INTERNATIONAL BUREAU FOR EPILEPSY

11 Priory Hall, Stillorgan, Dublin 18, Ireland
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epilepsy scotland
Scotland's voice for epilepsy

EPILEPSY SCOTLAND

ACTIONS SPEAK LOUDER THAN WORDS

PURPOSE

Epilepsy Scotland works with people affected by epilepsy to ensure their voice is heard. We believe they have a right to:

- Determine their own way of life
- Be free from stigma and discrimination
- Be valued and included in society
- Have access to high quality medical, social, educational, support and information services

We help to empower all those living with epilepsy to work for change.

"Thirty minutes after I came out of a seizure, I broke the world record in an international race. Dreams can be achieved despite having epilepsy." Paralympic swimmer **Maggi McEleny**.

METHODS

Established in 1954, Epilepsy Scotland is a full and founder member of the International Bureau for Epilepsy (IBE). We are a campaigning body that represents the 40,000 people with epilepsy in Scotland, their families and carers.

"Epilepsy Scotland is there for our family when we need any advice and support." Young carer **David Cherry**.

Our membership includes individuals, organisations and professionals involved in epilepsy care.

In April 2008, our organisation merged with Edinburgh-based charity, Enlighten – Tackling Epilepsy. The membership agreed unanimously to this action because it strengthens our cause.

"As a recent Epilepsy Scotland board member, I can be directly involved in their important work. They have helped give me and my family the confidence to be who I am and live life to the full." Chief Inspector **Ross Bennet**.

RESULTS

Knowledge is powerful for making choices and achieving goals. Anywhere in Scotland, people can access our services:

- Confidential freephone helpline: **0808 800 2200** with a translation line for 170 languages and a type talk service for people with hearing impairments
- SMS information service: **07786 209 501**

"More than anything I wanted to talk to an understanding person about what was happening." **Marilyn Bryce**.

- Website: **www.epilepsyscotland.org.uk**
- Epilepsy information and fact sheets
- Exhibitions and talks to schools/community groups

"After their talk I stood up and told everyone I had epilepsy. People were surprised and concerned to hear this. But since then, they've all been very supportive. In a way, Epilepsy Scotland helped me to 'come out' and be open about my epilepsy!" Media contact **Doreen Jobson** (left).

- User involvement and consultations
- Seminars, forums and training courses

"Epilepsy Scotland's training is first class. I'm now aware of what to look for if someone has a seizure." Hansel Alliance carer **Siobhan Devlin.**

- One-to-one community support service (Glasgow)
- Network of support groups and nationwide information events
- Youth projects, parents groups and parenting classes
- Newsletters and policy briefings

"My son Max needed an adapted car seat. Thanks to an article in Epilepsy Scotland's newsletter, I acted and received a grant for a rotating car seat." Member **Nicola Reid**.

- Public awareness campaigns
- (insert campaign leaflet More Epilepsy Nurses, Better Epilepsy Care here)
- Supporting the Scottish Parliament's Cross-Party Group on Epilepsy

"The most successful thing the Cross-Party Group on Epilepsy has done is to raise awareness of the issue in the Parliament. We have helped to de-stigmatise this condition and that is tremendous." **Christine Grahame** MSP

- Work with NHS Boards and medical professionals

CONCLUSIONS

We encourage people living with epilepsy to influence their own destiny. Much has been achieved by our members' actions. More still needs to happen before people with epilepsy can reach their potential in life.

We are working in partnership with many agencies to ensure equal access to services across Scotland. Our 2008 campaign is to increase the number of epilepsy specialist nurses from 24 to 62.5 posts. This will provide nurses for children, adults and those with learning disabilities in all health boards:

Over 200 people took action and signed our electronic petition on the Scottish Parliament website

- Many wrote to their parliamentary representative and local health board in support of the campaign
- The Scottish Parliament will consider this petition for more nurses
- Two more epilepsy specialist nurses have been appointed since the campaign started in May.

"Being an Epilepsy Scotland volunteer has, in a way, helped me deal with my epilepsy. From making speeches to politicians in the Scottish Parliament to doing the photocopying in their office, Epilepsy Scotland has helped me turn my diagnosis into something positive." Volunteer **Jane Williams**.

CONTACT DETAILS

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Joint Epilepsy Council of the UK and Ireland member
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Registered in Scotland No 163987

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B U D A P E S T
28th INTERNATIONAL EPILEPSY CONGRESS
Eisai Supported by an educational grant from Eisai Co. Ltd
1909 2009

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EPILEPSY SOUTH AFRICA

TYPE OF IBE MEMBER

Full member since May 2001

TYPE OF ORGANISATION

Not-for profit organisation, with individual and corporate or organisational memberships available.

Epilepsy South Africa is a national organisation, with branches across the country. The organisation was established in September 1967 and provides services to the 1% of persons with epilepsy residing within South Africa. We also support persons with other disabilities, as well as all those affected by epilepsy through our service programmes.

MISSION STATEMENT

Epilepsy South Africa is a dynamic organisation providing developmental services nationally to promote equal opportunities for people with epilepsy and other disabilities.

VISION STATEMENT

To provide integrated services that are equitable, accessible, sustainable and people-centered with and for people with epilepsy and other disabilities all affected by epilepsy, and to promote social justice.

CURRENT FOCUS AREAS AND PROGRAMMES

National media awareness and marketing programme
People with epilepsy and other disabilities are faced with continued discrimination and isolation on a daily basis due to a lack of knowledge within society about epilepsy and inclusion aspects. This programme redresses the lack of knowledge about epilepsy as a condition as well as the organisation itself, in order to decrease discrimination and to increase the sustainability of the programmes, facilitated by Epilepsy South Africa.

We are privileged to have South African Celebrities who acts as ambassador's for the organisation and launched a very successful advertising campaign in 2008 and 2009.

NATIONAL SUSTAINABILITY PROGRAMME

With this programme we aim to provide sustainability to the organisation and all its programmes through the identification of partners and activities, including donors and the development as well as maintenance of long-term funding.

NATIONAL SOCIAL DEVELOPMENT PROGRAMME

This programme encompasses a variety of national programmes and initiatives. The main purpose of this programme is to combat discrimination towards persons with epilepsy and other disabilities as well as to enhance their inclusion in mainstream society.

The National Office of the organisation coordinates and facilitates national social development programmes and initiatives throughout South Africa. New initiatives are identified through research, liaison with branches as well as members. Through such consultation and liaison, interaction with grassroots communities and consumers, including the youth, women, the aged and persons living with HIV/AIDS, are ensured. Projects that forms part of our social development programme are: Child and Youth development, rural development, training & education, vulnerable group development and research.

Due to the continued discrimination that people with epilepsy and other disabilities have to this programme also focuses on the identification and empowerment of people with epilepsy and other disabilities to undertake self-representation and advocacy. It motivates to improve ownership by people with epilepsy and other disabilities within the organisation and enhances transformation within the organisation.

NATIONAL ECONOMIC DEVELOPMENT PROGRAMME

The main purpose of this programme is the economic development of people with epilepsy and other disabilities and to work toward their inclusion within the mainstream economy. Training is provided to personnel, responsible for the operation of the organisation's protective workshops. Workshop transformation is continually being attended to in order to meet requirements of legislation and demand. Assistance is further provided to protective workshops regarding national marketing of their products.

Training is provided to skill and development workers to facilitate the establishment of income generation groups. In addition, the Start and Improve your Business Programme of the International Labour Organisation are utilized to facilitate the training of small business advisors, to assist beneficiaries with the establishment of own small and micro enterprises.

This programme also entails providing assistance to beneficiaries regarding further education opportunities and career placement.

NATIONAL ORGANISATIONAL DEVELOPMENT PROGRAMME

The role of the National Office of Epilepsy South Africa has historically been to coordinate service delivery, establish and maintain service standards and facilitate service development at a national level amongst the branches. It also provides strategic leadership to these in order to ensure service excellence, sound management and financial stability.

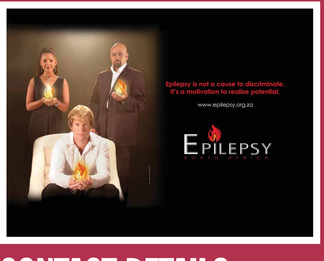
NATIONAL SKILLS DEVELOPMENT PROGRAMME

The National Skills Development Programme aims to ensure excellent service delivery through skills provisioning to all staff, volunteers and consumers within the organisation. To interact effectively with skills initiatives of Government and enhance the employment opportunities of people with epilepsy and/or other disabilities.

MORE INFORMATION

The organisation provides online counselling to individuals, with no prerequisite to receive this information. They also liaise with individuals on the organisation's Facebook and blog amongst some social networking avenues.

Epilepsy South Africa motto:
"Changing obstacles into true potential!"



CONTACT DETAILS

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EPI-SUISSE

epi suisse

BELONGING

…is enjoyable
…eases everyday
…brings you further

WHO ARE WE?

Epi-Suisse is an organisation throughout Switzerland that is occupied with the psychosocial issues of both those suffering with epilepsy and their relations. Epi-Suisse was founded on the second of July 2002 by various Swiss epilepsy organisations, and business was inaugurated on the first of January 2003.

WHAT ARE OUR AIMS?

Epi-Suisse not only improves the standard of life but encourages the social integration of epileptic people in schools, advanced education, careers and hobbies. A well-founded and decent standard of life should and ought to be matter of fact for epilepsy sufferers, too.

Epi-Suisse looks behind the principal restrictions of everyday life for those inflicted with epilepsy, and goes on to examine these in a systematic manner. It is only the knowledge of such correlations that will enable possible action in the way of lobbying and the opening of «fairchance» channels as well as the encouraging of self responsibility in all aspects of life for epileptic people.

WHAT DO WE DO?

Epi-Suisse distributes information concerning epilepsy and its consequences in order to awake a better understanding of the illness and the problems of those inflicted. This is not only a practical activity, but one that is connected to scientific projects as well as the research of the psychosocial aspects of epilepsy.

With a multiple palette of specifically aimed services, the striving for comprehensive care of epileptic people and their relatives can be supported by the following:

- Regular circulation of a magazine
- Publications
- Self help groups- Information events
- Advice and dialog
- Leisure and hobby activities

Acting as a proxy on behalf of the patients towards employers, authorities, institutions, media and above all society as a whole, is additionally of major importance to Epi-Suisse.

SELF-HELP

Meeting kindred spirits, exchanging thoughts, discussing problems and nurturing friendship: all these things as well as the possible acquaintance of a friend for life are offered by the various self-help groups for epileptic people.

Epi-Suisse also encourages the formation of new self-help groups throughout Switzerland and supports those already established with their activities.

We will help you find a self-help group that is nearby.

ADVICE

During a personal conversation or even on the telephone, many of your questions can be answered. With Epi-Suisse both epilepsy sufferers and their relations will always find an open ear. Furthermore, you may rest assured that your requests will be handled in a careful and discreet manner. Spontaneous visits to the premises are also more than welcome.

We are here for you five days a week so just give us a call:
Tel. 043 488 68 80

EXCURSIONS

Hiking, a visit to a museum or simply the enjoyment of a delicious meal. Incongenial company all of these things can form an unforgettable experience.

Epi-Suisse regularly organises excursions for epileptic patients together with their relatives, and it accompanies these excursions, too. This enables all participants to take part lightheartedly. A program is chosen in accordance with both the possibilities available and the interest of those taking part.

As a member of Epi-Suisse you will receive a personal invitation.

PORTRAIT

Confidence and the joy of living

Dieter Brucker was a renowned and successful gymnast prior to being hit by a lorry in 1971. He recovered rapidly from the accident for which he was not to blame, yet fourteen years later epilepsy struck him as a belated result of the scull brain trauma.

Sport and fellowship had always played an important role in the life of Dieter Brucker and now it became even more important. The newly struck Dieter Brucker spoke openly about his short term drop outs caused by the illness and about the positive results achievable with drugs. His gymnast colleagues never turned their backs on him and he found understanding at his place of work, too.

A REAL CHALLENGE

During his free time Dieter Brucker remains active, whether with company football, fastball or as a supervisor for other gymnasts. From an occupational point of view hehas somewhat retreated as his absences could not always be curbed with the use of medicaments. Furthermore, he has been urged to give up driving which automatically complicates his journey to work.

ENDURANCE PAYS OFF

After several months of difficulty , Dieter Brucker finally grasped newly found courage. With an appropriate and exactly suited therapy he made enormous progress and gained new impetus that propelled him to concentrate on the positive side of life. Endurance and team spirit coupled with confidence are certainly the best recipe for him in life, regardless of the situation.

Fellowship is not only found in sports but with Epi-Suisse too.

Dieter Brucker (front row, right) with colleagues.

BUDAPEST

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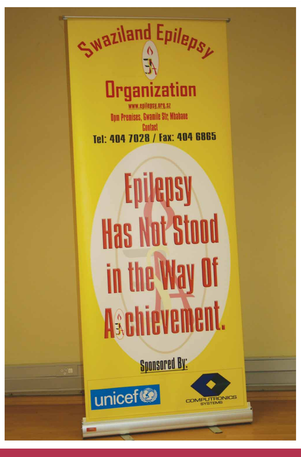
SWAZILAND EPILEPSY ORGANIZATION



Swaziland Epilepsy Organization is an Organization situated in the Kingdom of Swaziland in the Southern Africa, whos main aim focus is to offer help and support to Epileptics around the country.

Swaziland Epilepsy was established in 2003 and is a full member of the I.B.E whom she affiliated to since 11 July 2007. Our membership includes individuals and professionals involved in Epilepsy education

We represent over 1000 swazis with Epilepsy. In campaigning we bring Epilepsy out of the shadow with its myth and traditional attachments, unity and togetherness is the policy to achieve best practice for epileptics. We fight discrimination and stigma by ensuring the right information reaches the people also the availability of medication. Support groups have also been established to help in the communities.

INFORMATION SERVICES

If you are living around Swaziland and surrounding areas you can access the events and information on Epilepsy through our newly launched website www.epilepsy.org.sz .Nation / Public awareness Campaigns. Offering support on Epileptics support groups in the rural areas.

"Since I was diagnosed with Epilepsy I never wanted anyone to know about my condition because it has always been associated with myths and traditional attachments" ***Patricia Dlamini support group***

HRH Prince Bandzile Patron of the SEO receiving a gift after he had toured one of the sugar mills in Swaziland creating awareness on Epilepsy in the work place.

Educating students in schools on Epilepsy had been going on as part of the Awareness Campaigns the Swaziland Epilepsy has been conducting. Here the stop student in essay writing on "Epilepsy in the Classroom" is being presented with an Award by the SEO's management. From left Mr Mbusomuni Mahlalela (National Director SEO), Mr. Victor Erwin (Board member), Award winner from St Marks High School Mr Siyabonga Menon (Student) and Mr Zwane (World Health Organization WHO representative)

This was a field trip by HRH Prince Bandzile to meet the support groups in the rural areas that are affected Epilepsy. This was try and see what can be done in terms of incoming generating projects in these fields. Delivering the presentation is the former Minister of Agriculture Mr Mtiti Fakudze

HRH Prince Bandzile presenting one of the Epileptic students at Lusoti Primary School with action zone game pack to try and sensitize Epilepsy in Schools around the region.

CONTACT DETAILS

For more information you can contact the national Director
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