

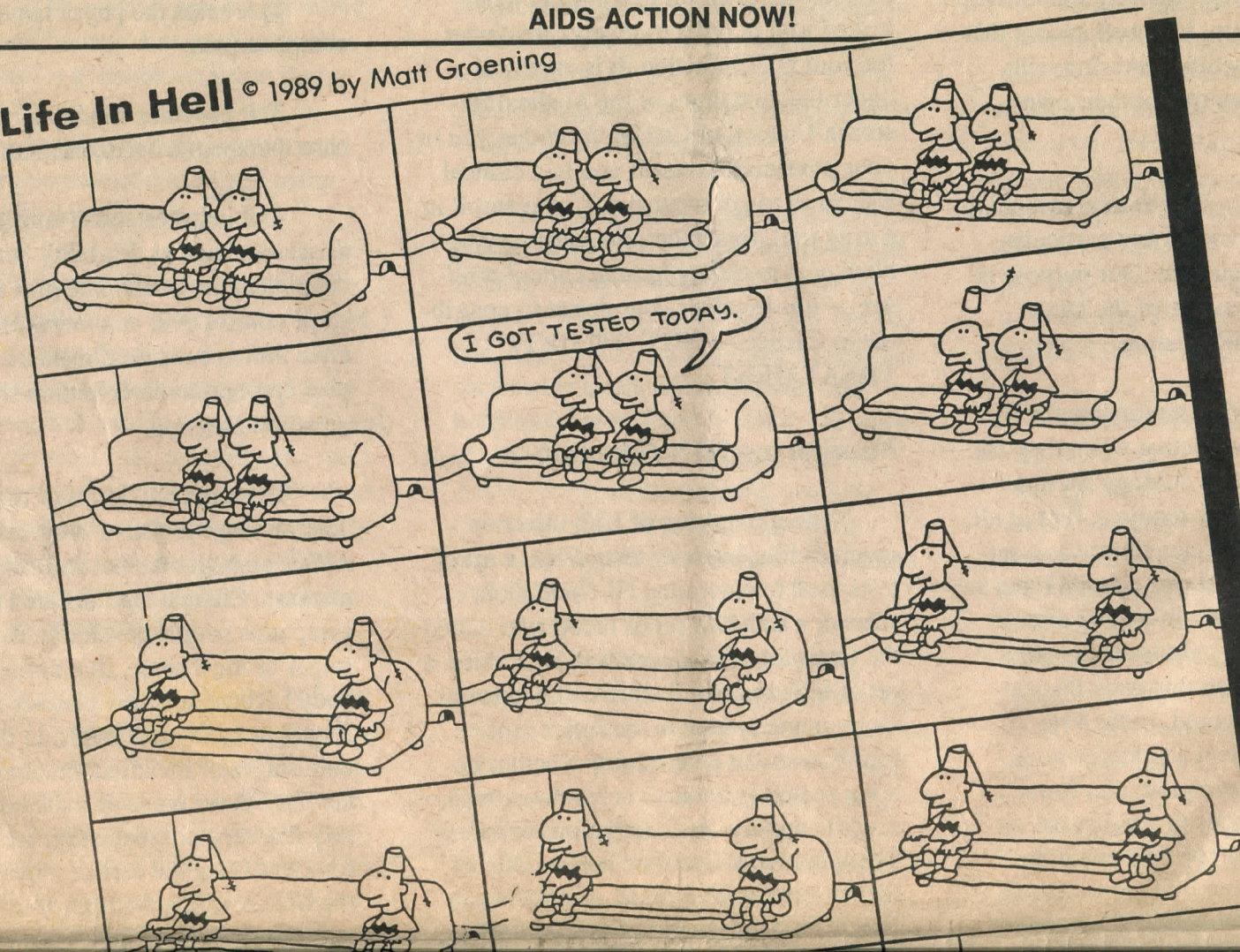
# TESTING AIDS

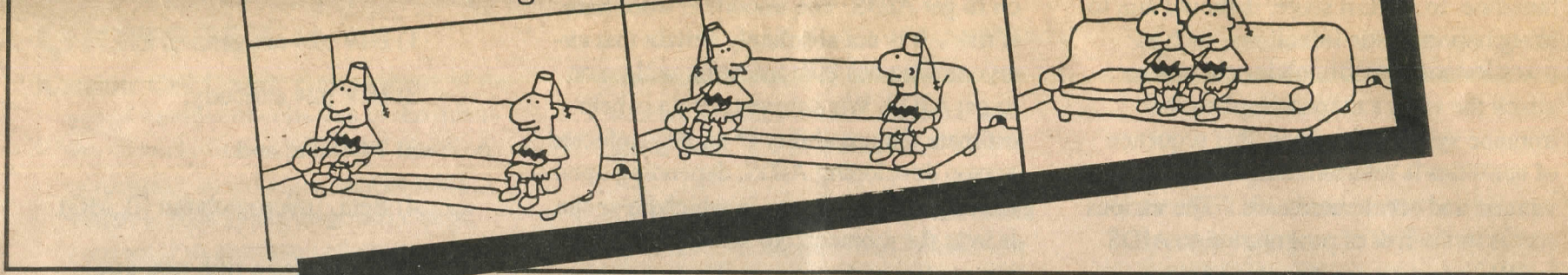
MAY 1989

AIDS ACTION NOW!

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Life In Hell © 1989 by Matt Groening





# DEALING WITH HIV INFECTION

Almost a year ago AIDS ACTION NOW! published TREATMENT AIDS for PLWAs, and for HIV-positive people. The message we brought was that AIDS, then thought of as a fatal disease, was in the process of becoming a chronic but manageable illness. This has come about, not just because new anti-AIDS therapies have been developed, but because new approaches to HIV infection have also been devised. New treatments, by themselves, are not sufficient. Long-term strategies for monitoring the infection are also required. Testing AIDS is designed to help individuals who are HIV-infected fashion a strategy for survival.

This publication has been designed for your use. It is intended to give you some of the basic information you need to begin monitoring HIV infection. Knowledge about HIV infection is increasing literally from day to day. While this gives cause for hope, it also means that medical approaches to this illness are in a constant state of flux. Even though the situation is

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## DEALING WITH HIV INFECTION

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often very frustrating, the disease is far too serious for individuals to try handling it by themselves. If you have HIV infection, you need a family doctor with whom you can have an ongoing, mutually supportive, working relationship. It is well known that those who are presently surviving with AIDS take an active role in their own treatment.

In making this information available, AAN! does not advocate any particular test, therapy, or treatment. Our purpose is to make you more aware of the latest developments in HIV testing.

It is the case that treatments for HIV infection are most effective when they are used within an overall strategy for handling the disease. This requires, first of all, thinking about AIDS, not simply as a set of opportunistic infections, like PCP, but as the final stage of a multi-staged disease that begins when an individual becomes HIV positive. Viewed this way, the purpose of treatment should, in the first instance, be to prevent a person who is infected, but still asymptomatic, from going onto later stages in the disease. At later stages, it should be to prevent the onset of opportunistic infections, like PCP, through the use of prophylactic therapies such as oral septrin and aerosolized pen-

through the federal Department of Health and Welfare's Emergency Drug Release Program. Your doctor should know how to get the treatments you need. You are advised not to enroll in a placebo-controlled trial in order to receive treatment for your HIV infection. It is unethical under the guidelines of the Medical Research Council of Canada for either you or your physician to enroll you in a clinical trial so as to get treatment. If you enroll in a drug trial, remember, *the purpose of a clinical is to test a pharmaceutical product.*— this involves your desire to contribute to science — **NOT TO GET TREATMENT.**

### Monitoring HIV Infection

The monitoring of HIV infection involves four kinds of tests: First, a set of tests used to determine HIV infection; second, a standard set of blood tests called the Complete Blood Count (CBC); third, a set of tests to predict what will happen to the immune system in the future; and fourth, tests for determining whether or not a person is liable to come down with specific opportunistic infections or cancer. These tests are described below. Of particular interest in terms of monitoring an HIV infection is the third group of tests—those used to determine the risk of going

1) it gives a realistic assessment of the risk of the progression for individuals with the infection;

2) it helps the physician monitor for complications;

3) it provides data upon which to base therapeutic decisions; and

4) it helps establish entitlement to assistance such as disability benefits. For the patient, however, it begins to provide some control over an otherwise uncontrollable illness because it makes it possible to plan appropriate intervention should the infection progress.

There are two kinds of markers for determining the risk of progression to AIDS: clinical markers and laboratory markers. Clinical markers are the kinds of symptoms people develop in the later stages of the disease, like bruises on the body because of a low platelet count. Asymptomatic individuals, in the beginning stages of the infection obviously do not have these kinds of indicators. Laboratory markers, consequently, are essential for identifying the earlier stages of risk. In the UCLA study, there are four laboratory tests that are used for determining the risk of progression to AIDS:

through the use of prophylactic therapies such as oral septrin and aerosolized pentamidine. In the last stage, it should aim to bring opportunistic infections, such as toxoplasmosis gondii, under control, to attack the virus and to strengthen the immune system. Together, this sequence of activities is referred to as "early intervention and accelerated care." The various stages in the risk of progression to AIDS in HIV infection are discussed below.

### A Program of Early Intervention and Accelerated Care

The first step in developing a program of early intervention and accelerated care is repeatedly to monitor the state of infection. The second step is, in consultation with your doctor, to determine what you should do to arrest the progression of the disease.

There is a major debate among medical practitioners about what treatments should be prescribed for asymptomatic individuals. A still controversial, minority medical opinion advocates treating HIV infection, like any other infection, as soon as possible. There are five different categories of intervention available: general health maintenance, holistic or complementary therapies, antiviral medicine, immunomodulating medicine, and preventative medicine against opportunistic infections<sup>1</sup>. Therapies that fall into the last three categories are outlined in *TREATMENT AIDS*.

Access to experimental treatments in Canada has recently been made easier

HIV infection is the third group of tests—those used to determine the risk of going on to get AIDS. The important word here is 'risk'. It is not absolutely certain that everyone who has HIV infection will go on to get AIDS. What these tests do is help estimate the possibility of an HIV-infected person developing AIDS, depending upon the stage of the disease in which he or she is in at the moment. No set of probabilities can predict with certainty the progression of any particular person's infection. There are many people with T4 counts below 200 who are still asymptomatic. Nonetheless, the markers described and discussed below can inform a person about what is likely to happen if no intervention takes place in the progress of his or her infection. The point of *TESTING AIDS* is to give you the information you need to begin monitoring your infection to determine when to intervene so as to make every effort possible to prevent your progression toward AIDS.

### Measuring the Risk of Progressing to AIDS

The system for classifying the risk of progression to AIDS used here was developed by researchers at the University of California at Los Angeles (UCLA) AIDS Center<sup>2</sup>.

There are other classification systems. At the moment, no standard method exists. From the standpoint of the physician there are four important uses for this kind of classification:

tests that are used for determining the risk of progression to AIDS:

- 1) HIV p24 antigen;
- 2) HIV p24 antibody;
- 3) T4 count; and
- 4) Beta<sub>2</sub> microglobulin (B<sub>2</sub>MG)

(There is also a fifth test, using serum levels of neopterin, recently reported in the Journal of Acquired Immune Deficiency Syndromes. See below.). These tests are described below. Most of them, unfortunately, are only available at major medical centres. Another problem is that provincial medical insurance plans usually do not pay for them. This situation requires HIV infected individuals and their supporters to bring political pressure to bear on provincial ministries of health to have these tests made available and paid for.

According to the UCLA AIDS Clinic study, there are five stages of risk in progression to AIDS (You can find an explanation of technical terms in the glossary):

#### 1. Markers of Recent infection:

May have detectable HIV antibody and p24 antigen

May have acute seroconversion syndrome

Normal T cells or elevated T4 cell number

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## Women and Testing AIDS

In general, women's testing issues are similar to those of men. Like men, women worry about the anonymity of test results, about the implications of a positive antibody test, about the integrity or the validity of various testing methods. But while gay men deal with these questions in the context of an aware and knowledgeable community, women are, for the most part, socially isolated from quality AIDS information.

Women who are HIV positive, or who fear they are HIV positive, must negotiate their health care in a system that tends not to work in women's favour; that has a tradition of not taking women's concerns seriously. This fact combines with the particular epidemiology of HIV in Canada, where the majority of people who are HIV-positive are men, making information about HIV infection in women difficult to come by.

Many doctors still believe that it is unlikely for a woman to contract the virus. So a woman worried about her antibody status may be discouraged from taking the HIV antibody test. She might be told that she is worrying too much (as women are thought to do) and that nice girls like her



Sunnys Sherman died of AIDS on Aug 10, 1986. During her illness she demonstrated remarkable courage in speaking to groups, appearing on TV, writing articles, and participating in a documentary film on AIDS prevention.

further along when they actually receive a diagnosis." Women are coming down with

control pill or fetal antibodies from a previous pregnancy may confuse the test. In an indeterminate test the ELISA shows

status may be discouraged from taking the HIV antibody test. She might be told that she is worrying too much (as women are thought to do) and that nice girls like her don't get infections like HIV.

Theresa Dobko, coordinator of the Women and AIDS project at the AIDS Committee of Toronto, says that doctors can try to minimize the possibility of women being at risk for HIV infection. Dobko says that a woman who thinks she needs an HIV test must be very clear in stating her wishes and should consider changing doctors if her concerns about HIV are not being dealt with to her satisfaction.

Although the situation is improving, there has been little research into the symptoms of HIV infection in women. While some symptoms seem to be the same as men's (swollen glands, night sweats, shingles, weight loss) others are specific to women and may not be recognized as indicators of HIV infection. For instance, it appears that women with HIV infection have repeat vaginal yeast infections and chronic respiratory infections. Women also complain of unusual vaginal discharges and menstrual irregularities. Any of these could indicate problems other than HIV, perhaps making it less likely for a physician to suggest a test for antibodies.

It also seems that the progression of HIV in women may not follow the same pattern as it does in men. Dobko says that women may not get the same opportunistic infections as men and so "they can be

further along when they actually receive a diagnosis." Women are coming down with PCP, toxoplasmosis and bacterial pneumonias. Only one woman in Canada has had Kaposi's Sarcoma which seems to be very rare in women in North America (and in all categories where homosexuality is not a factor in transmission), unless they are of Mediterranean or African background. What does the different shape of HIV infection in women mean for the possibility of early testing and early treatment?

Given the inadequacy of information about women's symptoms it's not surprising to find that few women are diagnosed on the basis of their own symptoms. According to Dobko, most find out about their HIV infection because of the infection of a male sexual partner or, increasingly, of a sick child.

Unlike gay men who are pretty much aware of the possibility of HIV infection, and who make decisions to get tested on the basis of that awareness, women usually never consider the possibility of their being infected with HIV. They may be illprepared, consequently, for a positive result. Further, they often have to deal with that result without the benefit of an organized and supportive community, perhaps while trying to care for a sick child. The isolation can be enormous.

According to Linda Gardner, who works at Toronto's Hassle Free Health clinic, women may have a slightly higher incidence of indeterminate results for HIV antibody tests than men do. The birth

control pill or fetal antibodies from a previous pregnancy may confuse the test. In an indeterminate test the ELISA shows a positive result while the confirmatory Western Blot is inconclusive. Gardner says that most of the indeterminate results they see in the women's clinic at Hassle Free eventually turn out to be false.

Previously, it was thought that women were more likely to obtain false positive results. However Dobko says that improvements to the testing kit have greatly reduced this possibility.

It has yet to be determined how suitable other types of tests are for women who are HIV positive. For instance the range of desirable results for a T4 cell count is based on research about men. Dobko asks whether we should expect women's results to be similar. Is the test more sensitive at different times in a woman's menstrual cycle? Dobko says women's results seem to fluctuate more than men's. It's not yet clear what this means for women's health.

One of the most critical testing issues for women who are HIV positive is access to information about tests that will help them monitor their condition. Without the networks that now exist for many gay men, women have to depend on doctors who may know little about HIV to begin with, let alone the particularities of HIV in women. Like men, women need both the information and the support that can come from an organized response to HIV. ■

# HIV RELATED TESTS

## I. Evidence of HIV infection.

### A. Antibodies:

Antibodies are proteins made by the body in response to invading organisms. In HIV infection antibody production rises considerably.

Normal values for the three main types of antibodies:

IgG 639-1,349 mg/dl.

IgA 70-312 mg/dl.

IgM 86-352 mg/dl.

### B. HIV antibody test (ELISA)

This test, known as an ELISA, detects antibodies produced by the body against HIV. The newer tests are more sensitive, but they sometimes pick up antibodies to other germs. This test does not tell us anything about the state of your immune system.

### C. Western Blot:

This is another test that confirms the presence of HIV antibodies. It must be used as a confirmatory test only when the ELISA test is positive and it is very accurate.

### D. PCR (Polymerase Chain Reaction):

A PCR is a state of the art test for HIV

### Normal range:

4.2 to 5.9 million cells per ml of blood.

### B. WBC (White Blood Cell count) or Leukocyte count:

This count tells us the total number of white blood cells present. A differential count tells us the various types of leukocytes. This is handy because some drugs can be toxic to certain white blood cells. An example is the anti-CMV drug ganciclovir which is toxic to neutrophils.

### Normal Range:

4,300 to 10,800 cells per ml of blood

### C. Neutrophils:

Neutrophils are the most common type of white blood cell. These are the immune system's primary defense against bacterial infections.

### Normal Range:

1,800 to 72,000 cells per ml of blood

### D. Hemoglobin:

Hemoglobin is the red substance in blood cells that binds to oxygen.

cells fall to the bottom of a test tube. ESR rises in a number of disorders. High SED rates are associated with HIV disease progression, but also with other infections and autoimmune disorders such as rheumatism

### Normal range:

Males: 1 to 13 mm/hr.

Females: 1 to 20 mm/hr.

### H. Platelet Count:

Platelets are blood cell fragments needed in order for blood to clot. In HIV infection a condition known as ITP (Idiopathic Thrombocytopenic Purpura) develops where the body attacks its own platelets. As the levels of platelets fall, the risk of bleeding becomes greater, although this is less true with HIV infection than with other forms of SGOT rise.

### J. Creatinine

Creatinine is a product of muscle breakdown used to indicate kidney function. When the kidneys are damaged, levels of this chemical increase.

### Normal range:

15 to 25 mg per kg of body weight per day.

**Polymerase Chain Reaction):**  
A PCR is a state-of-the-art test for HIV. It can detect HIV even if only trace amounts are present. While a positive PCR means that infection has taken place, its prognostic value (its usefulness in predicting the course of the infection) is not known. As of writing this brochure, this test is not widely used in Canada.

#### **E. p24 Antigen Test:**

This test detects the HIV core protein p24 which is usually produced when HIV is replicating (making new viruses). (see page 5 and the **Glossary** for more information about p24).

### **II. Complete Blood Count (CBC)**

In order for a physician to determine the state of a patient's health, standard blood tests are often done. Many of these tests are useful in HIV infection and this will explain the more relevant ones. We have also added at the end of this section two tests concerned with the functioning of the liver and kidneys. Both these organs can be adversely affected by the toxicity of various HIV therapies. A CBC or Complete Blood Count includes the following:

#### **A. RBC (red blood cell count or erythrocyte count):**

This count tells us the number of red blood cells present in a litre of blood. There is usually a decrease in the RBC when anemia occurs during AZT therapy.

blood cells that binds to oxygen.

#### **Normal Values:**

Males: 13 to 18 gm per dl (decilitre or 1/10 of a litre) of blood

Females: 12 to 16 gm per dl of blood

#### **E. Hematocrit:**

Hematocrit is the volume of red blood cells expressed as a percentage of the total volume.

#### **Normal Values:**

Males 43 to 52% of total blood volume

Females 37 to 48%.of total blood volume

#### **F. MCV (Mean Corpuscular Volume):**

This measure is the ratio of hematocrit/RBC. It is useful because it tells us the average size of a red cell. Some elevation of MCV is expected during use of aerosolized pentamidine and ribavirin therapy. By monitoring the rise in MCV physicians can adjust the dose of the drug before it becomes too toxic. Another use may be in determining if a patient is receiving a placebo in ribavirin trials.

#### **Normal Values:**

86 to 98 cubic micrometres.per cell.

#### **G. ESR or (Erythrocyte Sedimentation Rate or SED Rate):**

ESR measures how quickly red blood

15 to 25 mg per kg of body weight per day.

### **III. Predicting What Will Happen to the Immune System.**

During a three year study of HIV-infected people in San Francisco, doctors found that certain substances in the blood seemed to give a more accurate indication of the state of the immune system than what had been possible previously. These four tests make the most sense when evaluated together along with neopterin levels. Ideally, an index which weighs and combines their results, the way for example a composite index is produced for the stock exchange, should be developed.

#### **A. T4 Cells:**

As HIV infection progresses, the level of T4 cells fall. The normal range of T4 cells is between 350 to 1200 per ml of blood. General picture: the period where the antibodies against HIV start being produced, also mark the point where T4 levels start to decline. The T4 count then remains stable at a lower level for some time, usually a period of years. During this period the person usually has no symptoms of HIV infection and the T4 count is usually around 500. Eventually the T4 count begins to decline once more. AIDS, the development of life threatening infections and/or cancers, and severe weight loss, etc.usually occurs when the T4 count falls below 200.



It should be noted that there are exceptions to the rule: there are HIV seropositives who developed PCP with T4 counts greater than 400 cells. The T4 count can vary with the time of day, with the lab where the blood was analysed and with stress, exercise and colds.

Thus the T4 count becomes more significant when taken with other the indicators discussed here. The important thing to remember with T4 counts is the trend over a period of time, for example, 6 months to 2 years.

**B. Beta<sub>2</sub> Microglobulin (B<sub>2</sub>MG):**

B<sub>2</sub>MG is a substance produced in small amounts by the body under normal conditions, as a result of cell breakdown. When people suffer from chronic viral infections B<sub>2</sub>MG production increases.

Levels of B<sub>2</sub>MG greater than 424 nmol/litre have the highest risk for progression to AIDS. A level between 254-424 nmol/litre is approximately 4 times less risk for pro-

antibodies. One group of antibodies attacks the envelope. The other attacks p24 (the core). Scientists have found that people who have high levels of p24 antibodies may be able to protect their immune systems from further damage.

Ordinarily, p24 antibody is measured together with p24 antigen. The usual pattern is:

Early HIV infection:

high p24 antibody  
no p24 antigen

ARC:

low levels of p24 antibody  
low levels of p24 antigen

AIDS:

low levels of p24 antibody  
high levels of p24 antigen

It should be noted that there will be exceptions to the above pattern and that this pattern should be treated just as a guide to interpreting these test results in relation to other tests.

**E. Test for Serum Neopterin Levels**

**IV. Tests for Opportunistic Infections (OIs) and Cancer:**

**A. Antibody Tests For Opportunistic Infections**

For people with functioning immune systems, antibodies can be detected which can be used as "markers" of prior infection by various micro-organisms. These infections are usually considered harmless. However, a failing immune system often allows these otherwise harmless infections to flourish. One way of seeing if you are at risk for contracting any of these OIs, is to determine whether you have already have antibodies to them. This can be done by testing you for the presence of these antibodies. Some of the more common of these OIs are: toxoplasmosis gondii (Toxo), cryptococcus neoformans, and mycobacterium avium infections (MAI). The tests are called: antiToxo, antiCrypto, antiMAI.

**B. Lumbar Puncture:**

A small amount of fluid is drawn from the spine by syringe. Testing this fluid is helpful when diagnosing brain and CNS infections. Note: Lumbar puncture should only be done when essential because it is a painful procedure (involving needles, etc) and there

AIDS. A level between 254-424 nmol/litre has approximately 4 times less risk for progression to AIDS while levels less than 254 nmol/litre have the least risk.

The scales for measuring B<sub>2</sub>MG still vary because this test is still experimental and has not yet been standardized. The values given here are Canadian as opposed to the US scale which is used in American publications like Project Inform publications.

#### C. p24 Antigen:

Antigen p24 is the core protein of HIV and is produced whenever the virus is replicating. When p24 is detected this condition is known as antigenemia. The usual pattern of p24 production is that p24 appears just after infection and then falls to very low levels. When p24 production increases, this suggests an increase in viral production. Increased p24 production is associated with progression to AIDS. p24 is a useful measurement when testing antiviral drugs. For instance certain anti-HIV agents such as AZT and DDC are used, p24 levels fall. Right now in Canada the p24 test results come back either yes (positive/which is bad) or no (negative/which is good).

#### D. p24 Antibody:

HIV is composed of two basic parts: an envelope and an inner core which is called p24. Despite the fact that HIV infected people produce antibodies against the virus, some of these people still develop AIDS.

There are basically two types of HIV

#### E. Test for Serum Neopterin Levels

Neopterin is a substance produced by certain cells of the immune system—such as macrophages—during inflammatory disorders including viral and parasitic infections as well as cancer. Scientists in California have noted a relation between the state of the immune system and neopterin during HIV infection. Around the time of seroconversion (when previously HIV antibody negative people begin to produce HIV antibodies, i.e., test “positive” for the HIV antibody) a person can have high levels of neopterin without low levels of T4 cells. However, once seroconversion has occurred, the general pattern is for the neopterin to increase while the T4 count drops.

According to a study of 799 men, as the T4 count decreases and the neopterin level increases, the probability of developing AIDS rises significantly. A person with a T4 count of less than 250/ml of blood and a neopterin level of less than 20 nmol/L had a 58% chance of developing AIDS. While a person with a similar T4 count who had a neopterin value greater than 20 nmol/L had a 90% chance of developing AIDS within three years. According to researchers, measuring the blood levels of neopterin may be a quick and inexpensive way of determining the effect of antiviral drugs in HIV infected people<sup>3</sup>.

infections. Note: Lumbar puncture should only be done when essential because it is debilitating (pain, dizzy spells, etc.) and there is a risk of introducing new infection.

#### C. CT (or CAT) Scans:

CT scans (Computerized Axial Tomography) are a series of X Rays which take pictures of sections of the body, performed typically on the brain, chest, abdomen, or spinal cord to aid in diagnosis. A contrast dye is injected to highlight areas of infection or tumors. The use of a CAT scan often makes procedures such as lumbar puncture unnecessary.

#### D. NMR (Nuclear Magnetic Resonance):

A scan of the body using magnetic fields. Useful in cases where CAT scans are unclear. However, due to lack of facilities, NMR is only done where absolutely required.

#### E. Induced Sputum Test:

This test is used for diagnosing lung diseases. The person inhales a mist of salt solution and then coughs up sputum which is then examined for blood and organisms. Pneumocystis Carinii Pneumonia (PCP) can be diagnosed in 75% of cases this way by an *experienced* team of physicians.

#### F. Bronchoscopy:

Having a bronchoscopy done involves placing a small tube down the wind pipe into the lungs while the patient is under sedation, to observe the tissue and/or remove samples of tissue. This procedure is useful in diagnosing lung disorders. Bronchoscopy is the only test that determines for sure the presence of PCP.

## Calculating Your Absolute T4 Count

Different laboratories have different procedures for reporting a person's T4 count. Sometimes the actual number of T4 cell is already computed. Sometimes it is not. If your doctors makes available to you the results of your tests, you can calculate this result for yourself. It is not difficult.

The most important thing to keep in mind is that T4 cells are a kind of lymphocyte cell, which in turn is a kind of white blood cell. The white blood cell count is expressed as an estimate of the actual number of cells per cubic millilitre of blood. The lymphocyte and T4 results are expressed in lab results as percentages. For example, usually lymphocytes make up 25% to 50% of all white blood cells. And, T4 cells usually make up 30% to 45% of all lymphocytes. So if you know how many white cells you have overall, you can calculate how many T4 cells per ml of blood you have.

1. Take the number of white cells. This is usually written out in a short form that is calculated by dividing the actual number of cells by 1000. So 6,900 white cells is written as 6.9 in the test results. The actual number of white cells per ml of blood, consequently, can be found by multiplying the

white cell test result by 1000.

2. The test results tell you the percentage of white cells that are lymphocytes. To find the absolute number of lymphocytes you have to multiply the number of white blood cells by the percentage of lymphocytes. For example, if the lymphocyte results were .37, you would multiply 6900 (from step 1) by .37. The result in this case would be 2553 lymphocytes per ml of blood.

3. You now carry out this same procedure for finding out how many lymphocytes are T4 cells. If your T4 results were reported as .14 (sometimes written simply as 14, no decimal point) you calculate what this percentage of your lymphocytes would be by multiplying the results of step 2 by .14. The result in this case would be 357 T4 cells per ml of blood. Because this is an estimate of the actual number of T4 cells rather than a percentage, it is sometimes referred to as the "absolute T4 count."

**One Final Point:** The reporting of laboratory results varies from place to place. If your test results do not fit the above example, ask your family doctor, or someone from the laboratory s/he uses, how to calculate your absolute T4 count. •

## ANONYMOUS TESTING

COMNTINUED FROM PAGE 7

The provincial government, which is legally in charge of these procedures, has begun to tighten up the system by trying to enforce nominal testing. The central argument is based on the practice of partner notification. The issue is one of enforcing

decided on a case-by-case basis, but by calculating the risks and benefits to the whole society.

Besides helping to stem the epidemic, anonymous testing has another advantage. It allows

## DEALING WITH HIV INFECTION

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### 2. Markers of an asymptomatic, and otherwise healthy HIV+ Individual :

No symptoms of HIV infection T4 cell number greater than 500

T4 cell number greater than 500

### 3. Markers typical of asymptomatic HIV+ individuals, but with a greater risk of going on to AIDS:

No symptoms of HIV infection

T4 cell number greater than 500

Falling p24 antibody or detectable p24 antigen

Elevated beta<sub>2</sub> microglobulin level

### 4. Markers typical of impaired cellular immunity and increased risk for progression towards AIDS

Tinea , thrush (fungal infections), or hairy leukoplakia

Other laboratory markers typical in people who progress to AIDS. (see: Predicting What Will Happen to the Immune System on page 4)

### 5. Markers typical of the onset of AIDS in HIV+ people:

T4 cell number less than 200

Elevated beta<sub>2</sub> microglobulin level

Detectable p24 antigen

The central argument is based on the practice of partner notification. The issue is one of enforcing the principle of the partner's right to know that he or she has possibly been infected with HIV. What the province is arguing is that the partner's right to know is more important than the infected person's right to privacy.

AIDS ACTION NOW! has taken the position that anonymous testing should be made available as part of a comprehensive public health policy in the fight against AIDS. The argument that infected people have the right to know seems compelling when it is considered on a case-by-case basis. But, if we look at all the unsuspecting people who have been unknowingly infected over the past ten years, then the best way of increasing the possibility that most of these people will come to know their HIV status is through the provision of anonymous testing for their partners who might have infected them, either through IV drug use or sexual contact. If their partners never get tested, because of a lack of anonymity, they will only find out when they, or (in the case of women) their children, come down with an AIDS related opportunistic infections. For the unsuspecting individual to have a "right to know" that will never be acted on is no right at all. It is a right that is recognized in theory, but actually does nothing to protect people. Public health policy is never

### An Important Notice:

Material for this bulletin is based, in part, on information that has appeared in Beta and publications of Project Inform. More detailed information on testing can be found in these publications and others, which should be available through your local AIDS organizations or contact the AIDS Resource Centre at the AIDS Committee of Toronto Office. (Box 55, Station F, Toronto ON M4Y 9Z9)

anonymous testing has another advantage. It allows people who might not otherwise know that they are HIV-positive to decide whether or not they want to begin a course of early intervention and accelerated care to control their HIV infection, and perhaps save their lives.

The issues surrounding HIV testing are complex. In the end it will be impossible to have a policy that protects everyone in every instance. What is required, however, is a public health policy that in actuality will help protect the largest number of people. Such a policy would include, among other options, anonymous testing.

#### Footnotes:

<sup>1</sup>Delaney, M. (1989)

"Staying Alive: making the ultimate political statement" The Advocate February 26th, 1989.

<sup>2</sup>Miles, S.A. (1988)

"Diagnosis and Staging of HIV Infection" American Family Physician 38(4):248256.

<sup>3</sup>Melmed, R.N. (1989)

Journal of Acquired Immune Deficiency Syndromes 1989; 2:7076. •

AIDS ACTION NOW! does not advocate any particular test or therapy. The sole purpose of this bulletin is to make its readers aware of the latest developments in AIDS testing. AAN! emphasizes, furthermore, that individuals should depend upon the advice of their doctor in interpreting test results. •

### Detectable p24 antigen

The discussion below of tests for predicting what will happen to the immune system gives more information on these risk markers.

### Interpreting Test Results

It is extremely important to make sure that the interpretation of your test results is something you do with your family doctor. Because they see a large number of patients, they have more experience in interpreting test results. Likewise, it is important to remember that no single test result and no single test can by itself be used to evaluate the status of a person's HIV infection. A person's T4 test, for example, can have considerable variation from the same laboratory at different times on the same day. To understand the risk of progression with this disease it is necessary to examine the trends found in a number of test results over time, and even these are not certain. Individuals in the early stages of infection should have a battery of tests every six months; those in later stages of the infection, every three or four months. One of the important things about monitoring this infection on a regular basis is that you are able to build "picture" of it that will be increasingly useful to both you and your doctor.

Because some of the tests discussed in this bulletin are newly developed and/or experimental, they have not as yet been standardized. This means that to make your tests results as useful as possible it is necessary always to be tested under the same conditions. For example, do not change laboratories. Also, make sure that you have blood drawn at the same time of day (morning, afternoon, etc.). Be sure that the condition of your health is pretty much the same, and that you are not doing things that might stress your immune system when you go to be tested. Not attending to these details will decrease the accuracy in reading your test results. Above there are instructions on how to calculate your T4 count. •

# Anonymous Testing

The confidentiality or anonymity of test results is always an important consideration when people are faced with deciding whether or not they should get tested for HIV antibodies. Any possibility that test results (or even the very fact that a person is taking certain tests) will be known by various doctors, nurses, and laboratory personnel discourage many people from being tested.

This issue is much more serious in rural and small town communities than it is in a large metropolitan area like Toronto, Vancouver and Montreal. Concern among individuals who have engaged in high risk behaviour is based upon the very real possibility that test results could fall into the hands of employers, or insurance agencies, for instance, or that the names of those testing positive might be added to government lists.

Some public health officials believe that the AIDS pandemic can be controlled by contacting the sexual partners of those who have tested positive for HIV. While the public health authorities are not actually supposed to give one's partner the test results, the fact that these individuals are informed by the health authorities that they are at risk for HIV infection usually

means that they can easily guess who is the source of their infection. While the public health authorities do not provide the actual name, for all practical purposes in situations such as this they cannot guarantee confidentiality. Furthermore, at this point the partner can give this information to whomever he or she wishes.

At the moment there is a serious political fight going on in Ontario on the issue of anonymous testing. Under the province's Health Protection and Promotion Act, physicians and other authorities, such as the heads of laboratories and hospitals, are required to report the name of anyone they even suspect of having AIDS. The kind of reporting that is required is called "nominal" reporting because it requires the person's full name and address.

The law, however, is not being strictly adhered to. For example, there are a number of places in the province where an individual can get some form of either "anonymous" or "non-nominal" testing. "Non-nominal" testing means that the person's name, as such, does not appear on the laboratory requisition slip, only his or her initials and birth date. However, the doctor ordering the test must be able to

link up the individual with his or her test results.

One of the main objects of reporting communicable diseases is so that the public health authorities can do contact tracing. In the case of non-nominal reporting, some medical officers of health have given family doctors authority to do the follow-up contact tracing, or at least to assure the authorities that the person's partner, if there is one, has been notified. This is particularly the case for gay men in Toronto.

In most cases (the exception being long-term monogamous relationships—but what guarantees are there?)—contact tracing is pointless in a disease with an average of about 8 years incubation. In fact contact tracing is widely understood as failing to stem the spread of syphilis—a disease with virtually no incubation period. At a time when the rate of sexually transmitted disease in the general population is skyrocketing, even with the use of contact tracing, it is amazing that public health experts are still flogging contact tracing as a way of controlling the pandemic.

CONTINUES ON PAGE 6

# Glossary

**Absolute Cell Count:** is an estimate of the actual number of cells in a given quantity (usually one millilitre) of blood. A percentage-based scale may be used which is equally accurate and can be converted to absolute cell counts. (see: Calculating Your Absolute T4 Count, page 6)

**Antigen:** a substance, which when produced in the body, by a foreign organism or sometimes by the body itself (as in allergies), causing the body to produce antibodies which attack the antigen.

**Antibody:** is a protein produced by the body which binds itself to an invading organism.

**ARC (AIDS Related Complex):** A term used to describe a variety of symptoms of HIV infection which are not as severe as AIDS. These symptoms may include low levels of T4 cells (usually around 400) recurrent fevers, unexplained weight loss, swollen lymph nodes and or fungus infections of the mouth and throat. ARC is not an official medical or epidemiological term. ARC also includes PLS (persistent lymphadenopathy Syndrome), PGL (persistent generalized lymphadenopathy), and other less common/severe conditions.

**Cerebrospinal Fluid (CSF):** a fluid which circulates around the brain and spinal cord.

**CMV Retinitis:** an infection of the retina by CMV (cytomegalovirus) which can cause blindness. In people with intact immune systems CMV cause such diseases as mononeucleosis.

**CBC (Complete Blood Count):** a standardized series of blood tests which indicates to the doctor the overall state of a patient's health.

**CNS (Central Nervous System):** the spinal cord and brain.

**Lymphocyte:** a common type of white blood cell that includes T4/T8 cells.

**nmol (Nanomole):** a quantity of a substance containing one billionth the number of molecules as there are atoms in a fixed amount of carbon 12 (the standard)

**Neutrophils:** the most common type of white blood cell. These are the immune system's primary defense against *bacterial* infections.

**Opportunistic Infections (OIs):** diseases which occur because of a suppressed immune system. Examples of OIs are:

PCP, Toxo, Crypto. These are the hallmark of AIDS.

**p24:** is a fragment of HIV that floats freely in the blood when the virus is reproducing. (see: HIV Related Tests, sec. III page 5)

**PGL (persistent generalized lymphadenopathy):** see: ARC

**PLS (persistent lymphadenopathy Syndrome):** see: ARC

**Pneumocystis Carinii Pneumonia (PCP):** a parasitic infection of the lungs; the most common life-threatening OI in AIDS.

**Prophylactic:** a drug or device (e.g. condom) which helps to prevent disease.

**Seroconversion:** the time when a person's HIV antibody status changes from negative to positive.

**Seroconversion Syndrome:** [Seen in a small proportion of individuals when they first produce antibodies against HIV] mild flu-like symptoms of aching, fever, mild sore throat, weakness or even enlarged lymph nodes. These symptoms usually disappear within a few weeks.

# TESTING AIDS

AIDS ACTION NOW!

MAY 1989

LABORATORY NAME AND ADDRESS

Laboratory Number

OHIP Number

Subscriber's Last Name (Please print or type)

Initials

Patient's First Name (Print)

Patient's Birth Date

Patient's Sex

Laboratory Accounting Number

Referring Lab Number

Service Date

Patient's Phone No.

Subscriber's Address (Print or type)

Town/City

Postal Code

Requisitioning Physician's Name

Requisitioning Physician's No.

Patient's Name

Clinical Problems, Medication etc. (optional)

X	Biochemistry	LAB CODE	OHIP CODE	X	Hematology	LAB CODE	OHIP CODE	Other tests, one per line (please type or print and use terminology of the OHIP Schedule of Benefits)		
	Bilirubin, total			<input checked="" type="checkbox"/>	Blood Film Exam					
	Chloride			<input checked="" type="checkbox"/>	Hemoglobin					
	Cholesterol			<input checked="" type="checkbox"/>	W.B.C. count					
	Creatinine			<input checked="" type="checkbox"/>	Prothromb. time					
	Glucose			<input checked="" type="checkbox"/>	Sediment rate					
	Phosphatase Alk.			<input checked="" type="checkbox"/>	Hematocrit					
	Potassium				<b>Immunology</b>					
	SGOT				Heterophile antibodies screen					
	Sodium				Rubella titre					
	T.3 Uptake				Pregnancy test					
	T.4 Total				Prenatal, ABO, RhD, antibody screen (titre and ident. if positive)					
	Triglycerides				Repeat Prenatal antibodies					
	Urea Nitrogen (BUN)				VDRL					
	Uric Acid									
	Urinalysis R&M				<b>Microbiology</b>					
					Sensitivities if warranted					
					Cervical, vaginal					
					Sputum					
					Throat					
					Urine					
					Stool culture					
					Stool for Ova and Parasites					
					other swabs					

**LABORATORY SERVICES REQUISITION AND OHIP CLAIM**

Ministry of Health Ontario

1. OHIP Copy  
2. Laboratory Copy  
3. Physician's Copy

I certify the tests ordered are not for registered in or out patients of a hospital.

REQUISITIONING PHYSICIAN'S SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

TOTAL FEE \_\_\_\_\_

I CERTIFY THIS TO BE A TRUE STATEMENT OF SERVICES PROVIDED AS REQUISITIONED. SIGNATURE FOR LABORATORY. (Medical Director if additional tests performed.)

A Lab service requisition form: a familiar sight for people getting tested in Ontario

**INSIDE:**

**HIV RELATED TESTS**

**CALCULATING YOUR ABSOLUTE T4 COUNT**

**WOMEN AND TESTING AIDS**

**ANONYMOUS TESTING**

# AIDS ACTION NOW!

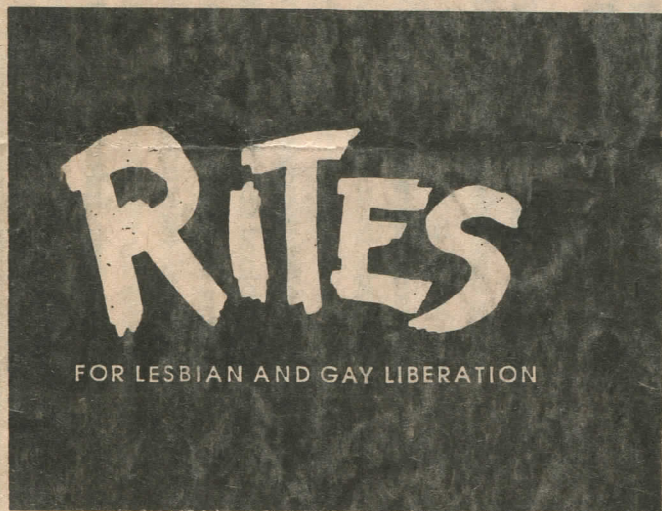
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**AIDS ACTION NOW!** is a political advocacy group. We focus on government policies — and lack of policies with respect to the availability of drugs, treatments and health care delivery for people living with AIDS. **AIDS ACTION NOW!** seeks no funding from government and relies on donations from Toronto's gay community to support our programs.

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A VOICE FOR LESBIANS AND GAY MEN

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