



EPIGRAM



Epilepsy Association of Calgary

July 2005

Volume 10, Issue 1

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

INSIDE:

50th Anniversary Volunteer Awards

Staff Comings and Goings

A Glimpse from the Past: Part 2
A Dream is Realized

Volunteers' Meet & Greet

Summer Bicycle Safety

The Gene Discovery Project

Did You Know...

EAC Events

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.

50th Anniversary Volunteer Awards

At this year's AGM, held on June 14, 2005 – four of EAC's volunteers were recognized with the "50th Anniversary Volunteer Awards". We couldn't think of a better way to recognize and thank these special volunteers who bridge past with present, and who collectively represent approximately 100 years of volunteerism! Thank you and congratulations to (l – r): George Waite, Donna Bernreuther, Roy Swanberg, and Lyn Swanberg, pictured with Executive Director, Kathy Fyfe (centre).



This year's AGM was definitely fun and memorable. Comedy alumni singers, "The Barenaked Neurons" and Dr. H. A. HA, the singing clown kept us energized and entertained! Joyce McPherson read poetry she'd written to honor the 40th and 50th anniversaries (to be included in an upcoming Epigram), and our mascot ECHO was on hand. To the right, the Barenaked Neurons, singing their rendition of "Splish Splash", are: Monique McPherson, Rob Stephenson, Melanie Bunnell, Kathy Rao, and Martin Bell.



CELEBRATING 50 YEARS SUPPORTING THE CALGARY COMMUNITY

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@telusplanet.net

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

Staff Coming and Goings

We recently welcomed Graham Thomas and Melanie Burnell to our staff. Graham, who hails from Halifax via Ireland is our new Office Administrator. Melanie is filling dual roles, as Volunteer Coordinator and to assist with some of our 50th anniversary activities. Welcome Graham and Melanie!

Board of Directors 2005 – 2006

Pat Frank
President

Donna Bernreuther
Secretary

Bill Broens
Director

Dan Pyper
Vice President

George Jacob
Director

Lisa Nowlin
Director

Marcel Ouimet
Treasurer

Kathryn Robson
Director

Linus Murphy
Director

50th Anniversary Advertising Opportunity

We are now accepting advertising in the Epigram Newsletter. If you have an advertisement you would like to included, rates are as follows:

Standard Business Card Size - \$50.00 – in recognition of EAC's 50 years

One Quarter Page - \$100.00

One Half Page - \$200.00

For further information, please call Kathy at 230-2764. Advertisements are subject to the approval of the Executive Director and do not constitute endorsement of any product or service by the Epilepsy Association of Calgary.



TOGETHER
WE ARE MAKING
A DIFFERENCE

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@telusplanet.net
Layout & design – Associations Plus Inc.

A Glimpse from the Past – Part 2

A Dream is Realized

Kathy Fyfe

In the previous edition of the Epigram, the early history of the Epilepsy Association was explored. This article will pick up from there, focusing primarily on finding EAC a permanent home.

As mentioned in the previous article, the dream originated firstly with Dan Taylor, EAC's first President and Executive Director. He envisioned a building that would be able to house a residence for persons with epilepsy, as well as other association programs. A great many difficulties were experienced in maintaining the Grand Trunk Cottage School as a residence. New licensing requirements enacted by the Province meant that the residence eventually had to be shut down in the mid-1960's, although programs and social activities were still run from the school. While the association was successful in obtaining small grants to make building repairs, it was insufficient to maintain the building properly. The situation was becoming quite a concern – documents indicate that the building had a “demoralizing aura” and gave an “appearance of hopelessness” due to the physical state of premises. There were concerns that potential program participants, volunteers, and other sources of community support would be put off by the dilapidated facility. Further, many were concerned that generalizations and judgements about people with epilepsy would be made strictly on the appearance of the building. At one point, programs were held in a converted mobile home placed adjacent to the building due to insufficient heating capacity and space. On the positive side, the land and building were leased from the city for only \$1.00 per year, which helped keep operating costs very low. EAC's programs were held at the school for over 20 years. Despite the dismal surroundings, the price was right, although the building became a money pit and a burden to the association. Additionally, the space no longer met the association's needs.

There were initial discussions during the mid 1970's with a service club about assisting the association in raising funds for a building; however, discussions with this club did not go ahead. It was not until 1978 that a partnership was struck with the Calgary Jaycees. There is nothing in the documents that actually outlines how this partnership came about, but it was certainly a significant one for EAC! The Jaycees and EAC formed a joint committee to carry the project forward. Early that year, the Jaycees held a television auction and pledged the proceeds of approximately \$14,500 to EAC for a building (with interest, this grew to \$17,000 by the time the funds were spent). A start – but a long way off of the projected costs of some \$400,000 that would be needed.

Prior to the partnership with the Jaycees, the association had developed a “New Premises Proposal” – Phase I of the project. Consideration was given to building on the Grand Trunk Cottage

School site, or looking for a building to buy and renovate. Since the land was leased from the city, the Jaycees advised against the first option. Phase II of the project thus became finding an appropriate site on which to construct a building. The New Premises Proposal had determined that any potential site needed to be near a bus route, have space for parking, and able to facilitate a 4500 square foot building on one or two stories. It was not long before the City of Calgary recommended a vacant site at 40th Avenue and 4th Street NW that met all of these criteria. On November 3, 1980, City Council agreed to sell EAC the proposed site at 40th Avenue NW, which allowed the project to move to Phase III – Funding of the Building. During this time, the Jaycees made an application to the Alberta, 75th anniversary committee and were granted \$378,500 towards the project! The Board of Directors of the Epilepsy Association of Calgary raised a further \$18,000. With the grant, the proceeds of the Jaycees' auction, and the proceeds of EAC's campaign, a dream that had existed for approximately 20 years was on the brink of realization! 1980 was EAC's Silver Anniversary. The prospect of a new home provided a reason for hope and celebration at the official anniversary event held in May of 1980.

Phase IV of the project consisted of the development and construction of the building. With the funds in place and a site secured, Swinton Architects was commissioned to design the building: a two-storey, wood frame structure comprising 4500 square feet – a design intended to meet current and future program needs. Nedco Construction was hired to construct the building. In addition to the Jaycees/EAC joint committee, which oversaw the project, a second committee of EAC volunteers was formed to oversee construction. The official sod turning was held on May 27, 1981. Guests included (see photo below) Mayor Ralph Klein and Nomi Whalen (who chaired Calgary's 75th anniversary committee on behalf of the province, and who made funding recommendations to the Province for local projects), as well as members of the Jaycees/EAC joint committee and EAC Board members. On December 3, 1981, the Epilepsy Association of Calgary moved into the new building – our home for the last 24 years.

Continued on page 4...



Although at first glance this reporting of how EAC's building came about may seem unremarkable, it is an amazing and inspiring story that unfolded over many years, involved countless volunteers and volunteer hours, and culminated in the completion of a building. It is also interesting in that although the journey was a long, often difficult one, some very wise decisions were made. For example – in 50 years, EAC has never paid rent! In the short term, it might have been easy to look for rental space; however, there is no evidence that this was ever considered as an option. Over the long term it most certainly would not have been best course of action. For many small organizations operating day to day, it is nothing short of amazing that EAC held so steadfast to its goal of a building over so many years! Although the Grand Trunk Cottage School came with many challenges, many charitable organizations face an uphill battle just meeting their monthly rental, which can be a significant portion of their budget. We are fortunate to be among the few charities that actually owns its own building and currently, the only epilepsy organization in Canada that has been so blessed (Epilepsy Newfoundland is currently undertaking a building project). Not only that, but in 50 years EAC has only had two addresses! Many other organizations have had to make several moves, which can create confusion and extra expense. EAC has been

blessed with people who had dreams and the fortitude to find a way to make them happen! Although Dan Taylor's initial vision and efforts for a facility that would house a residence and programs changed over time, a seed was planted, nourished, and developed into the lovely building the EAC calls home!

As the association marks its 50th anniversary, it is important to remember and celebrate such a remarkable achievement. In a letter written near the conclusion of the project, a Jaycee member reported that initially, there were many Jaycee members who believed the project would never succeed. Thank goodness they were wrong!

We are forever indebted to the following individuals. Without them, the dream for a permanent home might never have been realized. Additionally, once completed, many volunteers helped move, furnish and complete the landscaping. We don't have all of these names at this writing; however – our hats are off to everyone who helped make the building happen!

Joint EAC/Jaycees Committee

- Ben Shykora, EAC & Jaycees - Chair
- Sheldon Quinn, EAC
- Fred Kreuger, EAC
- John Rouse, EAC
- Ben Shykora, EAC
- Barry Steffen, Jaycees
- Donna Munroe
- Reig Pierie

EAC Construction Oversight

- | | |
|---------------|---------------|
| Sheldon Quinn | Roy Swanberg |
| Ben Shykora | John Costello |
| John Rouse | R. A. Hayes |
| Bonnie Kaplan | Blaine Clarke |
| George Waite | Gary Dvorkin |
| Don Mathieu | Sam Darwish |
| William Omery | Leigh Spicer |

These are the names of individuals recorded in our documents. There were no doubt others. Our continued thanks to all who were involved in such an historic moment for EAC! The two plaques placed in the building to commemorate this monumental achievement read as follows:

In cooperation with the Alberta 75th Anniversary Civic Committee of the City of Calgary, the Calgary Junior Chamber of Commerce dedicates this building to the Epilepsy Association of Calgary in 1980.

This project is dedicated to the people of the Province of Alberta who have worked with enthusiasm and pride to make possible the celebration of Alberta's 75th Anniversary. It is made possible in whole or in part through a gift from the Alberta 75th Anniversary Civic Committee of the City of Calgary in 1980.

Then... and now...



"Never doubt that a small, group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." - Margaret Mead

Volunteers – Meet and Greet

Carla Archer & Charlotte Lewis

The Meet & Greet for volunteers, held on April 13, 2005 was a great success. A number of volunteers attended and brought their enormous enthusiasm. The night started by sharing ideas on how to improve our existing volunteer opportunities. Years of experience and knowledge came together to give us guidance. The rest of the night was full of humor and fellowship – as well as munchies! Thanks to all in attendance for their excellent ideas, feedback, and eagerness to contribute. For those who could not attend we still are eager to hear your thoughts and ideas regarding the volunteer program. We would also like to obtain updated information from all volunteers. This will allow us to keep you up to date via e-mail, and enhance opportunities to communicate with you. If you would like to receive news via e-mail, please let us know by phoning or e-mailing us your e-mail address. Thank you again for all the great contributions you make to the Epilepsy Association of Calgary.

(Please note, we have a new Volunteer Coordinator, Melanie Burnell – you can e-mail her at epilepsy.mburnell@telusplanet.net If you haven't met or spoken with her yet, she will be in touch very soon!)

The Gene Discovery Project

The Epilepsy Foundation of America has launched a project focused on learning about epilepsy and genetics in order to further understand the role of genetics in the development and treatment of epilepsy. Participation is completely voluntary, however, you must be 18 years of age and have an e-mail address in order to participate. At least one member of your family must have epilepsy. If you would like more information you can visit the Epilepsy Foundation of America website: www.epilepsyfoundation.org/gene/

Why Aging isn't so Bad

- Kidnappers aren't very interested in you.
- Your secrets are safe with your friends because they can't remember either.
- No one expects you to run into a burning building.
- There's nothing left to learn the hard way.
- Your joints are more accurate than the national weather service.
- In a hostage situation you are likely to be released first.

(Source: Canadian Reflex Sympathetic Dystrophy Network)



Summer Bicycle Safety

Every summer the important message that wearing a bicycle helmet to help prevent head injuries is advertised. Head injuries can cause epilepsy in individuals who have no previous history of a seizure disorder. Those who

live with seizures should also protect their heads while cycling. It is important that a bicycle helmet fits the cyclist so it can effectively absorb the impact of a fall, protecting the head from injury. For a helmet to fit correctly it should sit level on the head just above the eyebrows. It can be adjusted by using the foam pads or fitting rings that are included. The chin strap should be snug so that if a person opens his/her mouth the helmet pulls down only slightly. The rim of the helmet should be barely visible when looking upward and the side straps should be positioned just below the ear. If the helmet can be moved more than an inch, readjust the size to make it more solid and comfortable. If it does not feel right or is too loose after adjusting, try a different one. Be sure helmet has a label indicating that it is approved by the Canadian Standards Association (CSA). Remember as well, helmets *must* be replaced after an accident to be effective. To ensure your safety, wear a properly fitting bicycle helmet every time you are cycling to prevent head injuries that can cause or worsen epilepsy. This summer – have fun – but be safe first!

Did You Know?

- The first Epilepsy Month held by EAC took place in November of 1974. During the years 1975 to 1984, the annual education campaign took place during "Epilepsy Week". In 1984, it was extended to the month of November, and has remained that way ever since. 2005 will mark 31 years that EAC has held this annual education and awareness campaign.
- The earliest newsletter on file at EAC is dated "Spring 1968". There are indications that the association distributed a newsletter sooner, although no copies could be found.
- Prior to the spring of 1969 the newsletter was simply called, "Newsletter". That spring, the association had a contest to name the newsletter. Entry names included, "The Flame of Hope", "Epi-Chatter", "The Edit", and "The Educator". The winning entry, submitted by N. Birch (a board member), was announced in September of 1969. Its title? THE EPIGRAM!
- In 1969 – the cost to mail the Epigram was 5 cents per copy.

..... **laughing
allowed
Corner...**

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

September 21, 2005

October 19, 2005

November 23, 2005

December 14, 2005

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

Taking Control of Your Wellness Skills Development Program

On-going 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". Taking Control of Your Wellness Skills Development is a holistic health approach that considers the entire individual - physiological, psychological, intra-psychic, interpersonal, and social components of the participant. The program provides skills and tools that help participants learn to control the impact of epilepsy on his/her life. The program consists of weekly individual sessions, with some homework in between. The required time commitment is 12 to 15 weeks. For more information, contact Janice at 230-2764.

Upcoming Information Sessions

The Uniqueness of Epilepsy

Wednesday September 14, 2005 - 7:00 to 9:30 p.m.

Every person is unique, and every person experiences epilepsy according to his/her own thoughts, feelings, and experiences. In this session, we will explore and share some of these experiences (i.e., déjà vu, memory problems, scattered thinking, etc.) with a view to increasing coping, self acceptance, and growth. It will be an opportunity to learn from one another and celebrate your individuality.

Movie Night

Wednesday October 12, 2005 - 7:00 to 9:30 p.m.

After many requests, we are going to hold a movie night. The movie (TBA), will focus on some aspect of epilepsy and could be drawn from popular films that portray epilepsy in some way. The intent of the session will be to generate thought, discussion, questions, queries - and possibly a call to action. If you have a film you'd like to recommend - please call Janice, and we will include it on the list of possible movies. We'll let you know the selected movie as soon as a decision has been made.

Epilepsy and Women's Issues

Guest Speaker: Dr. Alexandra Hanson, Neurologist
Wednesday November 16, 2005 - 7:00 to 9:30 p.m.

Throughout the female life cycle, epilepsy presents a number of challenges and concerns. Hormonal changes at puberty, during the child bearing years, and at menopause can have an impact on epilepsy, and most women have many questions about how these life changes may affect them. We are pleased that Dr. Hanson will be available to explain and discuss issues of concern to women living with epilepsy.

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.
For more information contact Janice at 230-2764 or email at epilepsy.jshaw@telusplanet.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 "unsung heroes" who have contributed, but don't wish their names published – our heartfelt thanks to you as well. You know who you are!

Individual donors are only identified in the print version of the Newsletter.

We would also like to acknowledge and thank the **United Way of Calgary donors** for donations received through their Donor Designation Programs. To date this year, we have received \$4008 in donations forwarded through the United Way of Calgary and Area.

CENTRAL ALBERTA OFFICE EVENTS...



**Will be included in our next newsletter
and posted on our website soon!**



For more information contact Krista at
358-3358 or 1-866-EPILEPSY
E-mail: epilepsy.kanderson@telus.net
Website: www.epilepsycalgary.com

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 _____

MEMBER/DONOR FORM

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

- Annual Membership\$20.00
(January to December 2005)
- 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@telusplanet.net

