NEWSLETTER OF EPILEPSY SOUTH AFRICA
MARCH 2013
Dear Readers

With the end of the first quarter of 2013 approaching, the year is well underway. According to Umair Haque (a contributor to the Harvard Business Review who is ranked as one of the world’s most influential management thinkers) it’s time to cut the garbage – life is short, you have less time than you think, and there are no baby unicorns coming to save you.

Tough love, sure, but advice worth taking to reach the goals and realise the ambitions you may have set yourself for 2013. Haque goes on to ask, “Do you want to have a year that matters?” If so, he recommends jotting down the answers to the following questions:

1. Why are you here?

To keep it simple, Haque suggests asking yourself why you are here. Why are you living the life you’re living and why are you working where you are working? How are you making your life one that is worth living?

2. What do you want?

Haque warns against the ‘easy’ answers: “money, sex, power, fame, keeping up with the Kardashians” and stresses that you need to have ‘better’ answers if you want a meaningful year that really matters. How about: ‘To make a difference’, ‘To create that which transforms’, ‘To build that which counts’ and ‘To experience what’s true’. These are ambitions that matter.

3. How much does it matter?

Of course, the year you have should matter: to yourself, your family, your boss, their boss, to shareholders, markets, and consumers. More than this, however, your year should matter to your society and to future generations “if you want this to be a year that one day, in a surprisingly short time, you don’t just remember, but that you still savour.”

4. What’s it going to take?

Haque stresses that having a year to be proud of will mean using your mind, heart, soul, and body. Discard office politics and instead focus on the ‘art’ of empathy, imagination, and humility. This being said, don’t lose your traits of passion and rebellion. These are critical to influencing others, transmitting charisma, and driving change.

5. Who’s on your side?

A life meaningfully lived does not happen by living in isolation. Haque states that it is crucial to “challenge, provoke, inspire, connect - and then, harder still, evoke the best in people.” If you want to make a difference, you need to acknowledge your mentors and your allies, whether these are family members, friends, colleagues, or peers. Haque adds: “Respect is earned - and love given - not just to those who pander, but those who matter.”

6. Where’s your ‘true north’?

To live a life that will matter, you need an ethical compass and some sort of belief system (religious or not) with a ‘true north’ that can help guide you toward values that are inherently ‘good’. Your ‘true north’ needs to point to “investment, accomplishments, relationships” rather than merely wealth, consumption and status.

7. What breaks your heart?

Haque tells us that we are often told to “follow our passions”, but many people battle to decide what these ‘passions’ actually are. He suggests that we look to the things that “break
our heart” or upset us so significantly that we’d want to change them. It is this that moves us and can motivate us to affect real change.

8. What’s it worth?

So, if you’ve read all this and still aspire to a life of VIP living, status, power and wealth, then according to Haque, you have chosen a life of mediocrity. He adds that it is impossible to find accomplishment, happiness, and wholeness in mere possession/conquest.desire. Rather, we need to explore ourselves and our possibility to reach our true potential.

Haque leaves us with the same question he asked us initially, “Why are you here?” and concludes, “The choice is yours. And it always has been.”

Regards
Marina Clarke

PARTNERS ASSIST WITH THE LAUNCH OF THE EASTERN CAPE BRANCH

Epilepsy South Africa has procured office space in East London in the suburb of Vincent! Together with this new office, the first Annual General Meeting on 14 March 2013 will mark the launch of the formal Epilepsy South Africa Eastern Cape Branch. The AGM will elect the new Branch Board and adopt a constitution for the Branch. Companies or individuals interested in attending the AGM are welcome to contact Mthobisi Madlala via email (development.ec@epilepsy.org.za) or telephonically on 078 362 1078.

The organisation is grateful for the support and generous contributions of the Eastern Cape Development Centre (ECDC), Shoprite Holdings (Pty) Ltd and the Passenger Rail Agency of South Africa (PRASA) towards arrangements for the AGM. With limited space in the new office, the ECDC is sponsoring the venue for the AGM. PRASA has agreed to sponsor the transport of six members of the Motherwell Support Group (the first one established in the Eastern Cape) to and from the AGM via the Translux bus service while Shoprite will provide catering for the meeting. Shoprite has been a partner since 2012 when they sponsored the Shoprite Soup Trucks for the Epilepsy South Africa Mobile Neurology Clinics in the East London area.

Epilepsy South Africa extends its sincere gratitude to these providers showing a mutual concern for and proactive approach to community development in the Eastern Cape.

A WIN-WIN SITUATION THROUGH REGGIES AND MY SCHOOL/MY VILLAGE

Reggies and the MySchool MyVillage MyPlanet initiative have launched a brand new competition. Now you can raise even more funds, PLUS your beneficiary organisation can win a R5 000 Reggie’s Gift Card in the MySchool and Reggies’s “Clown Around for a Good Cause” promotion. This promotion started on February 22nd and encourages MySchool MyVillage MyPlanet cardholders to swipe their card at Reggie’s stores. The winning card holder will win a R5 000 gift card for themselves, plus a R5 000 gift card for their beneficiary organisation.

Register yourself here: www.myschool.co.za/reggies and remember: Every swipe counts as an entry.
Every year on Casual Day, thousands of South Africans and their companies participate in this biggest support drive for people with disability in South Africa. Every year, more and more people and companies join this fun and easy campaign to affect change in thousands of South Africans’ lives by buying their stickers for R10.

This year, the management of Casual Day changed from the Marketing Team (who ran the project for 18 years) to the National Council for People with Physical Disabilities (NCPD), the original owner of the project. The new in-house team will drastically reduce operational expenses providing even more support to persons with disabilities in the country.

The Casual Day theme for 2013 is: “Go Big” and promises to have people going to the extreme in support of Disability. Big hats, big hair, big shoes, big uhm… everything!! Dress up, have fun, but most importantly: Join your fellow South Africans and show your support for services to people with disabilities.

Casual Day is also a great opportunity for team building in your office at just R10 per person. And all this while contributing to persons with disabilities!

Can you or your company really afford not to be part of this vital campaign? Contact your nearest Epilepsy South Africa entity for more information and to order your Casual Day stickers for this year’s truly life-changing “GO BIG” event!

If you don’t have a MyVillage card yet, simply apply for your free card now and select Epilepsy South Africa as your favourite beneficiary. Once you start swiping your card the Organisation will start receiving funds at no cost to you.

If you already have a MyVillage card, but would like to change your beneficiary or add Epilepsy as a charity, simply call the Client Service Centre on 0860 100 445 or email them on cs@myschool.co.za - there is no need to get a new card!
In January 2013, two years away from the expiry of the 2000 Millennium Development Goals (MDGs), the Post 2015 agenda has already created a buzz in Monrovia and Johannesburg. As Liberia’s President Ellen Johnson Sirleaf hosts the United Nations High Level Panel on the Post 2015 Development framework this week, I was privileged to have joined an energetic group of ONE Africa staff, friends, partners and members at the launch of ONE’s new post 2015 SMS and social media campaign called ‘You Choose Campaign’. The main objective of this campaign is to engage Africans from all walks of life on what the new MDGs should focus on.

At the launch event Nigerian music star, Dbanj, urged the audience to write personal MDGs so that the collective MDGs can happen. Dbanj told the audience that he joined ONE because he is passionate about engaging on how best to end poverty. He noted that the ‘You Choose’ platforms provide opportunities for all to speak out so that barriers can be removed - or until they find their Jesus Christ! “We can make it, I am an example ... Nigerian born, Nigerian made, Africa is more than what people think we are. We have more and have the opportunity to be more”, he said. The Nigerian-born music star and ONE member ‘Dbanj’ called onto the audience and his supporters to participate in this campaign that will influence their futures.

As Africa has close to 700 million mobile connections, the ‘You Choose Campaign’ will take advantage of the African mobile revolution to reach millions of Africans to add their voices. African Youth too who are 24/7 on social media will be encouraged to add their voices in shaping the new MDGs through ‘You Choose’. This campaign has already hit major airwaves in South Africa on the South African Broadcasting Corporation (SABC) TV, SABC SAFM and Metro FM. Citizens are encouraged to text their top priority issue to 30667 (South Africa), 54111 (Malawi) and 234 (Zambia). Campaign participants just have to submit their priority in a simple format via a free SMS or the web-based platforms. Their priorities could be as simple as food, land, jobs, public transport, skills, hospitals, leadership, accountability, corruption or another critical issue. On Thursday, 31 January 2013, a caller named Bongi told other listeners on SABC’s morning talk radio show in Johannesburg it is critical that leadership ensure that current and future MDGs are met. He cited how former President Kenneth Kaunda of Zambia inherited a country with only a few schools and colleges and no university. Within the first years of independence, he was able to establish a countrywide network of primary and secondary schools and a university. Bongi Chose, and sent a free text to 30677 (South Africa). What do you choose? To choose, send a text for free to 30677 if you are in South Africa, 54111 if you are in Malawi and 234 if you are in Zambia or submit your issue at www.one.org/c/international/actnow/4585 if you are outside SA.

ONE hopes that citizens views collected via this campaign will be a helpful contribution to the multi-level United Nations led process that is formulating the future development goals. Unlike when the 2000 MDGs were formed, the post 2015 MDGs process is seeking advice this time from citizens on what future MDGs should address when the current ones expire in 2015. ONE is working in partnership with more than 20 organisations and influential parties that include the UN, civil society organisations, churches groups, radio stations and various media houses in rolling out this drive. ONE is particularly working closely with the UN My World team so as to ensure that the feedback collected through ‘You Choose’ will be included in the meeting of the High Level Panel on the Post 2015 agenda to be held in March 2013 in Bali, Indonesia.

ONE is thrilled that African icons such as Hugh Masekela, Dbanj, Lira, Benni McCarthy, Chris Katongo, HHP, have joined hands with ‘You Choose’ to urge ordinary
African citizens to join the call to action. Launches in Malawi and Zambia will follow on the 12th and 19th of February respectively. In Zambia, the campaign will be backed by local celebrities that include former Big Brother Housemate, Mampi, singing sensation, Slap Dee and Zambia’s own TV producer, Mary Magambo, and one of the hip and hottest artists on the Zambian music scene Kachanana. In Malawi the campaign will be backed by Malawian stars Dan Lu, and Bon Kalindo. You Choose participants will have an option to join ONE so as to have opportunities to join current campaigns ONE is running on improving health and Agriculture investments in Africa. Remember to choose by texting for FREE to 30667 (South Africa), 54111 (Malawi) and 234 (Zambia)!

Source: [http://www.ngopulse.org](http://www.ngopulse.org), 13 February 2013

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**PREVENTING EPILEPSY – A NEW APPROACH**

Epilepsy South Africa is seeking to assist in the elimination of Neurocysticercosis, known as NCC, a preventable tapeworm infection that is known to cause epilepsy. The infection is considered a serious problem in southern Africa. The tapeworm is spread easily between human and pigs, however because of the life cycle and the steps required controlling its spread it has determined to be eradicable. Eliminating this infection would mean fewer cases of epilepsy and improved health and well-being of many.

Unfortunately, a 2004 study revealed that nearly 35,000 people in the Eastern Cape have epilepsy due to the infection; the numbers are expected to be growing. The same study revealed the economic burden due to productive losses were estimated to be nearly R150 million.

The loss was due mostly to the prevalence of epilepsy and related productive losses. This is particularly significant considering the Eastern Cape's lagging economic growth and high incidence of poverty. Furthermore, the social consequences of epilepsy, such as being stigmatised and alienated, are often even more profoundly felt by people with epilepsy.

While there are a few researchers and neurologists around the world who have studied the infection, Epilepsy South Africa has worked diligently to fill the gaps with information and training tools.

The National Office, in collaboration with the Northern Cape Coordinator, is developing a tool kit with resources such as posters from various international sources as well as their own material that will be used as training material in the Eastern Cape and beyond.

The only way to eradicate the infection and reduce the incidence of epilepsy is to raise awareness on the issue through education and training. It is vital not to look only on the rural areas, but throughout the province as there are also squatter settlements around Eastern Cape due to urbanization. For example there is an area called Ziphunzana/ Gompo, and although only 10kms from town, they are the potential victims of the NCC infection.

The Eastern Cape Coordinator has developed an action plan that includes various pilot areas where he will not only target the victims or potential victims but the whole community. He will also work strongly with community health workers all over targeted areas.

This will also open eyes of the community members and the gate for future development.
The internet has always fascinated me.

Once I joined Epilepsy South Africa, I was keen to do research on epilepsy; this led me further and further into the internet world.

Searching, finding out more information and generally communicating with others worldwide is one of my favourite daily tasks.

Through Facebook, Google, Hotmail, Twitter and Yahoo, to name just a few, one is connected to a variety of incredible websites that are available. The choice is yours!

My first experience with Facebook was one of total awe. I didn’t understand or realise how the site worked or the extent of one’s privacy.

I didn’t know anyone for friendships to be formed, and generally couldn’t find my way around. Confusion set in, I wondered whether I had done the right thing by opening up an account, but eventually found the confidence and urge to experiment more!

By searching through Facebook, sending Friend Requests and joining Groups, I found an abundance of caring, loving and understanding people, all of whom have and share one thing in common - epilepsy.

I continued to make new friends, found more information/knowledge, and was able to start off by giving advice, guidance, love and support.

A great network has now been formed; I am now Admin to at least five groups and have also spread my wings through Twitter, which works in the same way (@LesleyDonnelly1).

Do not be afraid to do research. Feel free to join our Epifriends Network (Group & Community) Pages on Facebook, give others your love and support, and socialise more.

Opening a Facebook account has been one of the most wonderful experiences of my life; it still is today!

Social media is such a vital part of our lives, so go ahead and enjoy the journey!

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The working relationship initiated between Epilepsy South Africa and Child Welfare East London in February 2012 was formalized when a memorandum of understanding (MOU) was signed on 14 February 2013. This MOU will enable the expansion of services to children with epilepsy through up skilling staff and volunteers of Child Welfare.
A NEW FUTURE FOR SADA

Epilepsy South Africa is a member of the South Africa Disability Alliance (SADA) established in 2007 as a platform for discussion, joint planning, collaboration and consensus-seeking amongst key role players within the disability sector.

During a strategic planning workshop hosted in Edenvale on 25 and 26 February 2013 a decision was taken to formalise this structure by registering as a Public Benefit Organisation (PBO). In addition to the structure of SADA discussions focused on:

- A revision of SADA’s terms of reference, mandate and protocol;
- Branding, identity and marketing strategy;
- Opportunities such as the annual ACSA Disability Conference & Lifestyle Expo;
- A communication strategy with stakeholders;
- Representivity of SADA;
- SADA as a resource for disability expertise and competence (including information dissemination):
- SADA’s advocacy role on key disability issues; and
- Funding sustainability.

Task teams were established in line with these discussions heralding a new and more effective era for SADA.

Current SADA members include Cheshire Homes, DeafBlind South Africa, the Deaf Federation of South Africa (DEAFSA), Disabled People South Africa (DPSA), Epilepsy South Africa, Muscular Dystrophy South Africa, the National Association for People with Cerebral Palsy, the National Council for People with Physical Disabilities in South Africa, the Quadpara Association of South Africa, the South African Federation for Mental Health, the South African National Council for the Blind and the South African National Deaf Association.
Blocking a seizure. The vertical green bar indicates online seizure detection, prior to the start of stage 4–5 behavior (arrow).

The yellow bars under the trace highlight the theoretical window for intervention.

UC Irvine neuroscientists have developed a way to stop epileptic seizures with fiber-optic light signals, heralding a novel opportunity to treat the most severe manifestations of the brain disorder.

Using a mouse model of temporal lobe epilepsy, Ivan Soltesz, Chancellor’s Professor and chair of anatomy & neurobiology, and colleagues created an EEG-based brain-waves-sensing) computer system that lights up hair-thin fiber optic strands implanted in the brain when it detects a real-time seizure.

These fibers “turn on” specially expressed, light-sensitive proteins called opsins, which can either stimulate or inhibit specific neurons in select brain regions during seizures, depending on the type of opsin.

The researchers found that this process was able to arrest ongoing electrical seizure activity and reduce the incidence of severe “tonic-clonic” events.

“This approach is useful for understanding how seizures occur and how they can be stopped experimentally,” Soltesz said. “In addition, clinical efforts that affect a minimum number of cells and only at the time of a seizure may someday overcome many of the side effects and limitations of currently available treatment options.”

More than 3 million Americans suffer from epilepsy, a condition of recurrent spontaneous seizures that occur unpredictably, often cause changes in consciousness, and can preclude normal activities such as driving and working. In at least 40 percent of patients, seizures cannot be controlled with existing drugs, and even in those whose seizures are well controlled, the treatments can have major cognitive side effects.

Although the study was carried out in mice, not humans, Soltesz said the work could lead to a better alternative to the currently available electrical stimulation devices.

The study was supported by the National Institutes of Health, the Epilepsy Foundation, and the George E. Hewitt Foundation for Medical Research.

Reference:

Esther Krook-Magnuson et al., On-demand optogenetic control of spontaneous seizures in temporal lobe epilepsy, Nature Communications, 2013, DOI: 10.1038/ncomms2376 (open access)

Source: http://www.kurzweilai.net/a-fiber-optic-method-of-arresting-epileptic-seizures, 19 Feb 2013
MEET THE BOARD

ZAK (SAKKIE) STEYN
Sakkie was born in Umtali Zimbabwe in 1953. He is a widower and proud father to three boys and a girl and a doting grandfather to his grandson.

Following a B.Proc from the University of the Free State in 1980 Sakkie was admitted as an attorney and conveyancer in 1981 (Northern Cape, Gauteng, and Western Cape Provincial Divisions). He completed his BA Honours in labour relations and HR at the University of Johannesburg (RAU) in 1993 and sharpened his skills through a number of courses arbitration and mediation (employment and commercial). From 1976 to 1985 Sakkie practiced as an attorney and conveyancer specialising in property and deceased estates tax in partnerships (Du Plessis & Viviers, Vryburg and Steyn and van der Vyfer, Willowmore). This was followed by a period with SASOL II as contracts manager managing local and international contracts and projects (1985 – 1987).

He joined OTK Coop Ltd as legal advisor from 1987 to 1990 dealing largely with contracts, employment matters, company take-overs and risk management.

In 1990 Sakkie took up employment as the Group Labour Relations Manager at Goldfields SA, Sakkie practiced law as a conveyance in partnership at Steyn Van der Westhuizen Inc. in Johannesburg from 1991 to 1995.

He was employed at the South African Police Services (SAPS) from 1995 to 2004 as Head Employment Relations at the rank of Major General stationed at the Head Office in Pretoria. He was awarded the South African Police Star For Outstanding Service S.O.E. in 1997 and served as vice-chairman of the Public Services Bargaining Council in 1995 and a member of the Joint Governmental Drafting Committee in 1995/1996. Sakkie served as a member of several structures, including the Police Board (1992/1994), the National Housing Board (1992/1994), the National Peace Accord Structures (1993/1994) and the Interim Metropolitan Council Kempton Park/Edenvale/Thembisa (1993/1994). Sakkie currently chairs the Epilepsy South Africa South Cape/Karoo Branch and was elected to the National Steering Committee in September 2012.

ROELAND WINTERSHOVEN
Roeland was born in September 1946 in Germany and carried a Belgian passport before immigrating to South Africa 1969.

He is an electrical engineer by profession and worked for several engineering companies for the first few years in South Africa.

When an opportunity he joined forces with partners to start a company manufacturing electrical switchboards and doing electrical construction at industrial level. Roeland served as managing director of this company until his retirement in 2007.

Roeland has had epilepsy for many years although his condition was largely controlled by regular medication. He has been seizure-free for the past five years without the need for medication. He has three sons with the youngest (diagnosed with epilepsy and a very limited IQ) a resident of the Daggafontein residential care centre of our Gauteng Branch for some 24 years.

Roeland has been involved with Epilepsy South Africa (and SANEL as it was previously known) for about 20 years at residential and Branch level. He was elected to the National Steering Committee in September 2012.
BRING & BRAAI FESTIVAL – 20 APRIL 2013

The Free State & North West will be hosting a Bring & Braai Festival on 20 April 2013 at the Afridome in Parys kicking off at 10h00. It promises to be a fantastic day for the whole family.

Come strut your stuff as a braai champion and stand the chance to win big prizes. Thys, die Bosveldklong and Gerhard Odendaal ("Vaatjie") will be judging the dishes. A junior braai competition offers an opportunity for the little ones to show their braai skills.

Various artists will be entertaining us with Thys, die Bosveldklong being the “entertainer-in-chief”. Don’t miss his performance at 19h00. Come and browse amongst the stalls and make sure your little ones visit the kiddie corner. Dust off your dancing shoes and join us for a day of fun.

Entry fees will be R50 per adult and R20 per child under the age of 12 years.

For more information and to enter the competition contact Derick Claassen on 082 856 3749. Only 50 entries will be allowed for the braai competition. Enter now to avoid disappointment!

PACIFIC RIM INTERNATIONAL FORUM ON THE RIGHTS OF PERSONS WITH DISABILITIES

You can’t miss the 29th Annual Pacific Rim Conference on Disability and Diversity: Being in Community, 2013 to be held on 29 and 30 April 2013 at the Hawaii Convention Center in Honolulu.

Formally called the Pacific Rim International Conference on Disabilities, Pacrim is one of the world’s top rated international educational offerings. The 2013 Call for Proposals were open from 1 August 2012 through 14 December 2012. We have many topic areas relevant to educators and researchers including Teach to Reach, Indigenous and Native Hawaiian Education, Post-Secondary Education and much more.

To learn more visit: www.pacrim.hawaii.edu, email prinfo@hawaii.edu or call us on (808) 956-7539.
Abstract submissions were opened in November 2012 with the submission deadline set for the end of January 2013.

Authors will receive an email acknowledgement of receipt of their abstract which will be reviewed by the International Organising Committee and considered for platform presentation, special poster sessions or poster tours.

For more information visit www.epilepsymontreal2013.org

MOBILE NEUROLOGY CLINICS – EAST LONDON

Dr. Potgieter and his team will be visiting the East London area from 6 to 10 May 2013 to offer neurology and psycho-social support services to people with epilepsy.

Services will be offered at Mncosho Clinic, Nothathambo Clinic (Mdantsane), Empilweni Clinic, Tsabo Clinic (Berlin) and Mooiplaas Clinic.

For more information contact Mthobisi Madlala on 078 362 1078 or via email: development.ec@epilepsy.org.za