

reACT-Believe

The AIDS Committee of Thunder Bay Winter, 1996 Volume 9, Issue 1



Impact Of New Provincial Government Initiatives



In this issue of reACT-Believe, Michael Sobota, ACT-B's Executive Director answers questions about the recent government initiatives.

We hear a lot about moves the new provincial government has made. How have these affected people living with HIV/AIDS in Thunder Bay?

Shortly after taking over power last summer, the government made a series of announcements including the reduction in the amount of monthly welfare payments, the freezing and/or reduction of non-profit housing initiatives, and cuts to hospitals - mainly in their capital and equipment budgets. There were also numerous reductions in funding for programs assisting women.

One piece that has affected our clients is mandatory user fees for each and every prescription filled. The nature of our clients' health needs usually requires a range of prescriptions for different treatments. And they are filled often. If you consider the provincial accumulative effect, the government will collect millions of new "health dollars", by hitting individuals who already have financial difficulties every month.

I can see how this will impact people living with HIV/AIDS. But what impact does this have on ACT-B?

These moves heighten the atmosphere of insecurity about health care. Already vulnerable people are having more stress added to their lives. We expect greater pressures on our

Emergency Financial Assistance Program (EFAP), and to see more complex counselling issues arise.

ACT-B's core funding has not been affected yet, and we acknowledge that the Minister of Health, Jim Wilson, has publicly stated that AIDS is a priority within his Ministry. It is important that the Minister has publicly taken this stand, as he must be our voice of advocacy within the Provincial cabinet when more reduction initiatives are being discussed.

What about Bill 26 - the government's "omnibus bill"?

The nature and sweep of this legislation is so broad that it is difficult to completely understand its impact.

For example, the Minister of Health (or his designate) will have the authority to view your personal health records. This authority will be free of litigation, should any of your confidential information become publicly known. That is, the government will not be able to be held at fault, should there be any leak of information. The intent of this power is to review and reduce the costs of "unnecessary tests and referrals" being done by physicians. The nature of the progression of HIV requires tests and referrals to specialists, perhaps more so than with other life threatening illnesses. There are two issues here: a challenge to the sacred concept of your health information being confidential, and looking at the application of health care

(tests, referrals) as a matter of economics first, rather than health care first. The bill will also give the Minister the power to control where doctors can practice. It is not illogical to project that we may lose physicians and much needed specialists.

The real danger of this legislation is that it is so complex (the draft runs to more than 211 pages) we will not see all of its potential negative ramifications until they begin to be applied.

Overall, how has this government responded to HIV/AIDS so far?

Again, it is important to restate that the Minister holds AIDS as a priority within his health mandate, and that he has stated this publicly. Direct, core funding to community based AIDS service organizations is stable, so far. The Premier and the Minister have been open to meetings with various community representatives (AIDS Action Now and the Co-Chairs of the Ontario AIDS Network). The Minister has stated his commitment to continuing the Ontario Advisory Committee on HIV/AIDS (OACHA) and ACT-B has representation on the committee. This relationship has to be strengthened and built upon.

At the same time, we need to network and build our alliances with other affected communities to address major, major reductions in the overall social safety net. We have some difficult years ahead of us.

10 Years of Service



1995 Annual General Meeting - a Celebration!

ACT-B's Annual General Meeting took place on November 15, 1995. The event, which marked our tenth anniversary in this work, was opened by a Native prayer ceremony delivered by Gabe Kakeeway. In addition to the usual business of reports, appointment of auditors, etc. the membership elected our 1995-96 Board of Directors. An Annual Report was distributed.

Following the "business portion" of the meeting, a panel of ten invited community members spoke on their experience of ACT-B and HIV/AIDS over the past decade. Panellists were chosen to represent a broad spectrum of personal experience and/or connection with ACT-B during the last ten years. Panel members included Dr. Fred Ball, Norm

Bowers, Ryan Bureyko, Marge Cross, Gabe Kakeeway, Betty Kruzick, Rob MacKay, Rev. Don Uhryniw, Pius White and Hazel Wohni. The personal stories were powerful, emotional, not without humour and ultimately very, very moving. This panel was our first effort to pay attention to and give honour to all the individuals in Thunder Bay who have contributed to the struggle against HIV/AIDS during the past decade. We hope to have other events, marking this decade, through out the coming year.

Five new directors were elected to the Board, together with seven continuing veterans. For a full listing of the 1996 Board of Directors, please refer to the last page of **reACT-Believe**.



My Greatest Wish

So many gone - so many lost to a fight that no one should have to face alone, but all too often do. My only wish - my last request if I had one more minute with all those who are gone, would be to thank them for all that they have left me - for entrusting me with the treasure that was and still is them. My voice will never fall silent - for if it does then their story, their hopes and dreams, may cease to be part of the chorus that many of us now find ourselves in.

My friend Ron has shown me so much - both while he was here and now that he is gone - and I am so thankful for all the things we shared. There are still days that I get angry that he is not here to enjoy the changes that he worked so hard to bring about. His greatest wish was to know that

I would be all right after he was gone. Today I grant him his last request as I go on with my life - missing him - but so much the richer for knowing him.

Death may be final, but love continues never ending. The love we show each other is the thread - the chorus - that will continue long after we have moved on. It will thread its way through time, weaving a pattern of love, strength and compassion. I have become an unwilling player in this chorus, but I find great pride in being able to add my voice to the song - and humility in knowing my part is only one in thousands - beautiful in its own right, but truly miraculous when added to the voices of so many others walking a similar path as I.

Today I give thanks for being allowed the privilege of

knowing so many men, women and children who are no longer here today. I recognize the inner strength it takes to acknowledge and appreciate my loss and the courage it takes to continue in my journey in spite of the pain and grief that comes with that loss.

Most of all I am thankful to the Creator for allowing me the honour of being able to call these people my friends. They are greatly missed. I can never express the love and gratitude to all who have been part of my journey - except to tell them all that they are loved and remembered in a thousand ways for every day that sees the sun rise and set over the path I have chosen to walk.

In Love and Light
Trevor Weenink.



NEW IN THE LIBRARY

Here is a list of materials that have recently been put into our library. The library is open to anyone with an interest; professional, academic or personal.

We thank Dorene and Edson Setliff for their generous donations of educational resource material over the past year or so. This kind of support is greatly appreciated.

PRINT MATERIALS

HIV/AIDS COMMUNITY RESOURCE

DIRECTORY FOR FAMILY PHYSICIANS

by Family Medicine North Residency Program and ACT-B

THE HIV DRUG BOOK by Project Inform
Comprehensively Illustrated Guide to the most-used HIV/AIDS treatments

MORNING LIGHT by Margaret Merrifield
An educational story book for children and their caregivers about HIV/AIDS and saying goodbye.

EMOTIONAL FIRST AID by Sean Haldane
A crisis Handbook Coping with Grief, Anger, Fear

LAST WATCH OF THE NIGHT by Paul Monette
Essays Too Personal and Otherwise

MY OWN COUNTRY by Abraham Verghese
A Doctor's Story of a Town and its People in the Age of AIDS

HIV-NEGATIVE by William Johnston
How the Uninfected are Affected by AIDS

BISEXUALITY AND HIV/AIDS edited by Robert Tielman et al
A Global Perspective

A ROCK AND A HARD PLACE by Anthony Godby Johnson
One Boy's Triumphant Story

GRIEF, HIV AND AIDS by Canadian Hemophilia Society

A Personal Manual for Comfort, Guidance And Information

AIDS: THE GOOD NEWS...THE BAD

NEWS... by Peter Duesberg and John

Yiamouyiannis

A look at controversial theory of Duesberg denying the role of HIV in AIDS

THE LIVING RESOURCE

A Workbook for People Living with HIV

OUTING YOURSELF by Michelangelo Signorile
How to come out as Lesbian or Gay to your Family, Friends, and Coworkers

SAFER SEXY by Peter Tatchell

The Guide to Gay Sex Safely

HOW WE DIE by Sherwin Nuland

Reflections on Life's Final chapter

EIGHTY-SIXED by David Feinberg (novel)

CANADIAN GUIDELINES FOR SEXUAL HEALTH EDUCATION by Health Canada

NOW THAT YOU KNOW by Betty Fairchild and Nancy Hayward

What Every Parent Should Know about Homosexuality Updated, with new chapter, AIDS and The Family

VIDEOS

FIT by Parkdale Community Health Centre

This video focuses on harm reduction for injection drug users

WORKING IT OUT by HIV Centre, New York
Stories from the Lives of Gay and Lesbian Youth

Is there anything gay about it?

Think about your reaction to meeting someone with HIV or AIDS. Are you seeing a person or judging a lifestyle? People with HIV / AIDS deserve the same acceptance and care as anyone else with a serious life-threatening illness. Trade fears for facts. For a free brochure call **1-807-345-1516**

AIDS Committee of Thunder Bay

Focus on Fund Raising



**"There is a crack in everything,
that's how the light get's in
that's how the light get's in"**

...Leonard Cohen

ACT-B is fortunate to have a Fundraising Committee which has been tireless in it's efforts to achieve our goals. They have done a remarkable job this past year. I would like to commend Richard DeVuono, Adele Evans, Cheryll Everall, Mary Ann Gabriele, JoAnn Jacomb, Sonya Matijek, and Robert Shepherd for their dedication and perseverance. I also acknowledge the contribution of the many volunteers who work at every fundraising event and in particular those who help us with bingos and casinos. Each of these volunteers helps the light get in.

Briefly, a few comments about a very busy AIDS Awareness Week which saw a lot of fund raising activity. ACT-B thanks the Darling Divas for the generous donation of the door receipts from their show. And our thanks to Ryan Bureyko and JoAnn Jacomb for organizing the Social. Of singular note, was the response of many local businesses to the AIDS Walk. In particular, we are grateful for the generous assistance from Lehto Printers, Corporate Graphics, Unisource and Mediacom. Over \$10,000 in pledges were collected for the Walk. Planning for next years Walk has already begun.

The Healthy Sex Cabaret will run for two nights, March 15 and 16. Tickets are \$15 and will be

available at the AIDS Committee office in March. Chances are that the Cabaret will be in a different venue...so stay tuned.

The quote which leads off this article is also the theme of Art AIDS 96. The auction will be on March 23, at the Nor Wester Resort Hotel. There will be some wonderful art and crafts up for bid. Also this year, the live auction will include several lifestyle and service packages in it's list. Tickets are \$20 for an exciting evening of fine art, jazz, wine, hors d'oeuvres and camaraderie.

Indeed, this will be a interesting year. Many service organizations are experiencing cuts to their budgets and will be fundraising in earnest. I am confident with the help of our new Board of Directors, the Fundraising Committee and many volunteers that ACT-B will once again meet its goals.

Thank-You Thunder Bay!

Our Holiday Basket project was again a success in 1995. 17 festive baskets and nine overflowing envelopes were distributed to clients and their families. ACT-B would like to thank project co-ordinators Kristen and Nikki Myles for their hard work and dedication to this project. Their volunteer efforts are gratefully appreciated by all! We would also like to thank the following individuals for their generous donations to our baskets: Kim Mauro-Hopkins, Eva Green, Michael Sobota, Linda MacKay, Helen Rose, Betty Kruzick, Ruth Racic and Richard DeVuono.

*You are cordially invited
to the
AIDS Committee of Thunder Bay's
Third Annual
ART AIDS 96 - Spreading the Light
art auction*

*Tickets: \$20.00
(available at ACT-B office)*

*includes complimentary hors d'oeuvres
cash bar*

*March 23, 1996
Nor Wester Resort Hotel
7:00 p.m.*

sponsored by CBQ Radio & the Chronicle Journal



PMPA in Perspective

by John S. James

PMPA is the experimental anti-HIV drug which gained national attention in mid November, after a government-funded study, published in *Science*, reported that once-daily doses for four weeks completely protected macaque monkeys from SIV (a virus which is closely related to HIV) even when given 24 hours after exposure to the virus; all the untreated monkeys developed infection and disease. No drug toxicity was found. No other potential treatment has been able to do this. AZT, for example, gave six percent protection when given before exposure and zero protection after exposure (in other studies, which were not exactly comparable). And another antiviral, PMEA, which is chemically related to PMPA, protected 10 of 12 monkeys when given before exposure, but only one of five monkeys which received the treatment four hours after exposure to the virus.

While the recent media coverage may seem excessive - especially since PMPA has never been taken by even a single person, and human toxicity is unknown - we believe that the new results are of first - rate importance. Besides the obvious potential uses in preventing infection after needle - stick injury, and in preventing maternal-infant transmission (which is believed to usually occur at the time of birth), PMPA is clearly an important lead as a possible treatment for established infection. Of course no one knows if it will be useful for this purpose until it is tried.

AIDS Treatment News could not finish an in-depth investigation of PMPA in time for this issue. But due to the widespread interest, we wanted to mention a few background points:

* Some people have tended to dismiss the finding that this drug can protect monkeys after exposure, since PMPA is chemically very close to PMEA, which is well known and already in clinical trials. We believe such quick judgement is a mistake. Even though the chemical change is small, PMPA is a new chemical entity. Even a small chemical change can have a huge impact on the safety, efficacy, and clinical potential of a new drug.

* PMPA, PMEA, another derivative of PMEA called bis-POM PMEA, as well as some other antivirals now being developed for human use, are members of a new class of drugs called nucleotide analogs (as opposed to nucleoside analogs such as AZT and ddI). Like nucleoside analogs, nucleotide analogs stop HIV replication by providing false building blocks which are incorporated into

new viral particles when they are formed. But nucleotide analogs do not need the chemical processing inside the cell which nucleoside analogs do; therefore, they are potentially able to work in all cells, not only cells which can provide the processing which nucleoside analogs require.

* Nucleotide analogs are being developed by Gilead Sciences, INC., of Foster City, California, not only for use in treating HIV, but also for treating CMV and other viruses. At this time it appears that the first nucleotide analog likely to reach widespread human use for treating HIV may be bis-POM PMEA - because it seems to have a better therapeutic window between active and toxic doses than PMEA itself, it can be taken orally, and it is already in human trials. No one knows how bis-POM PMEA will compare with PMPA.

* It may be hard to tell quickly how well nucleotide analogs are working. For reasons which are unknown, viral load usually shows only modest reductions - comparable to that from AZT - even when other information suggests that these drugs may be working better than the viral load changes imply. (We would suggest using symptom-reduction trials to study this kind of drug - small, rapid human trials to see if an anti-HIV drug can help people recover from ongoing AIDS-related symptoms which have been resistant to conventional treatments.

* PMPA illustrates some of the problems of delay in AIDS drug development. The newly-published results on protecting monkeys with PMPA were mostly available about a year ago (untreated monkeys were clearly infected at three weeks after exposure to the virus, but the paper reports results for up to 56 weeks after exposure). During this year few people knew about PMPA, which was previously mentioned in only two published AIDS-related articles, both highly technical; many who might have been involved in advancing this line of work were not. (We do not blame Gilead Sciences for the delay, as it was not their study, but a government study - and Gilead's plate is full with at least six different treatments it is now developing for HIV and related conditions, as well as other treatments for other diseases. The paper was submitted to *Science* in April 1995, and accepted in September.)

PMPA is now undergoing standard animal toxicology testing, in preparation for human trials as a potential treatment. The first human test, however, will only use a single dose, to determine whether the drug can be absorbed orally (it was injected in the monkey-protection

study). If the drug is not orally available, development will probably wait until an oral version can be designed. For years there has been a myth that an injected HIV treatment would not be acceptable in the marketplace; and there is also a regulatory disincentive to proceed immediately with a treatment that must be injected, as the company will later have to start over again if it wants an oral version.

These delays do not appear to be anyone's fault. But they do show that we have a problem which needs to be addressed. It is not being addressed today.

reproduced from AIDS Treatment News, Issue Number 236, December 1, 1995

Thalidomide's Elusive Access

by Dave Gilden

In September, Treatment Issues reported the imminent availability of thalidomide through a compassionate use program for those with AIDS-related wasting. Thalidomide, which blocks tumor necrosis factor (TNF) production in the body, is a possible alternative to the largely expensive human growth hormone - another experimental anti-wasting treatment. (For more on human growth hormone and thalidomide, see the May, 1995 Treatment Issues.)

Lamentably, the expanded availability of thalidomide has not come to pass. The delay has been due to the difficulties in working out the details of the protocol under which thalidomide is offered and the "cost recovery" provision through which Celgene, the manufacturer, is to charge for the drug.

The original version of the protocol elicited considerable criticism from the AIDS community. The thalidomide expanded access program sounded almost like a trial to many. It was to randomly assign applicants in a blinded fashion to a relatively low dose (50 mg) or a high dose (200 mg) of the drug and record their response. Program participants would have to pay \$550 for a three-month drug supply regardless of which dose they were receiving - a price that was only approved by the FDA on October 13.

"The issue is that in trying to avoid granting another compassionate use program, the FDA has created a far worse problem: undoing years of a simple ethical standard that keeps pharmaceutical companies from charging trial participants to be guinea pigs," complained Sally Cooper in a widely circulated open letter. Cooper is director of New York's PWA Health Group, a buyers club for unapproved drugs with AIDS-related applications.

In a meeting between FDA officials, Celgene and AIDS activists on October 24, the randomized dose portion of the program was eliminated. Patients' physicians will determine the dose of thalidomide they will receive, and the data collection effort will focus on safety information. "Now, (the protocol) will have a more compassionate use slant," said Sol Barer, president of Celgene. The company will still charge for the drug but is committed to providing thalidomide free to a substantial number of people who could not otherwise obtain it.

While awaiting the start of the Celgene program, thalidomide is available to people with AIDS-related wasting in three ways. The first way is through one of several trials, including Celgene's placebo-controlled eight-week trial for people with AIDS-related wasting and not active or recent opportunistic infections. (Call 800/TRIALS-A for more information).

Free thalidomide may be obtained temporarily through an FDA screening process that previously was only concerned with thalidomide for people with aphthous ulcers, but now is also trying to bridge the gap until Celgene puts into practice the expanded access protocol. The FDA does not ship thalidomide but rather authorizes Celgene to send out drug on an individual basis to those in need, to whom there is no charge. The FDA says its eligibility criteria are very loose - there is no specific percentage of weight loss to qualify, for example. For more information, call the Food and Drug Administration at 301/443-9553 or fax 301/443-8445.

Another way to obtain thalidomide is through two buyers clubs, New York's PWA Health Group and San Francisco's Healing Alternatives Foundation. The PWA Health Group charges \$22.50 for a ten-day supply (\$15.50 for people on Medicaid) - less than half of Celgene's "cost recovery" charge. Like the FDA, the buyers clubs say they will end their distribution of thalidomide when Celgene commences its program.

When the thalidomide expanded access protocol goes into effect, people with HIV and an involuntary weight loss of ten percent will be eligible to receive thalidomide, regardless of concomitant opportunistic infections or other medications (including other anti-wasting therapies). Because of thalidomide's propensity to cause severe birth defects, women engaging in "reproductive sexual intercourse" will be required to practice two methods of contraception, preferably one hormonal and one barrier method.

Celgene's "thalidomide hotline" can be reached at 1-800-896-8766.

reproduced from Gay Mens Health Crisis - "Treatment Issues" Nov. '95

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ACT-B thanks the following businesses and Corporate supporters who so generously assisted us in 1995. Your partnership is our lifeline!

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The Kidney Foundation
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Bandito Video
Galaxy Bowling Lanes
Mario's Bowl
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Global Experience

**We thank
our
community
partners!**





Lawrence Korhonen

In the AIDS movement, Lawrence Korhonen would be considered a dinosaur. He has worked at the AIDS Committee since January 28, 1988. Lawrence recalls those early years fondly. "Back in 1988, ACT-B was funded for 2.5 people. I was the point 5 staff. I was only half as big as I am now", he quips.

Lawrence feels that he has grown with the position over the years. "When I first started, I did lots of different things; fund raising, education and some volunteer management. As the agency has grown, my position here has become more specific." Now, Lawrence is employed full time as the Office Manager.

Lawrence has a passion for the arts and spends his spare time volunteering with a local amateur theatre group, Cambrian Players. He recently played the challenging role of John Merrick, in the group's production of The Elephant Man. He was also in the cast of The Cocktail Hour, Jitters and Glenarry Glenross. Lawrence serves on the Cambrian Board and assists with financial matters.

One of Lawrence's most notable achievements was bungee jumping. His intent was only to watch, but before he knew it, had a rope tied around his ankles and was plummeting off a tower. Any disbelievers are welcomed to view his souvenir video!

Over the years, Lawrence has been instrumental in many major changes at ACT-B. He helped to facilitate the move to our new office space by developing the blue prints and overseeing many aspects of the operation. He organized the Annual General Meeting for three years running and coordinated the event that featured Svend Robinson as the keynote speaker. Attendance at this meeting

was over 300 - a record! He participated in bringing two Ontario AIDS Network meetings here. He continues to support and facilitate change at ACT-B and is a dedicated employee.

Darryl Williams

The mid-winter snows find me tucked away in Darryl Williams's cozy apartment nestled amid his vast angel collection. There are angels displayed everywhere; all shapes, sizes and textures, representing only a small part of his collection. Every one has a story, most are hand-made by special people in Darryl's life.

Darryl is one of ACT-B's angels. He came to us a year ago to "only serve on the Board". Soon, he was sitting on various committees, working the bingos and casinos and even did a shift "sitting above" the dunk tank at Harbourfest!

Volunteering has always been a part of Darryl's life, starting with the Sea Cadets and Navy League in his younger years. After Business College, he began volunteering at McKeller Hospital and eventually landed a part-time job there. He is now entering his 14th year of employment with the Hospital and is currently working as pharmacy stock clerk/purchasing and inventory control.

Why did Darryl start volunteering at ACT-B? "I knew people that were involved with ACT-B and others who had AIDS. I thought this would be a good opportunity to be of service in the community. I am a firm believer that one should put back into the community rather than always taking. One should be involved - be productive with your life."

Darryl's future plans include entering a live-in relationship with his partner. He is also eager to continue his work with ACT-B as President of the Board. We thank Darryl Williams for his hard work and effort on behalf of ACT-B. He joins the ranks of ACT-B's angels!



In 1995, over 212 Volunteers donated more than 7,900 hours of service to the AIDS Committee of Thunder Bay! Thank-you Volunteers!



**ACT-B presents the
8th annual
Healthy SEX Cabaret**

March 15 & 16, 1996

Dr. Bill stars in

"THE SEX TRIAL CABARET"

**with Deb Patterson, Kim Hanson, Rodney Brown
and many more!**

Two new locations to be announced!

Call 345-1516 for details

3TC

3TC (Lamivudine) has recently been approved in Canada. As a community based worker, my main concern with the approval of 3TC is the accessibility of this new drug.

According to Diedre Maclean at the Community AIDS Treatment Information Exchange (CATIE), this drug will cost \$4.20 per pill or \$3100.00 per year. For people who are receiving social assistance (FBA, GWA), they are at the mercy of the Ontario Conservative Government to add this drug to the Ontario Drug Benefit Formulary (which is a list of drugs that the government will provide free of charge). Sources inside the government are reporting that the Conservatives will NOT be adding this drug to the formulary.

We are currently mobilizing our resources to ask the government to add this drug so if people wish to access it they can. We live in a country that used to have a health and social safety net where by every single person had equal access to basic human needs, we are now

seeing an erosion of these basic services in favour of "debt reduction". Is this a path that we as citizens wish to follow? Not this kid!!!

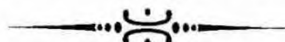
by Ian Ritchie

WISH LIST

We are in search of a TV/VCR stand on wheels, for use in training sessions. We also require building supplies - sheets of plywood, 2 x 4's, hinges and nails to build a garbage container. If you have any items to donate, please call Jo-Ann at 345-1516.

OMNIBUS HEARINGS

On January 10, 1996, Michael Sobota presented a brief to the parliamentary committee holding hearings on the Omnibus Bill in Thunder Bay. He voiced concerns about the confidentiality of client's health records and anonymous testing. We have yet to see if these hearings will have any effect on the substance of the new bill.



Parting Glance



The AIDS Committee of Thunder Bay acknowledges and thanks our various funders:

-  Ontario Ministry of Health - AIDS Bureau
-  Health Promotion and Social Development Office, Ontario Region, Health Canada
-  Thunder Bay WINS!
-  All of the people involved in general fund raising and the support of many local businesses and individuals.



I want to become a member of the AIDS Committee of Thunder Bay!

- _____ Enclosed is my \$10.00 Membership fee.
- _____ I want to be a Supporting Member. I have enclosed \$25.00
- _____ I would like to help more! Here is a donation of \$ _____

Name:

Address:

City

Province:

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Please address any comments or concerns to:

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