

# THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SPRING/SUMMER 2005

VOLUME 7 ISSUE 1

## ABOVE AVERAGE

**Joe Average** on the art of life



TRIAL BLAZER

DOWN BY THE LIVER

WE CAN WORK IT OUT

PHARM ASSISTS



Canadian AIDS Treatment Information Exchange  
Réseau canadien d'info-traitements sida

### PUBLICATIONS

**Bloodlines**, a quarterly magazine by the Vancouver Red Road HIV/AIDS Network, is a vibrant publication by and for Aboriginal people living with HIV/AIDS that's packed with personal stories, treatment tips and regional resources. The most recent issue (#3) centres on the needs of Aboriginal women. Go to [www.red-road.org](http://www.red-road.org) for *Bloodlines* in PDF format (click on "Documents").



For print copies, contact the Vancouver Red Road HIV/AIDS Network: 604.913.3332, 1.866.913.3332 (toll-free)

The 3rd edition of BCPWA's **Positive Living Manual** is now available. Learn how to live well with HIV—from dealing with your diagnosis to making complex treatment decisions to healthy eating. A soft-cover booklet is available for free to BCPWA members, all PHAs in B.C., and B.C. health care professionals and ASOs for their clients. People elsewhere in Canada can get it for \$10 per copy. A hard-cover tabbed binder edition helps health professionals, front-line workers and ASOs better care for their clients. Click on [www.bcpwa.org/pubs\\_livingmanual.php](http://www.bcpwa.org/pubs_livingmanual.php) for the manual in PDF format.

For print copies, contact BCPWA: 604.893.2250, 1.800.994.2437 (toll-free in BC only), [manual@bcpwa.org](mailto:manual@bcpwa.org)

The Quebec government has published a timely guide called **Lipodystrophy: Information for people living with HIV**, revised by the *Comité consultative pour la prise en charge clinique des personnes vivant avec le VIH-SIDA* in collaboration with COCQ-Sida and CPAVIH. The guide leads readers through an understanding of the symptoms of lipo and discusses potential causes and interventions for treating this syndrome. A more detailed document is available in print for health care professionals. Go to [www.msss.gouv.qc.ca/en/documentation/publications.html](http://www.msss.gouv.qc.ca/en/documentation/publications.html) for the guide in PDF format.

For print copies, fax 418.644.4574 or e-mail [communications@msss.gouv.qc.ca](mailto:communications@msss.gouv.qc.ca)

**Life Goes On: Pregnancy and HIV**, a plain language, no-nonsense booklet from Voices of Positive Women, empowers HIV positive women to learn about all of their options in pregnancy—from deciding to get pregnant, to treatment options during pregnancy, right up to care considerations for the newborn and mother. Go to [www.vopw.org](http://www.vopw.org) (click on "Info & Links") for the booklet in PDF format.

For print copies or more info, contact Claudia Medina: 416.324.8703 (ext. 25), 1.800.263.0961 (toll-free in Ontario only), [cmedina@vopw.org](mailto:cmedina@vopw.org)

### DRUG ACCESS

**Disponibilité des médicaments anti-VIH au Québec 2005**—CPAVIH has produced handy charts (in French only) showing exactly which antiretrovirals are available on the provincial

formulary—and which are not. The charts also show which meds are available in the United States but have not yet been approved for use in Canada.

[http://cpavih.qc.ca/cpavih-new/inf\\_nouvelles/dispo/](http://cpavih.qc.ca/cpavih-new/inf_nouvelles/dispo/)

### Reimbursement status of HIV medications in Ontario—

The Immunodeficiency Clinic at the Toronto General Hospital provides a chart of how to obtain antiretrovirals in Ontario. With a useful breakdown of which provincial program to use to access each specific HIV med, the chart also lists the accessibility of other drugs (such as antifungals, appetite stimulants, etc.) used to treat aspects of HIV infection. Although it's geared to health care professionals, PHAs can use the chart to find out about the practicalities of obtaining meds.

[www.tthivclinic.com/pdf/reimb\\_stat\\_ONTARIO.pdf](http://www.tthivclinic.com/pdf/reimb_stat_ONTARIO.pdf)

**Note:** CATIE has all the provincial formularies, so feel free to call us toll-free at 1.800.263.1638 to find out which meds are covered in your province.

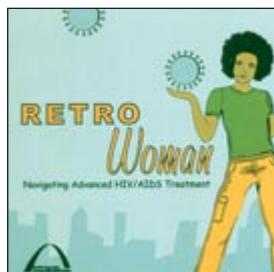
### FACT SHEETS IN DIFFERENT LANGUAGES

**Africans in Partnership Against AIDS (APAA)** has teamed up with CATIE to provide fact sheets on 30 treatment topics for African communities. So far the fact sheets are available in Swahili, English and French, with Hausa soon to be added. Check them out at [languages.catie.ca/African](http://languages.catie.ca/African).

Thanks to **Asian Community AIDS Services (ACAS)**, this treatment info is also available in Tagalog, Vietnamese and traditional and simplified Chinese at [www.acas.org/treatment](http://www.acas.org/treatment).

### CD-ROM

**Retro Woman: Navigating advanced treatment information for women.** Produced by BCPWA in partnership with the Positive Women's Network, this interactive CD-ROM is useful for HIV



positive women and their health care providers. Learn about treatment options and self-care in a fun and easy-to-follow way, with fact sheets, slide lectures (which have a voiceover option) and a resource list. Good for all literacy levels.

For a free copy, contact BCPWA: 604.893.2244, [retrowoman@bcpwa.org](mailto:retrowoman@bcpwa.org)

### EDUCATIONAL CONFERENCE

**CATIE's Annual General Meeting and Educational Conference** will take place this year in Ottawa on June 20 and 21. Don't miss this great opportunity to learn about what's new in HIV treatments and to network with PHAs. Once again, our event will follow the PHA Forum and Annual General Meeting of the Canadian AIDS Society. If you are interested in attending, conference scholarship applications are available.

For more info, visit [www.catie.ca](http://www.catie.ca) or call CATIE toll-free at 1.800.263.1638.

—Compiled by Susan Massarella

## EDITOR'S LETTER

Vancouver artist Joe Average—who graces our cover along with a painting from his “Palm Tree Study” series—said something during our interview that stuck with me: “HIV saved my life in that I decided to make art my life.” (He painted the Palm Tree series when he desperately needed a vacation but wasn’t well enough and couldn’t afford to get away.) Facing his own mortality provoked Joe to spend his time doing “something I like”—so he took a risk, picked up his paintbrush and turned a hobby into his livelihood.

The rest is history. Today, Joe’s art—with its bold, graphic lines and vibrant, playful imagery—is instantly recognizable to his fellow Canadians as well as to people all over the world, many of whom first caught a glimpse of his talent at the 1996 International AIDS Conference in Vancouver. Joe created the image for the conference logo, which put him on the map. He’s won numerous awards and his work has been compared to that of the late Keith Haring, the famous American pop artist who also had HIV.

But Joe hasn’t painted in five years. Managing his health, he said, has become a full-time job and there’s no time or space in his life to produce art. His health has become his most challenging masterpiece to date.

Although HIV inspired Joe to make art his life, it’s now forced him to make his life his art. And there’s something very profound in that for each of us. Though HIV disease is largely about labs, numbers and science, managing your life with HIV disease is, ultimately, an art unto itself.

With *The Positive Side*, we hope to provide you with some tools for creating your very own masterpiece. In this issue: Dietitian Doug Cook serves up nutrition tips for insulin resistance. Physiotherapist Kelly O’Brien flexes the benefits of exercise. Greg Robinson puts his liver on the line. Also, read about what your pharmacist can do for you and get the scoop on clinical trials.

As always, we’d love to hear from you, so don’t be shy. Pick up your pen (or paintbrush) and drop us a line, or e-mail us at [info@catie.ca](mailto:info@catie.ca).

—RonniLyn Pustil

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## THE POSITIVE SIDE

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several treatment options that are all medically sound,” says Cara Hills of the Northern Alberta HIV Program. “The final decision often depends on practicalities, such as whether there are food restrictions. As a pharmacist, I’m often able to spend a lot more time on those issues than a specialist can. People can then go back to their doctors with a much clearer sense of their preferences.”



## 2 Easy-access treatment information.

Your pharmacist is probably your best bet for info and tips on meds management. Jeff Kapler, an HIV specialty pharmacist in Calgary, says specialty pharmacists can “help by teaching people about meds and treatment options—and we’re very accessible.” Kathryn Slayter, clinical pharmacist specialist at Queen Elizabeth II Health Sciences Centre in Halifax, seconds that notion. “People can call me any time. We don’t say, ‘Here are your pills, see you later’—we chat about how to work your pills into a busy day, or whatever it is people need.” When your doc’s day is booked, your pharmacist can be the most accessible part of your health care team. “We always give people private, one-on-one time where they can discuss anything regarding medication,” says Linda Akagi of St. Paul’s Hospital Outpatient Pharmacy in Vancouver. And quick questions can often get answered right away.



## 3 Advice on avoiding drug interactions.

Medications can affect each other, sometimes in a harmful way—“and that includes complementary and alternative medicine (CAM) as well as over-the-counter products,” Kathryn Slayter says. “My one rule with CAM is that it not interfere with HAART or add toxicity.” Your pharmacist is your best bet for checking up on interactions—stay on the lookout by letting them know *everything* you take. Also, sticking with a single pharmacist keeps it all under one roof, where it’s easier to flag potential problems.

# The Pharmacist List

## 7 reasons to get to know the person behind the counter

BY DEREK THACZUK

AT THE VILLAGE PHARMACY on Toronto’s Church Street, pharmacist/owner Zahid Somani was busy with a customer. I waited patiently—customers first, journalists second! This particular young woman had dropped in to ask about the safety of an herbal supplement she was considering. “It’s good you asked,” Somani told her, because, he said, supplements can sometimes interact with medications. After checking her meds lineup, Somani assured the woman that it should be fine. But, he said, “If you start taking larger dosages of the supplement, come back and let me double-check.”

This was just the sort of thing I’d come to interview Somani about: Should every pharmacist know about drug/herbal interactions? While it makes for more information to keep on top of, Somani says it’s just part of his

job: “Pharmacy is not just lick ‘n’ stick the labels, count ‘n’ pour the pills. It’s about the patients, not the pills.”

After speaking with Somani and four other pharmacists who also specialize in HIV care, my suspicions were confirmed: Pharmacists are the unsung heroes of HIV care—a valuable and often-untapped resource for people with HIV/AIDS (PHAs).

Here are seven sorts of good pharma dharma you can get from that professional behind the counter:



## 1 Help choosing a drug combination.

When starting or switching highly active antiretroviral therapy (HAART), it’s tough to narrow down all the options. While the final choice is up to you and your doctor, pharmacists are ready and willing to pitch in. “There may be



#### Tips on how to deal with side effects.

Pharmacists often have useful tips for avoiding or managing side effects. “Some people are lucky and hardly skip a beat when they start new meds,” Jeff Kapler says. “Others may have mild or serious adverse effects.” Pharmacists can often suggest solutions, such as over-the-counter remedies or supplements. “If we can’t resolve the problems,” Kapler says, “we work with the physician and patient to pick alternate medications.”

Pharmacists can also shed some perspective on the appalling lists of “possible” side effects of medications. “When people look at all the listed side effects and say, ‘Oh my God,’ we can allay some of those fears by talking with them,” Kapler says. “By drawing on our experience with our other patients, we can give people that real-life perspective.”



#### Adherence assistance.

Taking all your meds on time every day can be a tough pill to swallow. Everybody has challenges, whether it’s the demands of a busy schedule, drug or alcohol use, or just trouble remembering. Pharmacists can help brainstorm creative ways to deal with demanding drug timetables. One of Somani’s patients had a very complex regimen—13 different drugs for HIV, heart disease and neuropathy. He found it too difficult to manage and keep track of them all. That’s where Somani stepped in: “I offered him a Dosesettes program, where we prepackaged all his meds in a weekly pill box, divided and labeled by day and time. That worked extremely well for him—it took out the guesswork and gave him time to do things besides worrying about when to take his meds.”

Adherence also has to do with attitude. “Some people dislike taking meds because it’s a constant reminder that they’re sick,” Jeff Kapler says. “I try to make them feel more positive—that taking their meds is a way to take control of their disease. I think people feel better when they’re empowered.”

Studies have shown that PHAs who work closely with their pharmacist stand a better chance of meeting adherence goals and, therefore, successful therapy. A study published in *AIDS Care* (May 2004) showed that patients were much more likely to take all their meds when they used a clinic pharmacy that offered personal support. “This study demonstrates the positive impact of the pharmacist in patient care,” says study co-investigator Linda Akagi. “It showed that patients with a higher level of involvement with a pharmacist were more likely to be adherent to their meds and keep their HIV suppressed.” In fact, the well-supported patients were 1.5 times more likely to maintain an undetectable viral load than those “off-site.” (For more on adherence, see “The Importance of Being Adherent,” *The Positive Side*, fall/winter 2004.)



#### Coverage costs.

Meds don’t come cheap, and coverage plans can leave a lot uncovered. “I often see patients for whom the high cost of meds is a barrier to their treatment,” Somani says. “I always try to find ways to work around financial constraints to get people the drugs they need.” Even if sometimes that means braving a tangle of red tape.



#### Advocating for your needs.

We PHAs don’t always see the snarl of rules and regulations that makes it hard to get the drugs we need, though we may be all-too-painfully aware of the end result when a prescription can’t be filled. Pharmacists who know the consequences of missed doses may be willing to become bulldogs, tackling red tape on their patients’ behalf. “We’ve handled negotiations with insurance companies where there have been questions about coverage,” Linda Akagi says. “When [PCP-fighting drug] Dapsone was withdrawn from the Canadian market [for marketing reasons], the whole process of getting it became a huge hassle. We explained the problems to a provincial committee that agreed to cover it, but they might not have known how bad the situation was if [pharmacists] hadn’t laid it out for them.” +

Derek Thaczuk has worked and volunteered within the HIV community for 10 years. His obsessions include health literacy, making research and information accessible, and penguins. He is now a self-employed medical writer and consultant whose website is at [www.readablewriting.ca](http://www.readablewriting.ca).

## PHA Prescription

When asked, “What could your patients do to get the most out of you?” our friendly pharmacists filled out the following ‘script:

- **Demand the best.** “If possible, pick a pharmacy that specializes in HIV that has a full-time pharmacist you can get to know,” Zahid Somani says. Ask your doc or ASO for suggestions.
- **Don’t wait until zero hour.** It may not be possible to arrange a refill right away. Call while you’ve got at least a few days of meds left.
- **Ask questions.** “We don’t judge people’s life situations, so if you have questions about anything related to your health, go ahead and ask!” Jeff Kapler says. “If you have all the information, you can make better decisions.”
- **Brown-bag it.** Every so often, bring in all your pills and bottles—including supplements and over-the-counter drugs—so your pharmacist can double-check for interactions. It’s good to do this whenever your meds change.
- **Be honest.** “I don’t want people to feel they have to lie about their adherence for fear of getting scolded,” Kathryn Slayter says. If circumstances have made it tough to take your pills, say so—between you and your pharmacist, you may come up with a solution you hadn’t thought of on your own.
- **Plan ahead if you’re moving,** especially between provinces. Linda Akagi says that people are often surprised to find that coverage varies between provinces—and that it may take months before coverage kicks in. If the grass looks greener elsewhere, check into drug plans to ensure continuous coverage. (Call CATIE at 1.800.263.1638 for info on provincial coverage plans.)

## What is the *one thing* you just can't live without as a person with HIV/AIDS?



“My **ART CLASSES** immediately come to mind. In 1994, I saw an ad for the Art Gallery of Ontario’s drawing classes entitled, ‘Drawing for the Absolute and Terrified Beginner.’ I absolutely hated art in school and decided to put the gallery to the test. In retrospect, perhaps this was a metaphor for the virus—what I could not control in my body I could achieve with my mind . . . anything to regain some sense of control.

“I did two sessions of beginner drawing until my teacher insisted that I was ready to ‘graduate’ to painting . . . and I love it! It is the only pastime/hobby I’ve ever stuck with. Painting is relaxing to the point that it sometimes becomes spiritual. I do it for myself and myself alone. What I feel helps this process is having teachers who totally support everything you produce. You can be dissatisfied but they always find positive aspects of the work. Maybe in life we need to surround ourselves with these types of individuals, too.

“Life is tough enough without adding the stress of health issues while trying to run a household and raise a family. It’s a constant challenge to keep from sliding into the abyss of depression. Though I tend to become quite depressed in the winter, I won’t miss my Friday morning class—it gets me out of the house and my teacher’s studio is a large, airy loft with lots of light. The creative and supportive atmosphere allows me the freedom to completely relax physically and mentally and enjoy the process without distractions or fear. Those times when my concentration is so focused are absolutely exhilarating—it almost feels like an out-of-body experience, like the paint brush is moving on its

own. Perhaps trying to recapture the sense of peace and tranquility you feel when you’re so focused is the ultimate appeal, while the painting itself becomes the means to the end.”

● **Marlene Freise, 58, Toronto**

“AIDS service organizations, out of necessity, concentrate on supporting people who lack family or societal support. I have a job I like that pays well and I have savings. As an educated male with resources, I feel left to myself in many ways. The magazine **LIVING +**, published by the B.C. Persons With AIDS Society (BCPWA), is the most important support I get as a positive person. I love its depth and diversity, and I love that it speaks to an educated audience. I would be lost without it. I learn from it and teach my doctor, peers and friends about things I learn from it. My brain is my most important resource for living and coping with HIV, and nothing feeds it like *Living +*.”

● **Chris Tyrell, 57, Vancouver**

“The one thing I’d say is most important to me in living with HIV is **SOMEONE TO LOVE**. That can include family and friends but especially a partner—someone to come home to, a warm body to snuggle up to in bed; someone who will put up with me in sickness and in health, in good moods or when I am a crabby little shit. Oh yeah, the sex helps as well. I feel a bit uncomfortable putting this at the top of my list because so many people don’t have it and can’t get it for various reasons, but for me it’s the one thing I would find it hard to live without. Fortunately, I have such a person in my life.”

● **Evan Collins, 47, Toronto**

“Having **REGULAR BOWEL MOVEMENTS** is the one thing I can’t live without.

Once or twice a day, long, well-formed, easy-to-pass stools are not only a sign of good digestion, but also feel good—kind of like mini orgasms.”

● **Susan Cohen-Becker, 47, Halifax**

“**ENSURE** helps stimulate my appetite and reduce early morning nausea and fatigue. It’s a complete meal replacement that is lactose free, so anyone can drink it. Each can of Ensure contains 250 calories. There is a variety of flavours (my favourite is Wildberry and then Strawberry, best poured slowly over ice and guzzled), and although they’re artificial they taste good. I’ve been drinking Ensure for years, and I know what works, having fought this battle for 20 years.”

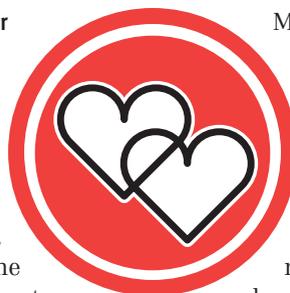
● **Jeremiah Douglas, 44, Calgary**

“What I’ve found I cannot live without as a person living with HIV/AIDS is my **FAITH IN GOD**. (I am not a ‘raving fundamentalist’—quite the opposite!)

My diagnosis forced me to do some serious self-assessment (soul-searching), including examining my spirituality. What I discovered in these past eight years was that while HIV may ostracize me from many segments of society, it has not separated me from my creator/sustainer. She, in fact, lovingly welcomes me.

“This sense of being loved, ultimately and unconditionally, impacts every aspect of my life with HIV. Because of it I am better able to cope with the rigours of treatment. It gives me hope to be able to get up and go to work every day and share the skills and experience I’ve acquired. It drives me to be a more ‘healthy’ person who happens to have a severely compromised immune system.

“Do I think I will one day live HIV-free or ‘cured’? Only if medical science



makes a breakthrough and achieves it. I don't believe in miracles—beyond the miracle of life itself. Life is bigger and more powerful than HIV. I feel that even as HIV invades the cells of my body, I live in a bubble of divine love that is unassailable.”

● **Ren Bowman, 52, Belleville**

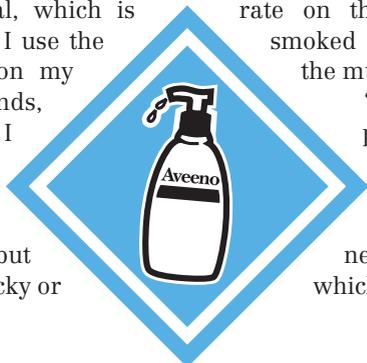
“The thing that I can't live without is, simply, **LIFE**. With all of its wonder and complexities, seeing the sunrise or a perfect snowflake helps me understand that there's so much more to living than existing. Appreciating things like a raging thunderstorm or the gentle trickle of rain brings me out of whatever pain or suffering I'm feeling and helps me understand that there is something bigger out there that needs to be appreciated for the beauty that it is.

“I find this beauty even on the days that start out to be the worst. When everything is going wrong in my life and it takes everything I have just to get myself off the couch, a sunbeam will come in the window and warm me when I'm cold or someone will land on my doorstep unexpectedly just to say hello.

“Moment by moment, life goes by and I am constantly reminded that I can choose to let it go by and act as though I am already six feet under—or I can choose to live it. On days that are physically the best, I maximize every drop of living I can get in. I'll try something I've never tried before or do something I haven't done in a long time. For me, it's not about living longer, it's about living better.”

● **Quinn X. Wade, 33, Edmonton**

“The product I couldn't live without is **Aveeno**—the lotion and body wash—because my skin is always dry. It's made out of oatmeal, which is soothing to the skin. I use the lotion all the time on my face, body and hands, but especially when I come in from the cold or after a shower. I've tried other lotions before, but I found them to be sticky or



oily. Aveeno works right away and stops the itchiness.”

● **Jaime Wagner, 34, west coast of Newfoundland**

“**YOGA** has given me a new way to look at my life. It has taught me to surrender my fear of being upside-down and on the edge of control and to just go with it. It's given me the confidence to get on with my life and try new things.”

● **Ron Rosenes, 57, Toronto**

“I smoke **MARIJUANA** almost every day, about two grams per month, for the following reasons: peripheral neuropathy, appetite, relaxation, relief and pleasure. And not necessarily in that order—it depends on my mood.

“Peripheral neuropathy: I took Videx (ddI) during my first antiretroviral treatment. Not having been informed beforehand about the possible side effects, I took it for too long before making the connection between the medication and problems with swelling and severe pins and needles in my feet. Consequently, I've possibly developed permanent damage. This, however, has improved markedly since changes were made in my medication and I started taking the complementary products L-carnitine and co-enzyme Q<sub>10</sub>. During the most intense period of peripheral neuropathy, pot helped to manage the pain in a very effective way.

“Appetite: HIV and/or its treatment both have an indisputable effect on my appetite. Wishing to stay in shape and remaining attractive are also part of this. Taking a small puff every day helps increase my appetite in the evening. I don't think I have to elaborate on this—anyone who's ever smoked marijuana knows about the munchies.

“Relaxation, relief and/or pleasure: The euphoric state brought about by the use of marijuana allows the muscles and nervous system to relax, which in turn helps relieve



peripheral pain as well as arouse the senses, including taste (appetite) and touch (making love). After all, there's no harm in treating oneself kindly.

“Access to quality therapeutic marijuana should be a top priority in helping to improve the quality of life of PHAS. Well-managed marijuana use can only be beneficial to PHAS, who must at times deal with hard-to-tolerate side effects. In any case, it works for me!”

● **Luc Gagnon, 40, Montreal**

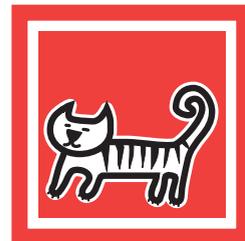
“Repeated trips to the toilet were tiresome and draining while I suffered with chronic diarrhea due to the very drugs that were keeping me alive and relatively healthy. I followed different diets, avoided certain foods, took calcium supplements and tried numerous over-the-counter and prescription drugs in my efforts to ease my churning bowels and burning butt. I'd forgotten what it felt like to have a good bowel movement, to pass a well-formed stool. Unless you've had chronic diarrhea, you wouldn't fully appreciate this comment and might even cringe at the very thought.

“Thanks to daily supplements of **L-GLUTAMINE**, 5 mg twice a day, in a smoothie or fruit juice, no longer do I dash to the bathroom, cheeks clenched, numerous times throughout the day. No more anxiety because I didn't know where the nearest washroom is, no more embarrassing accidents. I am once again enjoying the regular pleasure of a healthy, well-formed bowel movement. L-glutamine is a product I would not want to live without.”

● **Michael Connidis, 50, Vancouver**

“My anchor is **MY CATS**, Shinshu and Xena. They are as close as family to me. They offer love and friendship, asking for nothing but basic life support. I pamper and spoil them outrageously, but we all enjoy it.”

● **Alexander Peters, 60, Ottawa**





# La Dolce Vita

The sweet and lowdown on blood glucose levels **BY DOUG COOK**

**A**s a dietitian in a medical clinic that serves many people with HIV/AIDS (PHAs), I get a lot of referrals for insulin resistance—a metabolic complication associated with HIV disease and its treatment. In fact, close to 50% of my referrals are for insulin resistance, among other metabolic disorders. Understanding metabolic disorders is important for PHAs because these complications may have a negative impact on quality of life, interfere with adherence to antiretroviral therapy and exacerbate long-term health problems.

### THE GOODS ON GLUCOSE

The body requires sugar, or glucose, to provide energy for all of its functions. Glucose is one fuel that your body cannot do without. The glucose that enters your blood comes mainly from the digestion of carbohydrates in foods such as fruits, vegetables, bread, cereal, pasta, rice, milk and other dairy products. Normally, the hormone insulin helps glucose enter your cells, providing food energy.

Insulin resistance is a condition in which the body's cells do not respond properly to the hormone and cannot take up glucose, which then builds up in the bloodstream. The pancreas, which produces insulin, responds by producing extra insulin to help move the glucose into the cell. If the body cannot produce enough insulin or the cells do not respond to it efficiently, the result is hyperglycemia, or high blood sugar. Ultimately, this can lead to diabetes mellitus (type 2), a con-

dition characterized by persistent hyperglycemia.

### KEEP YOUR EYES ON PIS

Before highly active antiretroviral therapy (HAART) became available, glucose abnormalities were uncommon among PHAs. But, ever since the introduction of protease inhibitors (Pis), insulin resistance and hyperglycemia continue to be reported in people on PI-containing drug regimens (the nucleoside analogue d4T is also emerging as a problem). It is estimated that some degree of insulin resistance affects about one half of people taking Pis.

Given that some degree of insulin resistance may occur when taking Pis,

the goal is to manage any blood glucose abnormalities that may develop while reducing your risk of diabetes. In many cases, blood glucose problems can be managed by lifestyle changes and diet modifications. Sometimes your doctor may switch your antiretrovirals and/or prescribe antidiabetic drugs to control blood glucose levels.

### WEIGHING IN

Maintaining a healthy weight (and losing weight if necessary) is recommended to help prevent or manage insulin resistance. Having excess abdominal fat and a large waist is considered a risk factor for developing insulin resistance. A waist circumference greater than 102 cm (40 inches) for men and greater than 88 cm (34.5 inches) for women is considered high risk. The best way to lose or maintain your weight is with exercise and a healthy diet.

Exercise can help you lose weight by burning calories, but it also helps by clearing glucose from your blood without the help of insulin. Exercise also helps to maintain muscle, and muscle gives your body something to store the extra blood sugar in. A combination of cardio/aerobic and weight resistance training is best to help burn calories and build muscle. If carrying extra weight is not an issue for you, building muscle is still beneficial. (For more info on exercise, see "Let's Get Physical," page 18.)

### DO OR DIET

The Canadian Diabetes Association ([www.diabetes.ca](http://www.diabetes.ca)) recommends a diet that includes a balance of protein, fat and carbohydrate. The type of carbohydrate may be more important than the amount. Starchy carbs (such as 100% whole wheat/grain breads and products, rice, pasta, yams, corn and beans) and carbs from dairy foods (such as milk, cheese and yogurt) are digested more slowly and stimulate less insulin production, so it's better to choose these carbs more often. Limit carbs that are typically added to food for flavour (such as sugars and syrups) as well as sweetened beverages and baked goods made with refined flour.



ILLUSTRATIONS: BEVERLY DEUTSCH

# From Insulin Resistance to Type 2 Diabetes



Insulin resistance and diabetes develop over time, moving from normal insulin production and insulin use by the body to a point where insulin is no longer being made adequately or used properly.

## Normal:

- Your body makes enough insulin and uses it well.
- A fasting blood glucose test result would be 4.0–6.0 mmol.

## Impaired fasting glucose (IFG):

- Your body isn't using the insulin it produces well and insulin resistance is present, resulting in hyperglycemia, or high blood sugar.
- A fasting blood glucose test result would be slightly high at 6.1–6.9 mmol.

## Diabetes mellitus:

- There isn't enough insulin being made by your body and you can't use glucose for energy.
- This is determined by a fasting blood glucose test with a result 7.0 mmol or higher, or a glucose result over 11.1 mmol after an OGTT.
- Diabetes can also be diagnosed with any blood glucose level over 11.1 mmol, if accompanied by diabetes symptoms such as frequent urination, unexplained weight loss, fatigue, and increased hunger and thirst.

The following nutrition recommendations can help you optimize your efforts in preventing and managing insulin resistance and have been consistently shown to be your best defense.

## FIGURE OUT FATS

The quality of the fat in your diet can influence insulin resistance over the long term. Studies have shown a link between increased insulin resistance and a high intake of saturated and trans fats—while the healthier polyunsaturated, omega-3 and mono-unsaturated fats are associated with a lower risk of insulin resistance. Reduce saturated and trans fats by choosing lean meats, skinless chicken and low-fat dairy, and limiting baked, fried and breaded foods. Read food labels and try to limit foods with “hydrogenated” oils. Emphasize healthier, monounsaturated fats by using canola or olive oil in cooking and baking, and eating nuts and seeds and avocado. The best sources of omega-3 fats are found in ground flax, soy products and fish.

## FILL UP ON FIBRE

Dietary fibre has been shown to improve both insulin sensitivity and blood glucose levels. There are two types of fibre—insoluble and soluble—which occur together in foods. Both are important for health, but soluble fibre has been shown to slow down the digestion of carbohydrate in food and, therefore, the rate at which digested carbohydrate (glucose) enters the bloodstream. Less insulin is released and the result is a lower post-meal blood glucose level, which helps to lessen the amount of insulin required and will help to lower your risk of insulin resistance and progression to diabetes. Aim for 5–10 grams per day of soluble fibre from oat bran, psyllium, guar gum and pectin. (To help you reach this goal, look for the soluble fibre content on food labels. If you're getting at least 5 servings of fruits and veggies and more than 5 servings of 100% whole grain breads and products per day, you'll easily get 5 grams of soluble fibre.) Good food sources of soluble fibre are barley, prunes, Metamucil, cold cereals (Quaker Oat Squares, Quaker Corn Bran, Bran Buds with Psyllium, Kashi), ground flax seed, low-fat popcorn, oat bran, oatmeal, apples, oranges and many other fruits and veggies.

## DISH IT OUT

To help control the amount of glucose absorbed by the digestion of carbohydrate, it's important to manage the amount of carbohydrate you eat at each meal and distribute it evenly over the course of the day. Try to eat smaller, more frequent meals. Aim to have 3 meals and 2–3 snacks each day, eating a variety of foods, with 50% of your plate comprised of veggies, 25% starch/carbohydrate and 25% protein.

## SUPPLEMENTS

Population studies (in which large groups of people are followed to see what kinds of foods they're eating and whether or not they develop certain diseases) have found associations between certain nutrients in food and a lower risk of insulin resistance and

diabetes. Studies that have used supplements have not obtained the same results. This may be because the nutrients found in food work together, and simply supplementing with a vitamin or mineral on its own doesn't work in the same way. It's always best to get your nutrients from minimally processed whole foods.

## THE SWEET HEREAFTER

While the exact causes of insulin resistance are not known, making healthier lifestyle choices is still an important first step in preventing and managing this complication. For PHAS on HAART, regular blood glucose monitoring (every 3–4 months) as part of your blood work is important to detect any changes before they progress to a potentially worse condition. If left untreated, high blood sugar can lead to a wide range of long-term health problems, including kidney dysfunction, retina damage leading to blindness, nerve damage, erectile dysfunction and pregnancy complications. As well, chronic high blood sugar can contribute to blood vessel damage and cardiovascular disease, including heart attacks and stroke.

Diagnosing blood glucose abnormalities is usually done through the following tests:

- **fasting blood glucose**—blood sugar is measured after an 8-hour fast, with no food or beverages except water
- **oral glucose tolerance test (OGTT)**—blood sugar is measured after an 8-hour fast, then you drink a sugar solution and blood sugar is measured every 30 minutes for two hours to see if blood glucose levels rise and fall normally

By working with your health care providers and linking up with support resources for diet and exercise, you can take control in preventing and managing the development of long-term insulin-related complications. +

Doug Cook, RD MHS CDE, is a clinical dietitian working in a university teaching hospital in Toronto and as a freelance nutrition consultant. Check out his website at [www.wellnessnutrition.ca](http://www.wellnessnutrition.ca).



He gave a face to AIDS in Canada by creating the first national AIDS awareness poster in 1991.

His pop art has captured the attention of art critics, royalty, celebrities and the public.

The logo he created for the XI International Conference on AIDS in Vancouver became Canada's first AIDS postage stamp in 1996.

He produced BCPWA's annual AIDS Walk poster for the past 13 years.

His vibrant artwork has helped raise money and awareness for a long list of charities.

He is . . .

# NOT YOUR AVERAGE JOE



Pop icon and artist  
**JOE AVERAGE**  
on his most  
challenging masterpiece—  
his health

INTERVIEW BY RONNILYN PUSTIL

**JOE AVERAGE:** I was diagnosed in 1985 at age 27, but I'm 99% sure I contracted HIV when I was 25. When I asked the doctor what it meant, he said: "You could last six months, you could last a year, five years, 10 years or forever . . . we just don't know." And I said: "I'll choose forever." I'd known a few people who were living with AIDS or had died from it, and one thing I figured out, just from watching people, is that if I let it take over my life it would. So I decided to live as normally as possible.

About three years later, I was working a crappy job and was let go. I thought, "If I've only got six months to live, do I want to spend it collecting unemployment insurance or welfare, or do I want to spend it doing something I like?" I decided to make a stab at living off of art. Art was something I'd done since I was a kid but had never taken seriously. It was a hobby, not a way to make a living.

I thought of it as urban camping: If I found myself alone in the middle of the woods, I'd figure out how to survive. So I took that approach and started making art and having little shows in my apartment. I priced things according to

my rent so that if I sold a piece I could pay a month's rent. HIV saved my life in that I decided to make art my life.

**And since then you've been living off your art?**

**AVERAGE:** Yeah. But I haven't painted for the past five years. Someone asked me when I decided to stop painting. I didn't decide to stop painting—things just got so intense. My mind was so full. At one point I had timers everywhere because I had to take some drugs every two hours with food and some every two hours without food. It was like air-traffic control.

My life became so complicated that there wasn't a clear area in my mind. Sketching is an organic process. My brain became so focused on surviving that the natural process of sketching kind of screeched to a halt. It's hard to be inspired when you're dealing with life and death stuff, horrific side effects and fear.

Not painting has lowered my self-esteem and hurt me financially. I had the foresight when I had chunks of money to produce lithographs, limited edition prints of my stuff, which is what's been keeping me alive.

You've donated a lot of your art to charity.

AVERAGE: As a kid I used to watch telethons and I always wanted to make donations like the adults. When I found out that I could donate a piece of art and it would generate money, it became my way of helping. It's a win-win situation—I get to help people and people get to see my art. I donate mostly to AIDS charities and stuff involving children. The canvases fetch a lot of money and the prints usually raise about twice their value, which is a great feeling.

Do you think your art has helped raise awareness about AIDS?

AVERAGE: Art is open to interpretation, that's the beauty of it. I've been invited to many elementary schools where the teachers have the kids study my art. Kids are so wonderful! I've left classrooms after two hours and the kids were saying, "We're coming to the AIDS Walk this year, Joe!" I talk openly with them about it.

I did a few images about AIDS—one called *My Thinking Cap (Life with HIV)* and one called *Ray of Hope*—when I first started the cocktail because I wanted that out of me a little bit. For the most part though, my images aren't so much AIDS-related—they're more about how the child in me wants to see the world: happy and with love. There is so much communication with colour. Over the years I've learned how much of a language colour is. Colour creates joy in me and it creates joy in other people.

There's a little thing I'm very proud of. For me, it's a reason to keep going with art. I've had parents come up to me and thank me. They say that when their child is crying, they've figured out that the only thing to make them stop is to carry them over to my painting or print and hold them up in front of it. And the child stops crying. I've somehow managed to communicate not only to parents but to babies.

What's your favourite piece?

AVERAGE: That's like asking a parent which is their favourite child. There are so many for so many different reasons.

## THE KITCHEN SINK

Let's hear a bit about your treatment history.



AVERAGE: I've never been hospitalised. I went for six or seven years on no drugs, and then my doctor suggested AZT—it was the only thing there was back then. But everybody I knew who was on AZT was dropping like flies, so I said "no thank you." In the early '90s, someone came up to me and asked how much I weighed. They said I looked like a skeleton. I'd dropped down to about 115 pounds. It actually timed out kind of nicely because it was right around the time when the first cocktail came out. I said, "OK, I guess this is the time," and I went on AZT, 3TC and d4T, and it helped. I've been on cocktails ever since.

How many different combinations have you been on?

AVERAGE: Well, I won't say everything, but everything my body can tolerate.

I became resistant to almost everything about two years ago. My CD4 count was hovering between 50 and 100. And

my viral load was off the chart. We were waiting for a new drug called T-20 to come in. It's very expensive and it took some time to get it. At one point my doctor pulled me off everything because the T-20 has to be taken in combination with other drugs, and if I'd stayed on all the drugs I would have become resistant to them all and the T-20 would have been useless. So he pulled me off everything for about six months and we just waited. In September 2003 the T-20 finally came in. I've been on it ever since.

What happened when you were off all the meds?

AVERAGE: I was very anemic, but fortunately I didn't get anything. I stayed very careful. I was like the boy in the plastic bubble, without the bubble. I avoided going places and shaking hands with people. I was really wary to go to functions or benefits that I usually go to. If I had to go, I wore a mask and latex gloves. I basically cut myself off from everything.

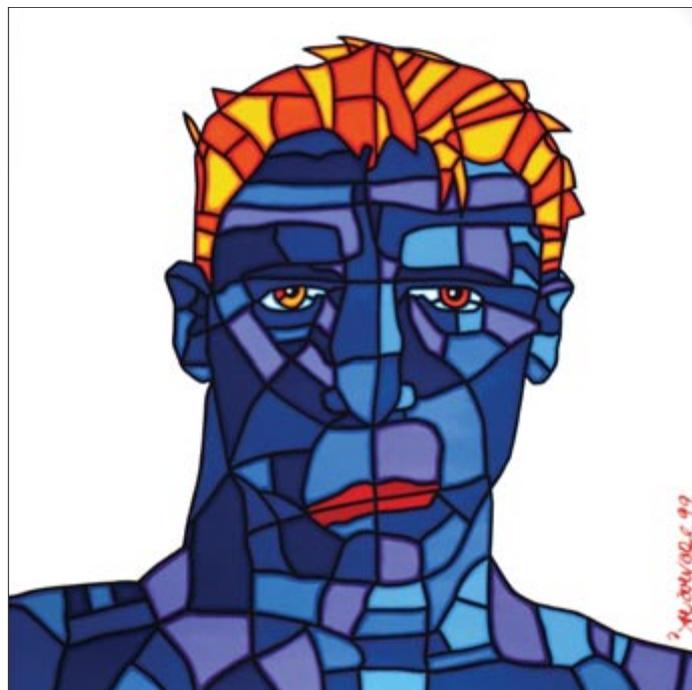
What other HIV meds do you take with the T-20?

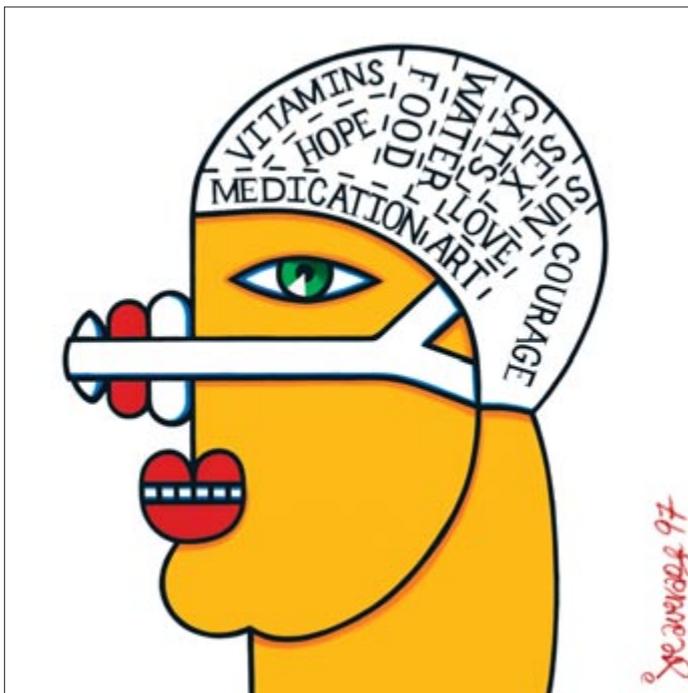
AVERAGE: I'll get my little pillbox. Let's see: tenofovir, d4T, 3TC, ddI, saquinavir and Kaletra.

Everything but the kitchen sink!

AVERAGE: Oh, that's a small one, only seven drugs. I've been on 13 before.

I did a self-portrait, **Me**. I was going through a lot—the side effects were intense, I'd just healed from a broken collarbone, I had to have surgery because cysts had developed on my penis. It was very traumatic. So I sat down and did this drawing of myself because if there was one more blow I was just going to crumble. I kind of overdraw the lines that I knew had started to weather themselves into my face, like a road map of my journey. Then I drew out from the wear marks to complete my head. I did it as stained glass to create that sort of fragile feeling. That was a self-portrait of me ready to crumble. It was my therapy at the time.





**My Thinking Cap** is a bald head with the brain sectioned out like diagrams of cuts of meat, and each section has different words like *hope*, *love*, *courage*, *sex*—what’s in the forefront of your brain to keep you going. The person has no nose; instead the pills 3TC, d4T and AZT are strapped to the head like a nose.

The back is also a spot. So, Anne would come over at 5 a.m. and 5 p.m. and inject my back for me. She’d do that for two weeks and I’d do my abdomen for a week, and that went on for about two months, until she said: “Why don’t I come over every day and do your back? Save your abdomen for when I’m sick or have to go away.” She’s been a little trooper.

My abdomen is scarred from the injections. It’s so dense with the nodes that the T-20 doesn’t absorb, so it takes a long time to inject and is extremely painful. But when you’re finished the injection, the pain is kind of over, unless you put pressure on the spot or hug somebody . . . and seatbelts are a bitch. If you have an injection-site reaction, the place where you inject stays painful for a couple of days.

It’s living with pain but it’s living. That survival instinct in me is quite strong. It’s been a very challenging year, but it’s way better than not having an immune system. Now my T cells are at about 350 and my viral load is back down to undetectable.

**Thirteen HIV drugs?**

**AVERAGE:** Yeah. Like, literally everything but the kitchen sink. I’ve been a guinea pig for many different things. My doctor has experimented with me with all sorts of therapies, including non-traditional things, just trying to keep me going.

### A TALE OF T-20

**AVERAGE:** There are a lot of things that have changed in my life, like my needle-phobia. With all the blood tests I’ve had over the years, I usually had to look the other way. I’d go completely white.

Now I’m doing T-20 injections twice a day. The day I was to start the T-20 my good friend Anne came with me to the hospital for moral support and to be an extra set of ears and eyes so I’d remember everything. I had no idea what was involved. I was told there was going to be a simple device that you just clicked. But when I got there, all these hypodermic needles were laid out. I had to learn on the spot how to inject myself. The thing about these injections is that they’re subcutaneous—and I have no body fat.

**So what do you do?**

**AVERAGE:** They had to figure something out with me. I have a tiny bit of body fat on my abdomen. When you look at me you wouldn’t think it, but when you squeeze it, it’s just enough. Traditionally, with subcutaneous injections, you pinch the skin and put the needle down at a 90-degree angle, like straight down. But because I have zero body fat, I pinch at my skin and go in sideways, almost transdermally.

**In the same spot all the time?**

**AVERAGE:** You have to rotate the injections. You can’t go into the same spot twice because it leaves a node. But now, because the areas on my body are so used up, I was told to just go where I can get the needle in.

### THE B SIDE

**What side effects have you had from all the meds you’ve taken?**



**AVERAGE:** I’ve had so many. One of the most frustrating was nosebleeds. If I leaned over to tie my shoes or pick something up, my nose would start gushing—sometimes for a half-hour. It was a drag because I work out a lot and I couldn’t go to the gym. I’m a biohazard—I couldn’t be hemorrhaging in public. After about eight months, my doctor figured out that it was the AZT in one of my drugs, Trizivir. He told me to stop the AZT but to continue taking the other drugs in the combination [3TC and abacavir]. Thankfully he found that out because it stopped the bleeding.

I was on Sustiva for just over a year. They told me that one of the side effects would be nightmares, which I got, but they didn’t tell me that the nightmares aren’t limited to the night. Finally, I was at my doctor’s one day and I said: “I think I’m losing it. I’m frightened. I want to kill my cats. I want to kill myself. I want to run people over with my car. I don’t know what to do. I think I’m getting dementia.” So I got pulled off that drug, but what a horrible year. I felt so out of control and like a danger to myself.

For the past four years I’ve suffered from folliculitis, an inflammation of the hair follicles, from my waist up and all over my chest, back and face. I went to specialist after specialist, and no one’s been able to figure it out. They’re like pimples, but they’re right on the surface and very itchy . . . I’m scratching 24 hours a day. There’s been an awful lot of pain that I’ve had to live with.

And what do you do for the pain?

AVERAGE: I could take painkillers all the time, but I don't want to. I want to be active. So I just deal with it.

And then there's the lipodystrophy. I started losing my body fat about four years ago, which has been emotionally traumatic. You look in the mirror and you look like a skeleton draped in skin. It's one of the reasons I started working out so intensely. Let me put it this way: I'm on my fourth butt. I lost it in the beginning. There was no fat left on my ass. It hurt to just sit down. I started working out with a trainer to get an ass back so I could sit on something, and also to create muscles, as a sort of armour. I've had to stop going to the gym a few times because of the nosebleeds and sometimes my anemia was so bad that I didn't have the energy, so this is ass number four.

My self-esteem is pretty low. Before body-fat wasting people could tell you had HIV if you had Kaposi's sarcoma on your face. But this is now the new face of AIDS—the sunken cheeks and skinny legs. When I meet up with people, I can see the shock in their face. People don't recognize me on the street.

Your appearance has changed that dramatically.

AVERAGE: Oh yeah. It's not just the fat wasting—it's the meds, the pain, the wear and tear. It's weathered me. I went from everyone saying that I was the youngest looking 35 year old they knew, to looking like Keith Richards on a bad day. I've got eczema and folliculitis. My face is cracked and scaly. Physically my body looks better than ever, but I've got Band-Aids all over my skin. My skin is rather angry all the time. I have very few mirrors in my house.



**Ray of Hope** is my hand holding the pills I was taking—3TC, d4T, AZT (and Septra)—with rays coming out of it because it was the first cocktail.

Are you angry?

AVERAGE: I live with anger all the time. Sometimes it's at myself, sometimes it's at the virus, sometimes just at the world. I shouldn't say all the time, but I get very worn down from the constant challenges—and lonely. You can't really explain to people what you're going through because they can't imagine. It's a lonely experience. Even when I was in therapy, everything was so overwhelming for the therapist; he'd cry or shake his head, saying: "I can't believe this." A lot of times, I'd leave feeling worse.

Have you taken drugs to deal with all the side effects?

AVERAGE: Oh, yes, tons of different things—which is what kind of financially ruined me. I try not to look at what I've spent at the drugstore. But one year my accountant told me I spent like \$10 grand just at Shopper's Drug Mart—all for drugs that might or did help with something.

Now that I'm broke, I'm eligible for Fair PharmaCare in B.C., so fortunately I don't have to pay for prescriptions. With Fair PharmaCare, if you're in a certain income bracket, the government will pay for drugs that are approved. So, for example, now I don't have to pay for my testosterone, which cost me like \$400 every couple of months. And all the other things, like Septra and my anti-depressants, are finally covered.

## THE PILL BOX, PART II



AVERAGE: The moment they put me on the first cocktail, I said: "I'm not doing this without both sides being covered." So I hooked up with my naturopath at the same time I started the drugs and I've been with her since. I take many supplements from her.

Like what?

AVERAGE: Let me go back to my pillbox. I take a multivitamin, alpha-lipoic acid, vitamin C, NAC (N-acetyl cysteine), co-enzyme Q<sub>10</sub>, selenium, Panplex for digestion, a fish oil combination called SEP EFA, SAT, DHEA, and Can Plex. Once a week I get an intravenous shot of a Meyer's cocktail—a vitamin and mineral protocol with vitamin C, magnesium, calcium, B-complex, zinc and more.

Is your naturopath experienced with HIV?

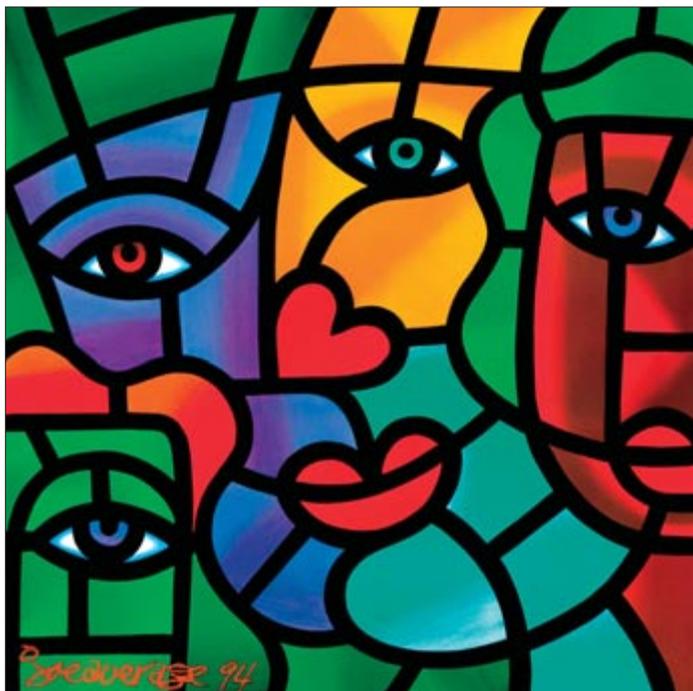
AVERAGE: She's learned a lot from me and she attends seminars. We're so intuitive with each other. She's really been there for me, like a therapist at times—I've sat and cried with her. She's a godsend.

With all the drugs and supplements, I can't begin to imagine how many pills you take each day.

AVERAGE: Probably about 40 pills twice a day.

How do you keep track and remember it all?

AVERAGE: I've got three pillboxes and I have all the names written down and how many pills I take. Every morning I get up and fill two small glass dishes with my morning and evening stuff. Then I take the morning dose, put the evening dose in the cupboard and do my injection. It's become routine.



The **One World, One Hope** image was for the XI International AIDS Conference in Vancouver in 1996. The conference organizers asked if they could reprint the image I did in 1991 that became Canada's first AIDS awareness poster. I said I wanted to rework it. The first image was just different faces, different people, and there was a heart in the centre to suggest that we're all joined together as a race—because we are—and to get through this we have to do it with love and compassion. When I reworked it, I decided to change it into stained glass to show the fragility of humankind, the face of AIDS, and that we are all connected. I kept the heart in the centre.

The original image, from the AIDS awareness poster, got me a lunch date with Princess Diana. I was invited to the national capital to be one of 50 Canadians to dine with the royal couple at Rideau Hall. But the invitation didn't include a plane ticket. When the owner of a local gay pub heard about it he had an idea to auction off the little painting that was the image on the poster. The auction raised enough money so I could fly to Ottawa. A local paper printed a story about the community helping raise money to fly me out, and Reuters picked it up. The title of the article: 'Joe Average to lunch with Princess Di.' Suddenly it was everywhere.

So I flew to Ottawa, and Princess Diana's staff had clipped all these articles and showed them to her. After lunch the Governor General's wife, Gerda Hnatyshyn, said the Princess wanted to talk to me. There I was—this little shy guy with a weird name and weird art—with the full attention of the Princess. It was one of the best moments of my life!

### ANGELS IN CANADA

How often do you see your doctor?

AVERAGE: I go to my GP once a week for a testosterone injection in my butt, and a B<sub>12</sub>/B-complex/folic acid injection in my arm. This is my second GP. My first GP rolled his eyes every time I mentioned the word "naturopath" and wouldn't even allow me to have a copy of my blood work to show her. So I searched out a GP who was naturo-

path friendly, and that was great because it cut costs at my naturopath. Now my GP does the vitamin injections, and I leave the Meyer's injection to my naturopath. I see my HIV doctor only when I need to.

How often is your blood work done?

AVERAGE: Usually once a month.

With all the meds you're on, what about drug interactions?

AVERAGE: We've learned the hard way. But right now things are pretty good.

How are your eating habits?

AVERAGE: I have to force myself to eat most of the time. With some of the drugs I've been on, the nausea was so bad. Pot is the only thing that helps. Both my doctors fully recommended it. I try to eat as well as I can, but when the money is low it's difficult. A Loving Spoonful provides me with seven frozen pre-made dinners a week, a loaf of bread and some fruit and juice. It helps out a lot.

You said you like to work out.

AVERAGE: I work out five times a week. I was working out on my own for a couple years here and there, but when I started losing the body fat I knew I needed some good advice and training. I'd saved some money as an "in case I get sick fund." But then I thought, "Instead of having this money sitting there in case I get sick, why don't I hire a trainer and get strong?" My trainer and I clicked immediately. He was very anxious to train me and I've been with him for over three years. About a year ago I was broke and called to tell him I had to stop. "December's on me," he said. He wanted to give me a little chance to get back on my feet. "Money's not an issue. Let's just make you stay healthy."

Working out makes me feel alive. My trainer makes me laugh. He's a friend now, and they're hard to come by. In my 20s and 30s, all my friends died. I've met a few friends along the way, but I've become more introverted over the years. The gym gives me an opportunity to interact with people, it gives me something to look forward to. Both my doctors said hiring a trainer and working out is the smartest thing I ever did. It helps mentally as well, so, so much. I've risen from the ashes a few times. When I first hooked up with my trainer, he knew I was HIV positive, and I said, "I don't want you to treat me any different. I want you to constantly challenge me." And he does, so it makes me feel like I'm winning.

It sounds like you have some angels in your life.

AVERAGE: I don't have many friends, but I've got a few really great angels. I approached my naturopath last year about the financial situation, and she said: "There are a lot of bare walls in my house." So I did a barter with her—I gave her enough prints to decorate her office. It's wonderful to get help, but I've tried to be as self-supportive as possible. It's really hard for me to take something like that, but I'm broke. It's just necessity.



To enjoy more Average artwork, go to [www.joeaverageart.com](http://www.joeaverageart.com)



# Treatments on Trial

On the road to better HIV therapies

BY MAIA JOSEPH

We

need clinical trials because we need new treatments for HIV,” says José Sousa, 43, from Montreal. Sousa, who was diagnosed with HIV in 1985, knows what he’s talking about: He’s the chair of the Canadian HIV Trials Network’s Community Advisory Committee and has participated in three clinical trials since the early 1990s.

Sousa has seen HIV research evolve over the years, but he knows the list of questions that still need answering is a long one. “We need drugs that are less toxic,” he says. “We need to know whether it’s OK to take a drug holiday. We need to determine the best way to treat HIV/hep C co-infection. We need to find ways to prevent HIV infection. And we need a cure. We can’t do any of this without clinical trials.”

Clinical trials, however, can’t run without participants. And with trial enrolment on the decline, researchers are having more and more trouble finding answers to those all-important research questions—answers that could prolong the lives of people with HIV/AIDS (PHAs) and improve the quality of those lives.

## ◉ WHAT IS A CLINICAL TRIAL, EXACTLY?

Clinical trials are carefully designed experiments that allow investigators to test their research questions on people. Of course, the testing of a new drug or other treatment never begins with humans—it starts in the lab, where investigators perform *in vitro* (test-tube) experiments to determine the effects of the treatment on animal and human cells. Eventually, if the treatment shows promise, investigators test it on living animals to get a better idea of how it will affect humans.

Ultimately, though, investigators will only know for sure whether a treatment is safe and effective by testing it on people—and that’s where clinical trials come into play. At first, the treatment is tested on a very small number of people. Then, if that test goes well, investigators conduct larger studies involving more participants. A drug will be

approved for sale only after it has made it through the clinical stage.

Clinical trials offer information about a drug’s effect on humans that investigators can’t get from test-tube and animal experiments. They are the gold standard of treatment research.

## ◉ THE CHANGING CLINICAL LANDSCAPE

HIV/AIDS clinical research has changed dramatically over the past two decades. In the early days, when the antiretroviral drugs that make up today’s standard regimens were still on the drawing board, PHAs participated in clinical trials simply to gain access to these lifesaving treatments. “I enrolled in my first trial in the early 1990s, and at that time it was all about access to drugs,” Sousa recalls. “There weren’t many treatment options approved for marketing, and clinical trials opened up possibilities for us. Researchers were still comparing most potential drugs to a placebo because there were no standard treatments to test against.”

Today, with four classes of antiretrovirals approved for treatment in Canada and with opportunistic infections on the decline in the developed world, clinical research is starting to focus on other pressing issues. Hot new areas of research include treatment management (for instance, the study of structured treatment interruptions, or “drug holidays”), vaccines and microbicides for HIV prevention, therapeutic vaccines (to boost the immune response against HIV), treatments for co-infections, and new classes of antiretrovirals.

These days, though, the rush to participate in a clinical trial has died down to a trickle. In a sense, HIV research has become a victim of its own success: Potential trial participants have found treatments that do a fairly good job of keeping their HIV in check and, understandably, they don’t want to rock the boat by enrolling in a trial.

Some trials don’t have much trouble recruiting participants. For example, a Canada-UK therapeutic vaccine

## Informed Consent: 10 things to know

Considering enrolling in a clinical trial? Your doctor should provide you with an informed consent form and discuss the trial in detail with you.

Before signing on the dotted line, here's what you should know:

- ☑ You must give informed consent in order to participate in a clinical trial.
- ☑ Informed consent is a process whereby the risks, benefits and requirements of a trial are clearly explained to participants.
- ☑ The informed consent form should describe the trial in plain language.
- ☑ Before you sign the form, consider all the factors involved in the trial, including your responsibilities, the time commitment, the benefits and the possible risks.
- ☑ Your doctor should be willing to answer any questions you have about the trial.
- ☑ You have the right to discuss the trial with anyone you wish.
- ☑ You have the right to take as much time as you need to make your decision.
- ☑ If you sign the informed consent form, you are considered enrolled in the trial.
- ☑ After signing the form, you still have the right to leave the trial at any time.
- ☑ Informed consent is an ongoing process: The investigator must continue to inform you of any new information that might affect your health or influence your decision to participate in the trial.

study of the Remune vaccine boosted with an agent called Amplivax has been enrolling steadily since it opened in mid-2004, likely because it presents an innovative new treatment option and PHAs do not have to alter their current drug regimens to participate. But recruitment success is becoming less common as more and more trials struggle just to get off the ground.

### ● THE RECRUITMENT RUT

Trial recruitment is a thorny issue within clinical research circles—one that's complicated by a range of factors. Perhaps most important is that clinical trials are a hard sell for PHAs who would have to interrupt a relatively effective treatment regimen in order to participate.

"Your primary reason for taking part in a trial should be to help others in the future," Sousa says. Indeed, in the HAART era, altruism plays a major role in the decision to enroll in a clinical trial, because even though review boards make every effort to minimize risk, the treatments are still experimental and there are no guarantees that a particular trial will work for you.

For a growing number of PHAs who want to help their community but don't want to sacrifice their fundamental right to personal health, the decision to enroll involves a careful balancing act. They must weigh the risks and responsibilities that participation in a trial might entail against the trial's potential future benefit and their own desire to make a contribution. No two people face exactly the same situation—the same health concerns, treatment options, lifestyle and support network. "It's always a completely individual decision," Sousa emphasizes.

But the personal decision faced by many PHAs is just one factor—albeit a critical one—in the participant shortage.

Some investigators are also finding it harder to make contact with potential trial participants, primarily because the HIV population has diversified. It's more difficult to disseminate trial information to street youth and Aboriginal people living on reserves than to reach the close-knit, predominantly urban community of gay men. Add to this the fact that the PHA population is generally healthier than in the past—meaning fewer clinic visits—and it becomes clear that investigators face a significant communication hurdle.

Another key factor in recruitment is the increasing number of clinical trials. More studies mean more competition for participants among the wide range of stakeholders who fund clinical trials. Trials driven by individual investigators—which are usually funded by the government, universities and non-profit networks or organizations—compete head-on for participants with heavily funded trials sponsored by pharmaceutical companies. Such companies often have the means to run large, multi-site trials, while some investigators lobby for years just to get their trials funded at all.

The result? Well, the best trials (whether investigator- or company-driven) do tend to go ahead. That said, the potential for private pharmaceutical interests to undermine the interests of the public is great.

### ● CLINICAL CATCH-22

Researchers' ongoing efforts to run trials on structured treatment interruptions (STIs) offer a revealing example of the recruitment issue's complexities. These researchers want to determine whether a planned drug holiday will lead to resistance or other problems. Such information could improve the quality of life of PHAs, given the high toxicity and complex dosing schedules of many antiretrovirals. Drug holidays could also decrease treatment costs.

Most pharmaceutical companies won't touch the drug holiday issue. Results from a few publicly funded Canadian trials that have struggled to address the question are eagerly awaited but have been slow in coming because clinical opinion remains divided.

"The beliefs held by doctors on this topic are quite variable," says Bill Cameron, MD, the Canadian principal investigator of the tri-national Options in Management of

**"YOUR PRIMARY REASON FOR TAKING PART IN A TRIAL SHOULD BE TO HELP OTHERS."**

Antiretrovirals (OPTIMA) study, which compares different approaches to treatment management, including planned drug holidays. "About half advocate STIs and half do not, and within those groups there are other differences of opinion as to the type of treatment regimen a patient should be on, when and for how long an STI should take place, and so on."

The fact that some physicians are skeptical about drug holidays means they're less likely to recruit for a study like OPTIMA. Moreover, because of the division in clinical

## Stages of Trial Participation

opinion, some PHAs worry about enrolling. The result is a Catch-22: Researchers can't get the answers they need about drug holidays because they can't enroll enough trial participants, and potential participants won't enroll because researchers don't have clear answers.

Dr. Cameron notes that answering treatment questions can take a long time, often owing to safety concerns. He points to an influential breast cancer trial from the 1970s and '80s, which compared the then-standard surgical procedure for breast cancer, a modified radical mastectomy, to a lumpectomy—a new, less invasive procedure. Despite the fact that the trial results could potentially improve quality of life, enrolment was slow.

"Breast cancer is a lethal disease, and physicians thought they knew how to deal with it," Dr. Cameron says. "Some felt they couldn't, in good conscience, recruit for the trial because they worried that the new procedure would not be as effective as the standard. It took eight years to enroll enough participants."

In the end, the results of the trial showed an absolutely equivalent survival rate between the two study groups. Today, lumpectomy is the most common surgical procedure for breast cancer.

### 🔍 DIAL "T" FOR TRIAL

What role can PHAs play in the complicated HIV research environment, where varied opinions and interests seem the order of the day? Staying informed and involved are paramount. PHAs who are active in clinical research circles can identify the trials that best cater to their needs and push to have those trials go ahead.

Lynn Stevenson of Nova Scotia is one such PHA. In search of treatment options, Stevenson enrolled in her first trial in the mid-1990s. Her experience was largely negative: She suffered a drug side effect that led to health complications. "You know there are no guarantees," she says, "but you never actually think that something will happen to you." Stevenson eventually left the trial and had the side effect treated, but she remained apprehensive about participating in another study.

All the same, Stevenson stayed active in clinical research: As a registered nurse and AIDS activist, she served on hospital and community advisory committees, where she helped review trial protocols. She was able to see her side effect documented and to help set higher ethical standards for clinical trials.

This window into the institutional side of clinical research gave Stevenson added confidence in the process. Being informed about the benefits of clinical research also kindled her desire to participate in a second trial when the right one came along.

Stevenson's decision to try another trial was partly motivated by altruism, but personal concerns also played a role. She liked, for instance, the fact that participating in a trial meant that her health would be monitored more often: "Suddenly you feel like you're the centre of attention. The clinicians and nurses are all there explaining the trial to you

Participating in a clinical trial involves a time commitment, but the payoff for many participants is the extra attention they receive from their doctors. If you enroll in a trial, you can expect to take part in many or all of the following stages:

- 1 **Informed consent:** You sign a form stating that you understand the trial and are willing to participate.
- 2 **Screening visit:** You are asked questions about your health and treatments and then given a physical exam, along with lab tests. The investigator then decides whether you meet the entry criteria for the trial.
- 3 **Randomization:** You are randomly assigned to a treatment group.
- 4 **Waiting period:** You may have to wait for the trial to begin. The investigator will monitor your health during this period.
- 5 **Washout period:** You may have to stop taking a certain medication and wait for a period of time. This allows the body to get rid of traces of the medication.
- 6 **Treatment period:** The period during which you are on a study treatment before researchers evaluate its effect (usually 12, 24 or 48 weeks).
- 7 **Follow-up visits:** Throughout the study you will be asked to come to the clinic for regular visits. The frequency of these visits is usually higher than for routine care.
- 8 **End of study:** The study usually ends when all participants have completed either the treatment or follow-up period.

To learn more about clinical trials, call the Canadian HIV Trials Network (CTN) at 1.800.661.4664 for the booklet *Clinical Trials: What You Need to Know*, or read it online at [www.hivnet.ubc.ca/ctn.html](http://www.hivnet.ubc.ca/ctn.html) (click on "Publications"). Info on clinical trials enrolling in Canada is also available at CTN or at CATIE ([www.catie.ca](http://www.catie.ca), 1.800.263.1638).

and trying to make you feel comfortable. And throughout the trial you make more clinic visits, you get more care."

"With the trial I chose," she adds, "I was confident that, given the extra monitoring, any problems would be caught early enough to be addressed. My decision involved very practical considerations. I felt that, for me, the risk was pretty minimal."

When asked if she can pinpoint a turning point on the road to participating in a second trial, Stevenson responds: "It's an ongoing experience. On the first page of every protocol review, each member of the committee must answer questions about the study. The last one always asks, 'If you were eligible, would you enroll in this trial?' If I can't answer yes to that question, then I have to ask, 'Why not?' And that brings me back to a safety issue or another fundamental issue that makes the trial seem inappropriate. Finally, I have to put my money where my mouth is."

Stevenson, like José Sousa, stresses that the decision to participate in a trial belongs to each individual and that it requires careful consideration. But it's also a decision that potential participants need to make—not avoid—because clinical trials are critical to advancing HIV care. "It's really important that trials go ahead," Stevenson says. "In the end, we need to know this information." +

Maia Joseph is a project coordinator and editor for the Canadian HIV Trials Network's Communications and Information Programme.

# LET'S GET PHYSICAL

PHYSIOTHERAPIST  
KELLY O'BRIEN FLEXES THE  
BENEFITS OF EXERCISE

making your muscles bigger and stronger. This could be especially useful for people experiencing symptoms of HIV-related wasting. Examples include: walking, weight-lifting, deep knee bends, push-ups, chin-ups, bicep curls and using nautilus machines. (You don't need a gym membership—try soup cans or milk jugs as weights.) **Isometric training**—when your muscles contract but your limbs don't move—is another type of resistance exercise. It's good for strengthening muscles that maintain your posture, such as the stomach and lower back muscles. Examples include: yoga, Tai Chi and Pilates.

**Stretching** is an important part of any exercise program because it improves joint and muscle flexibility and may help to prevent injury. Warm up before you stretch with a few minutes of light activity, like walking. Stretches should be held for at least 30 seconds to maximize the effect. Don't forget to stretch after your activity as well.

## THE FITT PRINCIPLE

**Frequency.** How often should you exercise? To maintain the benefits, exercising 3–4 times per week for an ongoing period of time is recommended.

**Intensity.** How strenuous should your activity be? Aerobic exercise is usually prescribed so that you're working at a percentage of your maximum heart rate (usually around 70%). A useful guide is to exercise at a pace where you can carry on a conversation without gasping for air. Resistance training is usually prescribed so that you're lifting a certain proportion of the maximum weight you're able to lift. It's recommended to do 8–12 repetitions (or "reps") of lifting at a comfortable weight for 2 or 3 sets. Make sure to rest for a minute or so between sets.

**Time.** How long should you exercise for? Generally, it's recommended that aerobic exercise be performed for at least 20 minutes, and resistance training for 35–40 minutes (including rest periods between sets).

**Type.** What kind of exercise should you do? Your choice will depend on which benefits you're after. Choose an

**AS THE COURSE OF HIV INFECTION** continues to change due to medical advancements, many people with HIV/AIDS (PHAs) in Canada and other developed countries are living longer, some with fluctuating periods of wellness and illness. As PHAs live longer, they may be dealing with health-related consequences of the disease and unwanted side effects of long-term HIV treatment, along with the general effects of aging.

Exercise may help to address these issues and improve the overall health and well-being of PHAs. While the benefits of exercise in the general population are well established, little research has investigated the effect of exercise on PHAs. The few small studies that have been done show that aerobic exercise, resistance training or a combination of both is safe and may be beneficial for PHAs who are medically stable.

**Aerobic exercise**, otherwise known as **cardiovascular** ("cardio") or **endurance training**, works the cardiovascular system (heart and lungs) by raising the heart rate and strengthening the heart. It involves doing a physical activity at low-to-moderate intensity for an extended time. Aerobic exercise helps improve your endurance so you can do an activity for longer without feeling tired as quickly. Examples include: brisk walking, jogging, aerobics, swimming, cycling, dancing and cross-training.

**Resistance exercise**, or **weight training**, strengthens muscles by contracting them against some sort of force. It can increase muscle mass,



activity you enjoy. Try mixing aerobic, resistance and flexibility exercises to maximize benefits and add some spice to your workout.

Don't start with a marathon—it's important to gradually build up to the recommended frequency, intensity and time that you exercise. As your physical fitness improves, you may want to slowly increase the intensity or duration of your workouts.

### EXERCISE AND ...

**The immune system.** The limited research available has shown that exercise won't boost CD4 counts or lower viral loads, but it does not seem to harm the immune system or worsen virological status for PHAS who are medically stable. Most studies that have been done were for a short duration, so we don't know about the long-term effects of exercise on the immune system.

**Weight and body composition.** Although the effects of exercise on lipodystrophy are unclear, a combination of aerobic and resistance exercise may help reduce fat buildup in the belly. Resistance training (with or without aerobic exercise) can increase weight and body composition, such as lean body mass and the size of arms and thighs, which is good news for people with HIV-related wasting. If you're thinking of starting an exercise program, be sure to talk to your physician or other informed health care provider about safe parameters for aerobic exercise.

**Strength.** Resistance training (with or without aerobic exercise) can improve overall upper and lower body strength for PHAS.

**Cardiovascular fitness.** Aerobic exercise improves cardiovascular fitness and endurance for PHAS—the more



intense the workout, the greater the improvements in physical fitness. Although we would expect that exercise might help reduce the risk of heart disease (as it does in healthy, HIV-negative populations), it's still unclear whether it can help reduce high cholesterol and triglyceride levels in PHAS.

**Bone problems.** Bone problems are on the rise in PHAS. Although we're not sure why these problems occur, weight-bearing exercise is recommended as a way to increase bone strength and reduce the risk of fracture. If you have any type of bone disease, talk with your doctor before starting an exercise program.

**Psychological health.** Research shows that exercise can improve quality of life, reduce stress, enhance mood and life satisfaction, and lower symptoms of depression.

**Anabolic agents.** Sometimes people take anabolic agents (such as steroids, testosterone or human growth hormone) in combination with exercise to increase body weight. Some anabolic agents may cause liver toxicity and elevate fat (lipid) levels, so if you're taking them, have your doctor monitor you closely. Some studies have shown that anabolic steroids do not improve strength, weight and body composition any more than exercise alone does.

### JUST DO IT!

It's important to gear any exercise program toward your physical capability and personal goals. It's a good idea to talk with your physician, physiotherapist or other informed health care provider to find out which program

## Training Tips

When working out, don't forget to:

- Breathe.
- Wear comfortable clothing.
- Drink lots of water before, during and after you exercise.
- Include a warm-up and cool-down period as a component of your workout.
- Listen to your body.
- Eat a nutritious, well-balanced diet with adequate calories and protein to fuel your body.
- Give yourself a break, such as days off between workouts, to let your body recover.

might be right for you. If you want to join a gym, ask if they offer membership geared toward income or check out your local Y for various activities and programs. Many non-profit gyms and community centres with gyms, pools and exercise classes offer free access or reduced rates to PHAS, particularly those on disability. This often means that PHAS can get free exercise counseling and supervision.

You may want to track your activity in a log book, including dates you worked out, along with the frequency, intensity, time and type of exercise, and how you felt during and after. That way you can monitor your activity level and progress over time. Working out with a partner or group of people who encourage you along the way may help you stay motivated. Exercise doesn't have to be a burden. There are many ways to build physical activity into everyday activities. Take the stairs instead of the elevator or walk to and from a specific destination. By picking up your feet, you'll not only pick up your health but you'll lift your spirits, too. +

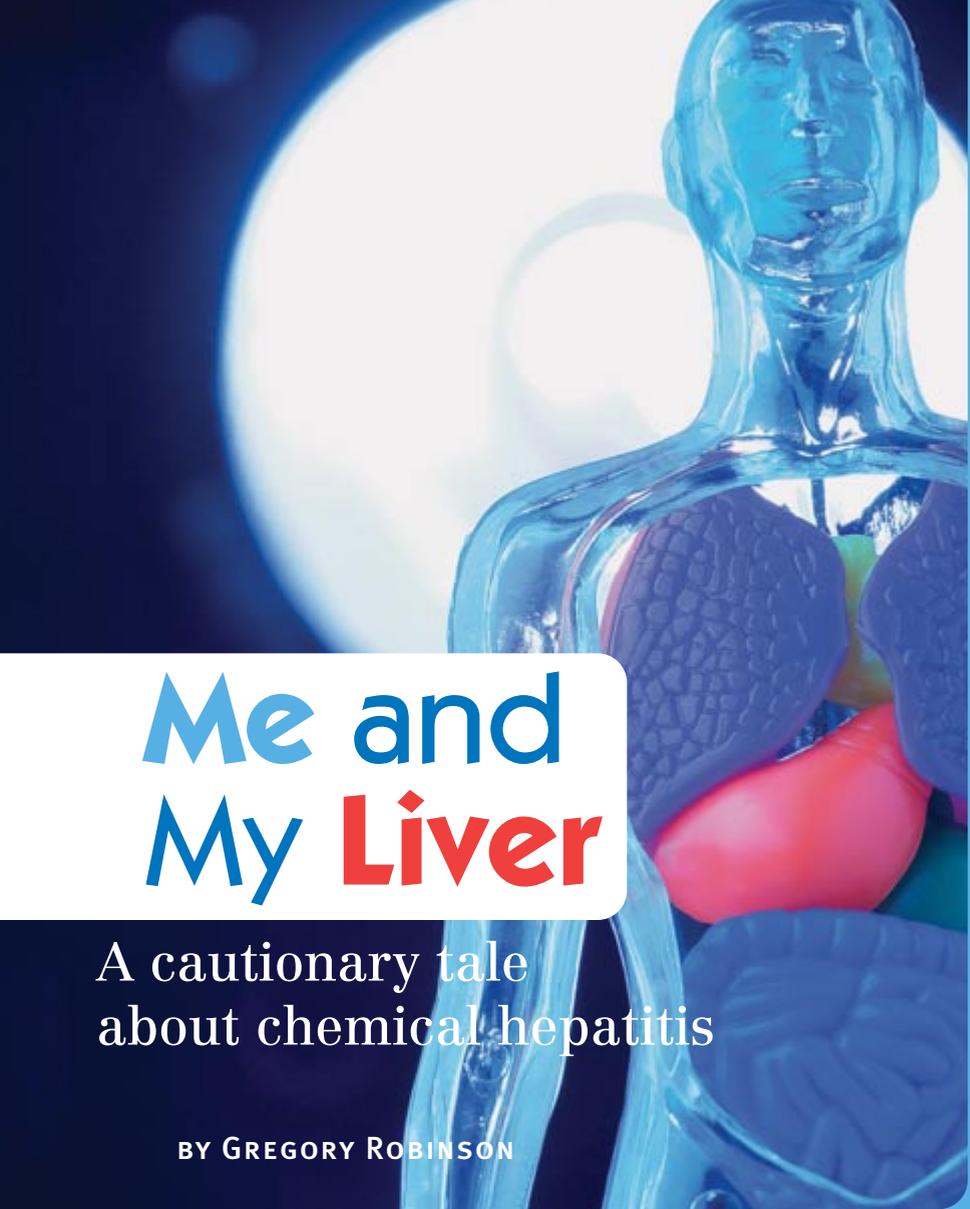
This article was written by physiotherapist Kelly O'Brien, in collaboration with Stephanie Nixon, physiotherapist at the University of Toronto's Department of Physical Therapy; Dr. Richard Glazier, scientist; and Anne-Marie Tynan, research coordinator at St. Michael's Hospital Centre for Research on Inner City Health.

See "Stairmaster to Heaven" in the March/April 2005 issue of BCPWA's *Living* + magazine for some PHA perspectives on exercise and fitness ([www.bcpwa.org/pubs\\_living.php](http://www.bcpwa.org/pubs_living.php)).

## 7 Reasons to Bust a Move

Exercise can lead to:

- more energy
- less stress
- an improved mental outlook
- improved heart capacity and lung function
- sound sleep
- more regular bowel function
- enhanced self-image and self-esteem



# Me and My Liver

## A cautionary tale about chemical hepatitis

BY GREGORY ROBINSON

**JANUARY 2002.** My year got off to a rocky start. I glanced up at the doctor from my hospital stretcher. He had a fateful look as he focused between me and the view from the scope that was down my throat. A physician myself, I recognized that look of surprise and fear. He hastily asked for my consent to tie off the bleeding and bulging varicose veins in my esophagus, which were threatening my life. I agreed with a nod of my head, unable to talk due to the obstructing tube.

It took a few more months and a biopsy to discover that the symptoms I'd been experiencing—the discomfort from an enlarged spleen; mildly elevated liver enzyme levels (2–3 times above normal, which is not uncommon in people with HIV); fatigue; nausea,

vomiting, appetite and weight loss; and the gradual changes in my mental abilities (feeling confused and having trouble doing more than one task at a time)—were due to liver cirrhosis (permanent scarring of the liver). Though I didn't have jaundice (a condition in which the skin and whites of the eyes turn yellow) that's also seen in liver disease, many of my symptoms signalled that my liver may have been ailing. However, each of these symptoms could have been attributed to many other different things, such as side effects, other infections or cancer.

When the liver fails, scar tissue piles up (fibrosis, then cirrhosis) interfering with blood flow and function. The swollen, bleeding veins in my esophagus were due to my rock-hard liver

## ALL OF THE SUBSTANCES

preventing blood from flowing back to my heart. The backed-up pressure made the veins around my esophagus swell, as they're used to getting the blood back to the heart. When this happens, eventually the veins blow up and there's a high probability of bleeding to death. Was my time up?

### LIVER LESSONS

This wasn't the first time I'd had news of a fatal disease. I've had HIV for more than two decades. Because I was operating in survival mode and assumed I was going die from AIDS, for all these years I focused on maintaining my viral load and CD4 count, not worrying so much about other health issues. If these counts are OK, I thought, I'll live on. However, when I was diagnosed with cirrhosis, my CD4 count was between 300 and 400 and I had an undetectable viral load. So much for that theory.

These days, many people with HIV/AIDS (PHAS) confront multiple health problems due to a combination of their HIV, other illnesses they may have and side effects from HIV treatment. The effects of long-term treatment with highly active antiretroviral therapy (HAART) are just becoming known as more of us are surviving longer and taking the medications for prolonged periods of time. It is increasingly recognized that many HIV meds have dramatic effects on our bodily organs. The liver is one of these organs.

Tucked into the lower right-hand corner of the ribcage, the liver is like a processing plant. It takes the raw materials (like food) that are absorbed from our gut and breaks them down (or metabolizes them) to make many of the basic nutrients for the cells of our body. We cannot survive without these liver-produced nutrients. The liver also has the important role of processing different substances we ingest—including medications, herbs, illicit drugs and alcohol—and then detoxifying and eliminating them.

### BEAST OF BURDEN

Hepatitis means inflammation of the liver (*hepat* = liver; *itis* = inflammation). The liver can become inflamed

# OUR LIVERS ARE EXPOSED TO BECOME A BURDEN ON THIS VITAL ORGAN.

due to a variety of reasons. There are two types of hepatitis that are common among PHAS:

- chemical hepatitis—induced by substances such as medicines, herbs, alcohol, illicit drugs
- viral hepatitis—predominantly caused by hepatitis A, B or C infection (hep C is the most common among PHAS)

Whether hepatitis is caused by chemical or infectious agents—and how severe and long the injury to the liver is—will determine if the liver can survive. The good news is that this organ can often regenerate itself even after it is insulted. Many forms of viral hepatitis can be treated with meds, but chemical hepatitis can only be “treated” by eliminating the cause(s) soon enough so that the inflammation subsides and cirrhosis doesn’t result. In people with chemical hepatitis, a liver that is not yet seriously damaged can restore cells to normal functioning in just a few months, a respite that a break from meds and/or other substances may allow. When the injury is too severe or has happened over a long period of time, eventually the inflammation causes cirrhosis. Once liver scarring occurs, it is permanent and not reversible. However, the liver can and does still function for a while in people with cirrhosis depending on how many liver cells are still working.

I’ve been on HIV meds for 15 years; for the past 10 years I’ve been taking four or more antiretrovirals. Many of these drugs on their own can be hard on the liver, so I can only imagine the effect of the mix of meds I’ve taken. Besides antiretrovirals (high doses of the protease inhibitors saquinavir and ritonavir as well as the nucleoside analogue ddI), some of the types of drugs I’ve been on include Lipidil (fenofibrate), for high lipid, or fat, levels; an antidepressant; and anti-inflammatory drugs, for arthritis—all of which are metabolized through the liver.

It is essential to maintain a healthy liver—it feeds our system and processes the multiple meds we take, including antiretrovirals and drugs for side effects and other diseases or

infections. All of the substances our livers are exposed to become a burden on this vital organ. When your liver is burdened, you have to start thinking holistically about your health and everything that impacts your organs.

## TESTING 1, 2, 3

So how do you know if your liver’s taking a licking? To monitor the health of this organ, your doctor should regularly take blood tests to measure your liver enzymes. (It’s a good idea to have them checked a few weeks after you start any new drug and then at least every 3–4 months.) These enzymes leak from the liver into the blood when liver cells are damaged or killed. Liver enzyme tests do not measure how well the liver is working, they just indicate that it’s been injured by something.

If your doctor suspects a problem, he or she may do more detailed tests to see if the liver is performing its essential functions—making proteins, making clotting factors to stop bleeding when you’re injured, and processing and eliminating the waste product bilirubin. These tests include serum albumin, bleeding time and bilirubin, respectfully. They are done when your liver enzymes are either acutely elevated or if they remain elevated for a prolonged period of time. When these tests are affected, it’s a sign that the liver is failing to do its job.

If liver damage is confirmed, other tests are done to investigate the cause and determine the severity. These include abdominal ultrasound or CT scans to examine the size and appearance of the liver; blood tests for the cause of hepatitis; alpha-fetoprotein blood test (for liver cancer); and sometimes special tests for gallstones.

Liver transplant doctors use a grading system called the Child Pugh criteria to assess how well the liver is doing and if and when you should be listed for transplantation. The Child Pugh has three categories (A, B and C) and uses the blood tests albumin, bleeding time and bilirubin, along with changes in mental abilities and the presence of fluid in the abdomen (ascites). If you have advanced liver disease (cirrhosis) and your liver is still functioning fairly

well, you are an A. When the liver shows signs of failure to function you progress to a B, a transplant is considered and you may be listed for transplantation. If you become a C, it is unlikely that you will survive.

Sometimes a liver biopsy is required, in which a needle is inserted through the skin into the liver to take a sample. A liver biopsy is necessary to diagnose cirrhosis and is used to assess the degree of liver scarring and inflammation. A liver specialist should explain the procedure to you, including the risks (such as internal bleeding), after-effects (pain), and the reason you need it. These risks can be minimized if the doctor has the right training and experience with this procedure and if you’re monitored in the hospital for a few hours after the biopsy. I sailed through my biopsy without pain or complications.

My biopsy confirmed that I had cirrhosis. All other tests led to an unknown cause for my liver disease (in medical lingo, this is referred to as

## Organ Grinders

All meds have the potential to cause liver side effects, including the following, which are commonly used by PHAS:

- all antiretrovirals carry a risk of liver damage—the risk is greater with ddI (Videx) and d4T (Zerit), nevirapine (Viramune) and full-dose ritonavir (Norvir)
  - antibiotics—trimethoprim-sulfamethoxazole (Bactrim/Septra), isoniazid and rifampin (both for tuberculosis)
  - statins and fibrates, used to help lower cholesterol and lipid levels
  - acetaminophen (Tylenol; found in many over-the-counter pain relievers), primarily when used in high doses with alcohol
  - some psychiatric meds
  - some cancer chemotherapy drugs
  - many anti-hypertensive agents used to control blood pressure
  - amiodarone and some other cardiovascular drugs
  - antidiabetic agents
  - estrogen
  - anabolic steroids
  - alcohol
  - street and recreational drugs (such as heroin, cocaine, ecstasy)
  - some herbs and herbal teas (comfrey, Kava)
- If you use any of these, have your liver enzyme levels checked regularly.

# PHAs ARE NOT ELIGIBLE FOR SOLID ORGAN TRANSPLANTS IN CANADA.

“cryptogenic cirrhosis”). I do not have hepatitis A, B or C, nor was any other cause found—I don’t use street or recreational drugs and I’m not a heavy drinker. But I have been taking multiple medications for the past 15 years. It’s taken a few years for the doctors to reconsider my diagnosis and start to believe that the cause in my circumstances was chemical hepatitis.

## LIVER SPOTS

I’d like to think that my situation is unique and that no other PHAs will be so affected by their treatment. But I’m afraid this isn’t the case. Taking multiple meds—antiretrovirals, antidepressants, cholesterol-lowering agents, anti-infective agents, over-the-counter drugs, herbs—is very common among PHAs. Many of our meds are now being found to have various adverse affects on our body organs (including our livers, pancreas, kidneys and heart). To further complicate liver health in PHAs are issues of alcohol and drug use, as well as the high prevalence of hepatitis B and C. If our organs fail, what are our hopes of getting a transplant? Not so good.

PHAs are not eligible for solid organ transplants (kidney, liver or heart) in Canada. This is a scary situation for those of us (and over time there may be many of us) who may need this medical treatment to survive. At the 2003 Conference on Retroviruses and Opportunistic Infections, U.S. researchers reported that PHA transplantees on stable and successful antiretroviral therapy do *just as well as* HIV-negative transplantees, with one-year survival rates of about 85 percent. So we Canadian PHAs have yet another battle on our hands—to get access to organ transplants. And we know it is possible: After much activism, organ transplants are now being done in PHAs in select clinics and hospitals in the U.S.

## GETTING ORGAN-IZED

January 2005. I’m still here. Now I’m diligent when it comes to protecting my liver . . . and my heart, kidneys, and so on. Life is more than just viral load and CD4 count. I eat well to maintain my weight, consuming enough

calories and protein. I exercise daily to maintain muscle mass and cardiovascular fitness. And I love yoga—it not only improves my well-being, it also expands my spiritual horizons. Yoga has changed my perspective. It inspired me to take hold of my health.

I avoid alcohol (except the rum balls at Christmas) and drugs, and I take over-the-counter meds only after discussion with my doctors. Most importantly, I work more closely with my primary care physician and various specialists to tailor my meds to avoid further side effects to my bodily organs. For the past three years I’ve been on an HIV drug regimen that reduces the burden on my liver.

I take daily multivitamin and mineral supplements. Some PHAs support the liver with nutrients that raise levels of glutathione (a major antioxidant in the liver cells)—antioxidants such as NAC (N-acetyl cysteine), alpha-lipoic acid and vitamins C and E. Some do acupuncture or take certain herbal therapies, such as silymarin (milk thistle extract). Much more is written about these therapies and other ways

to protect your liver in “13 Ways to Love Your Liver” (*The Positive Side*, spring/summer 2002).

I’ve outlived the highest risk of bleeding to death, although I need regular examinations of my esophagus to tie off the veins that pop up. My liver enzymes have returned to normal since I switched some of my daily HIV and other meds and, so far, my Child Pugh remains in the A category. So, while I don’t need a liver transplant just yet, I may in the future. I’m hoping that with my new approach I can stall or even eliminate my need for a transplant. In the meantime, I’m busy trying to push for our right to access a lifesaving medical treatment—solid organ transplants—a modern-day dilemma to an age-old problem in AIDS activism. +

Greg Robinson, MD, is a doctor in public health and community medicine who is on disability. He now does volunteer work, like writing this article. He lives in Toronto with his long-term partner and his wonderful Westie.



## Screen Test

When your liver is inflamed, how do you decide whether to switch, stop or stick with your meds? Though all six liver markers should be taken into account, here is a rough guide to one important liver enzyme, **alanine aminotransferase (ALT)**: ALT below 40 is safe; minimal elevation above 40 is unlikely to be significant; anywhere between 200 and 600 is dangerous. It is rare and controversial to stay on meds if this enzyme count rises above 600.

Check your liver function at least every 8 weeks for warning signs of damage. Any value above normal may mean your liver is experiencing stress and that you should start taking steps to care for it. Values 3–5 times the upper end of normal may signal a red alert; consult your doctor right away. Note: Each lab has its own scale, so numbers may vary slightly.

NAME	DESCRIPTION	NORMAL RANGE
AST (aspartate aminotransferase, sometimes called SGOT)	a liver, heart and muscle enzyme	10 to 40 IU/l
ALT (alanine aminotransferase, sometimes called SPGT)	a liver enzyme	10 to 30 U/ml
ALP (alkaline phosphatase)	a liver and bone enzyme	20 to 90 IU/l
GGT (gamma glutamyl transferase)	an enzyme present in bile and blood	5 to 37 u/l
Bilirubin	a waste product of red blood cells, processed in the liver	total 0.1 to 1.2 mg/dl
LDH (lactic dehydrogenase)	heart, liver, kidney, brain, lung and muscle enzyme	total 80 to 120 IU/l

Chart from *POZ*, September 2000. Reprinted with permission. Copyright 2000. CDM Publishing LLC.

# Lights, Lipo, Action!

Essay by **MARTIN MAILLOUX**



I was diagnosed with HIV in 1994 with 140 T cells. After seven years of antiretroviral therapy, I started to develop lipodystrophy. My legs got thinner, my belly got bigger, and my bum became almost “undetected.” With sunken eyes and shrunken cheeks, I felt like I had AIDS written all over my face. I looked weak, exhausted and sick. My family worried because they thought I was trying to hide a new terrible disease. I worried about my new metabolic problems, like rising cholesterol levels, which increase the risk of heart attack.

I switched one of my drugs—d4T (Zerit), because it's well known that it's implicated in lipodystrophy—to something more lipid-friendly. I also made some changes to my diet and did a lot more Taoist Tai Chi. Shortly after the switch, my cholesterol returned to normal and my body fat slowly began to reappear. In 2003, with the help of generous friends and family, I got shots of New-Fill in my cheeks to restore my face. With more Tai Chi, my legs and bum also came back.

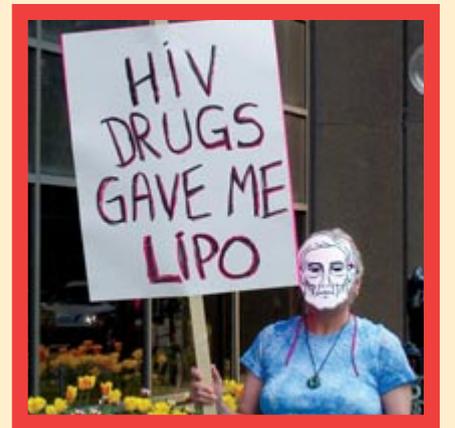
During this time, I became more aware of the lipodystrophy stigma experienced by a growing number of PHAs—as well as the lack of relevant information and support. I was exasperated by the slowness of the health network to recognize the serious effects of lipodystrophy on the health, physical integrity and quality of life of PHAs. I wanted desperately to do something about this, so I joined LIPO-ACTION!—a direct action group in Montreal that was created by lipo-laden PHAs and their sympathizers. I was on my way to becoming an HIV Lipo Warrior!

The medicine of LIPO-ACTION! is taking action. Since the beginning of our public action campaign, we have seriously disturbed those who claim that lipodystrophy isn't so bad. By breaking the silence together, we inform,



sensitize and mobilize the public about the impact of lipo on PHAs. With 70 active members in Quebec, we've organized many creative and theatrical demonstrations at HIV events, where our lipo characters wear masks and balloons as bellies and humps, hold up placards with smacking slogans and shake our big noisy pill boxes. Our troop of “HIV mutants” and archetypal characters represents different facets of the reality of lipodystrophy, including the HIV Lipo Warrior (fighting for a better quality of life), The Scream of Munch (loneliness and despair), and the three insensitive and denying doctors—Dr. Blindpills, Dr. Bouché (deaf) and Dr. Motus (mute). The use of symbols enables us to fire the imagination and touch people. After a skit you can see the rising of dignity again in the eyes of participants.

In just a few months—with demos, workshops, lobbying politicians and the media, and participating in press conferences and meetings of AIDS organizations—LIPO-ACTION! has managed to break the silence about the reality of lipodystrophy. Now we can hope for a better response to a problem that is recognized.



I strongly recommend the medicine of LIPO-ACTION! By coming to our monthly meetings or creating a group in your area, you can better face lipodystrophy and strive together for concrete solutions. You can reach us by e-mail at [lipoactionquebec@yahoo.ca](mailto:lipoactionquebec@yahoo.ca). +



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The latest on what is known about the various aspects of treatment, including a description of the virus and the immune system, the stages of HIV disease, the tests used to assess health status, and anti-HIV medications.

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The latest on what is known about various side effects related to treatment, from appetite loss to sexual difficulties, and tips for countering or preventing them.

### + A PRACTICAL GUIDE TO COMPLEMENTARY THERAPIES FOR PEOPLE LIVING WITH HIV/AIDS

This guide provides an overview of many CAM therapies used by PHAs. Included are descriptions of several forms of massage, mind-body medicine and an introduction to complementary medical systems such as Ayurveda and homeopathy. This guide also offers lists of

resources where people can find more information about the various therapies in Canada.

### + A PRACTICAL GUIDE TO HERBAL THERAPIES FOR PEOPLE LIVING WITH HIV/AIDS

This made-in-Canada reference tool provides PHAs with information regarding non-pharmaceutical treatment options.

### + FACT SHEETS & SUPPLEMENT SHEETS

Concise overviews of conditions, symptoms, medications, side effects, complementary therapies, vitamins, herbs and other treatment issues.

### + MANAGING YOUR HEALTH, 1999 EDITION

A must-read guide for PHAs which addresses social, legal, health-related and practical issues comprehensively and from a national perspective.

### + PRE\*FIX

A harm reduction booklet for HIV+ drug users.

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**MISSION:** The Canadian AIDS Treatment Information Exchange (CATIE) is committed to improving the health and quality of life of all people living with HIV/AIDS in Canada. CATIE serves people living with HIV/AIDS, and the people and organizations that support them, by providing accessible, accurate, unbiased and timely treatment information. CATIE works in partnership with a network of other information providers to ensure that people have access to the information they need, in the form they desire, to make informed health care choices.

This publication is available in English and French, on-line at [www.catie.ca](http://www.catie.ca), or by calling 1.800.263.1638.

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Ask questions of our knowledgeable Treatment Information Service Representatives when it is convenient for you.

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