



EPIGRAM



Epilepsy Association of Calgary

February 2007

Volume 11, Issue 4

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

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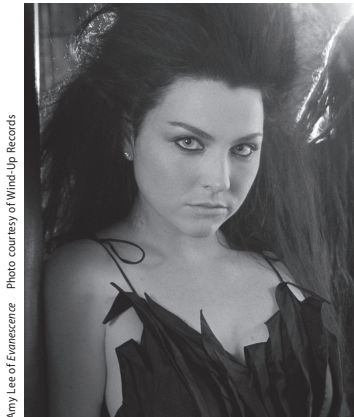
Donors

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**.



Amy Lee of Evanescence Photo courtesy of Wind-Up Records

Rock Group Evanescence Gives Concert Tickets to Epilepsy Association of Calgary in Show of Solidarity

that will help shatter myths, misinformation, and fear, especially for young people who are living with it.

When asked in a recent interview by *EpilepsyUSA* what advice she would give people who have epilepsy and who may be victims of stigma, Ms. Lee said, "They are not alone... It's not something that has to make them different for the rest of their life. No matter what life throws your way, you should just try your best to do what you love and live a full life." In the same interview, Amy says, "I think we can conquer the stigma, I really do – just by exposing it." In case you're wondering, Amy has a

younger brother with epilepsy, so she has witnessed firsthand how epilepsy can affect young people.

We would express our sincere thanks to Amy Lee and concert promoter Ryan Balaski, House of Blues for donating four tickets to her January 15, 2007th concert at the Saddledome. Along with the tickets, a press release was distributed by EAC throughout Calgary which helped raise epilepsy awareness and Ms. Lee's involvement in "Out of the Shadows" in a very positive way. We were informed by Ms. Lee's publicist that she

Continued on page 4...

Stigma is still a huge problem among the 2% of the population who have epilepsy... especially among youth. According to a recent survey, nearly **four in ten teens** think kids with epilepsy are likely to get picked on or bullied and **nearly one-third** are not sure whether they would tell their friends if they had epilepsy.

We were thrilled to hear that Amy Lee of the rock group, *Evanescence* recently became the American Chair of the International "Out of the Shadows" campaign, a global effort to increase epilepsy awareness, eliminate stigma and end discrimination of those with the condition. We were even more thrilled when she agreed to help us raise awareness about epilepsy while in Calgary on her recent tour. We need someone who can speak to today's youth about epilepsy, and draw attention to the condition in a way



Epilepsy Association of Calgary staff Graham Thomas & Janice Shaw make the draw for tickets to see Evanescence on January 15, 2007 at the Saddledome.

Volunteer News

Welcome Aboard:

Rory, Marilyn, Lena and Adeline have just finished orientation. Welcome! You are now "official" volunteers... and we're thrilled to have you!

Congratulations:

Congratulations to Karen W. for your new position as manager at a local luggage store. You've been a great volunteer... and we know you'll be a great manager too!

United Way Campaign:

This year, our dynamic volunteers, Bill and Donna, spoke to employees at 17 different corporations! People were entertained, emotionally moved and definitely "enlightened" from the experience! United Way also tells me that "Collectively, the Epilepsy Association of Calgary participated in 21 speaking engagements. Very few agencies had higher numbers!" So a big thank you and "two penguin flippers up" for Bill and Donna. You rock... and we salute you!

"Two Flippers Up" to:

- Hoda, Lena and Elizabeth, for all your help mailing out donor requests, school literature, party invites, etc. We couldn't have done it without you... at least not soon enough!!!!
- Elizabeth for phoning people to let them know about upcoming events
- Monica and Karen P. for raising awareness and funds... and fun at the Farmer's Market on Halloween. Scary!!!!
- Monica, Monique and Lena for "blitzing" Kensington with posters for Epilepsy Education Month
- Lena and Bill for selling almonds and chocolate penguins, raising awareness AND entertaining the crowd with ECHO'S merry antics!
- Adeline for helping Carla to further educate the crowd at University of Calgary's Wellness Fair
- Jodi, Monique and Pam for selling more chocolate penguins and bracelets at the Farmer's Market ...at the end of November in the FRIGID temps! What troopers!
- Lena for making our office look festive; Ken and Aaron for putting it all away
- Rory and Marilyn for putting up posters, distributing information kits and placing donation cans throughout Banff. It is so great to have you on board to help spread the word all the way to Banff!

Upcoming Events:

- Mac's Cans - March, April and May of 2007 (We raised so much money last year... we thought we better do it again!) Volunteers are needed in Calgary and Central Alberta (Red Deer, Innisfail, Sylvan Lake)
- IGA Forest Lawn's Grande Opening of their new store - April 21, 2007. They are going from 1900 sq. feet to 4300... and are going to celebrate BIG TIME! We've been invited to join in on the fun, which means a lot of public exposure for EAC and epilepsy.

- Farmer's Market Display and Sales - Dates TBA

- Raffle Sales - Dates TBA

...and much, much more

Please call Melanie if you'd like to help out with any of the above... or find out about other future events. We'd also love to hear from you if you know of any prizes for our upcoming raffle. Thanks to ALL the volunteers! You're all marvelous!!



Our 2nd annual "Jazzy Penguin" was held November 28th, 2006, and it was a very entertaining event, although a very cold

one! Even the cold could not dampen the spirits of those who were present for most enjoyable music of Johnny Summers his quintet. Thank you to all who braved the weather and came out to support this FUNd-raising evening!

A very special thanks to our event sponsors – **Spartan Controls** and **Smith Bros. Floors**. We are thrilled and very appreciative of your involvement! Many, many thanks for helping make the evening such a success!

We would also like to thank the following – donors and volunteers...TEAM WORK – MAKES THE DREAM WORK!

SILENT AUCTION

- Donna Bernreuther
- Lisa Nowlin
- Calgary Tower
- Cindy Davis
- Audrey Shannon
- George Jacob
- SeaBreeze Esthetics
- Mel's Lawn Care
- Thomas Jeffrey Men's Wear
- Kathy Fyfe
- Linus Murphy

DOOR PRIZES

- Donna Bernreuther
- Sandy Kakze – The Happy Cooker
- Jubilations Dinner Theatre
- Heritage Park – Historical Village
- Kathy Fyfe
- Salon 512

VOLUNTEERS

- PAM ATKINSON – Talented Caricature Artist
- LENA ALLEN – 50/50 ticket sales star
- LYN & ROY SWANBERG – Committee
- DONNA BERNREUTHER – Committee
- LISA NOWLIN – Committee
- GEORGE JACOB – Committee
- And all of the volunteers in our office that helped us get things done – THANK YOU!

PRINTING

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284-5700

Your Children May Qualify for THE ALBERTA CHILD HEALTH BENEFIT PLAN



The Alberta Child Health Benefit Plan is for Alberta Families with limited incomes. It will help cover the costs of dental care, eye glasses, ambulance services, prescription drugs, and diabetic supplies. To qualify, you must have your most recently completed tax return available and must complete an application form.

Depending upon your income and number of children, you may be eligible to receive this benefit. It will allow families peace of mind, as their qualifying children will be able to access needed care for their children on an on-going basis, instead of waiting for an emergency or worrying about the cost. If you would like an application package, please contact Janice Shaw in our office. You can also call 1-877-469-5437 to request a copy, or check online at www.gov.ab.ca/hre/achb.



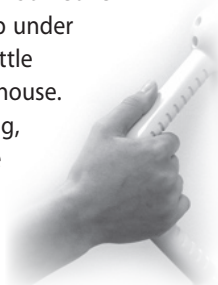
Home Safety Tip – Baths and Showers

While the majority of people with epilepsy live normal, productive lives, things that many of us take for granted can become hazardous. The good news: with some caution and simple adaptations, most hazards can be minimized. A particular danger for someone with epilepsy is the shower or bath tub and most avoidable accidents that have been brought to our attention in the past few years have involved accidents while bathing. When you are showering or bathing PLEASE, PLEASE, PLEASE:

- Leave the bathroom door unlocked
- Have someone else in the home with you who can look in on you – frequently!
- Consider a shower bench (ask your doctor for a referral to a home medical supplier) and a hand held shower over a bath
- Place a rubber mat on the shower floor
- Place padding on the edges of the bath and consider a padded toilet seat
- If you are alone, consider a sponge bath
- Avoid glass doors on your tub and/or shower
- Keep your hot water heater turned down enough that hot water will not scald you and turn on your cold water first

Consider this – people have been known to drown in less than two minutes and in less than two inches of water. Someone entering the clonic phase of a seizure can slip under the water without a sound and drown with little disturbance – even if there are others in the house.

A bath or shower can be a wonderful, relaxing, experience, but if you have epilepsy, we urge you to take the necessary precautions in order to protect yourself and your loved ones from the devastation of a preventable accident.



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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.

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TOGETHER
WE ARE MAKING
A DIFFERENCE

EPILEPSY ASSOCIATION OF CALGARY



Epilepsy Discussion/Support Group Meetings

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

at the Epilepsy Association of Calgary

4112 – 4 St NW, Calgary AB

Feb 7, 2007 - March 14, 2007

April 18/07 - May 16/07

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. The program provides a variety of skills and tools that help participants learn to minimize the negative impact of epilepsy on 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.

Continued from page 1...

was thrilled to hear that we had managed to create epilepsy awareness as a result of her visit to Calgary. A draw for the donated tickets was held on January 12, 2007 - we congratulate **Monica Black** and **Geraldine Panther**, who correctly answered the skill-testing question, and had the luck of the draw. We hope you enjoyed *Evanescence*! For those who missed the skill testing question – the question was: **What famous Canadian rock star has epilepsy?** The answer – **Neil Young**. We look forward to future opportunities to raise epilepsy awareness in Calgary and across Canada when Amy Lee's travels bring her back this way. We extend a HUGE thanks to everyone who participated in the contest and the promotion, especially to Amy Lee for helping bring epilepsy out of the shadows!

Upcoming Information Sessions

Life Issues of Women with Epilepsy

Guest Speakers: **Dr. Nathalie Jette & Janice Shaw, Epilepsy Association of Calgary**

Thursday, February 22, 2007 – 7:00 to 9:30 pm

NOTE LOCATION: Grace Women's Health Centre
1441 – 29th St. NW • Phone 944-2260 to register

Women with epilepsy can face unique health challenges. By popular demand, this workshop will feature guest speaker, Dr. Nathalie Jette who will talk about hormones and epilepsy, the effects of anti-seizure medication on birth control, and pregnancy. Dr. Jette works with the Department of Clinical Neurosciences at the U. of C. and is currently developing a program in health services research focused on quality of life for those living with epilepsy. Janice Shaw will talk about wellness issues as related to women and epilepsy.

When Seizures Aren't Caused by Epilepsy – Clearing Up Some Confusion

Guest Speaker: **Dr. Michael King – Clinical Neuropsychologist**

Wednesday, March 28, 2007 – 7:00 to 9:30 pm

Dr. King works as a Clinical Neuropsychologist with the Calgary Health Region, at Foothills Medical Centre. He will help clear up some confusion about the differences between epileptic and non-epileptic seizures. He will explain the conditions that may lead to a non-epileptic seizure, and how they are diagnosed. He will also discuss the types of treatment used when someone is diagnosed as having non-epileptic seizures. If you have ever needed clarification on epileptic versus non-epileptic seizures – you won't want to miss this session!

All Sessions (except where noted) 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.

Celebrate Summer Picnic

Tentatively scheduled for June 16, 2007 – more details to come!

CENTRAL ALBERTA OFFICE



Upcoming Epilepsy Discussion/ Support Groups

Thursdays from 6:00 pm to 8:00 pm
at the Epilepsy Association of Calgary –
CENTRAL ALBERTA OFFICE
#303, 4822 – 50th Street, Red Deer AB

February 8, 2007 – March 8, 2007

PLEASE NOTE: The Parson's Clinic Doors are now locked at 6:00 pm. We will wait by the doors until 6:05 pm to ensure people can get in. Please call ahead to let us know you are coming – and especially let us know if you will be delayed. We don't want you locked out!

Available through the EAC resource library...

Epilepsy and Pregnancy (2006)

By Stacey Chillerni & Blanca Vazquez, M.D.

This book addresses the many issues and concerns faced by women with epilepsy who are, or who are planning to become pregnant. It asserts that with proper prenatal care, more than 90% of women with epilepsy can deliver healthy babies. It offers insight and suggestions on the potential risks a woman with epilepsy faces during her pregnancy, and insight, tools, and suggestions for overcoming them.

Partial Seizure Disorders – Help for Patients and Families (2001)

By Mitzi Waltz

Partial Seizure Disorders offers readers a practical, sensible, and step by step approach to living with partial seizures. Based on real life experiences as well as medical research, it helps readers learn to live and cope on a day to day basis, gain insight on medical treatment options, obtain a proper diagnosis, and much more. Partial seizures are often misunderstood, and more common than most people realize. This book will help readers gain insight into partial seizures, along with suggestions and resources for coping with them.

Both books are available for reading at our resource library – however, please note that we are unable to loan these books out.

Upcoming Information Sessions

Demystifying the Effects of Seizures

Guest Speakers: Dr. Braxton Suffield

April 5, 2007 – 7:00 to 9:30 p.m.
Red Deer Museum, 4525 – 47A Avenue
Red Deer, Alberta

Dr. Braxton Suffield is a clinical neuropsychologist. His assessment and rehabilitation practices are focused on helping people with brain injury lead productive and fulfilling lives. He also teaches and does research on this topic. In this session, Dr. Suffield will explore the effects of seizures on the brain – before, during, and after the seizure. He will also provide insight on why many people do not remember their seizures – and some of the things that happen between the seizure and the stretcher. He will also discuss implications for employment. It promises to be a very interesting session and we are very pleased he will be coming to Red Deer.

Epilepsy and Children

Guest Speaker: Nancy Thomson, Clinical Nurse Specialist,
Alberta Children's Hospital

April 26, 2007 – 7:00 to 9:30 p.m.

Red Deer Museum, 4525 – 47A Avenue
Red Deer, Alberta

Nancy Thornton and some of her colleagues (a pharmacist and social worker) will talk to us about the various implications of parenting a child with epilepsy. This will be a great opportunity to get answers to your questions and enhance your understanding about the medical impact and treatment opportunities of epilepsy and children.

Call us, or check our web-site (www.epilepsycalgary.com – Central Alberta Link) for updates.

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 contact Krista at 358-3358 or 1-866-EPILEPSY. (Email: epilepsy.kanderson@telus.net)

Non-Epileptic Seizures (NES)

The term Non-Epileptic Seizure (NES) or Pseudoseizure is not heard everyday but at times we may be told about or know an individual that has this condition. How many of us really understand what it means and how to assist the person? Non-epileptic seizures are not associated with electrical abnormalities in the brain as is the case with epileptic seizures. Examinations and test findings are found to be normal indicating no electrical disturbances. Those with this condition experience symptoms such as a loss of consciousness, twitching or jerking, and unusual emotional states, such as intense feelings of fear or déjà vu. These symptoms are involuntary and the person isn't faking or trying to deceive anyone. Most seizures with abnormalities within the brain are finished within seconds or minutes. NES seizures however, can last up to twenty minutes. It is believed that this type of seizure is a psychological defense mechanism induced by stress or severe emotional trauma. It occurs when the person avoids dealing with current or past traumatic situations or stressors.

NES occur more frequently in women than in men and typically begin in young adulthood. It has also been shown to affect other age groups such as children, teens and seniors. People at risk of having these kinds of seizures are those who experience trauma, anxiety or depression. Indications that someone may be having NES seizures may include:

- A resistance to anti-epileptic drugs.
- The presence of specific triggers unusual for epilepsy. Stress and becoming upset are commonly reported. Others may include pain, certain movements, sounds, and lights, especially if they are consistently triggering a seizure.
- NES usually occur in the presence of others.
- NES usually do not occur during sleep.
- Fibromyalgia, chronic pain, or chronic fatigue are associated with NES.

It is important to note that an individual may present with both NES seizures as well as epileptic seizures. Diagnosis is not always easy and usually takes the monitoring of both an electroencephalogram (EEG) and video camera in order to examine the appearance of the seizures experienced. After the seizure, the patient and family are often questioned by medical staff to determine level of awareness, memory and feelings during the seizure. Physicians also consider the person's history, especially if it includes traumatic events, in order to obtain an accurate diagnosis.

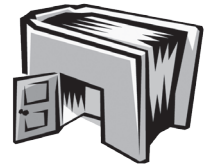
When a person is determined to have NES, a plan is established by the physician. This plan firstly includes a discussion of the condition with the individual. It is important that they realize the cause of these seizures and are reassured that this is a real condition. If anti-convulsant medication has been prescribed, it would be discontinued, as it could be making the problem worse. At this time, medication for the treatment of anxiety or depression may be recommended. Finally, counseling services are offered to help deal

with the underlying issues causing these seizures. These steps can all help in reducing the frequency of NES or eliminate it completely.

Medical professionals have developed a detailed plan to assist those patients with NES, but what can we as friends or family do? Becoming educated about the condition and offering understanding is great first step. Also, if a NES seizure does occur, treat it as you would any epileptic seizure, giving seizure first aid and making sure the individual is safe and cared for. This condition isn't an easy one to deal with and often those who have it are met with apprehension and judgment by those around them. It is important to remember that they need support and care just as much as anyone one else and should be treated with dignity and respect. Also remember that at the Epilepsy Association of Calgary, we provide support to anyone affected by seizures – regardless of their cause – and this includes non-epileptic seizures. We are here to help. We have also arranged to have Dr. Michael King come to our offices to talk more about non-epileptic seizures early this spring (see the Upcoming Events page), as this is a condition that needs more awareness and understanding.

NEW RESOURCE FOR TEACHERS!

Opening the Door to Understanding



THE EPILEPSY SCHOOL KIT

The epilepsy school kit is a new resource produced by the Epilepsy Association of Calgary. The booklet and DVD contain information on epilepsy, seizure first aid, second aid, and other valuable information for teachers dealing with epilepsy in the classroom. We also offer in-person education for teachers based on the information contained in the kit – a great way to enhance understanding and support students affected by a seizure disorder.

To request an education session and *obtain a copy of this valuable resource please contact either the Calgary or Central Alberta Epilepsy Association offices.

**Cost to mail is \$5.00 per copy.*

We extend our sincere thanks to the following donors, who made the production of the Epilepsy School Kit possible:

In Calgary our hats are off to:
Rotary Club of Calgary Centennial
Rotary Club of Calgary Heritage Park
Rotary Club of Calgary Olympic



In Central Alberta we salute:
Central Alberta Telus Employees



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 are not published in the online version of the *Epigram*.

Many thanks to the **United Way of Calgary Donors** who designated **\$720.00** to EAC since our last *Epigram*.

A huge thank you to the management and staff of **Forest Lawn IGA!** Over the past year, you have supported many of our activities and events – donating delicious food for our AGM and Christmas Party, inviting us to your events to promote our work, providing instore can placement and display space – and more! We are fortunate and blessed to have your support and thought we should let you know!

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 _____

Did You Renew YOUR Membership?

Annual memberships expire each year at the end of December. If you haven't renewed yours yet, please don't forget to! Memberships show your support for EAC, and help cover the cost of producing/mailling the *Epigram*. Annual and Life members are also entitled to vote at AGMs and SGMs. Cost is \$20.00 for an annual membership and \$200.00 for a life membership. A member/donor form is included on the back of this newsletter and can also be found on our website.

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
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Toll Free: 1-866-EPILEPSY
Fax: (403) 230-5766
Email: epilepsy.calgary@telus.net
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MEMBER/DONOR FORM

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

- Annual Membership.....\$20.00
(January to December 2007)
- 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.

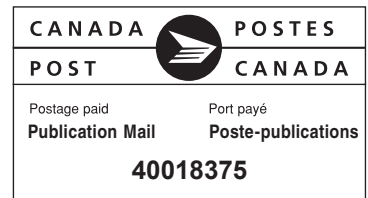
A WORD ABOUT PRIVACY

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:

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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.