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Table of Contents:

[Bill 159 is Dead](#)

[Work Opportunities!](#)

[Viatical Update Part II](#)

[Coroner's Inquest Report](#)

[ODSP Update: April 1st changes](#)

[Blood Samples Act Back](#)

[You Asked Us](#)

[We're Growing - Again!](#)

Bill 159 is Dead - For Now

Bill 159, the Personal Health Information Privacy Act (PHIPA), died on the order paper when the Harris government prorogued the house in late February. This means that this particular piece of legislation, which had been referred to committee hearings after first reading, will go no further. But you can bet your bottom dollar that it will be back.

Bill 159 was the latest version of PHIPA to be tabled in the house. In 1997, an earlier version of this legislation, the *Personal Health Information Protection Act, 1997* was presented in draft form and made available for wide public consultation. At that time, HALCO was involved in the development of an Ad Hoc Committee which put together a

community response and drafted a submission to the Ministry of Health setting out our concerns with the proposed legislation. This position paper was distributed to all AIDS Service Organizations in Ontario for endorsement and was then submitted to the Ministry.

After receiving a great number of critical responses from a wide variety of stakeholders, the Ministry indicated that they would take all of these submissions into consideration and would be reworking the legislation.

Following this, on October 15 1999, the Federal government introduced Bill C-6, the *Personal Information Protection and Electronic Documents Act* (PIPED) through First Reading. This legislation, which was then approved by the House on October 26 1999, is described as “an act to support and promote electronic commerce by protecting personal information that is collected, used or disclosed in certain circumstances...” Under the PIPED, which received Royal Assent on April 13, 2000, each of the provinces has a time limit within which they must prove that they have “substantially similar” legislation or else PIPED would apply to the collection, use or disclosure of personal information in that province.

This time limit expires January 1, 2004. At that time PIPED will cover the collection, use or disclosure of personal information in the course of any commercial activity within a province, including provincially regulated organizations. The federal government may exempt organizations or activities in provinces that have their own privacy laws if they are substantially similar to the federal law. To assist in making that determination, the Privacy Commissioner is mandated, under the Act, to report to Parliament on the extent to which provinces have passed legislation that is in fact substantially similar.

In order to meet this time limit, the Ontario government released a consultation document in September 2000, regarding a proposed Privacy Act for Ontario. The proposal talked about a piece of general privacy legislation, to which schedules could be attached, including one specifically related to personal health information, entitled the “health sector privacy rules”. HALCO submitted a response to the proposed health sector privacy rules document, which you can find on our website at www.halco.org.

On December 7, 2000, the provincial government changed their tune and introduced the proposed Personal Health Information Privacy Act, 2000 at first reading. The draft legislation was sent to the Standing Committee on General Government for public hearings after first reading in order to allow for public consultation earlier in the process. These hearings were held at the end of February, 2001. Four HIV/AIDS organizations were able to secure a time slot before the standing committee on General Government: the Algoma AIDS Network, the AIDS Committee of Toronto, the Ontario AIDS Network and HALCO. Together we were able to present a well-rounded picture of the concerns of the HIV community with respect to this legislation and detail our opposition to many of the provisions.

In particular, we expressed very serious concerns in four broad areas: the scope of the legislation; the overly broad ability to disclose information without the individual's consent; the difficulties in accessing one's own personal health information records; and the lack of effective remedies for breaches of confidentiality. A complete copy of HALCO's written submissions are available on our website at www.halco.org, by selecting "Position Statements" from the menu on the left.

At the Standing Committee hearings, the Federal Privacy Commissioner, George Radwanski indicated that he, and his office, had significant concerns about the proposed legislation and felt that it fell far short of the objective of effectively protecting the privacy of personal health information in Ontario. During the course of his submission, he specifically indicated that he could not recommend to Parliament that Ontario be exempted from Bill C-6 based on the proposed legislation as it was certainly not substantially similar legislation. The Ontario Privacy Commissioner, Ann Cavoukian, was also critical of the proposed legislation and indicated that it would need significant changes.

At the conclusion of the hearings, the provincial government announced that the house would be prorogued, which means that any legislation still on the order paper (i.e. that had not yet received royal assent) would die. It remains to be seen what the government's plans are with respect to provincial privacy legislation in general, and legislation regarding personal health information in particular. We will keep our eyes and ears open for the next steps of the government. In the meantime, to learn more about what Bill 159 had to say,

and our concerns with it, please read the submissions available on our website, or contact Matthew Perry at 416-340-7790 or 1-888-705-8889 to have the document sent to you.

Work Opportunities!

At a recent meeting, the HALCO board approved a plan to provide an opportunity for HALCO's membership to earn some money while helping the clinic to provide legal services.

In the course of our work, staff at HALCO are frequently in the position of having to serve documents on other parties. This activity is usually called "process serving". Occasionally we have had to pay for process servers to carry out this work for us, or to do it ourselves, which can take time away from the office, and limit the time we are available for our clients.

The board proposed that we offer to the membership the chance to carry out this role on our behalf, and earn a little bit of money at the same time. The board has proposed that we pay \$50 to a member who acts as a process server for the clinic. If you are currently in receipt of disability benefits from a private insurance company, the Ontario Disability Support Program or Canada Pension Plan and have concerns about how this kind of income might affect your eligibility for benefits, check out the You Asked Us column in this issue of halco news.

If you are a member and are interested in finding out more about this opportunity, please contact Matthew Perry at 416-340-7790 or 1-888-705-8889 or by email at perrym@olap.org. We expect to offer opportunities on a rotating basis to interested members. If you're not a member, contact Matthew to find out how to become one. Membership in HALCO is free and valid for one year.

Viatical Update Part II

Selling Your Life Insurance Policy: Is it legal or not?

For many years the law in Ontario has been that you could sell your life insurance policy but only to an insurance company. It appears that is about to change.

Selling a life insurance policy is often called “a viatical settlement”. Say you have a life insurance policy from when you were working for \$100,000. You agree to assign the proceeds of that policy upon your death to someone in exchange for cash up front. This is a straight sale or “viatical”. Insurance companies in Ontario have offered “living benefits” for several years now. “Living benefits” are not really viatical settlements. Rather they are a loan against the value of the policy upon your death.

Despite the fact that viaticals outside of insurance companies in Ontario are illegal, a small industry has grown up. Because the industry is illegal however, there are no legal protections for consumers. There is a rule of law that says that the courts will not enforce an illegal contract, so if an illegal viatical company fails to pay you what they agreed to, it is difficult to get the money they owe you.

The provincial government recently passed Bill 119, the Red Tape Reduction Act. Schedule G of that bill repealed the section in the Insurance Act that said no one could trade in life insurance policies except the insurance industry and replaced it with two new sections. First, trading in life insurance policies will be illegal unless the company or person buying your policy gets an exemption. Second, and more importantly, the new section gives the Ministry of Finance the ability to regulate a viatical industry: to issue licenses to viatical companies; and to regulate it, presumably in the public interest.

Bill 119 has passed and received Royal Assent, but the sections about viaticals have not been “proclaimed” yet so they are not in force. The Ministry of Finance has indicated that they will not proclaim Schedule G until they have drafted regulations and consulted about their content. If you have ideas about how a viatical industry should operate to protect people with HIV, contact the Minister of Finance, Jim Flaherty, at Frost Building South, 7th Floor, 7 Queen’s Park Crescent, Toronto, ON M7A 1Y7, phone: 416-325-0400 .

Coroner's Inquest

Into the death of Michael Leblanc

The following article has been submitted by Joanne McAlpine, Executive Director of HIV/AIDS Regional Services (HARS), Kingston

After two and a half days of hearing evidence, the Coroner's Inquest jurors (one man and 3 women) delivered their verdict on the death of Michael LeBlanc. Michael died in the regional hospital, within the walls of Kingston Penitentiary (KP), a maximum security prison, on Nov 18/99. He was found to have died of acute bronchopneumonia and damage from hepatic cirrhosis. Michael was also HIV positive.

Michael was a service user of HARS and, given the amount of time he had served in federal institutions, it was possible, if not probable, that he contracted both HIV and HepC inside. We had concerns about the responsibility of Correctional Services of Canada (CSC) with respect to prevention of both viruses, given their mandate to protect the health and safety of all inmates. We had grave concerns about the "palliative care" provided to Michael and the failure of CSC to utilize their own compassionate release or "release by exception" protocol in time for Michael to die in the community, which was his wish.

The HIV/AIDS Legal Clinic (Ontario) (HALCO) agreed to represent us at the Inquest which was held on January 30, 31 and February 1, 2001. It was the first inquest for HARS and for Glenn Betteridge, a new lawyer at HALCO. He argued our case extremely well (noted by the jurors in their verdict as well) and brought out the issues of concern to us. Witnesses included Patti McGuirk, Prison Support Co-ordinator at HARS, Marilyn Duphney from Hospice Kingston, HIV specialist Dr. Peter Ford and Dr. Ralf Jurgens, Executive Director of the Canadian HIV/AIDS Legal Network.

The evidence was hard to hear at times. For example, we had been told by a nurse at KP that Michael died a peaceful death. In fact, Michael died in pain and both emotional and psychological distress.

The jurors had a tough job. They were expected to sort through a lot of evidence relating to HIV/AIDS in prison, nursing care, drug use, harm reduction, palliative care and CSC policy and procedures. Making recommendations to prevent a death in similar circumstances was optional for them but they chose to make one in their verdict, as well as draw attention to the issues raised by HALCO and HARS. It is of interest to note that neither the lawyer for CSC, nor any CSC employee was present when the jurors delivered their verdict.

The recommendation reads “That the regional hospital at Kingston Penitentiary seek outside accreditation by an independent agency as is done for other public hospitals in Canada.” However, the jurors added “Other issues that concerned the jury and which should be of ongoing concern to the CSC are these:

- the prevalence of diseases such as HIV/AIDS and Hepatitis C within the penitentiary system which underlie the need for both prevention and harm reduction methods through assorted proactive strategies and pilot programs (read “needle exchange”),
- the need for CSC to continue developing the palliative care program at KP in conjunction with outside agencies such as Hospice Kingston, and
- the need for CSC to develop clear and well-publicized guidelines for those individuals who may be eligible for compassionate release.”

The inquest received lots of media coverage, both local and national. Maureen Brosnahan was heard daily on CBC Radio World Report with interviews with witnesses and Glenn.

The situation has to change because advocates such as PASAN, Peterborough AIDS Resource Network, the Legal Network, HALCO and HARS will continue to press CSC force changes. Inquests are only one avenue for raising issues but they are clearly not the most desirable one – a death has already occurred, instead of being prevented.

ODSP Update: April 1, 2001 Changes

Effective April 1, 2001, a couple of changes will be coming into effect which will have an impact on those applying for benefits under the Ontario Disability Support Program (ODSP). Currently you can apply for ODSP in one of two ways: through Ontario Works (OW), whereby you can receive OW assistance while waiting for your ODSP application to be decided; or as a self-referral at the ODSP office. The changes discussed below only apply to those individuals who are applying for ODSP through the OW route. A third change, about liens on property, actually came into effect January 1, 2001.

Asset Level Exemptions:

Until now, you could use a once-in-a-lifetime option to apply the ODSP asset limits when applying for social assistance through OW. In this way, you could receive benefits from OW, including a drug card, while waiting for your ODSP application to be processed, even though your assets were too high for OW. If you were ultimately denied ODSP benefits, you would then have to meet the OW asset limits, which are much lower (equal to one month's assistance). In that case, you would be suspended from OW assistance and have to spend down your assets to meet OW requirements before being able to go back on.

Effective April 1, 2001, OW can require that you agree to repay some or all of the OW assistance you received if your ODSP application is ultimately unsuccessful. In this case, you would be required to repay either the OW assistance you received during the months you used the higher ODSP asset limit, or the value of the your assets in excess of the OW asset limit on the day that your ODSP application was finally denied, whichever is less.

Automatic Deferrals from OW participation:

April 1, 2001 also marks the start of a new approach to deferrals from OW participation requirements if you have applied for ODSP. Currently, if you apply for ODSP through OW or while on OW, you are automatically deferred from any participation requirements with OW

until your ODSP application was finally decided. If your ODSP application was unsuccessful, at that time you would have to enter into a participation agreement with OW in order to maintain eligibility for assistance.

Beginning April 1, 2001, there is no longer an automatic deferral. In order to have a deferral from participation requirements, you will have to demonstrate that there are grounds for deferral. This will take the form of medical documentation from your physician or other health care provider showing that you should not have to meet participation requirements. This is the same system used for OW participants who are temporarily unable to meet their participation agreements due to illness or injury.

Liens on Property:

Since the ODSP came into effect, recipients have been exempt from having a lien placed against their principle residences. Lien provisions only applied to second or third properties, in particular circumstances. ODSP applicants, therefore have so far not been required to sign consents to a lien being registered against their property. Under the change, which became effective January 1, 2001, ODSP applicants who are applying through OW will be required to sign a consent to a lien being registered against their property. This form does not mean that a lien will be registered against your property immediately, but that you consent to it being done. If your application for ODSP benefits is successful, the consent will be voided and no lien will be registered against your principal residence. If you are ultimately unsuccessful in your ODSP application, the consent to lien would then be used to register a lien against your property if you continued to receive OW assistance for 12 continuous months. Finally, it is important to note that effective April 1, 2002, a lien can be registered against the property of any person who has been in receipt of OW assistance for a total of 12 months in any five year period, and not just 12 continuous months.

Blood Samples Act is Back!

In the fall of 1999, halco news (vol. 4 no. 3) reported that a bill designed to allow for the taking of blood samples to detect

the presence of certain viruses, or the “Blood Samples Act” had received first reading in the House of Commons. The bill was a private member’s bill sponsored by Keith Martin, a British Columbia Reform member. The bill did not proceed beyond first reading in that instance. Unfortunately, however, the bill keeps getting reintroduced to the House of Commons. It was reintroduced by Chuck Strahl, a Canadian Alliance member as Bill C-244 on October 18, 1999 and its most recent version was re-introduced as Bill C-217 in the current session of Parliament, receiving first reading on February 5, 2001.

Bill C-217 would allow forced testing of people for HIV, and Hepatitis B or C where a “good samaritan”, a peace officer, firefighter and other emergency services personnel, as well as other health care workers, may have been exposed to a risk of infection with these viruses. Under the terms of the proposed legislation, the applicant (the person who may have been exposed) could request a warrant be issued by a judge which would force the “source” person to provide a blood sample to be tested for HIV and/or Hep B or C. If the “source” person refused to provide a blood sample, they could face up to six months imprisonment. The Canadian HIV/AIDS Legal Network (CHALN), along with Justice Canada and Health Canada have expressed their concerns about the bill. Organizations like the Police Services Association have continued to lobby hard for the bill to be passed.

The Standing Committee on Justice and Human Rights held hearings in the early summer of 2000 about the bill. Among those presenting to the committee was Richard Elliott, Director of Policy and Research for CHALN. The network outlined their concerns with the bill, underlining the positions that such legislation is unnecessary, unethical and unconstitutional.

While those in favour of the bill have consistently argued that having knowledge of the source person’s serostatus would assist them in making decisions about post-exposure prophylaxis (PEP), CHALN and others who are critical of the bill have noted that the time it would take to find a judge and seek a warrant, execute the warrant and test for HIV and Hepatitis would far exceed the proposed 2 hour window for starting PEP. In addition, if the source person was him or herself in a window period during which they

were in fact infected but had not yet produced antibodies, their test would come back negative. This might lead someone to make a decision about whether or not to initiate PEP therapy on false information.

As for Hepatitis A and B, there are currently vaccines available to prevent against infection with these viruses, and all emergency and health care providers should be required to have up-to-date vaccinations – thereby eliminating the need to require a “source” person to undergo forced testing. Finally, with respect to Hepatitis C, there is currently no vaccine or PEP-type treatment, so forcing a “source” person to be tested is not necessary. The exposed individual, in this circumstance, would be better off to get tested themselves.

CHALN went on to discuss how the proposed legislation also fails to ensure the confidentiality of the test results for an individual who was ordered to provide a sample, how Bill C-217 fundamentally does away with the notion of informed consent, and how it violates a person’s right to security of the person, which is guaranteed under the Canadian Charter of Rights and Freedoms.

CHALN has a number of materials related to this issue available on their website, at www.aidslaw.ca. Included in the online materials is a memo to the CHALN membership outlining the Network’s concerns with the legislation, as well as a copy of a letter sent to Justice Minister Anne McLellan urging her government to oppose this legislation. Finally the text of the Committee’s hearings on this bill can be found by linking to [Http://www.parl.gc.ca/InfoComDoc/36/2/JUST/Meetings/Evidence/JUSTin-E.htm](http://www.parl.gc.ca/InfoComDoc/36/2/JUST/Meetings/Evidence/JUSTin-E.htm), and scrolling down to “**Blood Samples Act (Bill C-244)—Strahl**”.

[CLICK HERE FOR THAT LINK](#)

Here you will find links to the text of three days of hearings on the proposed legislation. If you would like to let the Justice Minister, Anne McLellan know what you think, you can reach her by phone at (613) 992-4524, by fax at (613) 996-4516 or by email at McLellan.A@parl.gc.ca. Her mailing address is Justice Building, 3rd Floor, 284 Wellington St., Ottawa, ON, K1A 0H8.

You Asked Us...

Q: I have been offered an opportunity to work as an extra on the set of *Queer as Folk*. (Hey, I hang out at Woody's anyway.) It would be one day, or half day at a time and not very frequently. But I am on disability benefits and the pay for even a day's work as an extra is pretty good. Can I do it without losing my benefits? What will happen?

A: When you say "disability benefits" you could mean one of three things: disability benefits from an insurance policy; Ontario Disability Support Program benefits; or Canada Pension Plan disability benefits. Or, your income could be from a combination of those three sources. The answer to your question is different depending which of these sources of income you are talking about.

If you are receiving LTD benefits from insurance, your insurance policy probably says that you have to report income from working and it will be deducted dollar for dollar from your LTD. The real question with LTD is: will this little bit of work trigger a medical review and put my benefits at risk? The answer to that question will depend a little on whether or not the definition of disability under your policy is "incapable of performing the pre-disability job" or, "incapable of regularly working at any job". We often call the first definition the "own occupation" period as the test for disability is: can you do your regular job? The second definition we call "any occupation" because the test is: can you do any job? It is normal for the definition of disability to be an "own occupation" test at the beginning of an LTD claim, and then to switch to an "any occupation" test after a few years. If your pre-disability job was not acting or being an extra, and you are in the "own occupation period" then working as an extra is less likely to cause problems with an insurer than if you have been on LTD a long time (where the definition of disability is "any occupation"). Before taking the extra job you should very carefully check the sections of your insurance policy or benefits booklet which state the definitions of disability, and the sections about work trials or vocational rehab. You also might want to have an insurance professional (say at ACT's Insurance Clinic) take a look at those sections and advise you.

If you are on ODSP, the situation is much brighter. Working as an extra will not trigger a medical review. You will have to report the income however. If you are single, ODSP will take the net amount of your earnings, subtract \$160 from that, then subtract a further 25%. The amount left will be deducted from your cheque.

If you get Canada Pension Plan disability benefits, or CPP-D, the situation is different again. CPP-D does not deduct earnings from your benefits. However, working can trigger a review of your eligibility and that usually means that your CPP-D is cut off until you provide another set of medical documents. The definition of disabled person under CPP should allow you to work occasionally, provided you do not earn very much. This is because the definition of disabled person under CPP talks about your being “incapable regularly of pursuing any substantially gainful occupation”. Theoretically, a one off kind of job like an extra should not cause a problem under CPP because it is not “regular” and it is not “substantially gainful”. Unfortunately, in practice, CPP often just puts your benefits on hold and asks for new medicals anyway. Some people have had great success in circumstances like this by “pre-empting” CPP-D. In other words, we suggest you send CPP information about the casual work immediately. Along with it, send a new doctor’s assessment that states that you may have been able to do one day as an extra but you cannot do it or any other job on a predictable or regular basis.

We’re Growing... Again

As always, it brings us great pleasure to let you know that the HALCO staff is growing again. Last July, we added an articling student to our staff, bringing us up to four. As many of you know, we are able to use a combination of support from the AIDS Committee of Toronto Community Partners Fund as well as donations to fund this position. In September, we were able to take advantage of a restructuring of our funding and hire a part time support staff person and an additional staff lawyer.

At the end of December, HALCO also learned that we had been awarded one of the new staff positions being created

out of the Legal Aid Ontario expansion initiative. After careful consideration, the HALCO board decided that we should hire an additional lawyer with a focus on litigation experience. This will help us to increase our capacity to work on issues like problems with private insurance companies, and some litigation in the prison system.

On a final note, we are sad to note that Sara Schaeffer, our part-time support staff person who joined us in September will be leaving HALCO on April 12, 2001. Sara has been an important part of HALCO's transition to more staff and helped us make it through our Quality Assurance Program evaluation in September 2000. Sara is leaving HALCO to accept a position with the Durham Community Legal Clinic. We are most grateful to her for her hard work over the last six and a half months, and wish her all the best in her new job.