FROM THE DESK OF THE NATIONAL DIRECTOR

Dear Readers

One of the highlights of April 2013 was the National meetings hosted in the beautiful town of Dullstroom by our Mpumalanga & Limpopo Branch from 16 to 20 April.

These meetings included the Directors’ meeting (16 and 17 April), the National Strategic Planning Workshop (18 and 19 April) and the National Board meeting (20 April).

The residents at the Dullstroom Centre challenged the Directors and Board members of Epilepsy South Africa to a game of Bocce. Despite our best efforts the residents easily won the game.

However, the fun and enjoyment of this interaction will remain with each of us for many years.

Tekkie Tax will be “levied” on 31 May 2013 for the first time enabling South Africans to support causes close to their hearts, including disability.

Contact Epilepsy South Africa to order your stickers and slip on your favourite tekkies to show your support!

We are pleased to announce that Newsclip selected Epilepsy South Africa for a third year as a partner in their corporate social responsibility programme – a rare feat that fills us with pride!

The Free State & North West Branch celebrated the crowning of the Barbeque King and introduced Martha and Mathilda (two donkeys) as the newest transport option in Parys while the Vryburg office aided people with disabilities with assistive devices.

The National Office expanded its entrepreneurial development programme through a partnership with Gender Links to develop an entrepreneurial programme for survivors of gender-based violence in ten SADC countries.

In addition to a review of a book (Becky the Brave) aimed at children to raise awareness and provide knowledge about epilepsy, our regular Epilepsy Facts Corner also contains information about a new application (E-Action) offering support to many people with and affected by epilepsy. Links to educational video clips about epilepsy and an article about research linking the use of valproate during pregnancy and autism can also be found here.

We look forward to a fun-raiser hosted by the National Office on 30 May 2013 at the Barnyard Theatre, Willowbridge, Cape Town celebrating Rock ‘n Roll with a tribute to The King!

Join us for an evening of nostalgia and hip-swinging golden oldies!

Regards

Marina Clarke
Tekkie Tax will take place annually on 31 May with the first opportunity to buy your R10 sticker to support your chosen community organisation on Friday, 31 May 2013.

You can choose to support any of the welfare sectors that touch your heart, including the disability sector. Other sectors include basic community welfare, children, animals and education.

All you have to do is to buy your R10 stickers for each of the causes you support from recognised distributors (such as Epilepsy South Africa).

Your sticker(s) allow you the right to wear your favourite pair of tekkies to work or school for the day (31 May), showing your support for important welfare issues in our country.

You can also become the Tekkie Tax champion in your school or company by liaising with our offices to receive your order of stickers and free marketing material to promote this vital fundraising campaign. Contact us at any of the detail below to find out more on how you can support this fun-filled event so vital to developmental causes in South Africa.

Casual Day will (as always) be celebrated on the first Friday in September; this year being on the 6th of September. You are more than welcome to support both these very important initiatives to benefit disability and other causes in South Africa.

CLARIFYING OUR FUTURE – NATIONAL STRATEGIC PLANNING WORKSHOP

Christiaan Vorster (Business Growth Africa) was contracted to facilitate the Workshop which aimed to review the organisational structure so as to manage the risks incumbent in the constitution and to clarify the roles of the various structures within the organisation. Further objectives of the workshop were indicated as:

- To reflect on the efficacy and effectiveness of the constitution.
- To define the roles of the National Office and its functions in relation to the Branches.
- To define the roles of the National Board and National Steering Committee (NSC) in terms of the constitution.
- To explore ways of improving internal organisational communication in pursuit of transparency and openness.

A formal report was submitted to the National Board with three sub-committees established to carry out recommendations. It is anticipated that the organisation will adopt a new constitution based on the work of these sub-committees.
Over the past two years, Epilepsy South Africa has had the advantage of comprehensive media monitoring services from the Newsclip Media Monitoring Service Company.

This company has almost 30 years of providing clients with up-to-the-minute access to clips acquired through the monitoring process. They also include a fully-fledged publishing division, a news review service and mobile communications solutions. Today they monitor over 1,500 print media, 500 commercially-viable websites and over 300 television and radio stations. To top it all, they provide clients with integrated research facilities, digital trend-based media analysis and industry-specific research analysis.

Once again, Newsclip has chosen Epilepsy South Africa as a partner for their corporate social responsibility programme which means that for the whole of 2013 the organisation will receive this service at no charge. This agreement is worth well over R90, 000.

Newsclip has already, through our previous 24 month partnership, assisted the National Office to remain abreast of the latest, up-to-date media coverage regarding the organisation. This enabled us on numerous occasions to respond to urgent situations and share congratulations within Epilepsy South Africa on news of the fantastic services rendered in local communities.

Surely, one can see the value of this type of service in the corporate world as well.

Epilepsy South Africa extends our gratitude to Newsclip for once again deciding that Epilepsy South Africa is a worthy recipient of their pro bono service and we commend Newsclip on this wonderful initiative and contribution through what they do.

For more information on Newsclip and its services, you can visit their website at www.newsclip.co.za or e-mail them at marketing@newsclip.co.za.

On 30 April 2013 IBE announced the election of a new Regional Executive Committee for Africa. Mr Youssouf Noormamode (Mauritius) was elected as Chairperson and Ms Marina Clarke (South Africa) as Vice-Chairperson. Elections are currently underway for the position of Secretary with two candidates being nominated: Clotilda Mujeyi Chinyanya (Zimbabwe) and Harmiena Riphagen (Namibia). Ballots close on 15 May 2013.

The Free State & North West Branch hosted a barbeque competition on 20 April 2013 in Parys with celebrities determining the winner. These included Vaatjie and Thys, die Bosveldklong.
During the National meetings held in Dullstroom, Mpumalanga in April the Epilepsy South Africa staff (Branch Directors and Board representatives) was challenged to a game of Bocce against Mpumalanga Branch residents.

This game, an Italianised version of the more well-known lawn bowls, is traditionally played on natural soil or asphalt. Unlike bowls, bocce balls are spherical and can be made of metal or various kinds of plastics, but have no inbuilt bias. Balls can be thrown through the air (underarm) to place closest to the “Jack” ball (the little target ball).

In an amazing show of prowess the residents proved their sporting potential and won the game despite the collective efforts of the staff. This was a result of the work done by the dedicated team at the Mpumalanga & Limpopo Branch to prepare people with epilepsy for participation in the Special Olympics. Special mention must be made of the efforts of Sonto Maseko and Allan van der Hoven who ably led the residents.

We congratulate the winning Dullstroom Residents Team and the Branch for hosting this set of National Meetings, showing us the positive change they affect in people’s lives.
violence. Stigma, isolation and lack of access to resources plague the lives of women with disabilities, making them particularly vulnerable. Providing women with information and access to resources to be able to engage in entrepreneurship will promote social justice and their empowerment.

It is envisaged that the programme will challenge existing gendered power dynamics to reduce gender based violence and support healthy communities for people with and without disabilities.

NEW ASSISTIVE DEVICES FOR PEOPLE IN THE NORTH WEST

Epilepsy South Africa through the office in Vryburg was involved in identifying and helping people to access much needed assistive devices. With the new devices we were able to make a positive change in the lives of 64 people. The devices included wheelchairs, walking canes, electric wheelchairs and much more.

To see the joy on the faces of the people that received their assistive devices made all the hard work worthwhile. Pictured above Mr Hendrik Meintjies (Meintjies and Neethling Orthopaedics Inc) is fitting new feet for one of the recipients.
**BECKY THE BRAVE – A STORY ABOUT EPILEPSY**

Epilepsy is tough on children and their families, and this story will help to explain the misconceptions that exists surrounding epilepsy. A short overview of the story:

In Sarah’s eyes, her older sister is very brave. Becky is not afraid of the new school or of the barking dog that they meet on the way. She’s not even afraid of the convulsive epileptic seizures that she sometimes has. But after a seizure at home she confides to Sarah that, although the teacher and the nurse know about her condition, she has not told her new classmates and she worries that she will have a seizure in school. One day her fears are realized, and her classmates stare and some laugh. The next day, Becky refuses to go back to school and Sarah has to conquer her own trepidation, walking there alone and going into her sister’s classroom to explain what happened.

The text reads easily with just enough information about epilepsy to help readers understand Becky’s feelings. The soft pastel drawings emphasize the loving relationship between the sisters.


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**ELVIS FOREVER! BARNYARD WILLOWBRIDGE, 30 MAY 2013**

The King of Rock ‘n Roll is back! Join the National Office for this fun-raiser on Thursday evening, 30 May at the Barnyard theatre, Willowbridge.

The show: “Elvis Forever” is a tribute to the legend that was Elvis Presley who dominated the world of Rock for three decades. The evening promises to be a hip-swinging fest of timeless hits such as “Hound Dog”, “Jailhouse Rock”, “Love me tender”, “Always on my mind”, “Viva Las Vegas” and many others. These hits will take you on a nostalgic trip to when Rock ‘n Roll was still a lifestyle, and bell bottoms and blue suede shoes the fashion of the day!


This will definitely be an evening of entertainment and fun that will include lucky draws and an exclusive auction – proceeds donated to the National Office. The Barnyard also offers a cash bar and a whole range of mouth-watering pizzas, or you can simply bring along your own picnic basket.

“Elvis Forever” starts strictly at 20h00 on Thursday evening, 30 May. Doors will be open from 18h30.

Only a limited amount of tickets are left. Book yours now at (021) 914-8898. See you there!
Whether you’re one of the ±500,000 South Africans living with epilepsy, or have friends or family affected by the neurological disorder, a new app serves as an excellent resource for your iPhone, iPad or iPod touch.

Called E-Action Info, this free App Store download provides medical info, media and an educational game - all designed to educate people about epilepsy in a clear, accessible manner.

For those living with epilepsy, the app covers management tips, a FAQ (Frequently Asked Questions) section, an interactive and colour-coded 3D model of the brain (zoom and rotate to learn about all of its areas and functions), links to epilepsy associations and the option to start a journal, called MyEpilepsyDiary, to help keep an accurate account of when seizures happen.

Be aware, however, this diary feature links to a login page at epilepsy.com as opposed to an integrated diary located within the app. While this requires an Internet connection, at least the info is not located on the iOS device itself, which could be a privacy issue if lost, stolen or damaged. Users are encouraged to login with a password to track their seizures, medicines and progress – all of which are accessible on a computer, Smartphone, tablet or other device with a web browser. If desired, users can share this information with their physicians to optimize treatment, plus there’s an option to request therapy reminders by email, text or Smartphone notification.

E-Action Info was also designed for those close to someone living with epilepsy. For example, along with educational info and a video (Internet connection required), there’s a section on the different kinds of seizures and a helpful First Aid resource for caregivers and the public (that is, what to do if you witness someone having a seizure).

(Credit: Marc Saltzman, Special reporter for USA TODAY, http://www.usatoday.com/story/tech/columnist/saltzman/2013/04/09/e-action-epilepsy-resource/2067787/)

EILEPSY AROUND THE WORLD – REPORTS FROM OUR COLLEAGUES

Listed below are four short videos covering the areas of the developing brain, paediatric surgery and treating children with epilepsy in Africa, presented by experts in the field from around the world.

• Our first video from Helen Cross (United Kingdom) covers the realistic expectations of
Maternal use of valproate (a drug used for the treatment of epilepsy and other neuropsychological disorders) during pregnancy was associated with a significantly increased risk of autism in offspring, according to a study in the April 24 issue of JAMA. The authors caution that these findings must be balanced against the treatment benefits for women who require valproate for epilepsy control.

“Anti-epileptic drug exposure during pregnancy has been associated with an increased risk for congenital malformations and delayed cognitive development in the offspring, but little is known about the risk of other serious neuropsychiatric disorders,” according to background information in the article.

Jakob Christensen, Ph.D., of Aarhus University Hospital, Aarhus, Denmark, and colleagues evaluated the association between maternal use of valproate during pregnancy and the risk of autism spectrum disorder and childhood autism in offspring. The population-based study included all children born alive in Denmark from 1996 to 2006. National registers were used to identify children exposed to valproate during pregnancy and diagnosed with autism spectrum disorders (childhood autism [autistic disorder], Asperger syndrome, atypical autism, and other or unspecified pervasive developmental disorders). Data were analyzed and adjusted for potential confounders (factors that can influence outcomes) such as maternal age at conception, paternal age at conception, parental psychiatric history, gestational age, birth weight, sex, congenital malformations, and parity. Children were followed up from birth until the day of autism spectrum disorder diagnosis, death, emigration, or December 31, 2010, whichever came first.

The analysis included 655,615 children born from 1996 through 2006. The average age of the children at end of follow-up was 8.8 years. During the study period, 5,437 children were diagnosed with autism spectrum disorder, including 2,067 with childhood autism. The researchers identified 2,644 children exposed to antiepileptic drugs during pregnancy, including 508 exposed to valproate. The authors found that use of valproate during pregnancy was associated with an absolute risk of 4.42 percent for autism spectrum disorder and an absolute risk of 2.50 percent for childhood autism.
“In this population-based cohort study, children of women who used valproate during pregnancy had a higher risk of autism spectrum disorder and childhood autism compared with children of women who did not use valproate. Their risks were also higher than those for children of women who were previous users of valproate but who stopped before their pregnancy,” the researchers write. “Because autism spectrum disorders are serious conditions with lifelong implications for affected children and their families, even a moderate increase in risk may have major health importance. Still, the absolute risk of autism spectrum disorder was less than 5 percent, which is important to take into account when counseling women about the use of valproate in pregnancy.”

Kimford J. Meador, M.D., and David W. Loring, Ph.D., of Emory University, Atlanta, write in an accompanying editorial that “women of childbearing potential should be informed of the potential risks of fetal valproate exposure before valproate is prescribed.”

“Despite the established risks of fetal valproate exposure, valproate continues to be a common treatment in women of childbearing age. Valproate is an effective drug, but it appears that it is being prescribed for women of child-bearing potential at a rate that does not fully consider the ratio of benefits to risks. This raises concern as to whether these women are receiving adequate information for informed consent based on a full understanding of the treatment risks and alternative therapies.

Given the accumulating evidence linking fetal valproate exposure to congenital malformations, cognitive impairments, and autism, the use of valproate in women of childbearing potential should be minimized. Alternative medications should be sought. If no alternative effective medications can be found, the lowest effective dose of valproate should be used.


National Epilepsy Week is celebrated annually to raise awareness about epilepsy, a neurological condition characterised by unusual electrical activity in the brain.

This year, National Epilepsy Week will be celebrated from 17 – 23 June with the theme, “Licence to Chill”.

The idea behind the theme is to give people the opportunity to take 15 minutes out of their busy schedules on National Epilepsy Day (21 June), to reflect and give thought to people with epilepsy.

The “Licence to Chill” can be obtained by taking part in Epilepsy South Africa’s cupcake challenge.

All you need to do is bake a cupcake, take a picture of it, share it on the organisation’s social media sites and get your friends to vote for your entry.

There are a number of myths and social stigmas associated with the condition. The goal of National Epilepsy Week, apart from raising awareness about epilepsy, is to dispel these myths and stigmas.

Limited public understanding of the condition has been found to contribute to stigma by breeding negative attitudes towards epilepsy itself and to people with epilepsy. Stigma has been shown to have a negative effect on seizure control and quality of life in epilepsy patients, with them often choosing to withdraw socially to cope with the discrimination and stigma.

As National Epilepsy Week focuses on educating the public about the right of people with epilepsy we decided to go with this theme to give people the chance to think about the reality of the condition and what it would be like to live with it.

For more information about National Epilepsy Week, contact us on 0860 EPILEPSY (0860 374 537) or visit www.epilepsy.org.za.

The 30th International Epilepsy Congress will be held in Montreal, Canada between 23 and 27 June 2013.

For more information visit: www.epilepsymontreal2013.org