

Drikie Snyman

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

Sent: 17 September 2009 12:44

To: marketing.no@epilepsy.org.za

Subject: September 2009 Newsletter



September 2009

Dear Subscriber

Michelangelo, the Italian Renaissance painter, sculptor, poet and engineer said: "The greatest danger for most of us is not that our aim is too high and we miss it, but that it is too low and we reach it."

This has certainly become the guideline and mantra for the National Office of Epilepsy South Africa. This means that we have set high goals and that we are running the risk of not meeting these. However, to the team at the National Office this is preferable to aiming too low.

This attitude has already resulted in a successful wine auction held in June this year and a photo shoot with achievers with epilepsy, including Jonty Rhodes and Pieter Walser. All of this forms part of "getting the message out there about epilepsy" which is the main focus of the National Marketing Programme. You have also contributed to this programme, simply by reading this newsletter. Why not forward it to your friends, family and colleagues to maximize your contribution to creating awareness about epilepsy?

August was (as always) a busy month, but probably more so for our National Director, Noëline de Goede and her husband Jaco. 19 August 2009 saw the arrival of Marli, sister to Corné who will turn 2 years old in December. Typical of a woman, Marli could not wait until her due date and arrived earlier than expected. While this resulted in a rather hurried hand-over for Noëline and the National Office staff, we wish her and her family joy and happiness.

The Epilepsy South Africa Job Grading Committee met early in August in Cape Town to review job grading within the organization. This process will inform the policy review later this year. In addition, the National Department of Social Development visited the National Office on 7 August to review work carried out in terms of the service level agreement for the 2008/2009 financial year and to discuss the 2009/2010 business plan.

One of the highlights during August was a visit to the Eastern Cape by the National Social Development Manager and National Economic Development Manager which focused on the establishment of a new Branch in this underserved province. The National Office has concluded an agreement with the YANA (You Are Not Alone) support group in King William's Town which will result in the establishment of this Branch before the end of the current financial year. This represents the achievement of a goal set some years ago. You can read more about this development in the article below.

Another example of the networking activities of the National Office is an agreement with the South African Federation for Mental Health (SAFMH) to host a Start and Improve Your

Business (SIYB) Training of Trainers (TOT) seminar in Johannesburg from 8 to 20 November 2009. More information is provided in the article below.

Every year the arrival of spring heralds Casual Day celebrated on the first Friday in September. This year the 4th of September dawned bright and sunny in the northern provinces, but grey, windy and wet in the Western Cape. Despite this, the National Office thanks all our supporters who purchased stickers to show their support for people with disabilities. Read more about the biker's rally and music festival hosted by the National Office in cooperation of the Rev Limiters and Plaasteater at the Plaasteater in Brackenfell. . Epilepsy South Africa wishes all our Muslim readers "Ramadan Mubarak to you and your family".

Yours faithfully

Marina Clarke

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

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Casual Day with Bikers and Bands: (National Office)

Epilepsy South Africa National Office is a happy partner in Casual Day. We endeavour to promote supporting this National Fundraiser for people with disabilities during July and August each year to culminate the first week of September. The National Office combined the celebration of this day with an interesting group of musicians and motor bikers that showed interest in supporting this day and especially supporting - Epilepsy South Africa.



The 5th of September marks the great motor cycle rally that took place from Acces City, Northern Suburbs of Cape Town to the Plaasteater, a wonderful venue in the midts of the winelands. The day was filled with food and fun in the form of music, and jamming it all together was a wonderful sunny day. The organisation often sees people being creative in showing their support through what they know and in what they do best. This is the first of many such events and we invite you to join us for the next event. Don't miss out, it will become the place to be!

A big thank you to the Plaasteater, Rev Limiters, Chattanooga, Stone Age, Mr Cat & the Jackall, and Sequence!

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On a fun note... the branch celebrated another successful Casual Day on the 4th September. Casual Day is a national fundraiser that benefits organisations that renders services to people with Disabilities. The branch distributed in excess of 16000 stickers to companies, schools, members of the public and other sectors who showed their commitment to support people with disabilities. We would like to thank Annalise DeJager and her team for organising this fantastic project. A huge thanks of appreciation goes to all who support us this years!



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Epilepsy South Africa Western Cape Celebrates 40 Years of Development

The Western Cape Branch of Epilepsy South Africa hosted it's AGM on the 27th August and it was well attended by our members, representatives of various Non Profit Organisations and also the local press. The Branch Chairperson highlighted our commitment to improve the quality of lives of people with epilepsy and thanked all our partners, volunteers, donors and funders for enabling us to achieve this vision.

Amelia Jones (picture included), CEO of Community Chest, shared her memories of our journey from being located in a garage and containers to where we are today...

proudly located in Lansdowne that accommodates our regional office and protective workshop. Tim De Villiers, the newly elected Epilepsy South Africa National Chairperson shared his journey as a person with epilepsy and inspired others with handy hints as to how to overcome obstacles towards reaching their full potential. The Regional Director, Wendy Nefdt reflected on the past 10 years and stated that despite challenges and transformation taking place in a post democratic South Africa, Epilepsy South Africa has kept abreast with the rapid pace change and has proudly transformed in keeping with the new democracy and focus on human rights and social justice. During the period, the organisation has grown from strength to strength in its vision, programmes and human resource capacity. Our annual report highlights our programmes and is available at our offices.



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Free Transport for People With Disabilities

(Press release ACSA Disability 2009, For Immediate Release, 7 September 2009)

Free transport for people with disabilities is being arranged by Metrobus for this year's ACSA Disability Expo and Conference 2009. The show – which is the only event of its kind catering for people with any kind of disability and will feature a range of products, services and lifestyle options - takes place from 17 to 19 September 2009 at Gallagher Convention Centre, Midrand.

Six special needs buses will be used to ferry people with disabilities and their families to and from ACSA Disability 2009. Five routes have been structured so that areas such as Johannesburg Central Business District (CBD), Hillbrow, Soweto, Alexandra and Roodepoort are covered - ensuring that people with disabilities from all backgrounds have access to this event. Pick-up at these various point will occur at 09h00 daily and buses will depart from Gallagher Convention Centre at 15h00 each afternoon. A dedicated hotline number, 078 018 0891, has been set up for any questions regarding transport to the show. People can SMS their questions to the hotline number and they will be contacted by friendly staff that will assist.

Commenting on the special transport arrangements being made by Metrobus, Justin Maree, spokesperson for ACSA Disability 2009 said: "We are delighted to be able to offer transport for people with disabilities, thanks to Metrobus. Our Vision is to make the show accessible to all. The lack of adequate transport facilities for people with disabilities has prevented many people from visiting the show. Through Metrobus' support, we can begin to address this."

Metrobus is a proud sponsor of ACSA Disability 2009. Kenney Kutu, Marketing and Business Development Manager, adds: "Metrobus demonstrates its willingness to assist wherever possible, to make life a little easier for persons who have to battle with disabilities in their daily lives. We are excited to be a part of this venture."

As the only municipal-owned transport service provider operating in the Greater Johannesburg area, Metrobus has fulfilled its social responsibility towards residents who have disabilities. Since 1997, Metrobus has catered for their special needs.

Kutu explains: "When Metrobus purchased 128 new buses from Mercedes-Benz (Daimler Chrysler) in 2006, it was important to include the purchasing of six special needs buses as well. These buses are equipped with hydraulic wheelchair lifts which hoist the wheelchair safely into the bus, where it can be strapped securely to ensure a safe journey. All special needs buses have steps which can be lowered to facilitate safe, easy boarding for passengers with disabilities."

ACSA Disability 2009 is committed to improving the lives of those with developmental and physical disabilities, their families, care-givers and professionals who work with them.

Target Audience

Targeting both trade and consumer audiences, ACSA Disability 2009 is aimed at anyone involved in purchasing equipment and services, as well as all end-users, carers and healthcare professionals. This includes: government (correctional services, defence, health, education, transport), private clinics, hospitals, medical specialists, orthopaedics, physiotherapists, the sports industry, shopping centres, old age homes, special schools, aid agencies and non-governmental organisations, employment agencies, pharmacists, orthotists, orthopaedic surgeons, prosthetists, disabled homes and institutions, clinics and hospitals, the corporate sector and consumers.

Supporting Organisations

The following Associations support the event:

SA Disability Alliance, including:

- Autism SA
- Cheshire Homes
- Deaf Federation of South Africa (DEAFSA)
- Disabled People South Africa (DPSA)
- Down Syndrome South Africa (DSSA)
- Epilepsy SA
- The QuadPara Association of South Africa (QASA)
- National Council for People with Cerebral Palsy (NAPCP)
- South African Federation for Mental Health (SAFMH)
- South African National Council for the Blind (SANCB)

Products on show include ADLS (assisted daily living equipment and service); communication aids; computers; easy reaches; emergency medical supplies; hand cycles; hearing aids; hospital furniture; mobility aids; occupational products; patient handling devices; physio equipment; products and aids for the deaf and blind; prosthetic artificial limbs; showering devices / building products; sports equipment; training institutions; walking sticks; wheelchairs; wheelchair clothing and, much more! And best of all, entry to the expo is free.

Conference

A two-day Conference runs alongside the Expo. On 17 September the focus will be on the FIFA 2010 Soccer World Cup and how ready the country is to accommodate people with disabilities for this global event. Speakers from Gautrain, the Tourism Grading Council and MATCH Event Services will address delegates on what that their organisations are doing to provide reasonable accommodation for soccer fans and their families. Day two will bring disability in the workplace under the spotlight.

Airports Company South Africa (ACSA) is a major sponsor of this year's event. Media partners for this year include Rolling Inspiration Magazine and SABC 1.

For more information on ACSA Disability 2009, please contact: Justin Maree of Fair Consultants SA. Tel: (021) 713 3360. Fax: (021) 713 3366.
E-mail: justin@fairconsultants.com Website: www.fairconsultants.com

ENDS
738 words

Date Issued: 7 September 2009
Published by: CVLC
Contact Person: Catherine Larkin
Telephone: (011) 789-7327 / 083 300 0331
Fax: (011) 787-7865
E-mail: catherine@cvlc.co.za
Postal Address: P O Box 44945, Linden, 2104

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International Symposium on Epilepsy in Neurometabolic Diseases

The International Symposium on Epilepsy in Neurometabolic Diseases (ISENMD) & 13th Infantile Seizure Society Meeting are offered by the Taiwan Child Neurology Society (TCNS) and Infant Seizure Society (ISS), from March 26th to 28th, Taipei, Taiwan.



Our Conference President, Dr. Ein-Yiao, Shen and Chairman of ISS, Dr. Yukio Fukuyama, together with the whole organizing committee have put together an abundant and informative program and also invited global renowned experts and specialists world wide. The 2010 conference in Taipei will attract around 500 professionals over 15 countries.

For more information and online registration, visit the Conference website at <http://www.isenmd2010taipei.org>

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People with Disabilities Continue to be Marginalised in the Workplace

(ACSA Disability 2009, For Immediate Release, 8 September 2009)

Despite the introduction of the Employment Equity Act and the implementation of the Integrated National Disability Strategy (INDS) White Paper, the number of people with disabilities employed in the workplace has not increased significantly. This is according to Ari Seirlis, National Director of the QuadPara Association of South Africa (QASA), one of the participating organisations in the ACSA Disability Expo and Conference which takes place from 17 to 19 September 2009 at Gallagher Convention Centre, Midrand. Disability in the workplace will be high on the Agenda at the ACSA Disability Conference on 17 September, when speakers from both the public and private sectors address issues such as recruiting people with disabilities, providing reasonable access and dealing with barriers facing people with disabilities in the work environment.

The Conference is endorsed by the South African Disability Alliance, which comprises twelve national organisations that represent disability in South Africa. The Alliance is dedicated to supporting business in understanding disability and incorporating people with disabilities in opportunities and activities into mainstream society. SADA represents a community of approximately 8% of the country's population – close to 3.8 million people - as well as the demographics thereof.

Topics that will be discussed include:

- Employers' perspective and recruitment of people with disabilities
- Employers' perspective on challenges and barriers for reasonable accommodation - Thuli Matlala, CSI Practitioner, Barloworld.
- Corporate perspective on reasonable accommodation
- South African Employers for Disabilities, a perspective on challenges and barriers facing disabled people at workplace

Seirlis alludes to the reasons why people with disabilities do not have equal opportunities to jobs. "There is a lack of integrated and accessible public transport for people with disabilities. Secondly there is not a co-ordinated database of people with disabilities who are looking for employment. This is compounded by the lack of understanding of the potential of people with disabilities in the workplace."

"Economic empowerment of people with disabilities is vital if our economy is to achieve sustained economic growth', continues ACSA Disability 2009 conference spokesperson Justin Maree. "There are however opportunities for both the public sector and private sector to include this grouping in the workplace, which will benefit all stakeholders. The Conference provides an opportunity for employers and people with disabilities to learn about what tools and information are available to facilitate access to the workplace and mainstream society by people with disabilities."

Estimates are that between 5 and 12% of South Africans are moderately to severely disabled. However this group of South Africans is often marginalised with respect to all types of services. Despite legislation people with disabilities have not been fully embraced as part of mainstream society.

"Employers view disabilities as a liability, as they feel they need to invest more money on infrastructure when employing people with disabilities," comments Thuli Matlala, Corporate Social Investment (CSI) Practitioner, Barloworld. "However this is unacceptable. People with disabilities can make an extremely valuable contribution and contribute equally alongside fellow workers, if employers remove the unfair discriminatory barriers in their offices and make reasonable accommodation for their needs. In addition a small amount of effort and a little understanding can go a long way to make the lives of people with disabilities more accessible and free. People with disabilities are people too; they deserve a chance at a full life with equal opportunities."

Thuli continues, "People with disabilities need to be mainstreamed into the open labour market so that they become better equipped to use their talents to become independent and thus will not rely on social grants for their livelihood."

The "Ag, Shame" phenomenon linked to fear and ignorance is rife in the workplace. It is often thought that people with disabilities are unable to do their jobs because of their

disability. This attitudinal behaviour needs to be addressed by sensitising non-disabled co-workers to treat people with disabilities as they would non disabled people. Seirlis adds: "Sensitisation needs to be addressed within and by the Department of Education. Children should enjoy inclusive education. All employers need to do is provide people with disabilities with what they need to carry out their job in the form of reasonable accommodation and not to overcompensate because of the disability."

Some simple cost-effective things that employers can do to make their workplace more accessible are:

- Adapting existing facilities to make them accessible and universal
- Adapting existing equipment and technology including computer hardware and software;
- Re-organising work stations;
- Changing training and assessment materials and systems;
- Restructuring jobs so that non-essential functions are re-assigned;
- Adjusting working time and leave; and
- Providing specialised supervision, training and support in the workplace.

Seirlis also suggests a number of strategies to assist employers in recruiting people with disabilities. These include networking with disability agencies, introducing "interview skills" for first-time potential employees, assisting with CV writing, and developing the self-worth of people with disabilities. "Workplace simulation" workshops for potential employees are also an excellent interactive tool.

Maree concludes: "The ACSA Disability Conference is an essential meeting ground for government, people with disabilities and other stakeholders to exchange ideas on the way forward to making people with disabilities become fully integrated members of society".

At this year's event visitors will be able to:

- Visit exhibitors of products and services aimed at people with disabilities.
- Meet with a number of disability associations and organisations working in the disability sector.
- Learn about the latest developments in technology to assist the disabled.
- Be entertained by a variety of displays, demonstrations and activities.

Supporting Organisations

The following Associations support the event:

SA Disability Alliance, including:

- Autism SA
- Cheshire Homes
- Deaf Federation of South Africa (DEAFSA)
- Disabled People South Africa (DPSA)
- Down Syndrome South Africa (DSSA)
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For more information on ACSA Disability 2009 Conference please contact:

Fuzlin Esau of Fair Consultants on:

(021) 713 3360

(021) 713 3366 (fax)

conferences@fairconsultants.com

www.fairconsultants.com

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Published by: CVLC
Contact Person: Catherine Larkin
Telephone: (011) 789-7327 / 083 300 0331
Fax: (011) 787-7865
E-mail: catherine@cvlc.co.za
Postal Address: P O Box 44945, Linden, 2104

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Epilepsy South Africa site visits and training in the Eastern Cape

(By Karen Robinson)

Introduction: The National Social Development Manager, Karen Robinson and the National Economic Development Manager, Marina Clarke visited the Eastern Cape from the 11-14 August 2009 to market Epilepsy South Africa's proposed project plan, gather information at the networking meetings (government and civil society) and to conduct training with identified project partners. The meetings were combined with training that was done with the Department of Economic Development and Environmental Affairs on epilepsy awareness in Eastern Cape.

A presentation was done at these networking meetings which focused on the following issues:

- Need Analysis
- Social development approach
- Multi-model approach
- Target market
- Possible Project Partners
- Project Plan

The training that was facilitated with the Department of Economic Development and Environmental Affairs focused on:

- What do I know of epilepsy?
- What is epilepsy?
- What causes epilepsy?
- What causes seizures?
- Types of epilepsy
- What to do if someone has a seizure?
- How to I deal with someone with epilepsy?
- Epilepsy in the world of work

Background

During a strategic planning exercise conducted in November 2004, EPILEPSY SOUTH AFRICA identified a need for development services in previously unserved/undeserved areas, with specific reference to the Eastern Cape and Northern Cape. It was thus decided to implement development programmes focused in these provinces with the view to ensure service delivery to and empowerment of people with epilepsy and related disabilities, as well as those persons affected by the condition.

A site visit was conducted from the 27 June to 1 July 2005 by the National Director, Noëline De Goede and the National Economic Development Manager, Marina Clarke in order to determine the needs in respect of service delivery towards people within the province.

On the 1st of March 2006, Epilepsy Support Group 'You Are Not Alone'(YANA) was created. It started with just 2 people, Lynn Jansen Van Rensburg (who had undergone neuro-surgery to control her epilepsy on the 1st of March 2005) and Gail Stratford. There are now over 320 people on the YANA contact listing. The support system is mostly done through internet emailing, sms and telephonically. In October 2008 EPILEPSY SOUTH AFRICA established a partnership with Lynn Jansen Van Rensburg, from the You Are Not Alone support group.

During a brainstorming and planning session held at the Epilepsy South Africa National Office on 6 July 2009 it was agreed that this project would aim to integrate social, economic and skills development to benefit people with epilepsy and/or other disabilities and to establish an EPILEPSY SOUTH AFRICA EASTERN CAPE BRANCH.

INFORMATION OBTAINED DURING DISCUSSIONS WITH IDENTIFIED PROJECT PARTNERS

- YANA will fall under the auspices of EPILEPSY SOUTH AFRICA NATIONAL OFFICE until a Branch is established and is registered as a Non-Profit Organisation.
- Mrs Lynn Jansen Van Rensburg (YANA) is in the process of recruiting members for the Branch Board and general membership of the proposed Branch.
- Mrs Beth Burton (Consultant) will be offering consultancy services to Mrs Lynn Jansen Van Rensburg on a part time basis to assist with establishing the EPILEPSY SOUTH AFRICA EASTERN CAPE BRANCH.
- Currently direct social development services (counselling) will be referred to the organisations that EPILEPSY SOUTH AFRICA NATIONAL OFFICE have a Memoranda of Understanding with. In the interim focus will be on advocacy and awareness training on epilepsy and economic development.
- A community meeting needs to be scheduled in order to establish an action committee which includes a multi-professional team and community members. The elected action committee will consist of persons who are available and eager to reach the communal aim. It is anticipated that the elected action committee would form the basis of a Branch Board once the Board is established.
- Office on Status of the Disabled People (OSDP) will link EPILEPSY SOUTH AFRICA NATIONAL OFFICE with key personnel in government departments that were identified as project partners
- Epilepsy training and disability awareness training will be marketed to government departments and civil society as a lot of myths still exist about epilepsy and epilepsy is not viewed as a disability.
- Statistics will also be provided by project partners to the EPILEPSY SOUTH AFRICA NATIONAL OFFICE pertaining to services rendered to people with epilepsy.
- EPILEPSY SOUTH AFRICA NATIONAL OFFICE will draft and re-draft Memoranda of Understanding with identified project partners that will prevent duplication of services and projects.

This site visits that was done in the Eastern Cape was a positive experience as project partners at the networking meetings and training agreed that a partnership approach is of utmost importance in order to ensure cost effective and efficient social service delivery. EPILEPSY SOUTH AFRICA NATIONAL OFFICE will be actively involved for the rest of the year in providing support and advise concerning the establishment of the EPILEPSY SOUTH AFRICA BRANCH, designing of training material for advocacy, preparation and planning economic empowerment training.

For more information about this project, or to become involved with this project, you are welcome to contact Karen Robinson at telephone number 021 – 447 3014

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The South Cape Karoo Branch of Epilepsy South Africa once again had a Casual Day Parade in collaboration with Knysna APD and the Sunridge Primary School Drum Majorettes. This year they involved several ECD Centres and invited them to support the fundraiser as part of their Spring celebrations. The branch presented a program for the children at the Knysna High Sportsfields with a dog show by the SAPS and a demonstration by the Knysna Emergency Services (Fire Brigade). It is not sure whether the children or clients had more fun frolicking in the foam.



As a marketing exercise the Workshop presented each of the participating ECD Centres with a wagon containing multicoloured building blocks to thank them for participating

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Visit our website or to contact any of our Branches or National Office.
Website: www.epilepsy.org.za

EPILEPSY SOUTH AFRICA – National Office, Cape Town

PO Box 73
OBSERVATORY
7935
Tel: (021) 447-3014
info@epilepsy.org.za

EPILEPSY SOUTH AFRICA
South Cape/Karoo
PO Box 107
KNYSNA
6570
Tel: (044) 382-2155
southcape@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Western Cape
PO Box 24573,
LANDSDOWNE,
7779
Tel: (021) 703-9420
wcape@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Mpumalanga / Limpopo
PO Box 55,
DULLSTROOM,
1110
Tel: (013) 254-0161/2/3
mpumalanga@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Gauteng Branch
Regional office
PO Box 1070
SPRINGS
1560
Tel: (011) 816-2040/57
gauteng@epilepsy.org.za

EPILEPSY SOUTH AFRICA Free
State & North West
Branch
PO Box 167
PARYS
9585
Tel: (056) 811-5959
freestate@epilepsy.org.za

EPILEPSY SOUTH AFRICA
Kwa Zulu Natal Midlands
Branch
PO Box 2165
PIETERMARITZBURG
3200
Tel: (033) 394-1041/8
kzn@epilepsy.org.za

PLEASE CONTACT 0860 EPILEPSY (0860 374537)
TO GET IN CONTACT WITH YOUR CLOSEST BRANCH OF EPILEPSY SOUTH AFRICA

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