



# EPIGRAM



Epilepsy Association of Calgary

November 2004

Volume 9, Issue 3

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

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## 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**.

## FEATURE ARTICLE

### Getting to the Heart of Dravet's Syndrome

By Paula Janfield

On January 10, 2004 I was standing in a Los Angeles parking lot staring at the celebrity I most wanted to meet! I had impulsively decided only two days before that I would come to Los Angeles and hear this person speak. Now here we were about to get on the same elevator and ride to the conference room where others were waiting to hear this individual speak. Who was this famous person? It was Dr. Charlotte Dravet, world renowned pediatric neurologist who identified Dravet's Syndrome (formerly Severe Myoclonic Epilepsy in Infancy).

My six year-old daughter Teigan has Dravet's Syndrome. Teigan started having seizures at four months old. She would seize approximately once per month, a generalized tonic clonic lasting anywhere from 50 minutes to three hours. We were frequent visitors to the children's hospital where they would medically stop these seizures. After months of having no idea why this was happening to my child, we finally found the diagnosis - Dravet's Syndrome.

Dravet's Syndrome is relatively rare, and it is fairly "new", only being identified as its own disorder since 1982. It is characterized by seizures beginning in the first year of life. The seizures are generalized convulsive events, often thought to be febrile convulsions, and are usually extremely long in duration. Development is typical until around 18 months old, when signs of speech delay become apparent. Other delays soon follow. Multiple seizure types, including tonic, myoclonic, absence, and complex partials are usually emerging around this age. Dravet's is known to be unresponsive to conventional therapies. We were fortunate to hear of a trial medication being used in France to treat Dravet's, called Stiripentol. Our neurologist was able to arrange to obtain this medication for Teigan, and it has now been three years since we have needed the emergency room at Alberta Children's Hospital. Teigan still has seizures, but they are all under five minutes now.

Once it was determined that Teigan had this disorder, I looked high and low for information, and could find very little. I met some other parents on an American web site who had children with this same disorder, and we started our own little web group. We have

49 families from around the world who have a child with the disorder. It was through our web group that I learned Dr. Dravet would be speaking in Los Angeles.

The Epilepsy Association in Los Angeles had asked five neurologists who were collaborating on a book if they would mind addressing parents in an informal setting while they were all in town, and they agreed. There were about 40 parents from the Los Angeles area there. I think I was the only parent who had traveled in from outside the USA, but the conference was not well publicized, so it was more of a surprise that I was even there.

The doctors all presented on different topics, followed by a question and answer session. It was very informal and wonderful to have such a small group, as all of my questions were addressed. There was a wealth of information on all aspects of epilepsy and I made some wonderful contacts while there. I exchanged email addresses with three of the neurologists, and they are fantastic about sharing information that may be of interest to me.

I would strongly recommend that any parent who gets the opportunity to attend a seminar pertaining to epilepsy attend at least one of these presentations. It is interesting to learn how these doctors study and come to the conclusions that they do.

Continued on page 3...

NOVEMBER IS...

## EPILEPSY EDUCATION MONTH

Calgary Mayor Dave Bronconnier and outgoing Red Deer Mayor, Gail Surkan, proclaimed November 2004 as Epilepsy Education Month in Calgary and Central Alberta.

This year, we launched a new poster and message: ***Epilepsy - Anyone Can Have a Seizure - Anyone Can Learn to Respond to a Seizure... Anyone... Even You.*** Participants portrayed in the poster are all affected by epilepsy. We wanted to portray a range of people of varying ages, backgrounds, and circumstances, since epilepsy does not discriminate. Virtually anyone can develop epilepsy at anytime in their life. Anyone, including our beloved family pets – portrayed on our poster by “Barney”, who is a precious companion to a member of our board. Just as anyone can get epilepsy, anyone can learn to assist with a seizure. We have taught people from five to eighty-five how to recognize and assist with seizures. It’s knowing how to assist that makes all the difference! There is currently a great deal of interest in assistive animals. On our poster, we have included a second dog, “Rudy”, who is able to assist his human companion with seizures. We hope this year’s poster will reinforce our message and encourage people from all walks of life to learn about epilepsy, seizures, and seizure first aid.

We would like to extend a huge thanks to our human and canine volunteers for helping us extend this message:

Barney – and his human companion – Pat Frank  
Rudy – and his human companion – Theresa Vianni  
Parry Mahal  
Paula Janfield  
Teigan Janfield  
Stan Cribbett

Thanks as well to Candy at Riley’s Reproductions, who arranged a printing discount for us.

Some activities for Epilepsy Education Month 2004 will include:

- Poster distribution in Calgary and Central Alberta
- Education Presentations
- Epilepsy nights at a Red Deer Rebels and a Calgary Hitmen Hockey Game
- Electronic Sign Messages (Calgary)
- Public Service Announcements
- Information Displays

Contact Carla in our Calgary office (230-2764), or Krista in our Red Deer office (358-3358) or either by calling 1-866-EPILEPSY, for more information, to request a poster or presentation, or if you’d like to volunteer your time for these and other activities.

**EPILEPSY**  
ANYone → CAN HAVE A SEIZURE  
CAN LEARN TO RESPOND TO A SEIZURE  
**ANYone** → **even YOU**

**EPILEPSY ASSOCIATION OF CALGARY**  
4112 - 4th Street NW  
Calgary, AB  
T2K 1A2  
403-230-2764

**CENTRAL ALBERTA OFFICE:**  
303, 4822-50th Street  
Red Deer, AB  
T4N 1X2  
403-358-3358

FOR MORE INFORMATION:  
→ [www.epilepsycalgary.com](http://www.epilepsycalgary.com)

### Why Support the United Way Campaigns?

United Way Campaigns are in full swing in both Calgary and Central Alberta. We’d like to invite anyone who is able to, to make a donation to their local United Way. You should be aware that the United Way in both Calgary and Central Alberta are driven primarily with the support of committed volunteers who do an unbelievable job of raising funds. We couldn’t possibly match the success that the United Way is able to achieve. Since both Calgary and Central Alberta benefit from this effort, we encourage you to help support these two great United Ways that support our work! Together – we really can make a difference!



## Board of Directors 2004 – 2005

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**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.

## Assured Income for the Severely Handicapped (AISH) Program is Under Review – Make Your Voice Count!

The Honourable Clint Dunford, Minister of Alberta Human Resources and Employment, has established a Government MLA Committee to review the AISH Program, which provides income support and health benefits for Albertans with a permanent disability. Do you have suggestions, concerns, or comments about what you think AISH Programs should look like in the future? This is your opportunity to make your voice count. The questionnaire can be obtained on the Government of Alberta website at [www.aishreview.gov.ab.ca](http://www.aishreview.gov.ab.ca), or you can call 310-4455 to get your copy. The deadline to submit your completed questionnaire and comments is November 30th, 2004.

## Changes to Supports for Independence (SFI)

For those who receive Supports for Independence, you are most likely aware of changes that came into effect in May of 2004. For those who are not currently receiving SFI, there are some changes you will no doubt want to be aware of. Supports for Independence was replaced by "Alberta Works", a new program that integrates

- Employment and Training Services
- Income Support
- Health Benefits
- Child Support Services

The overall goal of Alberta Works is to help unemployed people find jobs, help low-income people cover their basic living costs, and help employers find skilled workers. Generally, it appears that those who receive support through this program will be expected to return to work as quickly as possible. Benefits may be available for those who experience short-term difficulties due to an illness, or other reason approved by the Benefit Worker. Some benefits, such as health benefits, may continue to be available after leaving the Income Support Program (via Alberta Adult/Child Health Benefit). A detailed guide about the new program, criteria, and application process is available on the Government of Alberta web-site at [www.gov.ab.ca/hre/albertaworks](http://www.gov.ab.ca/hre/albertaworks). We were also recently provided with copies of the "Guide to Services for Lower-Income Albertans". If you would like a copy, you can call our office (230-2764), or the Alberta Government (310-4455 or [www.gov.ab.ca/servicealberta/LowerIncomeGuide](http://www.gov.ab.ca/servicealberta/LowerIncomeGuide)).

*EPIGRAM is published quarterly by the  
**Epilepsy Association of Calgary***

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The Epilepsy Association in Los Angeles will be holding another one of these presentations early next year, and I will definitely be attending once again. The plan is to have the same neurologists back and organize smaller groups to meet with particular neurologists who specialize in certain aspects. An example would be Dr. Dravet, who specializes in Myoclonic epilepsies, addressing parents who are affected by myoclonic seizures.

Some of the neurologists in attendance at the session included Dr. Renzo Guerrini (Italy) and Dr. Marco Medina (Honduras). If you are interested in hearing more about the conference, I can be reached through the Epilepsy Association of Calgary Office.

### 211 Information and Referral Service is Available in Calgary

- 211 is a three-digit telephone number that connects you to a full range of community, social and government services information in Calgary.
- 211 is free, confidential and multilingual.
- Trained Information and Referral Specialists answer 211 calls. They link you to the best available information and services.
- You can access 211 services outside the City of Calgary by dialing (403) 266-1605.
- Got Questions? Get Answers. Dial 211 to get connected to the community services you need. Online: [www.211calgary.ca](http://www.211calgary.ca)

## **Adult 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

**January 26, 2005**

**February 23, 2005**

**March 23, 2005**

For more information contact Janice at 230-2764  
or email at [epilepsy.jshaw@telusplanet.net](mailto:epilepsy.jshaw@telusplanet.net)

## **WE'RE HAVING A PARTY!!**



Mark your calendars for Wednesday, December 8th, 2004. We will provide the food. The party will be held at 4112 - 4th Street NW, from 6:00 p.m. to 9:00 p.m. PLEASE RSVP TO CARLA BY DECEMBER 3, 2004 to ensure that we have food and refreshments for all! She can be reached at 230-2764 or by e-mail at [epilepsy.carla@telusplanet.net](mailto:epilepsy.carla@telusplanet.net)

## **ARE YOU IN NEED OF MEETING SPACE?**

We can help! We have meeting space available at reasonable rates and flexible access. To view or book meeting facilities, please call Lynda at 230-2764. We can accommodate groups of five to 35. Our meeting space has the following amenities:

- Kitchen facilities (some restrictions apply)      Half day or Evening rates - \$50.00  
Full day rate - \$100.00
- TV/VCR      Coffee - additional charge
- Whiteboard      25% price reduction on bookings of five to seven consecutive days
- Overhead Projector
- On-site parking (evenings and weekends only)      Location: 4112 - 4th Street NW, Calgary, Alberta
- Street parking nearby (week days)

## **Upcoming Information Sessions**

### **Taking Control Alumni - Refresher Course**

**Wednesday - January 12th and January 19th, 2005**  
**7:00 to 9:30 p.m.**

This is for participants who have completed the Taking Control Course. We will revisit and refresh some of the skills and learnings from the course and from one another.

### **Funny Valentine Improvisation Workshop**

**Wednesday - February 9th, 2005**  
**7:00 to 9:30 p.m.**

This workshop will consist of humorous story telling and improv activities facilitated by Bill Melathopolous of Icarus Theatre. An evening of laughter - just what the doctor ordered!

### **Building Positive Self Esteem**

**Thursday - February 17th, 2005**  
**7:00 to 9:30 p.m.**

Back by popular demand - a session designed to help you develop and maintain a positive self-concept and face the world with a sense of renewed self-worth and self-confidence.

### **Epilepsy and Employment - Job Search Tips and Strategies -**

**Wednesday - March 9th, 2005**  
**7:00 to 9:30 p.m.**

The session will provide practical tips and techniques for those seeking employment, cover the issue of disclosing epilepsy, interviews, and provide information on community resources that may be of help in undertaking a job search.

**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](mailto:epilepsy.jshaw@telusplanet.net).**

### **Our sincere condolences to...**

The families of Jean Yoshida and Don Quinlan. You are in our thoughts during this difficult time. Both Jean and Ted Yoshida and Don and Delores Quinlan (and family) have had long associations with EAC. We are truly saddened for both families.

## **Upcoming Support Group Meetings**

Thursdays - 7:00 p.m. to 9:00 p.m.  
At the Epilepsy Association of  
Calgary – Central Alberta Office  
Parson's Clinic Building - Room 303  
4822 - 50 Street, Red Deer

**November 18, 2004**

**January 20, 2005**

**February 17, 2005**

**March 17, 2005**

For more information contact Krista:

Phone: 403-358-3358

Fax: 403-358-3595 (new April 30, 2004)

Toll free: 1-866-EPILEPSY

Email: [epilca@telus.net](mailto:epilca@telus.net)

## **You're Invited!**

**December 2, 2004 is the Central  
Alberta Office Christmas Party**

Time - 6:30 p.m.

Location - Red Deer and District Museum

4525 - 47A Avenue, Red Deer, AB T4N 6Z6

Potluck munchies; we'll supply the refreshments.

Please RSVP to Krista by November 29, 2004 if you plan to attend, at 358-3358 or by e-mail [epilca@telus.net](mailto:epilca@telus.net). We look forward to having you join us!



## **Upcoming Information Sessions**

**Epilepsy and You – What Everyone Needs to Know**

**Time - November 20, 2004 – 1:30 to 3:30 p.m.**

**Location – Red Deer and District Museum**

**4525 47A Avenue, Red Deer, AB T4N 6Z6**

**Red Deer Rebels – Epilepsy Awareness Night**

We'll be having an awareness night at the Rebels game on November 20th, 2004. We'll have an information booth, raffle ticket sale, and public announcements. If you'd like to volunteer at our booth, please call Krista at the number below. Hope to see you there!

For more information on the workshop or Rebels night contact Krista at 358-3358; 1-866-EPILEPSY e-mail [epilca@telus.net](mailto:epilca@telus.net)

**The Epilepsy Association of Calgary  
Central Alberta Office**

## **Fund Raising Raffle**

Tickets are now on sale for our 4th annual Central Alberta Fund-Raising Raffle. Tickets are \$2.00. Prizes include:

- One night of Deluxe Accommodation and Dinner Theatre Tickets for Two at the BLACK KNIGHT INN – Red Deer, Alberta
- Roots - His and Hers Stainless Steel Watches
- For the Love of Chocolate – Gift Basket

Proceeds help support two great organizations – The Epilepsy Association of Calgary – CENTRAL ALBERTA OFFICE, and, the United Way of Central Alberta.

We are in need of enthusiastic, dedicated people to help us get these tickets sold. It would be awesome to sell all 2000 tickets – and we have from now until the end of November to do it!

There is a dinner certificate for the individual who sells the most tickets. The location will be determined depending upon whether our winner is from Calgary or Central Alberta.

Please call Krista in our Red Deer Office (403) 358-3358, or Kathy in our Calgary Office (403) 230-2764 if you can help us out by buying or selling tickets – your help is greatly appreciated!

*"You may be only one person in the world, but you may also be the world to one person."*

*"Don't cry because it's over; smile because it happened."*

## On the Eve of Our 50th and 5th Anniversary...

As this newsletter goes to print, we have a volunteer committee considering the ways in which we will mark our 50th anniversary in 2005. At this time, a number of initiatives are being planned and pondered as we consider how best to celebrate this milestone. This is a remarkable achievement by anyone's standards – and even more notable when one considers the stigma and fear so commonly associated with epilepsy have made it a challenging journey.

It will be a time to give thanks and remember the many dedicated volunteers who have contributed their time and talents throughout our history. We will also give thanks to funders, donors, and others who have supported our work. We have much to be thankful for and we hope that the 50th anniversary will provide an opportunity to reflect on our history and reconnect with those who have made a difference. In addition, it will provide a wonderful opportunity to promote and leverage epilepsy awareness and understanding in the community, and consider the future.

As we celebrate 50 years of serving the Calgary community, we will also celebrate 5 years in Red Deer and Central Alberta, and though the history there is not as extensive, so too, have we been supported and encouraged by funders, volunteers, and citizens of the Central Alberta Region. Five years is worth celebrating too – especially when you consider that six years ago, there were no local services for Central Albertans affected by epilepsy – so – we'll find ways to promote and celebrate this milestone as well!

In preparation for the 50th anniversary, we'd like to invite you to get involved. If you have a story to share, or would like to get involved in the 50th & 5th Anniversary activities, please call or email Kathy (230-2764; epilepsy.kfyfe@telusplanet.net). We'd love to hear from you. *We would also love to connect with anyone who can tell us about our founding member, W.D. Taylor – as we have very little information. Are there any friends or family members out there who can help?*

As for what's in store for the 50th & 5th Anniversary year – we'll keep you posted in upcoming editions of the newsletter and throughout 2005.

### Advertising Opportunity

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

- Standard Business Card Size - \$50.00
- 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.

**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

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

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

**Lois Currie, Administrative Coordinator**  
epilepsy.lcurrie@telusplanet.net

**Lynda Hussey, Administrative Assistant**  
epilepsy.calgary@telusplanet.net

**Central Alberta Office – Red Deer**  
**Krista Anderson, Program Coordinator**  
epilca@telus.net

### Staff Comings and Goings

We were saddened to bid farewell to Pam Campbell in early September, who left us to pursue other interests. For those who had the pleasure of working with Pam, she will be missed. We naturally extend our best wishes to Pam in her new endeavors. They say every dark cloud has a silver lining. I think we managed to find that silver lining as we welcome Carla Archer to our staff. Carla joined us on October 1, 2004 in the position of Public Education Coordinator. She brings a great deal of energy and enthusiasm to the position, and we're certain she will do a great job at getting epilepsy awareness to the community and working with our dedicated volunteers. Welcome Carla!

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!

## Note: Donor names are only published in the print version of the Epigram newsletter.

We would also like to acknowledge and thank the United Way of Calgary and the United Way of Central Alberta donors for donations received through their Donor Designation Programs. To date this year we have received \$8,601 from the United Way of Calgary and \$538 from the United Way of Central Alberta.

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 \_\_\_\_\_

### Laughing Allowed Humor Corner

#### New Virus Warning!!!

**This virus only affects those who were born prior to 1965.**

*Symptoms ....*

Causes you to send the same email twice

Causes you to send a blank email

Causes you to send email to the wrong person

Causes you to send it back to the person who sent it to you

Causes you to forget to attach the attachment

Causes you to hit "SEND" before you're finished

Causes you to hit "DELETE" instead of "SEND"

Causes you to hit "SEND" when you should "DELETE"

This virus is called - the "C-Nile Virus"

At present there is no patch or repair available.

# MEMBER/DONOR FORM

Name \_\_\_\_\_ Address \_\_\_\_\_  
City \_\_\_\_\_ Province \_\_\_\_\_ Postal Code \_\_\_\_\_  
Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_

Annual Membership.....\$20.00  
(January to December 2004)  
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

