



EPIGRAM



Epilepsy Association of Calgary

November 2006

Volume 11, Issue 3

To support independence, quality of life, and community participation for people with, and affected by, epilepsy.

INSIDE:

The Jazzy Penguin Returns!

November is Epilepsy Education Month

Volunteer News

Epilepsy Association of Calgary Events

Central Alberta Office Events

The United Way Goes All the Way to Support the Community

Popular Daytime Soap Character Develops Epilepsy

Partial Seizures

Donors

CALLING 1-866-EPILEPSY

If you live outside the Calgary and Red Deer local calling areas, you can reach us at no cost to yourself at our toll free number to ensure that support, information, and answers to your questions are just a telephone call away.

If you live within the Calgary calling area, please call us at 230-2764.

If you live within the Red Deer calling area, please call us at 358-3358.

The Epilepsy Association of Calgary Presents

The Jazzy Penguin

Proceeds from the Jazzy Penguin support programs at the Epilepsy Association of Calgary



The Evening Will Include:
Silent Auction
50/50 Draw
Caricature Portraits

Featuring

Talented local musician
“JOHNNY SUMMERS”

And his band
(www.johnnysummers.com)



Event Details

DATE: Tuesday, November 28, 2006
LOCATION: The Rose & Crown Pub
1503 – 4th St. S.W.

(attached parking lot, pay lot, & street parking available)

DOORS OPEN at 6:30 p.m.

Johnny Summers Performs from 7:30 to 10:45 p.m.

TICKETS – \$50.00 Each
Available from the Epilepsy Association of Calgary
4112 – 4th Street N.W.

www.epilepsycalgary.com

Order by Telephone with your Visa or Mastercard

Tickets include admission, one beverage ticket, and a variety of hot & cold hors d'oeuvres

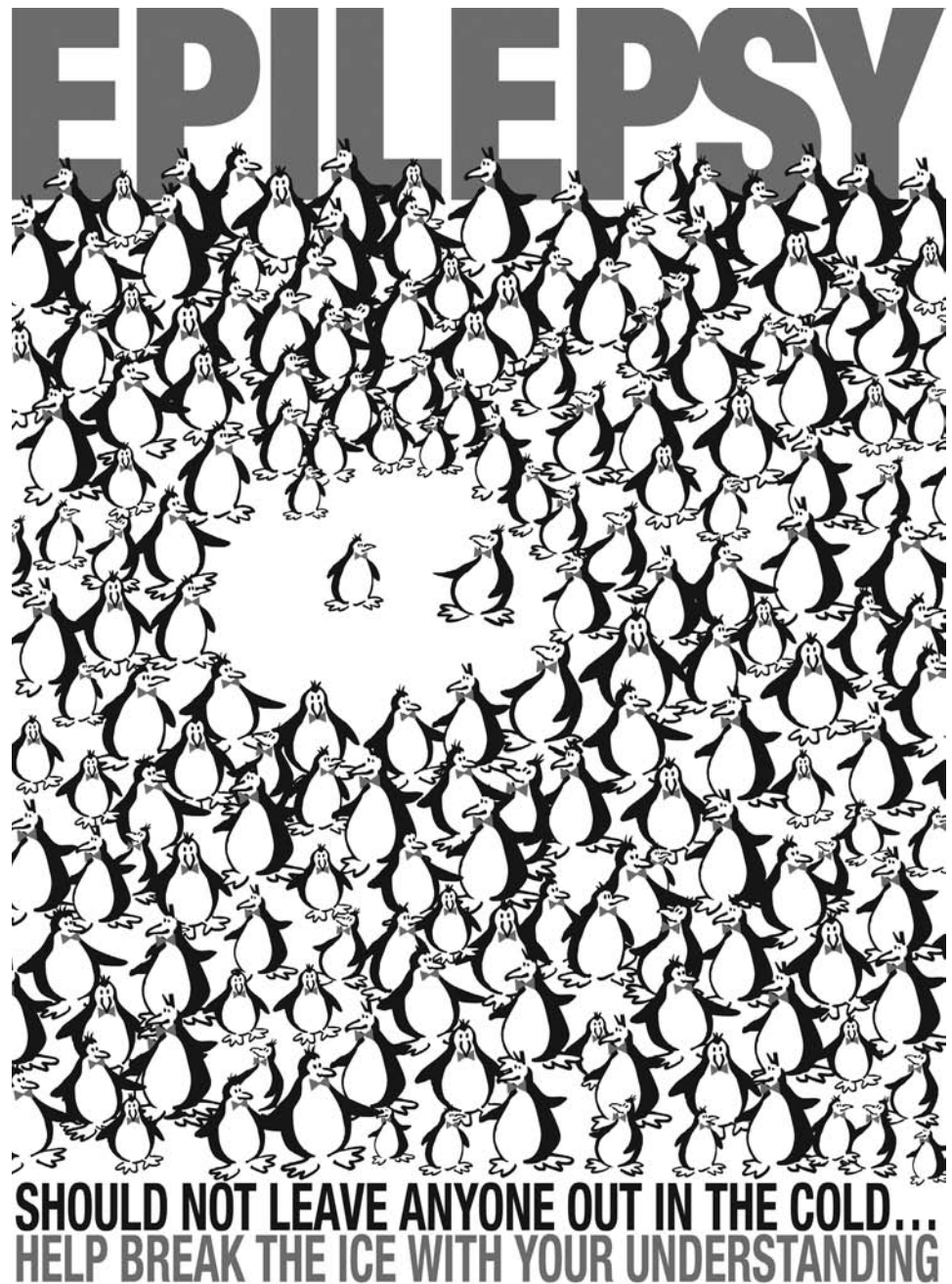
We extend a HUGE thanks to our sponsors for making this event possible:

SPARTAN CONTROLS
 SMITH BROS FLOORS

NOVEMBER IS EPILEPSY EDUCATION MONTH

Once again, November has been proclaimed as **Epilepsy Education Month** by Calgary Mayor, Dave Bronconnier, and Red Deer Mayor, Morris Flewwelling. We will be busy distributing posters, educating people about epilepsy, holding public information displays, and more. Watch for electronic sign messages around the city of Calgary as well. Activities that you can be involved in include:

- **Kensington Area Poster Blitz** – scheduled in Calgary for Saturday November 4th, 2006 from 1:00 p.m. to 4:00 p.m., followed by refreshments. **If you can help, please contact Melanie at 230-2764.**
- **Champions for Epilepsy** – We are looking for champions to help us spread the word! Perhaps your classroom, workplace, neighbourhood community centre, or other places you go. Become a Champion for Epilepsy! **In Calgary - Call Carla at 230-2764 to arrange for your kit. In Central Alberta, contact Krista at 358-3358.**
- **Lavendar Bracelets** – We'll have lavender bracelets available at activities throughout November. They are \$2.00 each, and are great for raising awareness about epilepsy. They are also available at our office.



FOR MORE INFORMATION ON EPILEPSY CONTACT
 THE EPILEPSY ASSOCIATION OF CALGARY: 4112 - 4TH STREET NW, CALGARY, AB, T2K 1A2, TEL: (403) 230-2764, FAX: (403) 230-5766
 CENTRAL ALBERTA OFFICE: 303, 4822-50TH STREET, RED DEER, AB, T4N 1X4, TEL: (403) 358-3358
 TOLL FREE: 1 866-EPILEPSY
 EMAIL: epilepsy.calgary@telus.net
www.epilepsycalgary.com
 CHARITABLE REGISTRATION NUMBER: 11890 0778 RR0001

- **Epilepsy Education Sessions** – if your group (school, daycare, employer, recreation group etc.) could benefit from a workshop on epilepsy, seizure

recognition, and first aid, call Carla in Calgary (230-2764), or Krista in Central Alberta (358-3358) to request a session. It's a small time investment that

can make a huge difference in the life of someone living with epilepsy and is available at no cost to the group.

Volunteer News

Mac's Convenience Store Fundraising and Awareness Campaign

We now have a total! **\$3851.75 was raised from our Mac's coin campaign!!!** In Central Alberta, **we raised \$250.00.** To all of you that delivered, monitored, and picked up the cans – WE SALUTE YOU! Thank you!

Thanks as well to **George Waite**, who arranged to have Cash Casino help us sort and roll the coins (all but the dimes and pennies) which made the job much easier! He also single-handedly carried all the heavy coin containers to the casino. That man's a super hero!!!!

Another million thanks (or at least \$1500) to all the volunteers who helped do the "dirty deed" of rolling all the dimes and pennies that the casino couldn't roll. (I now know why they say "filthy rich"! Money is DIRTY!) With the help of our volunteers, this effort has been a great success!

Public Education – Thanks to volunteers **Bill and Monica**, who helped promote awareness at the "Women and Wellness" and "Calgary Learns" fairs.

Upcoming Events

It will be a busy time for volunteers as we promote epilepsy awareness and the Epilepsy Association at many events and venues this fall.

- **United Way Ambassador Presentations** – Our speakers will be busy educating community organizations and Corporate Calgary about how their donations to the United Way will help the Epilepsy Association of Calgary and the important work that we do.
- **MRC Volunteer Fair** – Recruiting and networking with students to promote the Epilepsy Association of Calgary to an estimated 1700 students.
- **University of Calgary Health & Wellness Career Fair** – Gearing up to be one of our largest Health & Wellness Fairs yet!
- **Calgary Farmers' Market** – We will be there at Halloween and again in November to sell our lavender epilepsy bracelets and chocolate penguins while educating the public about epilepsy and the Epilepsy Association of Calgary.
- **Casino** – Our next FUNd-raising casino is scheduled for February 4 & 5, 2006 at the Cash Casino on Blackfoot Trail. We will need volunteers to fill a variety of roles from chip runners to cashiers. There are day time and evening shifts, and applications will be available soon. Contact Melanie if you'd like to help.

Many more events to come (including several displays and a poster blitz for **Epilepsy Education Month** in November). If you would like to help us accomplish GREAT THINGS TOGETHER, please call or e-mail Melanie at 230-2764 or epilepsy.mburnell@telus.net.

Our thanks to the Wild Rose Foundation for making our Volunteer Program possible!



Board of Directors 2005 – 2006

Pat Frank President	Lisa Nowlin Secretary	Dan Pyper Director
Donna Bernreuther Vice President	George Jacob Director	Marcel Ouimet Director
Linus Murphy Treasurer	Kathryn Robson Director	Bill Melathopolous Director
	Bill Broens Director	

The staff and Board of Directors of the Epilepsy Association of Calgary extend heartfelt thanks to all our donors, members, and volunteers for support of our Calgary and Central Alberta offices.

Kathy Fyfe, Executive Director
epilepsy.kfyfe@telusplanet.net

Graham Thomas, Office Administrator
epilepsy.gthomas@telus.net

Janice Shaw, Support Coordinator
epilepsy.jshaw@telusplanet.net

Carla Archer, Public Education Coordinator
epilepsy.carla@telusplanet.net

Melanie Burnell, Special Projects/Volunteer Coordinator
epilepsy.mburnell@telus.net

General Mail Box
epilepsy.calgary@telus.net

Central Alberta Office – Red Deer
Krista Anderson, Program Coordinator
epilepsy.kanderson@telus.net



**TOGETHER
WE ARE MAKING
A DIFFERENCE**

EPILEPSY ASSOCIATION OF CALGARY



Epilepsy Discussion/Support Group Meetings

Wednesdays - 7:00 p.m. to 9:00 p.m.

At the Epilepsy Association of Calgary
4112 – 4 St NW, Calgary AB

**Nov. 8, 2006 – Jan. 10, 2007 – Feb 7, 2007
March 14, 2007**

For more information contact Janice at 230-2764 or email at epilepsy.jshaw@telusplanet.net.

Taking Control of Your Wellness Skills Development Program

Ongoing registration is available for this program based on the work of Joel Reiter, MD., Donna Andrews, and Charlotte Janis, who developed a book and program, *Taking Control of Your Epilepsy*. This program is a holistic health approach that considers the entire individual including the physiological, psychological, and interpersonal, dimensions of the person. It provides a variety of skills and tools that help participants learn to minimize the negative impact of epilepsy in their lives, while enhancing an overall sense of wellness. The program consists of weekly individual sessions over 12 to 15 weeks. **If you'd like to make some positive changes in your life, then this could be the program for you!**

For more information, contact Janice at 230-2764.

JOIN US FOR OUR ANNUAL CHRISTMAS PARTY!!

Mark your calendars for **Tuesday, December 5th 2006**. We will provide the food – you will provide the fun! The party will be held at 4112 – 4th Street NW, from **6:00 p.m. to 9:00 p.m.** **PLEASE RSVP TO GRAHAM by November 30th** to ensure that we have food and refreshments for all! He can be reached at 230-2764.



Thursday Afternoon at the Movies

If you like to go to the movies, but just can't afford to, the Calgary Public Library is holding Thursday afternoon movies every week between September and December. **All you need is a library card.** The movies are held at the W.R. Castell Central Library on the 2nd Floor in the John Dutton Theatre. No registration is required. For more information call the library at 260-2702.

Upcoming Information Sessions

Career Links – Enhancing Workplace Participation for Adults With Employment Barriers

Guest Speaker: Career Links

Wednesday November 22, 2006 – 7:00 to 9:30 p.m.

Career Links is a service that provides employment preparation and placement for adults who have experienced employment barriers. Recognizing that everyone should have the opportunity to become a contributing member of the community, Career Links places an emphasis on changing workplace and community environments, rather than the individual. A representative of Career Links will be with us to discuss employment concerns, tell us how they can help, and how to access their services. If you are thinking of entering the workforce, or are experiencing difficulties finding and maintaining meaningful employment, you won't want to miss this session!

Understanding Guardianship

**Guest Speakers: Lola Swanson & Heather Perrault,
Office of the Public Guardian**

Wednesday, January 24, 2007 – 7:00 to 9:30 p.m.

If you are a parent of an adult or child who is likely to remain dependent through their lives, you won't want to miss this session. It is important for parents to consider the needs of an adult child when they are no longer living, or able to provide care. As we witness the aging of baby boomers, we have also witnessed a number of situations in which on-going arrangements must be in place to provide on-going care for dependent adult children, especially in situation where parents have provided lifelong care and support. Having arrangements in place to ensure the physical, emotional, and social needs in place, will help ensure the on-going well-being of your child. This session is designed to help parents of any age begin to consider these difficult realities.

**All Sessions will be held at the Epilepsy Association of
Calgary, 4112 – 4 Street NW, Calgary, Alberta.**

**Anyone with or concerned with epilepsy (parents, friends,
spouses, peers) are welcome to attend these sessions.**

**Check our website for additional sessions and updates
(www.epilepsycalgary.com)**

**For more information contact Janice at 230-2764,
1-866-EPILEPSY, or email at epilepsy.jshaw@telusplanet.net.**

CENTRAL ALBERTA OFFICE



Upcoming Epilepsy Discussion/ Support Groups

Thursdays from 6:30 pm to 8:30 pm

at the Epilepsy Association of Calgary – CENTRAL ALBERTA OFFICE
#303, 4822 – 50th Street, Red Deer AB

**Nov. 2, 2006 – Jan. 11, 2007 – Feb. 1, 2007
March 1, 2007**

**PLEASE NOTE: The Parson's Clinic Doors are now locked
15 minutes after the group starts at 6:45 p.m.** Please call ahead
to let us know you are coming – *especially* if you will be delayed.
We don't want to lock you out!

Join us for a Celebration of the Christmas Season

December 14, 2006 • Time – 7:00 p.m.

Location – Kerrywood Nature Centre
6300 – 45th Avenue • Red Deer, Alberta



We'll provide the snacks and activities. You provide the spirit!

If you'd like to help out with the preparation, or have a great
activity, call Krista! **Please RSVP to Krista (358-3358) by
December 8th, 2006.**

Teen Program for Central Alberta Teens Living with Epilepsy

A small group of young people affected by epilepsy began meeting
last fall. If you are a young person living with epilepsy, and would
like to learn more about the opportunity to meet others who share
your concerns – the group would love to meet you. There are no
meeting dates scheduled at this time; however, if you are interested,
contact us and we will let you know when and where the next
gathering will be held. This group is interested not only in meeting
and supporting one another, but in looking for ways they can
contribute to creating understanding about epilepsy.

We are currently arranging for some great speakers for the new year.

We are also seeking space in which to hold information sessions
and support and information meetings. If you know of space that is
accessible and inexpensive, please contact Krista.

For more information on any of these events, contact Krista at
358-3358, 1-866-EPILEPSY, or email: epilepsy.kanderson@telus.net.

Keep checking our website for updates (www.epilepsycalgary.com,
'Central Alberta Office' link).

The United Way Goes All the Way to Support the Community

The United Way Campaigns are in high gear in both Calgary and
Central Alberta. Both have set lofty fund-raising goals – which we
know they'll meet – with our support!

- The United Way of Central Alberta has set a **1.6 million dollar**
campaign goal
- The United Way of Calgary and area – **50 million dollar** goal

These campaigns work with the help of hundreds of dedicated,
community minded volunteers and the support of the community.
Programs in Calgary and Central Alberta receive United Way
funds – which helps us make a difference in the lives of those
living with epilepsy. No donation is too big or too small. If you
can help with a donation to the United Way of Calgary or Central
Alberta – we all win! For more information:

403-231-6265 www.calgaryunitedway.org

403-343-3900 www.mycommunityinformation.com/caunitedway

Popular Daytime Soap Character Develops Epilepsy

In our last newsletter, we let you know about a new story line that
was being developed on the popular daytime soap opera, *The Young
and Restless*, which airs daily on Global Television. At that time we
had little information other than the fact that the character, Victor
Newman, would be diagnosed with epilepsy and that the storyline
would be introduced sometime in July.

The Canadian Epilepsy Alliance made a request to Global Television
that they air a CEA public service announcement on days when the
story line appeared, and we were thrilled that they agreed to allow us
to use the story line to leverage awareness about epilepsy. We have
learned as well that CBS worked in consultation with the Epilepsy
Foundation of America in developing the story – also good news
– and an opportunity they jumped at. As we all know, this type of
consultation is practically unheard of. More often, when epilepsy is
portrayed in film and television, it tends to be negative or derogatory,
and usually does nothing but perpetuate myths and misinformation.

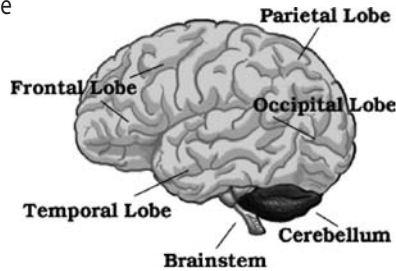
Since we first reported that this storyline would occur, Y&R character,
Victor Newman (played by Eric Baden) has been diagnosed with
temporal lobe epilepsy. During this period, he also underwent
some very noticeable personality changes, most notably, a kinder
persona contrasted against a generally manipulative and hard hearted
personality. Response from across Canada – at least in the epilepsy
community – has been quite positive, although some have questioned

Continued on page 6...

PARTIAL SEIZURES

By Carla Archer, Public Education Coordinator

Generally, when people think about epilepsy they imagine a person falling to the ground and convulsing. Although alarming, generalized tonic-clonic seizures are not the most common type of seizure in adults. Instead, it is complex partial seizures that are most prevalent. Another type of partial seizure are simple partial seizures. People are often confused by the names of these seizure types and find it helpful to first clarify what partial seizures are, and what happens within the brain, before learning how to recognize each seizure. Simply put, partial seizures begin in a single area of the brain and then affect the functions that area controls. The diagram and chart should help you identify the areas of the brain and identify their purposes.



Frontal Lobe	Frontal Lobe	Occipital Lobe	Temporal Lobe
Reasoning	Movement	Vision	Perception and recognition of what is heard
Planning	Orientation		Memory
Parts of speech	Recognition		Speech
Movement	Perception		
Emotions			
Problem solving			

With some understanding about partial seizures we can now look at complex partial seizures. In this type of seizure the individual experiences a loss of awareness and appears in a dreamlike state. They may look conscious but may be unaware of movements, speech or actions that are occurring. An onlooker may witness repetitive actions such as lip smacking, picking at clothes, wandering and the repetition of words. The person having the seizure is unaware of these actions and needs someone with them to gently guide them away from harm such as stairs or the street. After a complex partial seizure it is not uncommon for an individual to be confused for awhile.

Simple partial seizures are another common type of seizure. In this seizure the person's consciousness is not impaired but it does briefly affect movement, emotions, sensations, and perceptions in unusual and sometimes frightening ways. Some examples of people's experiences during a simple partial seizure are: smelling burnt toast, tasting something sour, objects changing in size/appearance, twitching of a limb or a sudden feeling of fear or conversely, happiness. These seizures can be followed by another seizure type. Simple partial seizures in these cases, may provide a warning that a more severe seizure is about to occur.

Partial seizures have a wide range of movement and actions associated with them. These actions are often misunderstood or confused with other conditions, such as a drunkenness or some kind of mental health condition. That is why it is so important to educate ourselves. If we confront behavior that seems unusual, we should be alert to the possibility that a partial seizure may be occurring and act accordingly. Detailed information on Seizure First Aid is available from our office.

Continued from page 5...

whether or not the personality changes offer an accurate portrayal of temporal lobe epilepsy.

It is important to remember, that first and foremost, that *Y&R* is about entertainment, and the producers are going to take as much dramatic license as they can to help keep the story interesting. According to the Epilepsy Foundation of America, while Victor's symptoms would be extremely rare, they are not completely out of the realm of possibility. More common to those who live with temporal lobe epilepsy are changes in perception or sensation, such as strange thoughts, emotions, sounds, sights, tastes, and smells. Generally, these changes are not long lasting, and they may occur in combination with convulsive seizures. Again, for the story line, the producers have taken a more extreme approach than is common for most people. Thank goodness most of us don't live the exaggerated lives that are a daily component to the life of a soap opera character!

On the plus side, the producers consulted with the Epilepsy Association of America in developing this story, and report that this is the first time a lead actor in a television series has been diagnosed with an on-going seizures. The physician who deals with Victor and his

daughter explains the seizures, advises that there are many types of seizures, and advises that Victor's character could experience more severe seizures. Seizure first aid is also discussed in the story line very accurately – for instance, debunking the idea that you should put something in a person's mouth – great information to provide to the millions of viewers who watch this series daily.

The story is still unfolding, and we do not know what will happen in future episodes, although it sounds as if Victor may soon have a seizure alert dog – this from a local viewer who shared her perceptions with us. We'll just have to wait and see. However, it is encouraging that this storyline has been developed with the support of the Epilepsy Foundation of America in a manner that gives more positive visibility to epilepsy than is usually portrayed in television and film, along with accurate information.

More information can be found on the Epilepsy Foundation of America web-site (www.efa.org). If you have any comments about the series that you would like to share with us about your perceptions of the *Y&R* storyline we will print them in the next edition of the *Epigram* newsletter. Send them to the *Epigram* c/o the Epilepsy Association of Calgary, or to epilepsy.calgary@telus.net.

We would like to extend our sincere thanks to all those who have supported our work and who share our commitment towards the promotion of independence and quality of life for those affected by epilepsy. To the many "Epilepsy Champions" who support our work with their donations, but don't wish their names published – we extend our thanks. You know who you are!

The following contributions have been received since our last Epigram Newsletter:

Donor names only appear in the print version of the Epigram

Many thanks to the **United Way of Calgary donors** who designated **\$446.48** to EAC since our last Epigram.

Many thanks as well to **United Way of Central Alberta donors**. Designated donations of **\$841.50** have been received for our Central Alberta Office.

We recognize our donors in our quarterly newsletter and our members and donors in our Annual Report. These documents are shared with members, funders, program participants, and others in the community who are interested in our work. In accordance with Privacy Legislation: **if you do not wish to have your name published**, please call us at 230-2764 or indicate your wishes in the form below and send it to us by fax or mail to the Epilepsy Association of Calgary, 4112 – 4 Street NW, Calgary AB T2K 1A2.

I do not wish to have my name published in the Annual Report or Epigram Newsletter.

Name (Please Print) _____

Signature _____

Date _____

NEWSLETTER DISCLAIMER

Material contained in this newsletter concerning epilepsy, research, treatment, and patient experiences is solely for information purposes. Each individual's experiences of epilepsy are different. Please consult your physician for medical advice. Articles published in the Epigram newsletter do not necessarily represent the official policies or endorsements of the Association and its members.

*EPIGRAM is published quarterly by the
Epilepsy Association of Calgary
4112 – 4 Street NW
Calgary, Alberta T2K 1A2
Calgary and Area: (403) 230-2764
Toll Free: 1-866-EPILEPSY
Fax: (403) 230-5766
Email: epilepsy.calgary@telus.net
Layout & design – Associations Plus Inc.*

MEMBER/DONOR FORM

Name _____ Address _____
City _____ Province _____ Postal Code _____
Home Phone _____ Work Phone _____

- Annual Membership.....\$20.00
(January to December 2006)
- Life Membership..... \$200.00
- Donation amount.....\$ _____
Total.....\$ _____

Payment method:

Cheque Money Order
 Credit card Visa MasterCard
Credit card number _____ Expiry Date _____
Cardholder signature _____

Pre-Authorized Credit Card Payment Program for Donations Only:

- Yes, I prefer to make a monthly donation that will help support the programs and services of the association year-round.
- \$ _____ per month, beginning on the 15th day of each month until otherwise notified.

A tax-deductible receipt will be issued for charitable registration number 11890 0778 RR001.

A WORD ABOUT PRIVACY

The Epilepsy Association of Calgary respects your privacy. As such, we do not share, sell, rent, or trade our membership lists, donor lists, volunteer lists, or participant lists with any outside organizations. Personal information provided in the context of program participation is never shared without your written consent, unless there is a legal or ethical obligation to do so. Information you provide us is used to deliver services, keep you informed about agency activities and opportunities, fund-raising initiatives and events, volunteer opportunities.

If you no longer wish to receive some or all of the information we provide, you can contact us by telephone, fax, or e-mail, and we will remove your name from any or all of contact lists in accordance with your wishes.

Return undeliverable Canadian addresses to:

Epilepsy Association of Calgary
4112 - 4 Street NW
Calgary, Alberta T2K 1A2
Email: epilepsy.calgary@telus.net



To ensure your Epigram Newsletter always reaches you, please contact us with address changes as soon as possible.