

## Drikie Snyman

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**From:** Epilepsy South Africa National Office [marketing.no@epilepsy.org.za]  
**Sent:** 07 December 2009 14:41  
**To:** Drikie  
**Subject:** Farewell 2009!



*December 2009*

### Dear Valued Subscriber

We have nearly reached the end of 2009 so this will be our last electronic newsletter on "this" side of the New Year. I am certain that you are also terribly busy trying to complete work and reach some due dates before your holidays can commence.

A highlight for 2009 within the the Disability Sector take place on the 3rd of December. The International Day for Persons with Disability's National Celebrations took place in the Western Cape, Stellenbosch. The need to stop discrimination against people with disabilities are strengthened by the International Day of Persons with Disabilities (IDPD), which is celebrated annually on this day. The theme for this year's IDPD celebration promoted the empowerment of persons with disabilities and their communities through the Millennium Development Goals. The Day provided an opportunity to mobilize action to achieve the primary goal of full and equal enjoyment of human rights and participation in society by persons with disabilities. Include! Organize! Celebrate! Take Action!

Epilepsy South Africa's message/statement for International Day for Persons with Disabilities 2009 was as follows:

**“As Epilepsy South Africa we believe in the rights of people with disabilities. People with epilepsy and other disabilities have experienced, and are still experiencing, tremendous discrimination just based on their condition. As Epilepsy South Africa we commit ourselves to redress such discrimination and we ask the nation to join us in achieving our goal. Let’s stand up and make our voices heard for the rights of people with epilepsy and other disabilities!**

**I also include our contact information to ask about our advocacy, awareness and other programmes please contact Epilepsy South Africa National Office at 021 – 447 3014 or phone 0860 EPILEPSY (374537) to contact your closest Branch of Epilepsy South Africa.”**

Some very note worthy days have been celebrated or will be commemorated in this time. We continuously draw compare epilepsy and those commemorated on each day, to identify and create awareness for the rights of people living with epilepsy. All of this to drive the urgency and motivate parents and people with epilepsy to stand up and speak for their rights. Please spend special time on the CALL FOR ADVOCATES article shared below if this interests you!

On 16 December we will celebrate Day of Reconciliation. “The intention is to foster reconciliation and national unity. The public holiday however came into effect in 1994 after the end of Apartheid. Before 1994, the 16 th of December was commemorated as the “Day

of the Vow”, also known as “Day of the Covenant” or “Dingaan's Day”. On the other side of the political spectrum, 16 December is also the anniversary of the 1961 founding of Umkhonto we Sizwe (Spear of the Nation), the armed wing of the African National Congress.”

I hope that we will not only think about reconciliation between different races and political groups within South Africa on 16 December, but that we will also think about reconciling disabled people with non-disabled people, truly making disabled people part of mainstream society and communities. During 2010 Epilepsy South Africa plan to take this message further and we invite people with epilepsy to contact us to become part of our advocacy programme as self-advocates.

Thank you's: I would like to thank all the supporters of Epilepsy South Africa for all your dedication and support during 2009! Without your assistance we would not be able to achieve our goals. To the Board members and personnel – thank you very much for your hard work, perseverance and commitment! You are an awesome team and we look forward to continue our work in 2010. To our Muslim supporters and readers - Eid Muburak for Thul Gadj which was celebrated on 27 November. To our Christian supporters and readers - A Happy and Blessed Christmas for 25 December.

I truly hope that all our readers and supporters will enjoy a blessed holiday season and a Happy New Year. That everybody who will travel and go on holiday will return home safely.

May 2010 hold many triumphs for people with epilepsy!

With thanks  
Noëline de Goede

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## December E-news Contents:

- [About the 16 Days of Activism Against Gender Violence:](#)
- [ADVOCATES NEEDED 2010-2011](#)
- [Epilepsy Seminar](#)
- [Green paper on National strategic planning](#)
- [Take control of your epilepsy!](#)
- [Reflections](#)
- [Stigma and Epilepsy](#)

## About the 16 Days of Activism Against Gender Violence:

*By Karen Robinson- National Social Development Manager*

***Seeing that disabled women and children also fall in this category, and are often found to be soft targets for perpetrators, we want to contribute to the awareness of this campaign and ask you to think about the crime and violence caused to people with epilepsy due to the continued stigmas, myths and discrimination on a daily basis.***



The 16 Days of Activism Against Gender Violence is an international campaign originating from the first Women's Global Leadership Institute sponsored by the Center for Women's Global Leadership in 1991. Participants chose the dates, November 25, International Day Against Violence Against Women and December 10, International Human Rights Day, in order to symbolically link violence against women and human rights and to emphasize that such violence is a violation of human rights. This 16-day period also highlights other significant dates including November 29, International Women Human Rights Defenders Day, December 1,

World AIDS Day, December 3, International Day People Living With Disabilities, December 6, which marks the Anniversary of the Montreal Massacre and December 10, International Human Rights Day.

The 16 Days Campaign has been used as an organizing strategy by individuals and groups around the world to call for the elimination of all forms of violence against women by:

- raising awareness about gender-based violence as a human rights issue at the local, national, regional and international levels
- strengthening local work around violence against women
- establishing a clear link between local and international work to end violence against women
- providing a forum in which organizers can develop and share new and effective strategies
- demonstrating the solidarity of women around the world organizing against violence against women
- creating tools to pressure governments to implement promises made to eliminate violence against women

Say NO – UNiTE to End Violence against Women is a global call for action, launched in November 2009, on ending violence against women and girls. It is presented by UNIFEM as a contribution to advance the objectives of UN Secretary-General Ban Ki-moon's campaign UNiTE to End Violence against Women through social mobilization. Based on South African data available, up to 70 per cent of women experience physical or sexual violence from men in their lifetime. It happens everywhere – at home and at work, on the streets and in schools, during peacetime and in conflict. Violence against women and girls has far-reaching consequences, harming families and communities, stunting human development, and undermining economic growth. Everyone has a role to play in combating this global pandemic; the time to act together is NOW.

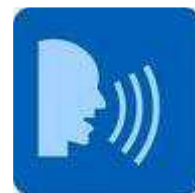
This year the campaign, coordinated by the Department of Correctional Services, is popularising the white ribbon as a symbol of personal and organisational commitment to the eradication of violence against women and children. The white ribbon, according to the department, symbolises the commitment of the wearer to "never commit or condone violence against women and children, and to speak out about violence where they see it."

[\[back to top\]](#)

## ADVOCATES NEEDED 2010-2011

*By Karen Robinson – National Social Development Manager*

Epilepsy South Africa National Office as part of their business plan for 2010-2011 will be focusing on advocacy of the youth living with epilepsy.



We are very excited about advocacy training as this will focus on defining what does it mean to be an advocate, knowing your rights, self esteem, starting own advocacy group and assisting you to conduct training to other youth living with epilepsy to become an advocate. It is time for youth living with epilepsy to reclaim its place and by telling their stories on different levels to create awareness of their felt needs, issues and also of the stigma's and discrimination that they are experiencing.

It is time that we should stop being complacent and take control of our lives and also do something positive about the issues that are affecting us. Epilepsy South Africa National Office objective is to do three training sessions which will consist of approximately 15-20 youth living with epilepsy per training. If you want to make a difference by being an advocate on all levels and collaborate with other youth living with epilepsy and mobilize yourself as a national youth epilepsy forum JOIN OUR ADVOCACY CAMPAIGN. Please contact us: 086 037 4537 or (021) 447 3014

[\[back to top\]](#)

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## **Epilepsy Seminar**

*By Epilepsy South Africa Western Cape, Anthea Emmanuel Social Development Manager*

The Western Cape Branch held their 4th Annual Epilepsy Seminar on the 21st of November 2009 at Red Cross Staff Educational Centre. In spite of being the 4th tenure, the Epilepsy seminar was buzzing with excitement and anticipation with an approximation of 50 people in attendance.

Wendy Nefdt, the Director of Epilepsy South Africa, extended a very warm welcome to all and introduced a successful opening with the Epilepsy South Africa DVD presentation. She also divulged the exciting news that one of the Epilepsy South Africa's protective workshops, Care Craft Mitchells Plain had won the International Labour Organisation's Social Business Competition!

Nonetheless, the focus of the seminar on Epilepsy and Human Rights enlightened and refreshed the people. The guest speakers, to whom we owe a lot of gratitude, included experts in the field of neurology. Professor Eastman, Dr. James Butler and Dr. Alvin Ndondo shared information about epilepsy, adolescents with epilepsy and the management thereof. Michael Bagraim, renowned Labour Law Specialist shared his expertise with regard to Employment and discrimination in the workplace; Damaris Fritz, Chairperson of the Community Health Centre Forums, reflected on real life case studies regarding the right to health and human rights; and Felicity September shared a personal story of trials and triumphs with her diagnosis.

In conclusion, Ruth Nugent gave an animated summary and evaluation that led to the closure of a very successful event. We anticipate that next years' seminar will be even bigger and better, so we look forward to seeing you then!

Western Cape Office Closure:

Our offices will be closed as of 18 December 2009 and will reopen on the 11 January 2010. Happy Holidays to all of you and May prosperity be a chief blessing in the New Year!

[\[back to top\]](#)

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## **Green paper on National strategic planning**

This Green Paper was published in September 2009 and sets out an institutional framework for planning and describes the outputs of planning. It proposes a National Planning Commission working under the guidance of the Minister in the Presidency for National Planning to produce a long-term plan for South Africa. A secretariat (based in the Presidency) will support the Commission's work and the Minister will lead interaction with broader civil society on the development of the plan.



The key outputs of planning include the development of a long-term vision and plan for South Africa – the Medium Term Strategic Framework (MTSF) produced every five years. The MTSF will provide the basis for the annual Programme of Action.

The country's high level aspiration will be broken down into focused strategies dealing with issues such as economic development, human resource development, building a

developmental state, enhanced regional stability, etc. Government will be pursuing:

- economic growth whose benefits are equitably shared,
  - decent jobs and sustainable livelihoods,
- accessible quality education and skills development,
  - reduction of poverty and inequality,
    - rural development,
    - improved health care for all,
    - community safety and
  - social cohesion in a united nation.

The main outputs of Government planning include a long-term vision and plan, a five-year strategic framework, an annual Programme of Action, spatial perspectives and occasional research. They also include ongoing leadership in the management of major social dynamics and key drivers of social development.

Outcomes and processes: A National Planning Commission, headed by the Minister in the Presidency for National Planning will lead in the development of a long-term national strategic plan. A 15-year horizon is envisioned at present. The long-term plan (South Africa Vision 2025) will spell out where South Africa wants to be as a society in 2025. It is envisaged that the first national vision be presented to the nation within a year of this Green Paper being published.

South Africa Vision 2025:

In broad terms, South Africa Vision 2025 could project a society in which:

- A democratic and legitimate state based on values of the Constitution works with all sectors of society to improve the human condition.
- People are united in their diversity – fully appreciating the common interest that binds them as a nation.
- Conditions have been created for the full participation of women in all critical areas of human endeavour.
- There are effective programmes to reduce poverty and inequality and protect the most vulnerable in society, including youth, children, people with disability and the elderly.
- The country's natural wealth and its human resources are harnessed to ensure a growing economy which benefits all, and which uses natural resources and modern technology in a beneficial and sustainable manner.
  - The private sector is afforded an environment to invest and make competitive returns while promoting the common interests of the nation.
- The State is efficient in providing services and gives leadership to the programme of national development.
- Able-bodied citizens and all work-seekers have access to decent jobs, workers' rights are protected and social security measures are comprehensive enough to cover all citizens in need.
- Individuals and communities at work and at leisure are informed by a value system of mutual respect and human solidarity.
- The State and all sectors of society work with their counterparts in Africa and across the globe to build a better world.

The Medium-Term Strategic Framework (MTSF) for 2009 – 2014 (Together Doing More and Better) has been adopted and published. This framework identifies priorities and a few key programmes for the current Government's term of office. It will be reviewed annually in the light of a changing environment and experience in implementation.

The current annual planning cycle, which will need to be improved, is as follows:

- The base five-year MTSF is adopted at the beginning of the mandate period. The annual update of the framework is adopted by Cabinet at the July Cabinet lekgotla. It is then circulate to government departments and provinces, by which time they would have finalised their initial budget submissions, which are forwarded to National Treasury during the same month of July.
- The Medium Term Budget Policy Statement is presented to Parliament in October.
- In December, the integration of detailed programmes for the following year begins, and these are adopted at the January Cabinet lekgotla and articulated in the President's State of the Nation Address in February. In other words, the detailed programme for the year contains items that are already budgeted for.
- The Programme of Action is an annual statement of government's priorities for the year. It is informed by the MTSF, the deliberations of the January Cabinet lekgotla and the President's State of the Nation Address.

The national spatial guidelines are tools for brining about coordinated government action and alignment. They will be developed under the supervision of the Minister for National Planning, working with the National Planning Commission and in partnership with relevant departments, clusters and specialist agencies outside of government. Spatial planning instruments include spatial development perspectives and guidelines for infrastructure investment and social spending.

What the planning function will not do

- Micro-planning and sector planning
  - Gate-keeping
  - Budgeting

Systems and structures

- Leadership of society by a legitimate and democratic state, with a variety of capacities to lead national development.
- The central role of the Presidency, working with the rest of the Executive to lead national strategic planning.
- A National Planning Commission (led by the Minister in the Presidency for National Planning) made up of prominent individuals with expertise and intellectual capacity to draft a long-term vision, and to assist in mobilising society around the vision and in other tasks related to strategic planning.
- Streamlined planning structures and processes across national government, relevant state agencies and the provincial and local spheres.
  - Partnership with research, academic and other institutions.

There are five key planning institutions. Two exist already, namely Cabinet and the President's Coordinating Council (an intergovernmental coordinating forum). Three new institutions are proposed:

- A National Planning Commission consisting of external commissioners;
- A Ministerial Committee on Planning to provide guidance and support to the planning function; and
  - A secretariat to support the work of the Commission.

The planning ministry would also interact with broader societal stakeholders in the development and implementation of a national plan.

[\[back to top\]](#)

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Epilepsy management is a daily challenge. Take control today using the same Web technology that you use to make the rest of your life easier!

Do you have trouble describing your seizures to your doctor? Do you often forget details that could be important in your treatment plan? Do you have trouble remembering to take your medicines?



Introducing [My Epilepsy Diary](#), the new consumer health product from epilepsy.com, designed by medical professionals specializing in epilepsy and tested by epilepsy patients just like you!

Tracking your seizures used to be time-consuming, complicated, and frustrating. No more! My Epilepsy Diary allows you to enter real-time data using your browser or smart phone. Anytime you experience a seizure, side effect, mood change, or other event relevant to your epilepsy, create a new entry in My Epilepsy Diary and quickly add details from the many common scenarios already provided. While you're logged in, enter email or text message reminders to take your medicines.

Before your doctor's appointment, just print out a report from My Epilepsy Diary. This not only gives your doctor a snapshot of your recent seizure activity, but also shows how effective your treatment has been over time and whether it needs to be adjusted.

Taking control of your epilepsy, or your loved one's epilepsy, has never been easier! More complete data from you means more effective treatment from your doctor. Try My Epilepsy Diary today!

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[\[back to top\]](#)

## Reflections

*Compiled by Sharm Knobe, Public Relations Officer Gauteng Branch*

It is that time of year again when we must pause and take stock. Have we made a positive difference? Have we changed lives for the better?

In line with the United Nations Convention on the rights of persons with disabilities, we have focused on working to promote, protect and ensure the full and equal enjoyment of all human rights by people with disabilities.



People with epilepsy are particularly vulnerable because although their disability is not always visible, the myths and misconceptions about the condition impact negatively on their lives. We have therefore stepped up on our education and awareness programmes and are happy to report that requests by government, business, universities, schools and other interested groups for this service has increased tremendously.

The Director and staff of Epilepsy South Africa, Gauteng Branch are pleased to say that our services have been put to good use during 2009. We are in the process of expanding our services and projects. This would not have been possible without the support of our funders

and partners and to them we would like to express our heartfelt gratitude.

The Director and staff of Epilepsy South Africa, Gauteng Branch wish our funders, partners, clients and colleagues in other provinces and national office a Blessed Christmas and the courage and strength to do what we must in 2010.

[\[back to top\]](#)

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## Stigma and Epilepsy

*By Karen Robinson, National Office Social Development Manager*

The biggest handicap for persons with epilepsy is social stigma, because misunderstanding and prejudice are prevalent. Stigma, the shame or disgrace attached to something deemed socially unacceptable, is more often associated with epilepsy than with other chronic diseases. Unlike asthma, diabetes, or arthritis, epilepsy has historically been viewed in many cultures as mysterious or even evil. We often think of stigma as external, something that exists in the minds of other people or is enacted in legislation. But many people living with epilepsy internalise stigma, and can come to think of their condition as shameful and of themselves as undesirably different: less worthy, less capable, and more likely to encounter negative reactions from others. This in turn can lead to lower self-esteem, anxiety, depression, and a poorer quality of life.

Although we now know that epilepsy is caused by brain activity rather than demonic possession, negative attitudes and beliefs are still common.

How parents and children can combat stigma?

How can parents help their children with epilepsy build resilience in the face of ignorance and discrimination? Obviously, people affected by epilepsy cannot educate the entire world and change every person's beliefs by themselves, but parents and children can have an effect closer to home.

Parents' attitudes are important:

According to Jacoby and Austin, "[Parents'] reactions to a diagnosis of epilepsy in their child seem to set the stage for the child's own interpretation of its significance." In other words, if parents are ashamed or embarrassed about their child's epilepsy, the child will grow to see epilepsy as shameful. If parents expect that their child with epilepsy will be treated badly by others, the child will learn that epilepsy is something that needs to be hidden. What is very sad is that I received several calls over the past two months of a 12 month old baby being left at the hospital after the parents found out the child diagnosed with epilepsy as the community will ostracized them as they label child as being possessed by evil spirits. Neighbours calling in to Epilepsy South Africa National Office reporting neglect of a child due to diagnosis of epilepsy. Children being kept separate from the rest of the family in a room with no windows and also no receiving the child's medication.

One of the key things about children who do well with epilepsy is the positive attitude on the part of their parents. Instead of highlighting the dangers and restrictions faced by a child with epilepsy, parents and other responsible adults need to focus on helping the child gain independence and capability. I also think that people need to examine their own beliefs about disability and difference. You as a parent should asked yourself "How do you handle negative comments or stares? You're modeling your response for your child." Parents in search of positive coping strategies may find it helpful to connect with other parents who have a child with epilepsy, a local epilepsy organisation in the different provinces.

Help your child build resilience:

Resilience refers to the ability of a child to deal with stress in a way that permits growth of

self-confidence and social competence. In order to promote this ability, talk to your child about epilepsy in an age-appropriate way. Highlight that epilepsy is only one aspect of who he is as a person, as opposed to a condition that defines him.

Focus on things your child can do:

Create an environment where your child can feel responsible, capable, and independent. Help him take on responsibilities, with adequate support systems in place to help him succeed.

This doesn't always have to be about learning new skills; sometimes it's enough for your child to participate in something fun that they can do. "What can you focus on that will not set your child apart, but instead will help him/her find a place with his/her peers?" You as a parent need to ask yourself "What activity is fun and easy to be a part of? That's often where you find success. "

Not all discrimination is due to stigma. Legitimate discrimination might include restrictions on driving for people with uncontrolled seizures, or restrictions from playing certain sports with a high risk of head injury. Where your child faces real limitations because of epilepsy, give him/her practical guidance and help him/her find alternatives.

Address negative coping strategies:

People, particularly adults, who feel a high level of stigma associated with epilepsy may adopt negative ways of dealing with it including:

- rejecting the diagnosis of epilepsy
- withdrawing and isolating themselves socially to avoid having a seizure in public
- hiding the condition
- lowering their expectations for the future

These types of negative strategies are harmful to a child's development. Your child needs to learn about his condition, share information about it in ways that he chooses, build a strong social network of trusted friends and family, and believe in his own abilities.

Positive coping strategies:

- Educate friends, caregivers, and your child
  - Misconceptions about epilepsy are very common. In the United States, 27.3% of people in a 2004 study thought people with epilepsy were very likely to die with every seizure, and 66.5% thought they would need to put something in the person's mouth during a seizure.
  - Make sure friends, teachers, and other people who have contact with your child know how to recognize a seizure and what to do if your child has a seizure.
  - Help your child respond to common questions about epilepsy. It may help younger children to have a "script" they can quote.
  - Check your child's understanding of epilepsy from time to time. As your child grows, he will be able to understand more complex information about epilepsy and seizures
    - Encourage your child to take ownership and become "the expert" on his/her seizures.

Give your child control

Seizures can strike out of the blue, and many children feel that they have little control over epilepsy. Seizures are unpredictable. Your child can have control in other areas, including telling others about epilepsy. Educating others does not have to mean educating everybody. Choosing what, when and who to disclose your epilepsy to is an important decision. It is also a good idea to put some thought into how you share the information. Take your cues from your child. Talk to your child about how much information he/she wants to share. Encourage your child to pick and choose what information he/she wants to share about epilepsy, with whom, how, and when.

Encourage social contacts: Encourage your child to make social contacts. Help create

opportunities for your child to play with other children. Children and teens with epilepsy may sometimes be excluded from activities because others are not sure what to do if the child has a seizure. For other parents there is a fear factor sometimes it's not so much stigma, in the sense of 'I don't want your child to play with my child,' as 'Oh no, what do I do if your child is at my house and has a seizure?'" And you may be nervous about letting your child play in a strange home that has not been seizure-proofed. In order to increase your child's social network, one idea is to make your own home a "hub" of activity. Through exposure, people will start to feel more comfortable responding to seizures.

**Advocate for your child:** Children with epilepsy often experience bullying, teasing, and social exclusion. Ask your child's teacher and school administrators for help if your child is being bullied. If a child is being bullied or teased, it is not the child's responsibility to handle it alone. Adults have to step in and monitor the situation on a daily basis. Teachers or other adults must be vigilant and demand an environment of safety and mutual respect for all children.

Parents may also need to advocate for their child if the school system is lowering its expectations for him/her. There's always a risk of the child being defined by their epilepsy. As the parent you have to be clear about your child's strengths and areas of difficulty and also question 'why wouldn't he/she do what everyone else is doing?'

One of the biggest parts of advocacy is communication. This means that if we want others to know about our situation we must tell them in a way they can understand. If we want them to change or do something different we must communicate what we want them to do.

**Seek help if necessary:** If you feel there are issues you cannot help your child with, discuss them with a professional person .

Contact us: 086 037 4537 or 021 447 3041

[\[back to top\]](#)

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

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