ReACT-Believe

The AIDS Committee of Thunder Bay newsletter
Spring 1991, Volume IV, Issue II

AIDS Committee of Thunder Bay P.O. Box 3586
Thunder Bay, Ontario P7B 6E2 (807) 345-1516
AIDS Infoline 345-SAFE

KEEWAYWIN

(Journeys)
AIDS in the First Nations

The AIDS Committee of Thunder Bay is pleased to offer the first video produced in Northwestern Ontario, specifically developed for use by First Nations communities. The video may provide basic AIDS information, create a climate of tolerance and understanding, and promote discussion about issues surrounding AIDS. KEEWAYWIN has received an enthusiastic response. A facilitator's guide accompanies the video. The video can be ordered on a cost recovery basis of $20 per copy. Order form on page 9. KEEWAYWIN is available for free on loan at the ACT-B Resource Centre Library at 285 Bay Street.

Smoking & HIV

- AIDS Calgary

It has been reported at the San Francisco Conference that there is a need to take smoking into account when monitoring HIV-infected individuals. More study is needed to confirm what type of relationship exists between smoking and HIV progression. There is mounting evidence that tobacco is an immuno-suppressive. Quitters have been shown to have higher levels of immunoglobulin and NK (natural killer cells) cell activity. Second hand smoke and short term smoking among non-smokers does not seem to have the same immuno-suppressive effects as chronic smoking. However the effects of second hand smoke on people with chronic broncho pulmonary disease and coronary heart disease is great, not to mention the effect of smoke-filled rooms on allergenic individuals and others hyper-sensitive to cigarette smoke. Such rooms can have levels of carbon monoxide greater than air pollutions standards.

Smoking also effects the rate of metabolism (accelerated) and the pharmocodynamics (effect within the body) of drugs used in the treatment of various disorders. This could cause toxicity to occur when smoking ceases such as when one is hospitalized or since nicotine can reduce the blood flow to the skin, absorption rates may be slowed, and lead to further complication. Overall, physicians may need to adjust doses or select different medications in patients who are cigarette smokers.

In conclusion, it must be noted that the physiology of the body is not designed to handle tobacco smoke. The effect alone on the lungs is striking. One cigarette will stop the cilia in the lungs for 20 minutes or more, from performing the task of keeping the air passages free of foreign material. Cigarette smoking increases the amount of mucus produced in the bronchial tree and interferes with the uptake of oxygen in the respiratory system. This along with a decreased oxygenation in the red blood cells can only further compromise the immuno-suppressed individual with HIV.

- by David C. Burke

Koffee Klatsch

"To talk about HIV/AIDS issues, whether or not you are HIV+"

Koffee Klatsch is held every 2nd Thursday. The location is confidential.

You can call Glenna, our Support Services Coordinator at 345-1516.

"an environment of unspoken understanding & support by being able to identify with each other's concerns"

Education materials are now available in Finnish!

Pamphlets, brochures and books range from educational cartoons to books full of factual information about AIDS - all written in Finn.

The information is available free at the ACT-B Resource Centre Library, located at 285 Bay Street. Drop in any time, Monday to Friday, 8:30 a.m. to 5 p.m.

**These materials are available in limited supply.*

Winner!

KEEWAYWIN, a project of ACT-B's Education Department, won the **Thunder Bay Press Club**, Alexander "Lackey" Phillips award for *Best Feature Television.*

Quite an honour!

ACT-B in the morning . . .

ACT-B now has their very own cups. They're classy clear mugs, with our logo on it. You can get them at the office for $6.00 each or 2 for $10.00

ACT-B Dictionary

ACT-B The AIDS Committee of Thunder Bay. A community-based AIDS Service Organization dedicated to confronting AIDS through prevention, support, education and advocacy.

HIV Human Immunodeficiency Virus - the virus believed to cause AIDS.

AIDS Acquired Immune Deficiency Syndrome - the immune system is disrupted by HIV leaving the body defenceless against opportunistic infections.

PLWA Person Living With AIDS

HIV+ Having tested positive for HIV antibodies.

Hospital bed, wheelchair, vacuum cleaner, fridge & stove.

These items are available on loan through our Support Services Department. Other items needed can be requested from Glenna, our Support Services Coordinator at 345-1516. Talk to her about your needs, together, ways can be found to fill them.

Join a fun crew of BINGO workers. 1 Tuesday a month we laugh & work like crazy, to raise funds for the AIDS Committee of Thunder Bay. To join, call Sheila, our Volunteer Coordinator at 345-1516.

The Support Services Committee is making a cookbook designed for PLWAs. We need submissions of hints, nutritious meals for 1 or 2, cheap meals, recipes for special diets, & if you are HIV+, please pass on your cooking hints to other PLWAs.

Submit your recipes to Glenna, Support Services Coordinator.

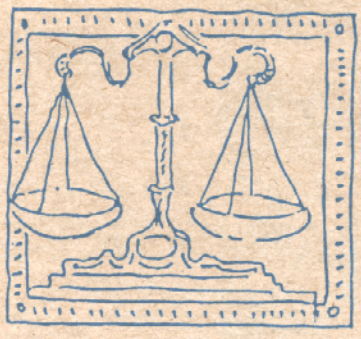
Treating Teens

by Dr. Roger Tonkin

reprinted with permission from
The Medical Post,
February 5, 1991

It's funny how so many people think that teens who come to a youth clinic like ours must be noisy, unkempt, light-fingered, manipulative and unreliable. Gail was just the opposite to this unfortunate stereotype. She was quiet, always carefully dressed, honest and straightforward, and a compliant patient who never missed her appointments. In fact, she was not at all atypical of the many "girl next door" type patients that form the core of most adolescent medicine practices. When we first saw Gail and her parents it was the spring of her Grade 8 year. She had lost 20 pounds over the first four or five months of high school. At the time she was pretty resistant, angry and evasive. She had all the typical features of the slow starvation syndrome. She had poor concentration and poor sleep. She was depressed and preoccupied with thought of food, counting calories, weight, fat, etc. She was pretty paranoid about her parents' motivation for bringing her to our clinic. When I examined her I found Gail to be hypotensive, brady-cardic and cold. She had many of the other stigmata of weight loss (lanugo hair, dry carotenemic skin) and a history of amenorrhea and hair falling out. She was noticeably restless and didn't like being asked to sit down. Clinically, she presented a pretty typical picture of an early onset eating disorder. Ideally, I would have admitted her to our adolescent inpatient unit and and put her on our weight restoration program. However, we were in the midst of our annual spring epidemic of new cases of anorexia nervosa and had already exceeded our bed allotment. After consultation about Gail's options, her parents decided to try and get her to gain weight at home. We sat down and worked out a strategy of restricted activity, increasing intake and stress reduction (a program that we have subsequently formalized into a "7 Day Dietary Challenge". Using a clinic history sheet, I wrote out hospital-type orders for the parents to follow and set out a meal plan that Gail agreed to try. As they left the office I told my nurse to expect a panic call the next day. I was not too hopeful for their chance of success. Gail and her parents fooled me. Their success with reversing her weight loss taught me how difficult it is to predict which patients will succeed on our 7-Day Dietary Challenge and which will fail. Over the course of the next few weeks we gradually increased Gail's intake and activity level. Within a month she had improved sufficiently to warrant a return to full-time school attendance and by summer break she had achieved her agreed-upon goal weight. I was able to gradually reduce the frequency of her clinic visits from weekly to monthly and things at home had resumed some semblance of normalcy. I continued to follow Gail in the clinic. She became less depressed and we settled into a fairly relaxed working relationship. She seemed to be getting on with her adolescence. While her weight had improved, her skin folds and body mass index indicated that she was still on the slim side of normal. However, she continued to worry about being fat and her parents reported that she still wasn't eating normally. As time passed she experienced several episodes where her weight dropped below goal levels. These episodes were usually associated with the stress of exams, too many late night-shifts at work, or conflict with her friends. Each time I would exhort her to increase her intake and to reduce the pressures she placed upon herself. Each time her weight would improve and we would relax again. As time passed Gail continued to present issues or concerns that needed discussion. Sometimes these were related to dealing with her eating disorder. For example, what to tell her friends how to regain her parents trust, what to do about eating on a school band trip and how soon could she resume her gymnastics. Other times she came in with problems that were unusal but typical for her age group. For example, once she came in with a bottle of prenatal vitamins and asked if they were safe for her to take. She and some other Grade 12 classmates had the idea that one of these pills daily would make their hair grow longer, stronger and faster ... a desired preliminary to having their grad photos done. Gail moved slowly but steadily through the normal adolescent developmental milestones. However, one development did cause everyone some grief. That was her relationship with Pete. Pete was a schoolmate, a star football player, and the object of attention from many of the girls in Gail's school. He was a good student and a responsible young man. He had his heart set on a professional career in football. Gail couldn't believe he would be attracted to her. It blossomed into a classical high school sweetheart story. Aware of the intensity of the developing situation and of how much time the two of them were spending together, I would from

Kinna-aweya Legal Clinic



The Kinna-aweya Legal Clinic is a member of the provincial-wide Community Legal Clinic system. These clinics were created in order to allow people with low incomes access to legal advice and representation with the kinds of legal problems unique to groups for which traditional legal services are usually not available especially on a cost-free basis.

For more information about how to access the services of Kinna-aweya Legal Clinic call 344-2478 in Thunder Bay. In Armstrong call 583-2631. In Geraldton call 854-1278. In Marathon call 229-2290. Other community legal clinics are in Kenora (468-8888), Sioux Lookout (737-3074), and Fort Frances (274-5327).

The word Kinna-aweya is Ojibway for **Everyone.**

Kinna-aweya Legal Clinic is one of the many agencies our clients can be referred to for specific needs. If you are living with HIV, and do not wish to contact Kinna-aweya directly, call Glenna, our Support Services Coordinator for more information, at 345-1516. All enquiries are confidential.

DISABLED IN ONTARIO

If an individual is disabled in Ontario whether as a result of injury or disease they usually find that there are two rather serious problems. The first of course, is their physical well-being and the second is their financial situation. This article is intended to be an overview of the various sources of income that a disabled person should be aware of and is designed to provide general information only. Naturally, all laws, policies or practices are subject to change at any time.

A person becoming disabled and unable to work might suddenly find that they have an interruption of their normal income from employment and at that time there are five major sources of income which they should consider and be familiar with.

1. **Private Insurance** - Anyone becoming disabled and unable to work should speak to their employer about any insurance policies which may be in place by virtue of their employment and might cover disability. Naturally, they should also review any individual and private policies which they may have to see what benefits they are entitled to. If there is any confusion or misunderstanding concerning any of the private insurance policies which may be applicable a disabled individual should obtain legal advice. I will outline two systems of doing that without incurring costs at the end of this article.

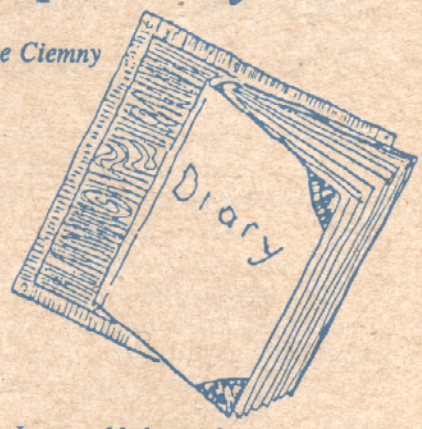
2. **Workers' Compensation** - Naturally, if the disability is in any way related to employment a claim should be made to the Workers' Compensation Board. Most people realize that if they are disabled as a result of a traumatic injury at work, they would be entitled to these benefits, however, it is also possible that a worker would be entitled to workers' compensation benefits if they have a disease which is in some way caused by their work environment.

3. **Unemployment Insurance** - As I think people know, there are sick leave benefits available under the Unemployment Insurance Act and whether you qualify for these benefits is determined by how many weeks of employment you have. The criteria is somewhat different than qualifying for regular benefits. Sick leave benefits are paid for a shorter period of time, however, if there is any doubt at all about whether you qualify for these benefits then an application should be made. Again, if you are denied benefits under U.I. you should obtain legal advice concerning the possibility of an appeal.

Continued on Pg. 10

My Spirituality

by Anne Ciemny



I was told that to have a spiritual feeling with God, one has to have a Soul. I know I have a Soul, because I have a spiritual feeling with God. God is my higher power, my keeper. Sometimes He is a man who stands above me and listens to my conversations, my prayers, my thoughts. Sometimes, He is the "spirit" who gives me the courage and determination to venture forth to do things I am afraid of doing, and sometimes He is love that I share with myself and others. I do not know really what form He should take, but I know He is in my heart at all times, and I am never alone.

He motivates me and my life. He is the reason I am what I am today. I can talk to Him about my sadness, my pain, my fears, my gratitude, my happiness, my hopes, my reason for being, and I always find solitude and understanding after I talk with him. He builds up my self-esteem when I need it, and He is my inner voice that leads me to new challenges and new beginnings in my daily life.

He allows me to "smell the flowers", to give love to my family and friends, and to receive love from them, to appreciate my health, my life, my happiness, my work, my children, my grandchildren and all the wonderful daily happiness that makes my life so complete. Without God in my life there would be a void that would be a feeling of just existing, and because I have God, I know He will allow me to grow more and more each day to the best of my ability, knowing I am unique in His eyes, and therefore, mine.

I have a great relationship with God, who is my spiritual guide and friend, and the keeper of my soul.

Anne Ciemny is an active volunteer with ACT-B.

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Gallois' Revelation

"If you put tomfoolery into a computer, nothing comes out but tomfoolery. But this tomfoolery, having passed through a very expensive machine is somehow enobled and no one dares to criticize it."

Please give us your feedback! Comments, concerns, compliments and criticisms about the newsletter, our publications, or about any aspect of the agency. You can phone or mail. You can remain anonymous if you wish. We'd like to know your comments in order to improve on weak points, and continue to deliver our strong points.

Thank you to the agencies and individuals who have given us their comments. They are greatly appreciated.

Write to: AIDS Committee of Thunder Bay
P.O. Box 3586
Thunder Bay, Ontario
P7B 6E2

(807) 345-1516
9:00 a.m. - 4:00 p.m.
Eileen Parker, Editor, ReACT-Believe

The opinions and medical information offered by ReACT-Believe are those of the individual authors and not necessarily those of the staff or Board of Directors of the AIDS Committee of Thunder Bay. Medical information offered by ReACT-Believe should be used with your own discretion. Please consult your doctor.

Call the **AIDS Infoline** at **345-SAFE** (345-7233) and get the facts about AIDS.

▲ Monday to Friday 8:30 a.m. - 5 p.m. talk to our staff & volunteers

▲ Afterhours and weekends listen to an informative taped message.

▲ **You do not have to give your name.**

▲ Outside Thunder Bay, call the Ontario Ministry of Health AIDS Hotline. It's toll-free!

English 1-800-668-2437
Monday to Saturday
10 a.m. - 10 p.m.
Sunday - 12 p.m. - 7 p.m.
Français 1-800-267-7432
TDD 1-800-267-7712

▲ If you want more in-depth **counselling**, want to join a **Support Group**, or would like to access our **Support Services**, just contact Glenna, our Support Services Coordinator weekdays at **345-1516**.

All enquiries are confidential.

No Survival

by Amanda Haymond

I am wondering how many teenagers think about AIDS. I don't mean telling jokes about it, but thinking about it seriously. It's sort of like car accidents - it won't happen to us if we are safe drivers, right? That's how I feel. I won't get AIDS 'cause nobody I know has it. But I am wrong.

AIDS, or Acquired Immune Deficiency Syndrome was first identified in 1981. It began as what seemed to be a "Homosexual" disease, but then it spread, and *normal*, everyday people were getting it. Nobody thought that these *normal*, everyday people **could** get it.

There are only three ways that you can contract AIDS: through sexual intercourse, intravenous drug use (shared needles) and mothers passing it to their children during pregnancy. Nowadays, attitudes about premarital sex are more liberal. We, as teenagers, are not encouraged by adults to have sexual intercourse until we are older, but according to a study done by Queen's University, 70% of Canadians asked in the 18 to 24 age bracket first had sexual intercourse when they were younger than 18. The AIDS virus has an incubation period of up to seven years or more, and the incidence of AIDS is high in 20 to 29 year olds.

That would mean that some of these people contracted the virus in their teens, making us very vulnerable to this disease. We may not see the signs now, but they **will** develop.

We all know how to prevent AIDS. We know that abstinence is the safest way to be protected, but it's unrealistic for most of us. Be careful of the person you are with, and be protected. We have to take AIDS seriously now, because we are at risk. It's not just a homosexual disease. It doesn't discriminate. It can be you, or your friend, or a relative. And remember, there is no cure for AIDS. You will die from it. You can not get better.

Amanda is 17 years old. She goes to Hammarskjold High School.

Treatment

Treatment Issues Coordinator, Craig Davis

The AIDS Committee of Thunder Bay does not recommend, advocate or endorse the use of any particular treatment(s) or therapy described in ReACT-Believe. The AIDS Committee of Thunder Bay therefore, does not accept the risk of, or responsibility for any damages, costs or consequences of any kind whatsoever which may arise or result, either from use or reliance on the information contained herein, or due to any errors contained herein. Persons relying on the information provided must do so at their own risk. Please consult your health professional. Any medical information should be used at your own discretion.

Reprinted from the Vancouver PWA Society newsletter . . .

MEDICAL FORUM REPORT

On January 23, 1991, Dr. Karen Gelmon spoke on Kaposi's Sarcoma and the Alpha-interferon Trial.

This was an excellent presentation, unfortunately the turnout was less than we had hoped for. The whole purpose of these forums are to give the members information on treatment, therapies, new trials and provide an excellent opportunity for the members to voice their concerns or complaints. The Forums are relaxed and give the opportunity to directly question the presenter. Despite the poor attendance. Dr. Gelmon did give a good overview of the difficulties in treating KS and the unpredictable course this disease takes.

She noted that some patients with the illness may only ever develop one lesion, then there are those who develop crops of lesions over a period of time, and finally, those who develop lesions quickly and often internally. The treatment prescribed depends upon the degree of involvement, and where the lesions are. Facial lesions are often treated for cosmetic concerns, either with radiation therapy or cryosurgery, which is actually freezing of the lesions with liquid nitrogen. With some of the recent studies that have been published in the U.S. where low dose interferon has been tried, the results have been encouraging, so the Canadian trial will hopefully support the efficacy of Interferon as a treatment.

This needs to be established so that the drug will be made available to people with KS through the various Cancer Control Agencies. As it stands now, the cost of this drug is not covered in B.C. for KS. The drug is to be administered daily by subcutaneous injection, much as a diabetic takes his insulin daily. The dose will depend to a certain extent on the individual's tolerance to Interferon. Side effects include depression of the hemoglobin, nausea, headaches, and fevers which may continue during the first few weeks of treatment. The cost? If an individual is using 3 million units daily, it works out to about $50,000 per year!

Dr. Gelmon explained that there has been a lot of difficulty in getting this trial going because the supplier of Interferon (Schering) has been very difficult to deal with. The investigators were initially told they could enroll as many people in the trials as they wanted, and then were told they could enroll no more than eight! Locally they have enrolled eleven participants and are hoping to have sixteen before too long. To quality for this trial, the individual must also be on AZT and appropriate PCP prophylaxis. Despite the restrictions they are working under, they do hope to gather useful information with the present trial design. Dr. Gelmon noted that a response is usually seen within two and one-half months to four months. Those who are responding favourably will be kept on the drug. A favourable response would be clearing of the lesions and a reduction in the number. Patients will be followed through IDC.

For more information on this trial, eligibility and possible enrollment, please speak with Pat or Nancy at Infectious Disease Clinic at St. Paul's Hospital 631-5060.

- Al Hawkins

AIDS Infoline - 345-SAFE

COMPOUND Q UPDATE

Trichosanthin, Compound Q, is one of the most promising drugs under investigation and in use. It has been in use in China for quite a while mostly as a drug to induce abortion. It has been in use in the U.S. for approximately 3 years. Martin Delany of Project Inform did the first study with 10 men who, as Delany put it "didn't have a 100 T-4 cells between them". They also had; many concurrent opportunistic infections including neurological involvement. He was very lucky only 3 of them died. There has been one other death possibly related to Compound Q in L.A., the man had a herniation of his brain stem. At this point it is estimated that somewhere between 800 and 1000 people have taken Compound Q. The drug is now in phase two trials with the U.S. Federal Food and Drug Administration.

Compound Q is very selective: it only kills infected Macrophages and leucocytes. Antiretrovirals, (also called chain terminators as they terminate the reproductive chain of the cells, mostly T-4 Cells like AZT) DDI, ddC, have little or no effect on infected macrophage or leucocyte blood cells. Compound Q, very importantly, crossed the blood/brain barrier. Obviously, this means that Compound Q will very significantly reduce viral load. It is thought that this great reduction is at least one of the reasons that we see an increase in T-4 cells, between 30% to 40%. The lower the number of T-4 cells before the infusions of 'Q' the lower the increase after, as a general rule.

Yes, it is true that some people with T-4 cells at higher ranges 350+ have become what Delany calls "his graduates" which means their T-cell counts and ratios have returned to "normal" levels.

It must also be said that Compound Q is a potentially dangerous drug. There can be very dangerous side effects including anaphylactic shock. Careful monitoring by a knowledgeable medical person during and

for 3 days after infusion is necessary. There should also be emergency drugs immediately available in case of a severe reactions. The usual side effects seem to be like the flu in reverse. You're really sick a few hours after the infusion and you get better over 2-3 days.

These side effects last for 2-3 days and can be very uncomfortable. Almost all the groups infusing Compound Q in the U.S. require the PWA having the infusions have 200 or more T-4 Cells, no current opportunistic infections, nor neurological involvement and liver functions in 'normal' range.

PWA with T-4 cells less than 50 who have infused Q usually have very little increase in their T cells and because of the killoff of infected macrophages and leucocytes these people are wide open in the weeks following their Q infusion to very serious O.I.'s which can be deadly.

Sources: Project Inform Perspectives
Lecture by Dr. Larry Waites, head of FDA phase II trials S.F.
California, conversations with Dr. Payne, researcher, Phoenix, Ar.

- Dan Cotton

EPO APPROVED!

The FDA approved a license for Procrit, a synthetic form of erythropoietin (EPO), which significantly reduces anaemia in people treated with AZT. A protein formed in the kidneys, EPO stimulates the production of red blood cells. EPO had already been licensed for patients with kidney failure and its marketed by Amgen, a pharmaceutical company, as a product called Epogen. Another company, Ortho Biotech, conducted trials of their version of EPO in people with AIDS. While these trials progressed, Ortho provided free EPO through a treatment-IND program. Now Ortho's drug, with the market name Procrit, has been licensed for anaemia in HIV-infected patients.

Procrit is an extremely expensive drug: one dose (7000 units) will cost about $70.00. Patients typically need three doses a week and Ortho speculates that the annual cost will be from $6,000.00 to $8,500.00.

reprinted from GMHC Treatment Issues, January 10, 1991.

Comment: This treatment is now available through the Infectious Disease Clinic at St. Paul's hospital. Contact Ann Beardsell at 631-5074.

MAJOR STRIDE IN MAI THERAPY

The price of keeping people alive longer with prophylaxis for PCP is that they develop other infections that interfere with the quality of life. Mycobacterium avium or MAI is one such infection. Before the 1980s, only fifty cases of this infection were reported in all the world's medical literature. Now, it is estimated that as many as 50% of PWAs may have MAI in the course of their HIV disease.

MAI manifests with multiple symptoms which may be non-specific. Very often, this infection can be confused with other things and is difficult to diagnose.

The current standard therapy for MAI includes the following: INH, Rifampin, Ethambutol, Ciprofloxacin, Clofazimine, and Amikacin.

We see a fairly good response rate to this regimen. There is some improvement of symptoms. The infection, however, does not get cured, and persistent, low grade symptoms may interfere with the quality of life. The four or five drug regimen, however, may be difficult to keep up, since some need to be taken intravenously.

Now there is a new antibiotic, clarithromycin, which may offer a one drug anti-MAI therapy. This compound is related to erythromycin, but has a wider spectrum of activity and is more fat soluble. Clarithromycin is available in Ireland, Italy and a few other countries (including Canada, under EDRP. See below).

We have two studies of clarithromycin as treatment for MAI. A 1989 study looked at how much clarithromycin was needed to treat MAI in the test tube. An effective dose was fairly easy to attain. The researchers found that clarithromycin was the single best drug that they tried as treatment for MAI-infected rats.

At the recent ICAAC, Paris researchers reported on a double blind study of clarithromycin for MAI in AIDS patients. The study was divided into two groups of twenty-three patients. The clarithromycin group showed a steady decrease in MAI levels of over the six weeks, whereas the placebo group showed a steady rise.

During the second six weeks of the study the first group received a placebo and four drugs from the standard regimen. MAI levels began to move up. The second group was given clarithromycin and the four drugs. Their MAI levels steadily decreased. The researchers concluded that clarithromycin either alone or in combination was a reasonably effective treatment for MAI.

Excerpted from "Being Alive" February 1991.
See also: AIDS Treatment News Number 113.

Comment: Thanks to lobbying efforts by our members, Clarithromycin is now available in Canada. for those unable to use the standard treatment.
Contact Dr. Sabih Khan
Emergency Drug Release Program
Bureau of Human Prescription Drugs
Vanier Place, Vanier Ontario K1A 1B8

Antibody positive?

You don't need to feel alone!

There are other people out there with concerns like you. At ACT-B, you can join a Support Group, take part in individual or family counselling or take it easy at the Thursday afternoon *Koffee Klatch* with others with concerns like yours. Just call Glenna, our Support Services Coordinator at **345-1516,** for more info and for the times & locations. If you don't want to go to anything, you can just chat on the phone. However you want it.

Book Review

by Michael Sobota

Surviving AIDS
by Michael Callen

I first heard Michael Callen in July, 1988, at the Boston Lesbian and Gay Health Conference. I met him a year later, summer 1989, in San Francisco. While there, I attended a presentation he made at a similar AIDS and Health Conference. He was part of a panel that carefully and intelligently explained why they believed HIV was not the "cause" of AIDS.

Michael Callen is a wonderfully engaging person. He is a singer - has a solo tape released called Purple Heart and is a member of the gay male choral group The Flirtations - and he is a long time survivor of AIDS. He has survived "AIDS" for about nine years now.

It was with real excitement that I purchased his book *Surviving AIDS*, hoping that this would be the volume to make his story available to a much wider audience.

His book is divided into three main sections. The first retraces the story of AIDS and HIV during the 1980's. This is probably the weakest part of the book. If you have read *And The Band Played On* or any number of newspaper and magazine analysis of AIDS during the past decade, this is all old stuff. What is significant and important is his passionate writing about being alive, when science and medicine said he should be dead. Well, statistically, anyway.

The second section of the book, and probably the best, is the middle section where he lets other people with AIDS tell their own first person stories. There are more than a dozen first person accounts here. Their experiences are told with passion, intelligence and a great deal of humour. And they are all different, so don't pick up Callen's book expecting to find the common, universal traits that determine what constitutes "long term survival". While some embrace macrobiotic diets, others spurn this. Some are guided by Louise Hay's self-love therapy, others think she is hocus-pocus. Each, however, is very willing to speak loudly about how they have come to where they are today. These stories break down the stereotype of the "generic PWA". Not all PWA's are the same, none of them are perfect, not all are "activists", etc .

The final section is personal. Here Callen says he will answer "for the first and last time what I would do if I were you." He carefully articulates nineteen separate points that he offers as guidelines to surviving AIDS. They range from: 1. Decide if you really want to live, followed by 2. Spring Clean emotionally, all the way through 19. Keep an open mind about holistic or alternative approaches to healing. You don't have to be HIV+ to benefit from his wisdom in this section.

You should know when you pick up the book that he has strong opinions. He does not believe HIV "causes" AIDS. He does not believe anyone should take AZT. Read his book for information he presents as a first person experience, together with the other accounts he includes. He also wisely admonishes you to make your own decisions about your own life.

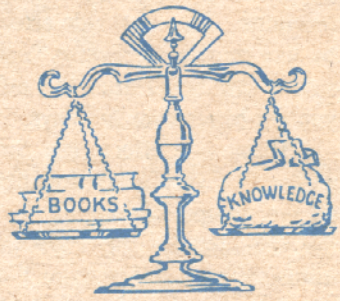
I recommend Callen's book for his information, his passion, his gay pride and his sense of humour. This is an important addition to anyone's library who is at all interested in AIDS/HIV.

Michael Sobota is our Executive Director and, is a professional reviewer.

Did you know . . .

If you use a petroleum based lube, like Vaseline, on a condom or with a condom, within 60 seconds the condom loses 90% of its strength.

The Library

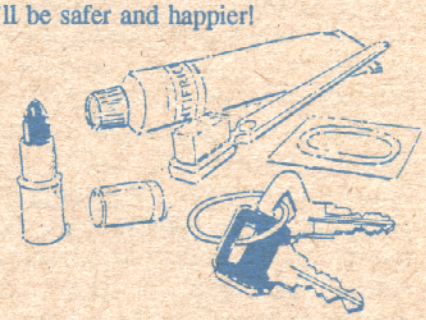


The ACT-B Resource Centre Library is located at 285 Bay Street.

Books and videos are available on loan. Resource books are also available for viewing in the agency. We also carry files full of newspaper clippings, magazine articles and studies. We subscribe to up-to-date **Treatment** newsletters, with the latest information on different types of treatments and therapies for AIDS and HIV.

'elpful 'ints from Eloise . .

For those times when you don't want to say, "Ah, excuse me for a minute". Always be prepared. Try Velcro-ing a condom package to places where sex may occur: the bed, the couch, the kitchen table, the door. And practise. You don't want to be fumbling around in the dark for an embarrassing eternity, or worse, risk breaking the condom. Become quick and efficient at putting on a condom properly. You'll be safer and happier!



". . . got money, cab fare in my shoe, Jody's gonna meet us at the bar, what am I forgetting . . . I heard Randy's not going out with Sherry anymore, got any hairspray?, I hate my hair, I hope he's gonna be there tonite, think this skirt is too short?, I'll see if I can get him to go party with us after, . . . Oh yeah, now I remember, you got any condoms in your purse?, oh wow, red ones, where'd you get them?, did you and Joey try those mint ones yet?, they're fun to put on!, I hate my hair . . ."

continued from pg.2

time to time, ask Gail about the extent of their sexual relationship. Eventually, they did engage in sexual intercourse and, as is so often the case with first intercourse in teens, it was unprotected and was followed by a missed period and a pregnancy scare. She wanted to deal with the scare on her own and not involve her parents or Pete. Fortunately, the pregnancy test was negative and a period quickly followed. Just the same I asked my nurse to see her in the hope that Gail might be less embarrassed talking with a female. In her characteristic fashion Gail listened carefully to the nurse, but chose not to deal with the issue of condoms or birth control.I had met Pete and we often chatted in the waiting room, but Gail usually resisted my efforts to get him to join us to see if he had any questions to ask me about her eating disorder. This time I thought he should join us, but she refused to allow him to join in a discussion of birth control and STD prevention (even though he was sitting out in the waiting room). I said that while they weren't dating others, and that Pete was a pretty responsible young man, I was concerned about what happened on school field trips or when she wasn't around to fend off the attractive girls who chase him or to police the situations where he might be tempted to use I.V. drugs (anobolic and street). My message was not well received and the discussion was ended with a terse "Pete isn't like that... you don't know him." I wasn't the only one concerned about the closeness of Gail's relationship with Pete. Her parents, who liked him, complained that they were never apart, that she was never home without him being there. Between Gail's 11th and 12th Grades her parents decided to encourage her to go on a school-sponsored summer tour of Europe. Because she was in French immersion they arranged to extend her time away by having her live for several weeks with a family in France. The parents were trying to give her a time away from Pete. Gail spent her first weeks of the tour on the phone back home to Pete. Otherwise she managed the travel, the meals, the pressures of meeting new people quite well. Gradually she gained some confidence and began to enjoy herself. By the time she got to France she was having a ball. The phonecalls home and the letters to Pete became shorter and less frequent. They stopped completely when she arrived at the home of her "French Parents." It was then that she met Pierre. He lived in the same village and worked on a local estate. They saw a lot of each other in those two weeks. She told me that while she was in love with Pete she was very attracted to Pierre. While Pete was steady, caring and patient, Gail found Pierre to be much more romantic and sensitive. She talked about how confused and guilty she had felt. They shared many passionate and sexually active hours but she resisted Pierre's pleas for sexual intercourse. That is until the night before she was due to fly back home. Pierre had offered to take her to Paris and see her to the airport. They decided to "see" Paris and spent a memorable day together. The decision to share a room in a quaint hotel came later (as did the unplanned and unprotected sex that followed). She cried all the way home on the plane. Upon her return to Vancouver, Gail told me of her Paris adventure. She told the story with a mixture of sadness and pleasure. At first, she reported difficulty being comfortable around Pete, but soon they were both back full swing at school and busy planning for graduation. By Christmas everything seemed back to normal. The two of them were still engaging in sexual intercourse, but only sporadically using condoms. Gail told me that Pete was being "careful". There were no further pregnancy scares. Pierre, who had written to her a couple of times, eventually stopped keeping in touch. Graduation came and went. Gail looked happy and beautiful. Her weight held up well during final exams. Her parents were proud of her. She and they looked very much the part of the "folks next door". Pete got accepted into a prestigious U.S. football college. The future looked bright and Gail's eating problem was history. I saw Gail intermittently over the next year. Things seemed to be going well for her and she and Pete seemed to be coping with their forced separation by commuting to see each other on long weekends. By this time she was on the Pill and her parents knew that she and Pete were sexually involved. Everyone seemed comfortable with that knowledge. That's when the bombshell burst. Pete was found (in a routine screen at his college) to be HIV positive. Gail was shattered. She called me in panic. She knew that she should be tested for HIV and wanted it done immediately. I asked her to come in and talk before we set anything up. It was really tough for her to accept that Pete could have given her HIV. After all they had been faithful to each other and she knew he didn't do I.V. drugs. We spent a lot of time talking about her trust in him and his strong denials that he had "done anything". I did point out that they had often had sex without using condoms. It was sad to see her trust in Pete so badly shaken. She was in despair but also angry. I arranged for the HIV testing and made an appointment for Gail to come in when the results were back. She too was HIV positive. I told her that we would have to go over her own history to check for other sources of infection or individuals that she might have shared a needle with. She vehemently denied any other source but Pete. She resented by implication that she might have been unfaithful or that she could be the source of Pete's HIV. It was then that she remembered Pierre and that night in Paris. The end to this story has yet to be written. Pierre proved to be HIV positive and had given a history of I.V. drug use and needle sharing. It is hard to think of how Gail had struggled to overcome her eating disorder only to be felled by the silent menace within seemingly innocent behavior that is but a normal part of adolescent experimentation and development. Gail and Pete rarely see each other. Their respective families are just shattered. It will be interesting to see how ordinary girls like Gail will cope with the tide of AIDS that has begun to sweep through the typical "family next door." No doubt Gail and her family will adjust better than I would predict. Working with adolescents is a humbling experience.

Roger Tonkin is head of the division of adolescent health, department of pediatrics, UBC.

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*Teens or parents with questions about AIDS can call the **AIDS Infoline at 345-SAFE**.*

*If you have any concerns about or are affected by HIV/AIDS, call Glenna, our **Support Services** Coordinator, at **345-1516**. Individual & family counselling is available.*

Three cheers for volunteers!

From October 1 to December 31, the volunteers at the AIDS Committee of Thunder Bay put in **1189 hours!** This was done by **126 volunteers.** That's equivalent to having a paid staff person doing over a half year's work! 29.73 weeks to be exact.

Thank you!

To David Hoe from the AIDS Committee of Ottawa and to Clarence Crossman of the AIDS Committee of London - thank you for being so generous with your wisdom. - *Michael*

Thank you to the generous people from our community who donated the fridge and stove.

Thank you to the Music Department at Lakehead University for the use of their music room to hold our Volunteer Orientations.

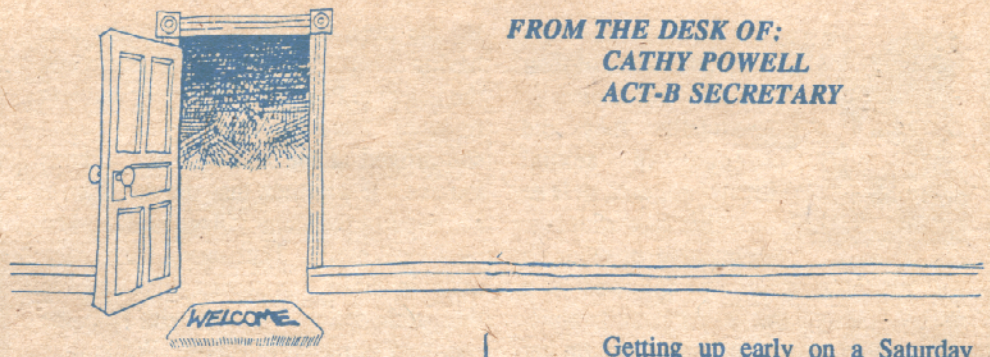
The Quilt

A Quilt Committee has been started, with two goals:

1. To bring the Canadian Quilt to Thunder Bay.

2. To produce Quilt panel(s) to commemorate people we have lost to AIDS.

For more information contact David Belrose, Education Coordinator at 345-1516.



If a friend of mine gave a feast, and did not invite me to it, I should not mind a bit.

But if a friend of mine had a sorrow and refused to allow me to share it, I should feel most bitterly.

If he shuts the door of the house of mourning against me, I would move back again and again to beg to be admitted so that I might share in what I was entitled to share.

If he thought me unworthy, unfit to weep with him, I should feel it as the most poignant humiliation.

- Oscar Wilde

Submitted by Susan Ivany, from a pamphlet produced by the AIDS Committee of Toronto

FROM THE DESK OF:
CATHY POWELL
ACT-B SECRETARY

Getting up early on a Saturday morning isn't my most favourite thing to do on a weekend, but this particular morning was well worth it, I must admit. A few cups of coffee and a muffin was just what I needed when I got to the Volunteer Orientation.

Sheila Berry, our Volunteer Coordinator started the morning off with a warm welcome and introduction. Dr. Fred Ball gave the group a biological overview which I might add was a refresher for me since my first orientation over two years ago. Dr. Ball sure knows what he is talking about.

We then had a catered lunch which included homemade soup and sandwiches. It was delicious.

After lunch, David Belrose, our Education Coordinator gave us quite an enlightening safer sex demonstration which included a few giggles here and there. He then briefed the participants on what the AIDS Committee of Thunder Bay does and what role ACT-B plays within the Community.

Once we got the picture of how ACT-B worked we had to put our memory to work for a Bingo Quiz. The quiz was both fun and interesting.

After a short break, Ron Rogers spoke on how HIV/AIDS has affected his life. Personally, this part of the orientation was the most moving segment of the whole day. After Ron talked for about an hour about his personal experiences, I must admit that Ron brought a few tears to my eyes. As I looked around the room I realized that I was not the only one who was emotionally drained. All I kept saying to myself was how much courage Ron had to get up in front of group of total strangers and spill his heart out. During Ron's presentation, I also noticed that there wasn't that usual fidgeting that sometimes occurs when people are speaking. Nobody was moving, whispering or doodling. All eyes and ears were directly glued to Ron. How he must have felt. His attitude was so

continued on page 10

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Telephone (807) 345-1516 or Fax (807) 345-6994

positive and after he had finished his presentation, it left me with the feeling that "I think I have problems". I would want my problems any day over Ron's problems. Thanks Ron for making me see myself in a totally different perspective.

Sheila wrapped up the day giving the participants an overview on the significance of volunteering and how important it is when someone makes a commitment to volunteer. As an active volunteer, I have found that people really do start to rely on you and isn't that what we all desire; to be wanted and needed? As a staff person, it gave me a real nice feeling to see all these new volunteers giving up their Saturday to come and see what the AIDS Committee of Thunder Bay was all about. Way to go Sheila, volunteering and working with you make it all worthwhile!!!

Q. What do you do with 365 used condoms?
A. Make them into a tire and call it a Good Year!!

Collectomaniacs . . .

ACT-B collects newspaper clippings, magazine articles, books, novelties . . . anything that relates to AIDS/HIV - Safe Sex, IV Drug Use, Palliative Care, etc . . . Just drop them off at our office at 285 Bay Street. You can also look at all the information we have on file in our library.

AIDS Awareness Week is coming soon!

October is soon?
AAW has grown to involve so many organizations, that our planning starts in January!

If you or your organization would like to join the AIDS Awareness Week Steering Committee, contact David Belrose, Education Coordinator at 345-1516.

***Kinna-aweya,* continued from page 3**

4. **Canada Pension Plan Disability Pensions** -If you are unable to work because of a physical or mental disability you may be able to get a disability pension through the Canada Pension Plan. You do not need to be over 60 years of age to get a disability pension and if you are refused this benefit, you have a right to an appeal. You are entitled to this benefit if you have made contributions to the CPP Plan, if your disability makes you unable to work regularly in a job that lets you support yourself, if your disability is likely to last a long time or if your disability is likely to cause death. This application should be made as soon as you are aware of your disability because if you wait too long after you have stopped work, you could lose your right to the CPP disability pension. Again, if the pension is denied or if you have any questions, you should obtain legal advice.

5. If you are unable to work and are a "person in need" in the province of Ontario you may well be entitled to benefits under the **General Welfare Assistance Act** or the **Family Benefits Act**. These benefits are what is called "needs tested" which means they will do a review of your financial situation to decide if you qualify for the benefits. This will include adding up your income from other sources and reviewing your assets to see if you qualify. Even if you are already receiving benefits from any one of the other programs you might be entitled to some "topping up" of your income through one of these programs. If you are presently receiving benefits under the **General Welfare Assistance Act** speak to your social worker about your entitlement to benefits under the **Family Benefits Act** as a disabled person because those benefits are paid at a higher rate. Again, if you have any problem at all with benefits under either of these Acts, you should obtain legal advice and consider your right to appeal.

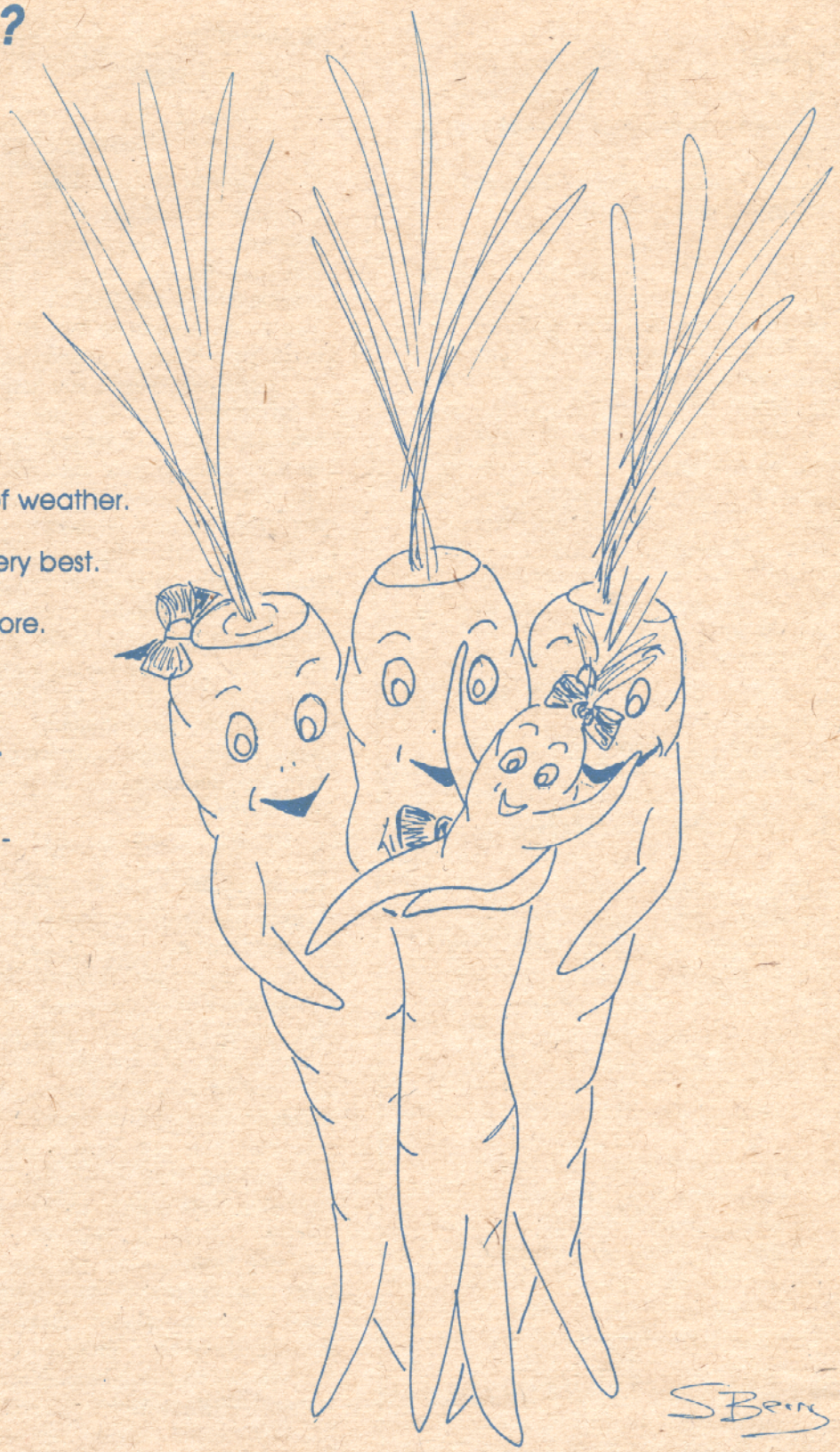
Other financial implications of a disability relate to the disability benefit under the **Income Tax Act** and any disability benefit connected with any loans or mortgages. You should check with any financial institution where you have a loan and see if you still need to make payments on that loan while you are disabled. Also, be aware there is a "non-refundable tax credit" which can be applied to your income tax calculations to reduce the amount of tax you have to pay. Some benefits such as CPP are taxable while others such as FBA are not. The disability amount during the taxation year 1990 was $3,327.00 and in order to claim this amount you must obtain a form from Revenue Canada and have your doctor complete the form and sign it.

With any of the above-mentioned benefits, if you have any problems, you should obtain clear legal advice. Concerning workers' compensation matters, you can obtain advice from the Office of the Worker Adviser and concerning all of the other matters, you can obtain advice either by contacting your local community legal aid clinic at the following address: Kinna-aweya Legal Clinic, 233 Van Norman Street, Thunder Bay, Ontario, P7A 4B6, telephone: 344-2478 or arrange for an interview with a private lawyer for one-half hour without charge through the Lawyer Referral Service. That service is accessed by phoning 1-800-668-8526 which will connect you with an office in Toronto where all of the lawyers in Ontario who participate in this program are registered. Simply advise that office that you are in Thunder Bay and wish to speak to a lawyer and then identify the issue and they will refer you to a lawyer in Thunder Bay who will review the matter with you and provide clear legal advice without charge.

I think we are all aware of how dramatically stress and anxiety can influence our physical and mental well-being. Any one who is experiencing and dealing with a disability or an illness needs as much help as possible to relieve all unnecessary stresses and anxieties. Certainly a person's financial situation can be an enormous source of stress and worry and knowing what benefits you may be entitled to can be very important in alleviating anxiety. Please remember there are individuals and agencies prepared to extend whatever assistance is possible and do not hesitate to ask for that assistance.

What are volunteers?

Volunteers are like Ford -
They have better ideas.
Volunteers are like Coke -
They're the real thing.
Volunteers are like Bell Canada -
They're answering your call.
Volunteers are like Midas Mufflers -
Nobody tops them.
Volunteers are like PanAm -
They make the going great.
Volunteers are like Dial soap -
They care more.
Volunteers are like VO5 hairspray -
Their goodness holds in all kinds of weather.
Volunteers are like Hallmark Cards -
They care enough to give their very best.
Volunteers are like Standard Oil -
You expect more and you get more.
Volunteers are like Benetton -
They work United together.
Volunteers are like Robin's Donuts -
They're the best part of your day.
Volunteers are like Thunder Bay -
They've got a giant heart.
Volunteers are like Thunder Bay Cellular -
They're wherever you go.
But most of all . . .
Volunteers are like Frosted Flakes -
They're GRRRREAT!



ACT-B volunteers are over 100 strong!

They do everything from Support Services, to planning, to stuffing envelopes, answering the phone, fundraising at BINGO, photography, writing, designing, typing . . . whew! the list is just too long to write.

If you'd like to join, contact Sheila, our Volunteer Coordinator at **345-1516**. Training is provided.

Thanks a Bunch!