



December 2008

Dear Valued Subscriber to the Epilepsy South Africa Newsletter

Epilepsy South Africa has the privilege of working with people that have epilepsy and/or other disabilities. 2008 has been an exciting year for Epilepsy South Africa and we are happy to report that our organisation is doing well and achieving our goals and objectives. This would not have been possible without the support of our donors, funders, partners, members, family and friends. Thank you so very much for your continued support and assistance!

We continually see what the donations of money, time or in-kind do for those directly or indirectly affected by the condition. By showing interest in the organisation's electronic newsletter, you present us with the opportunity to bring awareness and this is seen as a donation of time.

It is our sincerest desire that you experience the same encouragement that you provide us with. We therefore want to wish you, your company and family a blessed and happy holiday season! May you experience a wonderful and special time with your family and friends during this period. Please travel safely and know that your assistance during 2008 will carry us into the new year of hope toward stepping up to the next challenge.

I also want to thank all the personnel members of Epilepsy South Africa for their hard work and dedication during the year. I hope that you will enjoy a joy-filled and peaceful festive season with your family and friends. Please also travel safely and may we return to work refreshed and ready for the challenges of 2009.

Noëline de Goede
NATIONAL DIRECTOR
Epilepsy South Africa National Office

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Epilepsy South Africa, Free State and North West Branch thanks the Voorspoed Mine!



On Friday 28 November 2008 Epilepsy South Africa Free State and North West Branch was visited by delegates of the Voorspoed Mine (De Beers Consolidated Mines Ltd). Renska Deetlefs (of Voorspoed Mine) told the residents that they are as special as the diamonds that they mine. It certainly left them all feeling valued and the treatment echoed this message. After they spoiled our residents with cake and soft drinks, she played organ and sang songs that the residents knew and enjoyed thoroughly.

They have arranged a special function for our residents staying in the Parys Centre and surprised us with two cheques. The staff of the Human Resource, Admin, Public and corporate affairs department raised R 6000.00 toward our residential care facility. Their management donated a further R 10 000. The cake used to celebrate this occasion was donated by Pick 'n Pay Panorama in Kroonstad and the transport was provided by Visco to and from the Centre. It just shows that people can come together to present something great.

The residents and staff of Epilepsy South Africa Free State and North West Branch wish everyone at the mine a Blessed Festive Season. This donation will help our Centre to go that second mile over this Festive Season. Thank you for making the personal effort to come and visit us.

Picture: The staff of Voorspoed mine handing over the Cheques to Mr Gary Westwood, Director of the Free State and North West Branch of Epilepsy South Africa

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The Jo Ellis Band moves, and still supports Epilepsy South Africa!



We received this report from the band, who stands proud to be ambassadors for Epilepsy South Africa, seeing that Zaan Ellis (the drummer) lives as a positive example of a person with epilepsy.

Their report for 1 December 2008:

We're extremely pleased to announce that our new album is finally done and available online from www.soundclick.com/joellisband where you can download it FOR FREE!!! Yes, that's right: It's called "Vent" and contains 13 new songs that you can download and share with whoever you want for absolutely no charge. The launch of the album coincided with a great WORLD AIDS DAY-gig on 1 December in George where we have played with a number of other artists. We decided that we would do this album launch a little differently and let the people who support us the most - our friends on Facebook, our website mailing list, those who come to see us play live and our friends at Epilepsy South Africa - know about it first. In the coming months we will be doing a big album-launch tour and the usual media stuff, but for now we just want you guys to enjoy it first as a way to say thanks for the continued support.

Because we know that some folks still want to buy CD's or are not in the position to download the album we will still have CD's at gigs at a minimal cost. Feel free to contact us at jo@joellis.co.za if you would like a CD sent to you.

Rock 'n Roll, The Jo Ellis Band, www.joellis.co.za

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Feedback on our Pilot Disability Internship programme: (Western Cape Branch)

The Pilot Disability Internship Programme with the Department of Social Development was developed in response to the requests from the disability sector for support in developing and improving access to the world of work for Persons with Disabilities who have graduated from institutions of higher learning. The main purpose of this project is to increase employment opportunities for disabled graduate students and to create awareness and understanding of how health and disability issues affect young people locally.

One of our interns, Buyiswa Jack who is visually impaired had the opportunity to attend

computer literacy and SIYB course These were offered by the Cape Town Society for the Blind. Buyiswa has shared that this has been a very exciting and interesting experience for her. For the first time she was introduced to working with computers and has now acquired the skill of computer literacy. The SIYB course gave her the opportunity to interact and work within a group. She was the only visually impaired person there, and was involved in preparing presentations. Through attendance of these courses, Buyiswa showed acceptance of her disability and learnt to be confident and independent. Buyiswa proudly said that she started to travel independently using public transport to attend these courses. She further claimed that she now feels confident to go into a workplace and utilise the skills that she has acquired.

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Epilepsy Seminar, 25 October 2008 - “Youth with a Future”(Western Cape Branch)



This year, our third annual epilepsy seminar was hosted at Red Cross Children’s Hospital. The theme for this year Was Youth with a Future, and the turnout was great. We had educators from Special schools, clients from our projects and workshops and community members. The morning began with the specialist doctors doing talks on various aspects of epilepsy. After tea, we had speakers from tertiary institutions informing us about the options available for people with disabilities and how their campuses have evolved to accommodate them. Kai Fitchen also did an inspiring presentation on his quest to summit Mount Kilimanjaro in January 2009. The morning ended on a positive note and people left there feeling optimistic about the future.

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Disability Awareness Day, 18 November 2008 – “Celebrating Disability with Dignity”(Western Cape Branch)



Epilepsy South Africa Western Cape Branch in collaboration with Rehoboth Age Exchange and the Department of Social Development, Athlone District, hosted a Disability Awareness Day on Tuesday, 18th November 2008. The event was held in Hanover Park at the Rehoboth Age Exchange Centre with the theme, "Celebrating Disability with Dignity." The programme for the day focussed on creating awareness about the Rights of People with Disabilities by using the Disability Rights Charter. The Right to Non-Discrimination and the Right to Education was work shopped with the delegates through various role-plays and other engaging activities. Approximately 250 persons were in attendance. This consisted of children from special schools, the aged from Rehoboth and the parents and caregivers/teachers of children/people with disabilities. All in attendance, from young to old were given the opportunity for their voices to be heard, sharing and expressing their opinions. The impact of this intergenerational workshop was phenomenal and the event a huge success!

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International Day for Persons with Disabilities 3 December 2008:



As motivation for observing the International Day of Persons with Disabilities, we share some extracts from the Programme of the International Day at UN headquarters, NY.

Dignity and justice for all of us is the theme of this year's International Day for Persons with Disabilities, as well as for the 60th anniversary of the Universal Declaration of Human Rights.

Dignity and justice for all persons are established universal principles. Since its inception, the United Nations has recognized that the inherent dignity and the equal and inalienable rights of all members of the human family are the foundations of freedom, justice and peace in the world. These principles, along with equality and non-discrimination, have guided the work of the United Nations for the past 60 years and are enshrined in various instruments such as the UN Charter and the Universal Declaration of Human Rights, as well as in

treaties such as the International Covenants on Human Rights, and the Convention on the Rights of Persons with Disabilities. These instruments are among those which make up the international human rights framework, are complementary and reaffirm that all human rights are universal, indivisible, interrelated, interdependent and mutually reinforcing.

2008 is a significant year in the international human rights movement given the entry into force on 3 May of the Convention on the Rights of Persons with Disabilities and its Optional Protocol, legally binding instruments which set out the legal obligations of States to promote and protect the rights of persons with disabilities, as well as the 60th anniversary of the Universal Declaration of Human Rights (UDHR). Article 25 of the UDHR provides that each person has "the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control". Several articles in the Convention on the Rights of Persons with Disabilities expound on this right to security, including article 10 on right to life and article 14 on liberty and security of person. Article 28 is more specific in that it asks that States Parties take steps to safeguard and promote that realization of the right to an adequate standard of living and social protection, including ensuring "access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care". These instruments mark a clear reaffirmation that persons with disabilities have the right to full and equal enjoyment of their human rights. They also mark a clear reaffirmation of the principles of 'dignity and justice for all of us'.

Around 10 per cent of the world's population, or 650 million people, live with disabilities. The Convention promotes and protects the human rights of persons with disabilities in civil, cultural, economic, political, and social life. However, all over the world, persons with disabilities continue to face barriers to their participation in society and are often forced to live on the margins of society. They are routinely denied basic rights such as to equal recognition before the law and legal capacity, freedom of expression and opinion, and the right to participate in political and public life, such as voting. Many persons with disabilities are forced into institutions, a direct breach of the rights to freedom of movement and to live in the community.

Eighty per cent of persons with disabilities – more than 400 million people – live in poor countries and there is a strong link between disability and poverty. For example, the statistics on employment for persons with disabilities are staggering. In developing countries, 80 per cent to 90 per cent of persons with disabilities of working age unemployed and in industrialized countries it is estimated to be between 50 per cent and 70 per cent. The rights to education and health are also routinely denied. Ninety per cent of children with disabilities in developing countries do not attend school, says UNESCO.

Approximately 20 million women acquire disabilities as a result of complications during pregnancy or childbirth. This continued marginalization against persons with disabilities highlights the need for all States to sign, ratify and implement the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

The United Nations and the global community must ensure that all its work is inclusive of persons with disabilities. The Millennium Development Goals will not be achieved if persons with disabilities are not included. Efforts to achieve the MDGs and implement the Convention are interdependent and mutually reinforcing.

On this International Day of Persons with Disabilities, as well during the year-long celebration of the 60th anniversary of the Universal Declaration of Human Rights, let us use

“dignity and justice for all of us” as a rallying call, as these principles are far from being realized for everyone. Dignity and justice are embodied in the civil, cultural, economic, political, and social rights promoted by the Convention. Therefore, the International Day of Persons with Disabilities is a time to make a renewed commitment to the ratification and full implementation of the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

One of the fundamental obligations contained in the Convention is that national law should guarantee the enjoyment of the rights enumerated in the Convention. States Parties should thus consider the best ways of giving effect to the rights guaranteed by the Convention in domestic law. Implementing legislation should include the terms of the Convention or a specific reference to them, in order to indicate clearly that the laws should be interpreted in accordance with the letter and spirit of the Convention.

Legislation alone will not ensure that persons with disabilities can enjoy their human rights. States will need to formulate effective policies and programmes that will transform the provisions of the Convention into practices that will have a real impact on the lives of persons with disabilities. For persons with disabilities, as for all persons, the denial of one right can lead to the denial of other rights and opportunities throughout their lives. Article 33 explains that States must set up national focal points governments in order to monitor implementation of the Convention's precepts. States must also set up independent monitoring mechanisms, which usually take the form of an independent national human rights institution.

The full participation of civil society, in particular persons with disabilities and their representative organizations, is essential in the national monitoring and implementation process. International monitoring is achieved via the Committee on the Rights of Persons with Disabilities and the Conference of States Parties. The first meeting of the Conference of States Parties was held on 31 October and then 3 November 2008.

This International Day for Persons with Disabilities is a time to make a renewed commitment to these principles of dignity and justice and to ensure implementation of the Convention on the Rights of Persons with Disabilities. All human beings are not only entitled to rights, but also have the responsibility of making universal human rights a reality for all of us.

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10th Cheff's Cookout, Epilepsy South Africa in Dulstroom:



We eventually had our 10th cook-out on the 5th November 2008 and it was very successful. We can only thank all the participating restaurants that made it happen. It would have been an evening with no "main course"!

Secondly we would like to extend our big "thank you" to all the supporters of that day. We can sincerely say that we would not have made it without your support and we can confidently say that we know you have enjoyed the evening with us.

Everything was made possible by some very involved and good hearted sponsors. The overwhelming generosity of couples, individuals and businesses in Dullstroom are so encouraging. It all contributed to the success of the chef's cook-out.

We want to mention the following entities for contribution toward the event, and therefore toward Epilepsy South Africa (Note how many hands it takes to make this happen, we really appreciate it) : Nottingham Road Hotel – KZN, Kloppenheim Country Estates – Machado, Walkerson's Hotel, Mrs. Simpson's, The Duck and Trout, Old Transvaal Inn, Green Olive Deli, Dullstroom Butcheries, Bobaas Biltong, Millie's Trout, The Rose cottage, Simply Carols, The clock shop, 2Chefs, Lydenburg Toyota, SA Trout, Lydenburg Abattoirs, Lydenburg Longtom Spar, Bergen Cheese & Wine, NH Kerk, Almar Groente, Dullstroom Country Bottle Store, Mavungana, Dunkeld Country Estates, Coastal Hire.

The best chef "winner" goes to Canimambo - Nando

The centre closes on the 12 December for the festive season. We have residents that stay behind with no one to visit. We want to invite you to send Christmas gifts and messages to encourage them during this festive season when you are enjoying your family.

We will be back again on the 12 January 2009.
We wish you a merry Christmas and a prosperous Happy New Year.

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Jonty at Delta Park in Johannesburg, on behalf of Epilepsy South Africa!



The Epilepsy South Africa Gauteng Branch had the privilege to walk a road with the Delta Park School students and teachers on - "Living with epilepsy!". With some individual cases enjoying preference, they also realized that the rest of the school needs to be equipped and prepared to cope with the ripple effect of the condition. It is always easier to live amongst people that understand the condition and people that do not discriminate or add to the stigma.

Jonty Rhodes is a good friend of the organisation and was nominated to feature in an M-net show where he could mention his "Cause". He used this opportunity to talk to the students of Delta Park School in Johannesburg. It could not have come at a better time, right before the exams. He presented a practical and motivational message to the students, and the whole crowd stepped out smiling and believed that they could also achieve despite the obstacles they face. He continues his message of "that one run that wins the match."

The program was aired on 22 November and we believe that people were made aware of the condition and that some reasons for stigmatising was shattered with a cricket bat!

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Buy your Christmas Products from us!



We still have some Christmas ornaments left and would love to see it hanging on your tree. Please contact us to place your order and enjoy a prettier season whilst supporting our good cause.

funddev.no@epilepsy.org.za

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A plan please? (Epilepsy South Africa South Cape and Karoo Branch)



One of the projects that Epilepsy South Africa takes pride in is our food gardens. With the heavy rains of the past weeks, the vegetable garden at Epilepsy South Africa in Knysna took a hard knock. This branch runs a residential care facility for people with epilepsy and other disabilities and the garden provides for 50% of the centre's vegetable requirements. The garden is at the foot of the centre which is situated on the top of one of the hills overlooking the famous Knysna Heads and the lagoon.

The slope is steep and Wilberforce Lindi, the clever gardener had to make plans to build terraces and trenches to enhance the chance of a crop being delivered. All efforts lead to a discouraging dead end in November when Wilberforce had to quietly look upon vegetables falling into the donga created by streams of water coming from above.

We realized that this is not only his problem and want to share in his quest to find an answer. If one of our electronic newsletter subscribers has experience in this field, we would gladly listen to suggestions and welcome any contributions to turn the garden into the Garden of Eden again.

Contact Mrs. Vivien Paramoer at branchdirector.sck@epilepsy.org.za

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