

ARC News

April, 2002
Volume 6, Issue 2

for the AIDS Resource Centre – Okanagan & Region

Seven Teachings

To cherish **knowledge** is to know wisdom

To know **love** is to know peace

To **honour** all creation is to have respect

Bravery is to face the foe with integrity

Honesty in facing a situation is to be brave

Humility is to know yourself as a Sacred part of creation

Truth is to know all these things.

WHAT'S INSIDE..

Disability (cont'd).....	2
Changes in Benefits.....	2
Tophers Talks	
Client's viewpoint.....	3
CATIE membership drive.....	3
O.A.A.S.....	4
Africa's AIDS Orphans	5
Volunteer Corner.....	5
Support Plus.....	6
The HIPPO Report.....	7
Notice Board/Thanks.....	8

Where did my Disability go?

As if by magic, many individuals in British Columbia, who woke up on the morning of April 15, 2002 with a disability, no longer had a disability as of 2:00 pm. With the introduction of the Employment and Assistance for Persons with Disabilities Act, many no longer qualify for provincial disability benefits.

This will result in untold hardship for many who may not understand how the government can just change the rules and definitions; how, with the wave of a wand, neither their disabilities nor the costs needed to live with dignity are acknowledged.

The disability community in BC has worked for over 10 years to put in place the Disability Benefits Program Act (1996). Despite the support of over 400 disability groups from across BC calling for the retention of the current Act, the provincial government is pushing through a bill that does away with the Act and its definitions of disability. This was done without any meaningful consultation with disabled persons or disability groups. The bill significantly restricts the eligibility criteria for new applicants. It mandates the Ministry of Human Resources to reevaluate all people with (permanent) disabilities currently receiving provincial benefits. This means that 45,000 people with

disabilities will be reassessed under a new definition of disability.

Some of the changes are:

The disability designation will no longer be permanent

- o The Minister will have the power to take away a person's disability status.

Unusual and continuous costs will no longer be part of the definition

- o Under the current definition, applicants qualify if they can demonstrate that they have need of assistance or have disability related costs. The cost criterion has been removed. In other words, the amount of money a person may need to spend in the care and management of their disability has no bearing on their application. This will affect, among others, people with soft tissue injuries, people who are HIV-Positive, or people who may not need (physical) assistance but who have ongoing costs related to their disability.

The age at which people with disabilities can qualify for benefits will go from 18 to 19

- o This means that children who have disabilities will have to wait longer to be recognized as adults with a disability. As well, because the new regular income assistance eligibility criteria (April 1, 2002) prohibit people from receiving assistance for two years after leaving home, a person may have to be 21 years old before they can apply for disability benefits

Daily Living Activity

- o To qualify for disability benefits, applicants will have to be directly and significantly restricted in their ability to perform daily living activities. Daily living activities will be defined in the new regulations. This means that there will be specific activities that applicants will need to show they need help with, for example, the (Federal) Disability Tax Credit (...pg. 2)

Disability (dis)continued

eligibility criteria are restricted to such things as feeding, dressing and grooming. "Extensive Assistance" replaced by "significant assistance"

o The words "extensive assistance" have been replaced with the words "significant assistance". We are concerned that this wording change introduces a more restrictive measure to the criteria.

Significant help

o Applicants will have to show that they require significant help to perform daily living activities. Significant help may be through the help or supervision of another person (current definition), or through 'assistive devices.' An assistive device is defined as a device that enables an individual to perform a daily living activity. As such, if someone needs help from an assistive animal for example, they will not qualify.

"Performing tasks within a reasonable period of time" has been removed

o This change means that applicants will not be assessed by the length of time that it takes them to perform tasks independently. Thus, people who struggle to remain independent, despite the difficulty and length of time it takes to perform daily tasks, will not qualify. "One year and likely to recur" duration test removed from the definition

o This change will have a particular impact on individuals with neurological disabilities, as well as people with cyclical disabilities such as rapid-cycling bipolar depression and anxiety disorders.

Other related issues:

All disability benefits recipients will have their ability to work assessed, and some will be required to look for work as a condition of receiving benefits.

Grandparenting of medical files for those who become self sufficient through employment will be altered, and will now be a time and means tested benefit.

People who are disabled but not receiving a monthly allowance will no longer qualify for enhanced medical coverage.

The above information was provided by the British Columbia Coalition of Persons with Disabilities (BCCPD) as an analysis of the new legislation.

Should you require further information please contact the Client Support Department of the AIDS Resource Centre.

At this time, we cannot say how this will affect the clients of the AIDS Resource Centre, or how the local offices of the Ministry of Human Resources will be dealing with this new legislation. We understand that the Ministry is currently working on the new regulations, which will support the legislation. We have been informed that most of the major changes will come into effect *September 1, 2002.*

DarIye Roberts

CHANGES

BCPWA

COMPLEMENTARY HEALTH FUND effective May 1, 2002

Maximum monthly claim:

-\$45.00/member

Eligible expenses:

- purified water (no designer lables)
- vitamins and supplements
- body work by pre-approved therapist or practitioner
- complementary and alternative therapies
- over-the-counter medications for conditions directly related to applicant's HIV disease (eg. aspirin, tylenol etc.)
- Counselling by approved counsellor/practitioner

NOTE: Items for which you have another source of funding (eg. Sched. C or F, private insurance or Monthly Nutritional Supplement) are NOT eligible for CHF. You must disclose on your application form if you have alternative sources of funding for health goods and services.

A fond farewell...

Chris Jenner completed her practicum with ARC on April 19, 2002. Chris came to us from the OUC Social Work Programme. She wishes to thank the staff, volunteers and especially the clients of ARC for their input, guidance and support. She leaves us with a better understanding of the complex issues facing people living with HIV/AIDS and the organizations that serve them. Chris hopes to renew her involvement with the centre in some capacity in the future. Thank you, Chris, for all your hard work and good luck to you in all your future endeavors.

ARC News

Ron van der Meer, Editor



This newsletter is the official publication of the AIDS Resource Centre - Okanagan & Region (ARC), formerly Kelowna and Area AIDS Resources, Education and Support Society. It is published four to six times yearly. The materials in this newsletter are meant

to be consistent with ARC purposes which are:

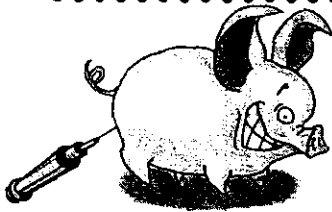
- * to promote awareness of AIDS and related diseases
- * to develop and provide resources to combat the spread of AIDS and the HIV virus
- * to develop and provide educational resources
- * to support those living with AIDS and those diagnosed HIV+, and/or their significant others.

Even so, the opinions and comments within this newsletter are those of the authors and do not necessarily reflect official ARC policy. The newsletter does not recommend, advocate or endorse the use of any particular treatment or therapy described as information. The board, staff and volunteers of ARC do not accept the risk of, nor responsibility for any damages, costs or consequences of any kind which may arise or result from the use of information disseminated through this newsletter.

Persons using the information provided through this newsletter do so by their own decision and hold the society's Board, staff and volunteers harmless.

Submissions for publication may be sent to our offices at any time; publication deadline is two weeks prior to publication date. Submissions will be returned if a request is made in writing and an address provided. Permission to reprint and distribute this newsletter is openly encouraged.

The ARC office is located at:
#202, 1626 Richter Street
Kelowna, BC V1Y 2M3
Phone: (250) 862-AIDS (2437)
1-800-616-AIDS (2437)
FAX: (250) 868-8662
Website: arc@silk.net
Internet: www.silk.net/arc/



TOPHER TALKS...

"A Client's Viewpoint"

Squeal like a Pig!

Do you ever get the feeling like you are a Guinea pig? Well some days I do; with everything from drug changes and new blood tests, to new diets and changing dosing schedules.

Some days I begin to feel like the Doctors are just doing 'make-work' projects. Actually I guess they are, it is called funding maintenance. Recently, I have undergone several blood tests, including one 12-hour test and a test to check out my mitochondria. The downside to many of these tests is that they have to be done in Vancouver.

The 12-hour drug test is to check the efficiency of my current medication regimen. This involved arriving before taking my morning meds and getting several vials of blood drawn. Then, after having breakfast, taking my meds and having more blood work done. Luckily the nurse at St. Paul's inserts a line into your arm, so you don't have to be stuck every time you give more blood. You then return every two hours for 12 hours. You are required to keep track of what you eat and all medications taken. If you think two hours is plenty of time to do things, think again. I had hoped to fit in some visiting while I had time away from the hospital. But by the time my day was over with, I was completely exhausted.

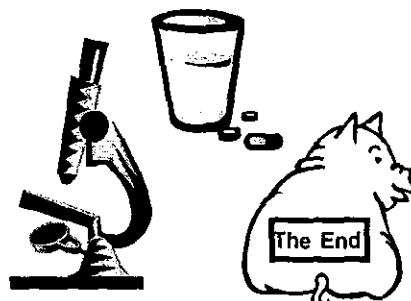
The interesting part of the pharmacokinetic test (to assess the amount of drugs in your system and how they interact) was that, four weeks later, when I went to get my results, two of the drugs were shown to negatively interact with each other, with the effect that by the time the second dose was due,

I was at medication levels that were deemed too low to be effective. BUT, luckily, my doctor decided since my drugs were working, he would not adjust my meds again; at least, not at this time.

Secondly, I have been donating blood for mitochondrial testing. This is a test that checks for defects in your mitochondria. (a component of cells which is involved in the process of turning energy from foods into energy available for use by cells). Mitochondrial activity is under investigation as a contributing factor for wasting syndrome. But, again, unfortunately the blood has to be drawn in Vancouver. I had actually gotten blood drawn here before I went down, but the sample got lost in the mail.

Another important test that everyone should get done is (viral) phenotyping. This assesses how the virus responds to the different medications you are taking; whether the virus is susceptible or resistant to a specific drug. This helps when looking for new drugs to add to one's cocktail.

All these tests will eventually help in the advancement of treatment for HIV, but until then, we will be offered up to the treatment gods as guinea pigs. In the meantime, however, these and other tests contribute to the general store of knowledge and help us to better understand the full extent of our own health and well-being.



CATIE Membership Drive

The Canadian AIDS Treatment Information Exchange (CATIE) has been providing HIV/AIDS treatment information to Canadians since 1989. In an environment of constantly changing and increasingly complex treatment combinations CATIE staff and volunteers cull medical journals for the latest developments in HIV testing methods, treatment options, side effects, clinical trials, complementary and alternative therapies, drug interactions, nutrition and research initiatives. Their award-winning Web site is accessed by people around the globe.

As with most membership-based organizations there is a desire to maintain a strong membership. But people forget to renew their memberships and the numbers drop.

Benefits of membership include: 1 year subscription to POZ magazine, TreatmentUpdate bulletin (10/year), InfoCATIE (quarterly newsletter for members and supporters), The Positive Side (2/year magazine about positive living - health options) and the knowledge that you are supporting an organization dedicated to improving the life of people living with HIV/AIDS through information.

Membership Categories Include:

Individual - Annual Fee \$20.00 allowed to nominate directors, stand for office and vote at AGM.

(HIV pos. may request fee be waived)

Institutional - any non-profit organization or institution, includes voting rights. Fee based on gross annual revenues:

\$0 -99,000	Fee: \$30.00
\$100,000 -999,000	Fee: \$50.00
over \$ 1,000,000	Fee: \$100.00

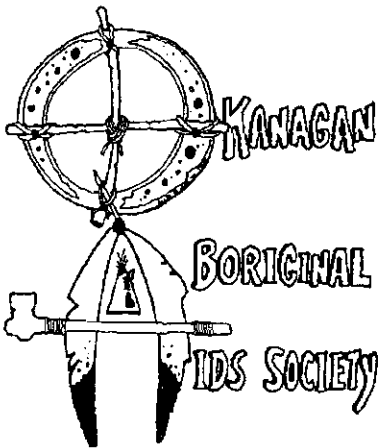
Associate - Any organization, association or institution that supports the mission of CATIE. Associate members cannot vote, nominate or stand for office. Fee based on gross annual revenues:

\$0 - 500,000	Fee: \$500.00
\$500,000 plus	Fee: \$1,000.00

Register on line at www.catie.ca or call Ron of ARC for an application.

Ron van der Meer
CATIE Director
Membership & Nominations Committee

O.A.A.S Okanagan Aboriginal AIDS Society



Julienne Desautels is the outreach worker for the OAAS

OAAS Notes

March 28th, 2002

Hello there

Well you would not know it. This is our second year that our office has been open. Let's see... what have I been doing? **HMMMM**... Ah yes the word **Flexibility** comes to mind. As an Outreach Worker, I have been taught the real definition of **flexibility**.

While in Kamloops at the beginning of March, I attended the PAN Conference and OAAS President, Adam and Directors, Brian and Sandi attended the 6th Healing Our Spirit Conference. There were enough delegates from both networks to make one really big conference. In January, I was elected to the Red Road HIV/AIDS Network Council for a 4-year term as Treasurer. I have been to Vancouver for the Red Road HIV/AIDS Network meetings since the Okanagan Aboriginal AIDS Society opened office.

We have been busy here at the office and it does not stop. We have regular HIV/AIDS and

HEP C speaks (going out into the region that we serve). In the Aboriginal communities, the rate of infections of HIV/AIDS and HEP C is on the rise.

Aboriginal people are testing positive for new HIV infections at the rate of 370 per year in Canada, that is more than one per day. This is too high for our communities; we need to reach everyone to make it count, that the **awareness and prevention** is heard by all, from children to Elders to Chief and Council, and by all our communities, because this is a preventable virus.

We all have to be **flexible**. We all have to learn from what comes our way, from being in the grass-roots stage to fully knowing what is going on. This is an everyday activity so if anyone asks you, "**What have you learned today?**", tell them. And if you haven't learned something, get out there and learn something new. Do it before you've wasted the day

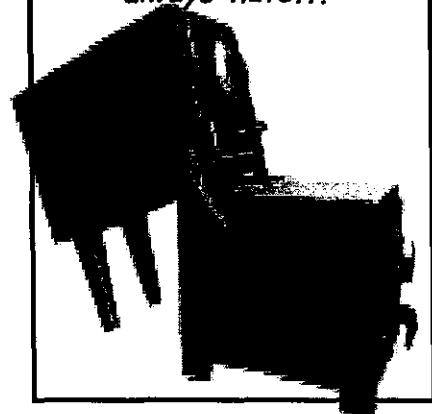
"A mind is a terrible thing to waste."

Motto: United Negro College Fund

We are gearing up for a new (fiscal) year. We are looking for people who can help out within the office, with upcoming events like the Candlelight Memorial, the annual AIDS Walk and a host of other awareness and prevention events. So if you have some time you can contribute to the Okanagan Aboriginal AIDS Society give me a call or come on down for a tour of the office and see how you can help.

**Julie Desautels
Outreach Worker
OAAS**

Julie says...remember to always have...



.....

The Silent Victims

In the past the focus of our newsletter has been primarily a localized one, treatment information, coming events and client support services. But what happens in countries where they don't have support for either people infected or affected by HIV and AIDS? I know the term HIV "victims" has been frowned upon as people prefer to think of the illness in terms of survival, but there is one group I feel are truly victims, of not only this devastating illness, but also of a society whose social safety net has been torn apart as an entire generation of parents, uncles, aunts and caregivers has been decimated as a result of AIDS. I am talking of the children left parentless, orphans that in past years would have been cared for by relatives or embraced by their entire village. The concept of adoption is not a part of most African cultures. There has never been much need as many African cultures have operated as collective societies. Having neither the tradition nor the structure to care for the vast number of orphaned children Africa is largely unprepared for this crisis. Almost 100 million orphans will be left during this decade from AIDS taking one or both parents and sometimes all of their family members. As I struggled to fathom what this really means I find myself trying to empathize what it must feel like for these innocent children, victims of something they cannot possibly understand. Many of them suffer from HIV themselves either contracted through birth or from the breast milk with which their mothers nurtured them. Even for the ones not infected, unfortunately, the future does not look hopeful. Children orphaned by AIDS are often starving and sick, many times unbeknownst to their own communities, or abandoned by

them. Others become prostitutes primarily to survive.

"In the east Rand [near Johannesburg] six children stayed alone for almost 18 months... at the time they were discovered they were almost dying and did not even want to go with the ambulance," said Lungi Mabude, a researcher on child-headed households. Alf Nghalaluma, director of the research agency, Africa Now, said that a check of the town of Melmoph, northeast of Durban, found 350 children heading households. The researchers learned that "food security was the biggest problem and biggest priority" for these children. "When you go to any of these children and ask what they need, the primary request is food... they tell you 'I have not had good food the last three days,'" said Nghalaluma."

This is not an isolated case. It is the norm. In Africa one in every ten children is an orphan. This translates to millions of children living with no one to care for them. Until recently, African nations have done little to help these children and now, unfortunately, the need has grown to a point that it greatly overwhelms the resources that have been directed into aid. Without outside support most of these children do not stand a chance. In my effort to understand this issue I came across a website on international adoption. Many of these are healthy children that need someone to care for them. There are dozens ready to be adopted right now, the fees are kept low and there are relatively few restrictions.

contributed by
Melissa Hill

The website is
www.all-as-one.org

**'It takes a whole village
to raise a child'**
African Proverb

Volunteer Corner



The AIDS Resource Centre depends on the contributions and involvement of volunteers. We would not be able to provide the level of service we are committed to maintaining if our personnel resources were not augmented by the active participation of those who donate their valuable time and effort.

Volunteer Opportunities include:

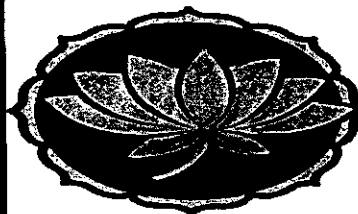
- Reception and Office Support
- Data Entry
- Awareness and Education Events
- 2002 AIDS Walk
- Speakers Bureau
- Home and Hospital Visits
- Care Teams

Come and be part of our winning team of everyday heroes.

Reiki and Healing Touch for clients

Enjoy the relaxing and balancing benefits of a quiet hour with

Toshie



Call 862-2437 to book
your free Tuesday session



Support Plus... Client Support Information

BC Benefits - Important Changes and Updates

We want to share information and support regarding the BC Employment and Assistance Initiatives that became effective April 1, 2002. The Ministry of Human Resources informed our clients who are receiving disability benefits, by letter, about the policy changes that are affecting them. Several clients phoned the office confused or concerned about "...the renewed emphasis on employment with temporary assistance for those who are able to work." The Ministry letter goes on to say the government will spend \$300 million in job placement and training programs. There has been belt-tightening for several months now with the replacement of Schedule C by the Monthly Nutritional Allowance and the need to choose to receive Ensure/Boost or high protein allowance; even if the physician and dietician think both are needed. In the future we will see the Ministry continue to cut back, add restrictions, demand payback plans, and to enforce accountability by demanding receipts for purchases.

The following are the benefit changes most likely to affect our clients receiving level 2:

Crisis grants now have monthly limits: · \$20.00 per person/month for food, · one month's shelter allowance per year, · \$100.00 per person for clothing or \$400.00 per family.

Income Exemptions: · 25 percent earnings exemption is discontinued, · (no earning exemptions for DB1), · DB2 may keep \$300.00 maximum (up from \$200.00), · no more exemptions for CPP family maintenance or orphans' benefits, · no WCB exemption, · Lottery/Gaming winnings deducted.

· Homemaker Services: · discontinued, · short-term, emergency nursing/home-support provided by health authority.

· Revised Asset Limits: · single, disabled \$3000.00, · Couple, disabled \$5000.00, · one motor vehicle, less debt up to \$5000.00 or fully exempt if modified for disability.

· Security Deposits: · will be deducted from cheques at \$20.00/month starting the second month after it has been issued, · maximum two outstanding security deposits, · 3rd issued if fleeing domestic abuse, sale or demolition of property.

Recipients of level 1 or level 2 disability benefits will not have time limits for the number of years they can collect. Time limits will be imposed on "Employable" Income Assistance recipients only. If you are affected by childcare subsidies, child in the home of a relative, shared parenting or student loans, some other changes may apply to you.

Please feel free to contact your financial aid worker or an ARC support worker for answers to your questions. We expect other policies and new conditions will be coming.

Our goal is to empower our clients by providing them with the information they need to get the services they need; to advocate on our client's behalf and to exert political influence on our government as is necessary to ensure the well-being and quality of life for our clients. If you experience negative consequences as a result of these changes please let us document them and make them count.

Prior to last November, anyone receiving BC Benefits (with or without DB 2 status) had their eye exams covered by MSP. When MSP reduced its coverage of eye exams last November, the Ministry of Human Resources announced that it would not cover the additional costs.

However, persons with HIV are eligible for eye exams free of charge every 12 months. Eligibility for free eye exams requires an HIV+ person to disclose their status to their optometrist. The individual has the right to share that information only with the optometrist and does not have to tell the receptionist.



**River Glen
Client Support Worker**

HIPPO update.....



New Support Groups Spring up in the South Okanagan

Through the efforts of Alex and Sandra a new support group has sprung up in Penticton. The very first meeting took place on Tuesday evening, March 4th, 2002 at the Frank Faulkner Building, a meeting room attached to the apartment complex at 524 Pickering Street in Penticton. Seven people were present at the inaugural meeting and attendance continues to be good. The meetings have been taking place weekly and it is hoped that this Penticton group will continue to grow and provide a good support network for individuals infected and/or affected by Hepatitis. The Hepatitis C Society of Canada has a new group in Oliver. The contact person for this group is Robin Conn and meetings are currently being held in the living/dining room of his apartment located at apartment # 308 - 44585 - 97th Street, Oliver BC. This particular group is meant to serve the Oliver - Osoyoos area. A minor problem of transportation exists for those residents of Osoyoos who wish to attend meetings in Oliver. However, by contacting the right people and ride sharing, this problem should soon be solved.

Other Hepatitis Support Groups in the HIPPO Region

The HEPKOP group continues

to grow in numbers. It was reported to me that the last meeting of this Kelowna-based group had an attendance of 10 individuals.

Hepatitis Support Groups Times and Places

**Penticton Skaha Regional
Hepatitis Support Group**
Box 309 113 - 437 Martin Street
Penticton BC V2A 5L1
Phone 487-1598
Fax 493-0099

Contacts Alex or Sandra
Time 7:00 pm, Wednesdays
Place 885 Fairview Drive - in the
Common Room

Hepatitis C Society of Oliver
(Serving Oliver and Osoyoos)
Contact Robin Conn
Phone 498-4598
Place Apt 308 - 44585 97th Street
Oliver BC V0H 1T0
Time Monthly meetings - call for times
and dates

HEPKOP (Kelowna)
Contacts Lisa Mortell
or Elaine Riseley
Phone/Fax (250) 766-5132
or (250) 768-3573
Email lmortell@silk.net
or eriseley@shaw.ca
Date & Time Last Saturday of each
month from 1:00 - 3:00 pm
Place Kelowna General Hospital,
Rose Avenue Education Room

HepLife (Vernon)
Contact Sharon
Phone 542-3092
Email sggrant@telus.net
Dates 2nd and 4th Wednesday of
each month
Time 10:00 am - 1:00 pm
Place The People Place
3402 - 27th Avenue
Vernon BC V1T 1S1

There is a great deal of enthusiasm among the members to make this a really successful group and it would

appear that Lisa Mortell and Elaine Riseley are doing an excellent job of facilitating these meetings. Here, it is of note to thank Wendy Turnbull, the nurse at the Hepatitis Clinic at Kelowna General for encouraging people having treatment there to check out the group.

Heplife, which is another group affiliated with the Hepatitis C Society of Canada continues to meet every 2 weeks and continues to have excellent attendance at their meetings. On the 27th, 28th, and 29th of March 2002, 3 members of Heplife and Lisa Mortell of HEPKOP traveled to the lower mainland to attend a workshop on peer support facilitated by Terry Howard, of the Canadian Liver Foundation and Gail Butts of the BC Centre for Disease Control.

Surveys

The Hepatitis Needs Assessment Surveys have had a return of 22 at this point in time. This survey will be ongoing until near the end of the HIPPO Project. The best return for these surveys are from those given out by Wendy Turnbull at the Hepatitis Clinic at Kelowna General Hospital. With regard to the surveys sent to the Ministry of Social Development and Economic Security, there has been a 90% return on these specific surveys. For the surveys sent to the Community Based Organizations, there is currently a 50 % rate of return.

**Merv McLeod
HIPPO COORDINATOR**

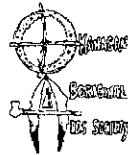
NOTICE BOARD

● ARC DROP-IN HOURS

River Glen, our Client Support Worker, has drop-in hours on Thursdays from 09h00 - 12h00. If you wish to see her at other times an appointment is necessary.

Aboriginal AIDS Society

For more information call Julie @ 250-862-2481



OUR THANKS GO OUT TO...

The board and staff of the Okanagan Aboriginal AIDS Society wish to thank the volunteers, Martin, Tammy, Lynne and Daryle whose contributions of time and effort enable us to get out into the communities we serve. We wouldn't be able to do it without you! *Become an OAAS volunteer and see YOUR NAME HERE!*

19th International AIDS Candlelight Memorial



"Our Global Village"
by Mona Sfeir

This year's theme is
"Share Your Vision for a Brighter Tomorrow."

Sunday May 26th, 2002 @ 7:30pm
Mission Creek Regional Park Gazebo
(On Springfield Past Orchard Park Mall)

For more information or if you know of an individual you would like to have added to the list of those remembered
Please Contact
Melissa at 862-2437

Share **YOUR** Vision
for a *Brighter Tomorrow*
and
View the *Contributions*
of *Others*

Visit www.arcok.com