

Drikie Snyman

From: Epilepsy South Africa National Office [info@epilepsy.org.za]

Sent: 09 October 2009 08:53

To: Drikie

Subject: Electronic Newsletter October 2009



October 2009

Dear Valued Subscriber to the Epilepsy South Africa Newsletter

In the Gregorian calendar October was the eighth month rather than the tenth as we know it. The year has flown by so fast that it almost feels like we should only be in the eighth month and not nearing the end of the year. However, as we move towards the holiday season it is right to start taking stock of the year that we have shared and to start looking forward to the long-awaited 2010!

In history, October has played host to many traumatic events such as the Yom Kippur War in 1973 in the Middle East, the Hungarian Revolution of 1956 and the 1917 Revolution in Russia. Small wonder then that October is characterised by national and international events celebrating the triumph of the human spirit such as the International Day of Non-Violence, German Unity Day, Thanksgiving in Canada and the United States and United Nations Day. Maybe this is the inspiration we needed at Epilepsy South Africa to initiate the development of an advocacy training of trainers programme. Our National Social Development Manager attended a training of trainers seminar hosted by Down Syndrome South Africa as the first step in this process which will culminate in a pilot project in the Eastern Cape. The aim of this programme is to equip people with epilepsy and/or other disabilities to know and understand their rights and to be able to advocate for these rights and to represent themselves more effectively. One of our celebrity ambassadors, Jonty Rhodes lives by the slogan "If you don't go, you will never know" and this is certainly at the heart of the advocacy programme.

If you want to know more about Jonty and his inspirational life, make sure to get your hands on the November 2009 issue of Joy Magazine to read the feature article about this ambassador for epilepsy. It will be easy to find the magazine as Jonty will be featured on the cover.

We want to be sure that the inspiration you find in these events continue for a whole year and will be launching our 2011 calendar very soon. This is a year-long celebration of people with epilepsy living fulfilled lives and contains photographs of celebrities such as Gerry Rantseli Elsdon and Jonty Rhodes and other role-models like Pieter Walser (a winemaker with epilepsy) along with their slogans. Each month also celebrates the art of a person with epilepsy. For more information and to order your own calendar contact Drikie Snyman at the National Office (marketing.no@epilepsy.org.za or telephonically on (021) 447-3014).

These are all events to help us turn obstacles into true potential and to break the stigma attached to epilepsy. In ancient times the birthstone for October (the opal) was believed to have the magical power to predict illness. Today, we understand that the human body responds to illness with increased temperature and that the increase in body heat causes the opal to lose its shine, leaving it dull and lacking colour. We look forward to the day

when (like this belief) epilepsy will no longer be stigmatised, allowing people with epilepsy to fulfil their true potential.

November and December traditionally offers us an opportunity to review progress made during the year and to plan for the last quarter of our financial year (January to March) with renewed vigour. In addition, November sees the return of our National Director from maternity leave and we look forward to welcoming her back.

“We would like to wish all our Hindu readers well during their Deepvali celebrations. May October truly be a festival of lights.”

Yours faithfully

Marina Clarke

(standing in for Noëline de Goede, National Director Epilepsy South Africa)

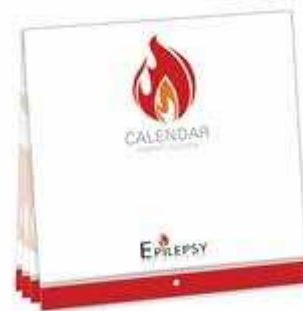
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Epilepsy South Africa Calendar 2011 (By the National Office)

The organisation is privileged to enjoy the support from celebrities and successful business people as well as from many aspiring talents, big and small. There are a bank of people that is standing up with us for issues regarding epilepsy and we know that this will become more and more prevalent in time to come.

In the course of 2010 - the organisation will sell specially designed and compiled calendars that contains some of the aspects that makes us stand up for the cause. People are motivation enough to persevere and make a difference, so we thought it a good idea to present a calendar filled with elements presented by people with epilepsy. Our celebrities contributed as well as some small children in special schools. We received elements from across the country and hope to spread it nationally or even internationally in the course of the year.



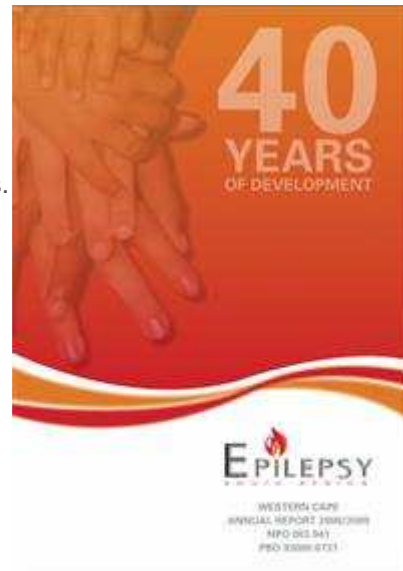
To order your calendar for a meager R50, contact Drikie Snyman at marketing.no@epilepsy.org.za, should you be a member (or want to be) of one of our branches you can contact them at 0860374537 to purchase your calendar.

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Epilepsy South Africa, Western Cape

Cordially invites you to our
Theme: Epilepsy and Human Rights

The focus for this seminar is Epilepsy and Human Rights. Experts in the field of neurology such as Prof Eastman, Dr. James Butler and Prof Wilmshurst will be sharing information about epilepsy and the management thereof. Michael Bagraim, renowned Labour Law Specialist will be speaking about Employment and discrimination in the workplace and Damaris Fritz, Chairperson of the Community Health Care Forums, will reflect on real life case studies regarding the right to health and human rights.



Date: Saturday 21 November 2009

Time: 8:30 – 13:30 (Registration to 08h45)

Venue: Education Centre,
J&J Lecture Theatre,
Red Cross Children's Hospital,
Rondebosch

Cost: Free (donations welcome!)

In order to try and assist with answering your specific questions, please forward them to our office beforehand so that the panel of experts could prepare appropriate responses.

RSVP by Friday 13th November 2009
Mrs Colleen Scott (021) 7039420/ reception.wc@epilepsy.org.za

We look forward to seeing you there!

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Joint Media Statement by Inyathelo – The South African Institute of King III fails to consider non-profit sector recommendation

Joint Media Statement by Inyathelo – The South African Institute for Advancement and Ricardo Wyngaard Attorneys, For immediate release: 7 September 2009.

The King Code of Governance Principles (King III) was released on 1 September 2009 and will become applicable on 1 March 2010. While the release of King III represents a significant advance in good corporate governance it falls short in responding to the distinct needs of non-profit organisations (NPOs) to which it is also applicable.

In April 2009 Inyathelo made a public submission to the Institute of Directors, endorsed by 57 civil society organisations and 17 individuals on the Draft King III report. This submission pointed out the key differences between non-profit and commercial entities and how the draft King III Code failed to give recognition to the distinctive features of non-profit entities. The submission cautioned against enacting superficial changes in addressing the Draft King III's fundamental shortcomings with regard to NPOs. The submission further

recommended that a sub-committee be appointed to develop a chapter within King III that specifically addresses non-profit governance.

This submission, which reflects voices of the non-profit sector was never formally acknowledged and the drafters noticeably opted to affect cosmetic rather than substantial changes with regard to the relevance of King III to the non-profit sector. King III has failed to acknowledge and respond to the fundamental concerns facing non-profit organisation and good governance practices and offers little value in meeting its own principle (8.2) of enabling entities to 'proactively deal with stakeholder relationships' in the case of the non-profit sector.

King III remains unquestionably designed for businesses. Although components of King III will benefit some NPOs, the final version of King III remains wanting in its appropriateness and applicability for the non-profit sector as a whole. More particularly, King III has not take into account the following important factors:

1. That the majority of South African NPOs are small community-based organisations. Procedures such as "integrated reports", "audit committees", "corporate citizenship policies" and "business rescue proceedings" would not find place amongst such organisations. Yet, NPOs will effectively be required to discern which of the principles contained in King III apply to them and explain to their stakeholders why other principles may not be applicable.

2. The Directorate for Nonprofit Organisations is tasked with the responsibility under the Nonprofit Organisations Act of 1997 to ensure that the standard of governance within NPOs is maintained and improved. One of the objectives of that Act is to encourage NPOs to maintain adequate standards of governance, transparency and accountability and to improve those standards. The Directorate for Nonprofit Organisations is accordingly a key stakeholder with reference to non-profit governance in South Africa. Contrary to its message of 'inclusivity of stakeholders', the committee has seemingly excluded this important stakeholder in developing King III.

3. Section 8 of the Companies Act of 2008 recognises two types of companies, namely: profit companies and non-profit companies. This Act notes that the main objective of a non-profit company is to pursue a broader public objective or to promote social change as opposed to generating profit. King III's main emphasis remains firmly on business. The non-profit sector is however not a sub-sector of the marketplace and it cannot be assumed that governance principles aimed at governing commercial entities should apply to NPOs.

King III has however addressed some key concerns with regard to its relevance and applicability to the non-profit sector, namely that:

1. King III now deems a company's stakeholders as its ultimate compliance officer, thus considering the fact that NPOs are not marketplace led.

2. Noting that NPOs do not have "shareholders", performance is deemed to be the ultimate responsibility of the board. Appropriately, King III applies the notion of "improvement of economic value" only in relation to "trading entity" and not to NPOs.

ENDS

Issued by Quo Vadis Communications on behalf of Inyathelo – The South African Institute for Advancement

About Inyathelo: The South African Institute of Advancement, colloquially known as Inyathelo (advancement in isiXhosa) is a world-recognised organisation dedicated to building a sustainable South African civil society. Its core work is to advance social change by working with key institutions and non-profit organisations to ensure their long-term sustainability. This is done by developing their own capacity to raise private investment towards advancing their objectives. Whilst working with organisations to develop their resource mobilisation skills. The Institute promotes social responsibility, personal philanthropy, voluntarism and self-reliance.

About Ricardo Wyngaard Attorneys: Ricardo Wyngaard is legal practitioner specialising on the non-profit law and governance. He has provided legal advice and assistance to non-profit organisations, facilitated various training workshops, produced booklets on non-profit law and governance and co-authored various submissions on non-profit legislation. He currently operates a solo law practice under the name of Ricardo Wyngaard Attorneys.

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Giant Mistake.....?(Juli Huisamen, Insert by National Office)

Definitely not! The beautiful – okay some weren't so beautiful – gathered at the Cape Grace Hotel for the launch of Giant Mistake.



Insert: Pieter Walser, a wine maker from Somerset West and a person living with epilepsy, had a major part to play in the wine reaching Woolworths shelves. Pieter's career is followed by the organisation and we continue to stand in amazement. A true ambassador for Epilepsy South Africa as he speaks at Casual Day Functions to prove that people with a disability are sometimes more able than what can be imagined. He also supported our calendar 2011, so support him in return. For more information visit his website <http://www.blankbottle.co.za/index.html>.

We all waited in anticipation for the launch of a wine made by The Parlotones. Let's face it – how much can these boys know about the art of making wine. Well, they got it right. With the help of Cape Wine Master Allan Mullins and Pieter Walser of BLANKbottle, they came up with a great wine. After visiting wineries and doing tastings of different varietals –yes, this was fun for all of them – they came up with the perfect blend of Cabernet Sauvignon, Shiraz, Pinotage and Cabernet Franc. The wine has a distinct coffee chocolate aroma with a hint of berries. As Kahn say “you will be consuming a little portion of this amazing dance we call Life..”

The launch of their wine and new album come at the eve of their World Tour to countries like the UK, Europe, Russia, Australia and of course South Africa. This is a South African band made good and if you go according to their huge following, this tour and wine will be a huge success. With an attitude of “...just do anything, because everything counts.” They can't go wrong. Giant Mistake will be available from October 2009 at Woolworths stores countrywide – go and get a bottle and be part of this great phenomenon. With words from the Giant Mistake label “Thank you for being a part of this glorious adventure. Much love and much wine. Kahn” “View their official website here www.theparlotoneswine.com”

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Epilepsy Tonic-Clonic Seizure Monitor (By APMedicalDevices)

The National Office of Epilepsy South Africa were pleased to meet the founder of APMedicalDevices and witness his passion for people with epilepsy. The organisation refers quite a number of people to them and commends them for taking care of these by presenting information and light into their situation. The product presents a possibility to some comfort to parents and spouses of those living with the condition. Please read carefully and contact them if necessary (Contact detail at the end). If you choose to contact us regarding this product please do so by emailing socdev.no@epilepsy.org.za



Emfit seizure monitor has proven its usefulness over 5 years and with thousands of units sold world wide. This unit is now available for the first time in South Africa through AP Medical Devices.

Its intended use is for monitoring a sleeping person who has risk of tonic-clonic seizures. It is the first alarm that detects and distinguishes strong muscle jerkings such as tonic-clonic seizures from normal movements, but also presence and absence of micro-movements caused by person's breathing and heart beating. So not only does it give notification to the caregiver when the person has the clonic phase of a tonic-clonic seizure, but also when the person leaves the bed (this feature can be disabled).

Based on Unique, Proprietary Technology

Emfit Nocturnal Tonic-Clonic Seizure Monitor consists of two main components. The first being the ultra thin and flexible but highly durable bed sensor which is placed under the mattress. The second component is the bedside monitor with sophisticated embedded software and electronics. Together they detect the micro-movements of a person lying on the bed - even heart beating and breathing, and the faster movements such as muscle jerkings when the person has a tonic-clonic seizure. There is no particular weight limits and the system is sensitive enough also for small children.

A connecting wire is attached from the sensor to the control unit. The control unit can be placed next to the bed or on the wall using the included fastening bracket. The monitor has an audible alarm with adjustable volume and a dry-contact output for connection to a wireless transmitter, nurse call system or carephone. The Emfit Nocturnal Tonic-Clonic Seizure Monitor is a Class 1 Medical Device. It has been tested and certified to meet medical device electrical safety standard IEC 60601-1 and carry CE mark accordingly.

Contact us: 083 928 77 77 www.apmedicaldevices.co.za info@apmedicaldevices.co.za

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