dangerous by many people. Often the risks are no greater for people with epilepsy than for able-bodied people. The risk of injury must also be weighed up against the positive effects of team participation.

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Remember!

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 generalise when talking about epilepsy.

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

- Emphasise what the person is able to do (while advising them about taking sensible precautions) and not what he or she unable to do.



- Treat the person the same as other people who do not have the condition.
- 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.
 - If someone in your family or a friend experiences a seizure consult a medical practitioner (preferably a neurologist) to obtain an accurate and specific diagnosis. If the person is 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

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National Office Epilepsy Week Campaign

During this special week the organisation plans to reach 280 000 people with epilepsy through messages by following the following plan:

- Day 1 activities will enable Epilepsy South Africa National Office to present an information package to 38 000 vehicles which are likely to contain between 105 000 and 140 000 people. This will be achieved by handing out 38 000 information packs to commuters traveling on the National Toll roads of South Africa as well as in the areas of Branch activity during this time. We also trust that people receiving this information package will be sharing the message with passengers.



The information package: will contain information about epilepsy to educate and raise awareness about epilepsy. (a. Why people get epilepsy, b. How to care for a person that is having a seizure and c. How to live with epilepsy)

We will present information about the condition creatively and directly to 38 000 commuters on the N1, N4 and N3 highways and to commuters in the operational areas of our Branches. Thousands of people will be traveling on these toll roads to holiday destinations, sporting events, cultural festivals or religious gatherings. This is an ideal "captive" audience, traveling by car, bus or taxi with nothing to do for at least five hours, providing an ideal opportunity to let the power of boredom work for awareness raising and the Epilepsy South Africa brand. The audience is ready to accept and interact with our message.

We will be handing out our information packages at the following toll plazas:

- Carousel Plaza: on the N1 - 120 km north from Johannesburg

- Mooi Plaza: on the N3- 428km south of Johannesburg
 - Kroonvaal Plaza: on the N1
- Middelburg Plaza: on the N4 -165 km east of Johannesburg
- Day 2, 3, 4 and 5: Sending a short educational message to public subscribers via SMS, but also through Facebook, Twitter and our Electronic Newsletter.

The successful implementation of this project (awareness raising of epilepsy as a condition) will ensure that society in general take responsibility to change myths and misconceptions surrounding epilepsy, especially since any person can develop epilepsy at any stage of their life.

We will sincerely appreciate any exposure or partnership toward reaching the goals of this project and look forward to enabling this powerful project to “Share Epilepsy!” during a “Soccer Drenched” communication period.

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Siyazenzela (“we are doing it ourselves”)

A Rural development programme for people with epilepsy in the Eastern Cape
By James Mkalipi

People living with epilepsy in the Eastern Cape have been marginalised to an extent that they have even been refused access to welfare services. This extends even to people presenting symptoms of either intellectual or physical disability. In response, Epilepsy South Africa decided to start vegetable gardens for families to ensure food security which enables people with epilepsy to follow their medication regime effectively by combining medication with a balanced and nutritious meal grown in their backyard garden. Ultimately this will lead to the development of income generation projects for people with epilepsy to ensure economic independence for them and ally viable and provide to their families.



James Mkalipi (Eastern Cape Development Worker of Epilepsy SA) reached an agreement with the village headman resulting in the first eight vegetable gardens for people with epilepsy being piloted in Mhlabathi village next to Potsdam in Mdantsane.

Gardening training was based on the principles of organic farming using natural resources and obviating the need for expensive chemicals like pest control and fertilizer.

During the course of the programme, participants enjoyed an opportunity to share knowledge, learning to understand each other’s shortcomings better and, most importantly, they were reminded of ancient methods such as praising the Creator for the land, praying for rain and offering thanksgiving for the harvest. This proved to be an eye opener for many of the participants, especially when they understood the reasoning behind these ancient ways.

These natural organic farming methods taught participants a lot regarding nature conservation and using naturally decaying products to produce manure, compost etc. In this way the project has grown beyond growing vegetables and preparing the land to include the importance of planting herbs with medicinal application (for example using yarrow for stomach ache).

Participants have taken pride in and ownership of the programme by ensuring implementation of their new knowledge in their gardens. Seeing growth and development in

their gardens has boosted the self esteem of many participants. This is evident from the comments made by one villager: "It is true that knowledge is more empowering than giving handouts to a person. I feel honoured to be part of the team and would like to thank the Almighty for bringing help to us when in distress. I am proud to be the first member of many to come that have benefited from this programme."

We invite people with epilepsy and/or their caregivers interested in being trained in natural farming to contact James MKalipi at 073 521 7630 or 043 722 1811. You are also welcome to refer any other question to James.

U-Epilepsy South Africa uzimisele ukunizela ngenkonzo zakhe ezilalini SIMAHLA kwaye abantu abanemeko yokuxhuzula kufuneka baxhamle kolu phulo.

Epilepsy South Africa is committed to rendering services in rural areas of the Eastern Cape and urge people with epilepsy to benefit from this campaign.

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WOMEN'S ENTREPRENEURSHIP DEVELOPMENT (WED) CAPACITY BUILDING

By Marina Clarke

A WED Capacity Building Seminar was hosted in Pretoria from 24 to 27 May 2010 by the Women's Entrepreneurship Development and Gender Equality (WEDGE) project of the International Labour Organisation (ILO). The seminar was attended by people involved in promoting entrepreneurship and WED from organisations in South Africa and Lesotho, including BDS Providers; SME support institutions; government, business and women entrepreneur support units; employers' and workers' organisations; women entrepreneur associations and disabled persons' organizations (DPOs); micro-finance and other financing institutions targeting women entrepreneurs.



The overall objective of the project is to create an enabling national environment for the promotion of women's entrepreneurship development and gender equality to support poverty reduction and job creation initiatives in South Africa.

The project is funded by the Norwegian Government and aims to strengthen the national institutional capacity of the Government of South Africa; to redress existing gender imbalances in enterprise development. This is done through approaches and activities aimed specifically at women and small enterprise initiatives that are gender sensitive. The overall objective of the WED guide is to promote the full participation of women in entrepreneurship and economic development, and facilitate the creation of new and better jobs by women entrepreneurs. It seeks to build institutional capacity in WED, particularly in developing countries. It has a strong focus on business creation, formalization and expansion.

The content includes the following topics:

- ILO's approaches for supporting women entrepreneurs, including basic principles on gender equality in SMME development and WED;
- A framework for offering effective business development services to promote women's entrepreneurship;
- The role of lobbying and networking in promoting women's entrepreneurship;
 - Various tools and instruments for promoting WED;

- Assessing the needs, challenges and gender-related issues of growth-oriented women entrepreneurs choosing to expand their business operations

Epilepsy South Africa will be rolling out the WED Capacity Building by hosting a training of trainers seminar in Cape Town from 16 to 20 August 2010. This event will form the cornerstone of our Women's Month celebrations.

Look for roll-out of the WED Capacity Building programme in your area. For more information contact Carmen Armstrong, National Project Coordinator, WEDGE South Africa on (012) 818-8000 or armstrong@ilo.org or Marina Clarke on (021) 595-4900 or economicdev.no@epilepsy.org.za.

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SOCIAL ENTERPRISE (SE) DEVELOPMENT

The work of the Social Enterprise Development Targeting Youth in South Africa (SETYSA) project seeks to support the ILO's constituents and partners in their efforts to promote social enterprise development in South Africa, supporting progress towards a conducive enabling environment and the development of appropriate business development service products for potential social entrepreneurs, with a particular but not exclusive focus on youth entrepreneurs.

The focus of the SETYSA project on social enterprise development is aligned with the Decent Work agenda, in particular the pillars on employment creation and social protection respectively, and the links between these two pillars. Thus, the ultimate objective of the project is to encourage the creation of employment opportunities within social enterprises, as well as the social value delivered by the goods and services that they produce.

Social entrepreneurship is an emerging field at both academic and practitioner level and there are no clear agreed definitions of social enterprise and related concepts. The emerging ILO approach used for the purposes of this project draws on the 2001 Report of the Director-General: Reducing the Decent Work Deficit – a Global Challenge, in which social enterprises were described as those which create “sustainable market solutions to social problems”. This approach does not categorise or exclude social enterprises on the basis of for-profit versus non-profit status or other legal form. It focuses on those enterprises with a viable business model, at least in the long term, which may incorporate a variety of income streams, in line with the ILO understanding of the term ‘sustainable enterprise’. However, the project recognizes that some institutions active in the field of social entrepreneurship use different definitions and that dialogue, capacity building and tool development facilitated through the project need to take account of this dissonance.

The project activities include measures to improve business development service (BDS) provision for social enterprises and social entrepreneurs. The project is working with partners to ensure that social enterprises have access to appropriate services that can help them to establish, improve and grow their businesses. At present, social enterprises often fall between the cracks – they have different needs to conventional non-profit organisations which are sometimes supported by the Department of Social Development or other institutions, but they are often turned away from conventional business support institutions as they are seen as ‘projects’ rather than businesses. This requires efforts to change attitudes as well as ensuring that service providers have the capacity and tools to reach out to, identify and serve social enterprises. As part of this work, the ILO is working with the African Social Entrepreneurs Network to create a Social Enterprise Toolbox for Africa, which contains links to existing resources for social enterprise development, including training materials on which BDS providers can draw to create their own training programmes and other tools. To complement this work, the ILO is working with ASEN and other partners on the development of new tools for social enterprise development specifically tailored for Africa.

Real Development based in Port Elizabeth is currently developing five tools:

- Introduction to social enterprise training tool: A half-day introductory training seminar on social enterprise with a trainer development programme;
- Generate Your Social Business Idea (GYSBI) training tool: An adaptation of the ILO Generate Your Business Idea (GYBI) programme with a trainer development programme;
- Generate Your Social Business Plan (GYSBP) training tool: A training tool designed to allow trainees to develop a social business plan based on an existing social business idea with a trainer development programme;
 - Assessment tool for social entrepreneurs: A rapid assessment tool to assess whether an individual has the qualities and characteristics associated with successful social entrepreneurs.
 - Assessment tool for social enterprises: A rapid assessment tool to assess whether an existing or potential business qualifies as a social enterprise, based on indicators of adherence to key principles such as social purpose and financial sustainability.
- This process is closely linked to the Motherwell Social Business Plan Competition. This Eastern Cape initiative rolls out in June 2010 with training seminars. The deadline for applications from potential competition entrants (registration forms) is 30 June 2010. Social business ideas will be submitted by 6 August 2010 and social business plans on 22 September 2010. An awards event is planned for 21 October 2010. For more information on the Competition contact Ricardo Dames on (041) 503-9100 or Ricardo.Dames@uyf.org.za.

Epilepsy South Africa will be incorporating a half-day Social Enterprise Awareness Workshop with the WED Capacity Building seminar to be held in Cape Town from 16 to 20 August 2010.

For more information contact Marina Clarke at the Epilepsy SA National Office on (021) 595-4900 or economicdev.no@epilepsy.org.za.

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