

# Carlton Hogan writings

Agit-Prop and Rantings

<http://www.biostat.umn.edu/~carlton/mine.html>

Below are some articles Carlton Hogan wrote for PWALive.  
PWALive, the Midwest's least Polite AIDS periodical!!

"PWALive is currently in 'hibernation', but we may be back in the near future."

How to be a Problem Patient  
A Professional Patient's Survival Guide  
Introduction, and jargon

This article will be the first in what we hope will be at least a semi-regular series on understanding and taking charge of your health. This article will serve as an introduction to the series, with some information and a whole lot of attitude. I'll talk a little about how medical terminology is constructed, and in a more general way about the skills necessary to be a "Problem Patient". Immediately following this introductory article will be the real beginning of the series, a short article on a couple of the most common blood tests.

Let's face it: "Problem patients" often live longer. We may not make a lot of friends in the medical establishment (although it is heartening how many doctors and nurses are beginning to recognize self-empowerment for the positive life force it is) but hey, if making friends was our main objective, I'm sure we could find better places than hospitals anyway. Problem patients have very strong opinions about what is in their best interest, and while willing to listen to reasonable alternatives, are tremendously stubborn when they feel it necessary.

Being a problem patient is easier than it looks. And the results are often quite satisfying. But the point is not to be obnoxious. As a matter of fact, in most situations, you truly can catch more flies with honey than vinegar (the proverb never said why you would want more flies, but maybe they're a necessary evil, like residents...) It's probably best to be Little Susie Sunshine until something comes up that might have serious impact on your health or comfort, and then dig in your heels and become the patient from hell until the problem is resolved, at which point you can go back to smiling angelically, and humming "The Sound of Music" or something. Positive and negative reinforcement. That's how you train them. Of course, if you are going to go off half cocked, and make a big noisy scene, it would be much more satisfying (and convincing, so that maybe next time you won't need the Oscar scene) to be Right. That obnoxious patronizing resident is going to listen a little better next time if you gently (and accurately) point out the essential lab test that he or she forgot, and then sweetly observe "Boy, that might have made a hell of a malpractice case, huh?"

Of course, you may be like me, and be fortunate enough to have a really good doctor who works in a team with you, your significant others, and all the other available resources to make sure that you get the best care possible. If you are so fortunate, your exposure to medical nimrods will be greatly reduced. Unless you happen to get your care in a teaching hospital, in which case all bets are off. But even in a teaching hospital, you may be able to find a half dozen decent "attendings", and a double amount of residents so that you are never out of range of a friendly face. Maybe.

Even if you have the best possible situation, with a tremendously committed, available doctor who has full privileges at the same hospital that your insurance pays for, you can still participate in

your own health care, and make a big difference. Your doctor may be one of the best HIV-aces in the country, but he or she just doesn't always have two or three hours to go to the library or to fire up the old PC, and research an obscure complication of HIV disease, or some new treatment made from Indonesian beetles. Many important innovations in HIV care have come from "Problem patients" who have demanded better than the status quo for themselves. The doctor-patient relationship can be a team: after all, the entire endeavor is focused on your body, so you should have some input, right?

Unfortunately, there is a long and infamous tradition in western medicine that you hand over the autonomy and control over your own body when you seek care. Put baldly, most of the doors are shut in your face. You can test this, if you don't believe me: go into the hospital or clinic where you receive your care, and ask someone beside your own doctor to let you look at your own chart. If you are persistent and aggressive enough, you will eventually find out that is your full right (with a few caveats, like if you are so out of it that someone else has legal custody of you), but most clinicians will just instinctively stonewall you, and deny you access. They are just so conditioned to treating you as less than a fully autonomous and competent individual. I've even met some clinicians who became very upset when they found out that a patient has full right to access to their chart. It's their Ju-Ju. Why, if patients got access to all their sacred knowledge, their status as witch-doctors of the tribe, those-who-are-not-to-be-questioned might be jeopardized.

Nowhere is this kind of belief set better exemplified than in medical terminology. Hermetic mystical societies have clearer, less obscure jargon. "Erythamateous" instead of the good, old fashioned "red"? There is not a single part of the body that doesn't have a separate medical-speak term. I can understand specialized terms to better delineate and discriminate things that are lumped together in lay terms, but am afraid that I simply don't see the difference between "edema of the lower extremities" and "swollen legs". How about "pulmonary? Lung-related seem to cover that OK. Same with "cranium" and head, "cardiac" and heart, "neoplasm" and cancer, "occluded" for blocked...the list goes on and on. If it was a self consistent rational terminology, it might be more excusable. But it's just an arbitrary mess, with no rhyme or reason to it. Latin and Greek roots are mixed up willy-nilly, sometimes in the same word.

I guess that this criticism might be more relevant if the intent of medical speak was to improve the precision of communication. But I believe that to be a secondary objective at best. As with all "buzz-words", it's more of a badge of office. Like the handshakes of the Masons, or those ridiculous fez's that shriners wear, it's one of those totems that is supposed to indicate "our guys" whoever they may be. You can see for yourself how protective clinicians are of their pet mumbo jumbo. If you come in spouting a bunch of medical terms, particularly if you use them scrupulously correctly, you will be a good way to having a diagnosis of Munchhausen's in many doctor's minds. They restrict access to their pig latin by making it pathological for a patient to understand what they are saying.

But it's also an essential skill for anybody with a chronic illness to understand this linguistic crazy quilt. If you hear the doctor mumble "prep for LP" to a nurse as he or she strides out of the room, wouldn't you want to know that means they are about to put a long needles into the center of your spine before the doctor is gone, and you can ask no more questions? Also, (and I can't emphasize this enough) you need to understand so that you can make sure your interests are being safeguarded. I have heard stories of people with bad cytopenias (lack of blood cells) being prescribed inappropriate myelosuppressive (bad for the bone marrow) drugs when other options are available; people with chronic hepatitis being given hepatotoxic (bad for the liver) ones; people prescribed two drugs simultaneously with synergistic (more than additive: like two and two making five) toxicities; people with bad oral ulcers (sores in the mouth) being given orange juice and pineapple to eat; and people given other drugs in the same family as ones they are allergic to (all true stories).

Face it, hospitals are big bureaucracies, as prone to screw ups, communication glitches, and mindless SNAFUs as any others. If you are like the typical person with AIDS, your chart is probably more than two inches thick. Do you really think that every doctor who meddles in your care reads it before charging ahead with treatment? Clearly, having someone with full, intimate knowledge of your case always available is essential. Who better than yourself? Of course, if you are in the hospital, you probably aren't feeling at the top of your form, and maybe you don't feel up to slugging it out with doctors. That's why it's really helpful to make sure that some one else— a family member, your partner or best friend— also knows this stuff, so they can watch the P's and Q's when you don't feel up to it.

But the most important thing is not letting that door be shut in your face. You are buying a service. You have full rights to demand the best possible service, and to use a consumer's prerogatives in safeguarding your interests. Doctors refer to "doctor-shopping" as a negative: manipulative, pathological, and a sure sign of the "problem patient". Well, they are partly right. It's certainly the last, as long as the consensual definition of "problem patient" describes someone who demands the best in care for themselves. And if it's "manipulative" to try and influence systems to take care of you properly, so be it. It's better they call you manipulative than if they call you "The late...".

The key to opening the door of the medical monolith, at least a crack is knowledge. The jargon can be impenetrable, at least at first, but with persistence, you can be spouting techno babble with the best of them. As you learn the roots, prefixes and suffixes that make up "medicalese", soon you will be able to dissect words that you haven't heard before, and figure out what they mean. Like the root "hepato" which denotes the liver. "itis" means inflammation or swelling, so "hepatitis" means that your liver is inflamed. "megaly" (as in MEGA!) means very big, so hepatomegaly (or hepatosplenomegaly, as the spleen often swells in concert with the liver, at least in some circumstances) means "giant liver" (or "giant spleen and liver"). "-cyte" at the end of a word means cell: words that end in "cyte" are always cells of one kind or other, like the well known blood cells: lymphocytes, erythrocytes, granulocytes, etc. You can combine this with "hepato-", and get "hepatocytes"...yes, this is a real word, and denotes a kind of cell in the liver. Words that end with "-cytopenic" means that you are lacking in the kind of cells identified by the beginning of the word (granulocytopenic, Lymphocytopenic, etc.....to my knowledge, however, there is no such word as "hepatocytopenic"). "-cythemic" means the opposite, that you have too many of a kind of cells (yeah, right, like PWAs need to worry about this one)

The word "metry" used as a suffix means to meter or to count, so "cytometry" is counting cells (usually blood). "-toxic" means toxic (what a surprise!) so cytotoxic means toxic to cells. As you get the hang of it, it gets pretty easy: the parts of the words just fit together like Lego. Going back to "erythamatus", my personal candidate for the most improbable medical word (it means "red"), we can break it apart: the beginning, "erythro-" means "red" as well. "Atous" means "having the quality of", so "erythamateous" means "this thing has the quality red to it". Can we keep mixing and matching? Sure. Let's try adding the "-cyte" ending. We then get "erythrocytes", which are (you guessed it) red blood cells. "erythrocytopenic", although it is never used, would be recognized by any doctor as meaning the same thing as "anemic": lacking red blood cells.

In a later column I will give a glossary of medical roots and their meanings. Some are from Latin, some from Greek, so readers with language skills will recognize many of them. You might want to consider buying a good medical dictionary. Community AIDS magazines, like AIDS Treatment News and GMHC Treatment Issues can keep you up to date in what is happening in AIDS, but there is often no substitute for going to original medical journal articles for all the details. Having a medical dictionary can help you navigate these journal articles until you are proficient in medicalese. Even after you speak it like a native, occasionally you will come across new words that

you haven't heard before. This even happens to doctors. A medical dictionary is essential for these times.

After a good medical dictionary, probably the next two most important resources are a PDR and a Merck Manual. The PDR, or Physician' Desk Reference, is a listing of all the medications sold in the United States. It has Generic and Brand Names, dosages, indications, side effects, and interaction information. It even has a color photo section so that you can figure out what those blue and yellow pills that you found in back of your couch are.

The Merck manual is sort of an all around Reader's Digest condensation of modern medicine. It has sections on all of the common diseases known to man, medications, organ systems, common toxins, weights and measures, and medical tests. It's definitely a book that you would want to have if you were stuck on a desert island

Knowing your way around will also help you to understand exactly what is going on with your care. There is no substitute for being able to read your own lab and consult reports, and to be able to understand any changes in your own health over time. And don't forget, you always get to ask questions. There is a sacred principle in medicine called "informed consent". It means that you have full rights to as much knowledge as you need to make your treatment decisions. Before any major medical procedure is conducted, some one needs to explain to you exactly what will be happening, and what the potential benefits and drawbacks are.

But what informed consent also means is that you get to ask as many questions as you feel you need to. If there is any part that you are unsure, you can ask them to repeat it, once, twice, or a hundred times. If there are any words you don't know, stop the doctor or nurse right in the middle of what they are saying, and ask them what it all means. Before you sign any consent, make sure that you get the gist of what it says. You have the right to fully understand what is going on with you. That is one of the main intents of those consent forms (the other, of course, is shielding the hospital from liability..). And despite my somewhat harsh words earlier about the medical profession's possessiveness about their terminology, often a sympathetic doctor or nurse can help you understand things that you need to know. Journal articles, on-line resources and textbooks can hold incredible amounts of information, but sometimes difficult points are much easier to grasp when they are explained personally. Don't hesitate to ask. Some clinicians may be abrupt, or overly confusing, but you will eventually find someone who "speaks your language", who can open lots of doors to you. And never forget. You have a right to know, and to ask, and to decide. It's your body. This isn't just nice philosophy. It's a principle that is woven into many laws and regulations.

So over the next couple of issues, we will be running this column, each issue dealing with some common aspect of HIV medicine. Feel free to write in with questions, or to share your favorite piece of medical knowledge.

There's no way around it. Having HIV or AIDS definitely sucks. But a good knowledge of medicine, your body, and the systems with which you are forced to interact can make the whole thing much easier to deal with. And never forget: you are a consumer of medical services. You should be able to expect good, appropriate care for your body as you should expect good services from any other service provider.

The Prudent Pariah:  
How to be a Problem Patient  
Article 1. The CBC and diff

This is the first real column of the semi-regular "Prudent Pariah" series (introduction in this issue). This will be an ongoing column, dedicated to demystifying medicine and HIV treatment. There is a world of excellent resources out there, like medical text books and journals. These are probably most useful for those already somewhat familiar with medicine, and familiar with the common terminology and conventions. This series is not intended in any way to replace those invaluable resources. It would be redundant, inefficient, and ultimately even a little deceptive to try and recapitulate what has already been written elsewhere.

Unfortunately, medical journals and the like are not always the easiest reading. Sometimes reading the journals, or even asking meaningful questions about your care can be a little bit like trying to get your first job: you can't get a job without experience, and you can't get experience without a job. In the same way, it's sometimes very hard to learn something about medicine without already knowing a lot about it. This series is intended to open the door, to give you a basis to be able to access the other resources out there, and to make informed decisions about your own care. It's not supposed to supply "the answers". I have no idea what works to keep AIDS at bay, and my particular regimen might kill other people. What I would like to share are the tools you can use to make those incredibly personal decisions for yourself.

In this column we are going to look at some of the most common blood tests and what they mean. Probably as good a place as any to start is the always popular "CBC with diff" (Complete Blood Count with differential leukocytes: "differential leukocytes" means the ration of different kinds of white blood cells). This is one of the most common panels used in virtually all medicine (a panel is a set of tests that are usually done together). If you are a person with AIDS, it's likely that you will get one of these panels drawn every time that you go to clinic. Generally, one or two purple top tubes are taken. These contain an anticoagulant, that keeps the blood from clotting, so it is liquid until it is tested. It's an incredibly standard and frequently used test. Results from a CBC and diff can come back very quickly, as fast as fifteen-twenty minutes if there is no backup at the lab (as opposed to some tests that take a long time in and of themselves, such as cultures)

The tests that make up a CBC and diff count various sorts of blood cells, red and white, and look at some characteristics of your red blood cells. All of the various blood cells are originally made in your bone marrow, and they all originally derive from common ancestor cells. As they develop, however, they change quite a bit, and become very different in appearance and function. Different cells develop in different parts of the body. For example, the reason that T-cells are called that is that they were originally thought to develop only in the thymus (a small gland in your chest). More recent research has shown that T-cells can develop in Peyer's patches (lining of your gut) and other places, but the "T" for thymus has stuck. The common ancestry of all the various blood cells explains why deficiencies often occur in several types simultaneously, at least under some circumstances. When this happen, this is a clue that the problem is in the bone marrow, where all the cells come from. This happens with drug toxicities, for example.

The study of the blood is called hematology and tests like this, looking at the make up of your blood are called hematological tests, as opposed to chemistry tests that measure the chemical composition of your blood, or immunological tests that look at the function and activity of your white blood cells. A lot of important information about your general health and functioning can be obtained from a CBC, although often specific diagnoses will require further tests.

### Normal Ranges

If you look at a lab report form, you will see a bunch of tests grouped together, sometimes under the title "Hematology". If you see things like "WBC", "RBC", "Hgb", "Hct", "MCV", "MCHC", "Plts", "Lymphs" then you are looking at your CBC. Generally, right near your results you will see two numbers, separated by a dash, which are sometimes labeled Normal range. Most labs will put these in parentheses, somewhere right near or under the name of the test. These are the what

they would expect the results to be for normal persons. They are expressed in a range, from the Lower limit of normal (LLN) to the Upper limit of Normal (ULN) because there is a fair amount of variation from person to person in their precise blood make-up, even for totally healthy persons. The LLN is the number to the left of the dash, and the ULN is to the right. For some tests, there is only a single number, that indicates the average normal reading, but hematological tests almost always use a range. The reason that they put the range or standard result right on the slip is that different labs can vary quite a bit in their accuracy and sensitivity. What one lab calls a "10", another might call an "8". By putting the normal range on the slip, it's easier to see what's really going on with you, and not get fooled by the variation from lab to lab.

For example, Looking at the results of a CBC, one of the first results you might see would be WBC, or total white blood cells. This is a total of all the lymphocytes, granulocytes, monocytes/macrophages, and other white blood cells that make up your immune system. A normal range for these might be 4,000–11,000 cells per cubic millimeter. Don't worry if your lab slip looks very different: it may be using other units to count by. For some tips on conversion, see the box. If you hate math, skip it. There's lots that you can figure out just by using the normal ranges and some good sense anyway.

Don't get overly worried if you are close to the normal range, but not quite there. People with AIDS can have chronic (all the time) abnormalities in blood counts, but that be normal for them, at their point in their disease. Drastic changes are far more important than day to day slight abnormalities. For example, a typical normal range for hemoglobin, which is related to red blood cells (more on hemoglobin below) might be 13–17. A person with AIDS might be slightly anemic (have low hemoglobin), and pretty constantly have a hemoglobin value of 12. Their doctor wouldn't get to excited about seeing that same 12 all the time, but she or he would be very concerned if it went down to 9. And it's important to remember that as powerful and useful as these tests are, they aren't all that meaningful all by themselves. Rather, it is the test results taken in combination with all your other clinical and symptom information that a doctor will use in figuring out what is going on with you.

## White Blood Cells

Going back to that lab slip: As I already mentioned, one of the first tests you might see in the results from a CBC will be the WBC, or the white blood count. The WBC is the amount of all the different kinds of white blood cells added together, Later on, in the differential, the white blood cell count is broken down into the amount of the various kinds of white blood cells, but the WBC lumps them all together. The WBC is a very important test, especially in infectious diseases (diseases caused by a germ that you can catch, like a virus or a bacteria). When you get an infection, whether you have HIV or not, your body tries to fight it by making lots of white blood cells. In persons with HIV, especially with later stage AIDS, sometimes the immune system is too wasted to respond as dramatically, but people with functioning immune systems can have alarmingly large elevations in the WBC in response to an infection. Because of this, the WBC is often used in the diagnosis and monitoring of infections.

For people with AIDS, however, the opposite problem is quite frequent: too low a WBC. Of course, as we all know too well, one of the characteristics of HIV is a low T-helper or CD4 count, which indicates a low number of CD4 lymphocytes, a kind of white blood cell. The loss of this one kind of white blood cell alone doesn't usually drag the whole WBC down too much, as all the other kinds of white blood cells can still be fine. So you can have low CD4s, and still have a normal WBC. In later stage disease though, other kinds of white blood cells can be depleted by HIV or the medications used in treating it, and very low WBCs are fairly common in PWAs.

## Red Blood Cells

The next few tests on the CBC sort of belong together, since they all are concerned with red blood cells. Red blood cells, or erythrocytes are the oxygen supply of the body. Their job is to carry life-giving oxygen from the lungs to cells all over the body, which need oxygen to do their work. Without the oxygen carried by the red blood cells, all of the cells in the body would "starve" quickly. For example, cutting off circulation to an arm or a leg can do real damage. Or, if the circulation is cut off for shorter periods of time, your arm or leg can "go to sleep", and get numb, tingly, or even blue. This happens because there isn't enough oxygen. The first red blood cell test is just a count of these essential cells, called a RBC. We'll come back to it in a minute.

Your red blood cells use a chemical called hemoglobin to carry the oxygen. Hemoglobin is a very special chemical. It can pick up molecules of oxygen, carry them through the body, and drop them off at the cells time after time, without being permanently chemically changed or used up itself. The hemoglobin molecule relies on special chemical properties of iron to be able to do all this work, which is why iron is often associated with the health of your blood. B vitamins are also very important in the production of new hemoglobin. Hemoglobin is needed by all mammals to survive. Some lower animals and plants use other chemicals that work similarly, and very small organisms can get all the oxygen they need directly through their cell walls or "skins". But for higher animals, hemoglobin is essential.

Part of the CBC directly checks how much hemoglobin is there. This is abbreviated as Hgb. Low Hgb can mean that you are low on red blood cells, or that the red blood cells that you have are low in hemoglobin or otherwise damaged. Hgb levels can hold important clues to the health of your bone marrow, the amount of iron that is available to make new hemoglobin, drug toxicities, and many other conditions, including MAI.

The RBC or Red blood cell count tells you how many red blood cells there actually are in the sample (generally a cubic millimeter is used, but see the box for other units). An anemia can result from a low number of red blood cells, a low amount of hemoglobin per cell, or both. Using Hgb and RBC together simplifies the diagnosis of hematological conditions, which can show up very differently in patterns of various tests. .

Another test, the hematocrit is intimately tied to the RBC. The Hematocrit, or Hct is just the proportion of blood cells that are red. You could actually calculate the Hct just by knowing the total cell count and the red blood cell count of a specimen. Sometimes the other measurements are preferred to the Hct because it is calculated from the other measurements, so any errors get multiplied. Usually the tests that are done directly are the Hgb, the RBC, the MCV, and the RDW. The other results are merely calculated from these tests, something that anyone with a calculator could do.

The hematocrit, however, is often useful for monitoring the anemias that are associated with AIDS, which often are the result of low blood cell counts, as opposed to those anemias that result from damage to the cells themselves. Of course, one thing that sometimes seems forgotten is that people with AIDS can have other health problems that are only partially or not related to HIV, or are caused by medications, so it's important to look at all these factors in a case of anemia so as to be able to diagnose it properly.

The next few tests, the MCV, the MCH, the MCHC, and the RDW are all measures of the condition of red blood cells. If in fact, an anemia is due damage to the cells, these tests can hold important clues to the nature of the damage. These are tests of morphology, or shape. The MCV, or mean corpuscular volume is a test that has great significance in the history of AIDS. For reasons that are still unclear, the drug AZT causes the MCV to go up. So persons who were on placebo-controlled trials of AZT (myself included), where they weren't told whether they were getting real AZT or a "blank" could unblind themselves, and find out the truth by watching their MCVs go up (or not)

The MCV measure the average size of a red blood cell. The MCV has more importance than just helping clinical trial participants assure themselves adequate treatment however. A high MCV can be a sign of pernicious anemia, which is often associated with vitamin B12 or folate (a kind of B vitamin) deficiency. In persons with AIDS, this can result from poor intestinal absorption, or from the side effects of antibiotics.

The MCH, or mean corpuscular hemoglobin is the average amount of Hgb per red blood cell. As noted above, this can be easily calculated from the Hgb and the RBC.

The MCHC or Mean corpuscular hemoglobin concentration is really another assay of the same thing that is measured by the MCH, expressed in a different way. The MCH is the amount of hemoglobin per cell. The MCHC is the proportion of the cell that is hemoglobin. As with the other derived measurements, like the Hct, these do not strictly need to be on the lab slip. It's really a matter of convenience, and to ensure that abnormal findings stand out. But if they weren't printed on the slip, they could be easily calculated.

Finally, the Red blood cell distribution width (RDW) is a measure of the variation in red blood cell size. A small RDW means that all the cells are about the same size. A larger RDW means that there is variation in the sizes. This gives you information that is not present in the MCV, which is merely the average size. The RDW can tell you if all of the cells are about the size indicated by the MCV, or whether there are cells that are both larger and smaller than the MCV that average out.

The next two tests directly address this issue: poikilocytosis measures the variation in shape of blood cells. anisocytosis measures the variation in size. Neither one of these tests is used very often in the diagnosis of HIV related disorders

These are some of the standard tests that are always performed on red blood cells. By looking at all of these together, you can get a pretty good idea of what is going on. But they are by no means the only tests that are done on red blood cells. There are also tests for what are called "reticulocytes", which are basically young, immature red blood cells. This is a good measure for the health of the bone marrow, where the reticulocytes come from. The average life span of a healthy red blood cell is 120 days, so if your marrow is making enough cells, 0.5% to 1.5% of your red blood cells should be reticulocytes.

There are many more tests that can be performed on red blood cells, such as direct microscopic examination of cells, which is used in diagnosing sickle cell anemia (a genetically transmitted disease that occurs mostly in persons of African heritage). And there are chemical tests, like those for different forms of hemoglobin, like hemoglobin-A, hemoglobin F, or methemoglobin, which is a damaged form. Other chemical test are for B vitamins, iron binding and ferritin, which is an enzyme that helps process iron, but none of these are part of the CBC.

## Platelets

Next in the CBC you will see the Platelet count or Plt. Platelets are kind of flat, Frisbee shaped things. What platelets do really well is stick to injured or torn tissues, and then to each other, so they are an important first step in clotting and wound repair. Lack of platelets can cause clotting problems, internal bleeding, and other complications. Recent findings have shown heavy HIV loads in platelets, but the clinical significance of this is still unclear. Platelet counts are of particular concern to PWAs. There is an HIV-related condition called idiopathic thrombocytopenic purpura, or ITP. If you read the introductory article to this series, you will remember that cytopenias are lack of cells, in this case thrombocytes, or platelets. The idiopathic in the name means that ITP is of unknown origin (-pathic means "is caused by"). Most researchers believe that ITP is caused by HIV infection itself (as opposed to an opportunistic infection), but nobody is sure how. Other thrombocytopenias (non-HIV related) can be caused by autoimmune phenomena,



where the body is tricked into attacking its own platelets. There are many who believe that this is the case with HIV thrombocytopenia, but what exactly is going on is still unclear. Some medications can also cause a loss in platelets, so the platelet count is an important test in HIV treatment. Other important tests related to blood clotting (but not part of the CBC) including prothrombin Time and partial prothrombin time, both of which measure the speed of certain chemical reactions that are important to clotting.

### Differential Leukocytes (the "diff")

Well, after all that, we finally get to the white blood cells. These should all be clustered together, under a legend like "differential leukocytes" or "differential white count". The various white blood cells in this section are sometimes expressed in absolute numbers, sometimes as a percentage of the white blood count, and sometimes as both. All of the counts in the diff are derived counts. That is, they are not actually counted directly. The WBC is counted directly, and then the proportions of each cell are found. So if you knew, for example, that neutrophils made up 60% of the WBC, you would just multiply the WBC by 0.6. On the other hand, if your lab gives the absolute counts (which they have precalculated for you), you could just divide the white count by the neutrophil count and then multiply by 100 to get the percentage.

### Granulocytes

The first three white blood cells listed are the neutrophils, basophils, and eosinophils. These are collectively known as granulocytes, because they all contain internal vesicles (pockets) full of a granular material that is used in breaking down unwanted cells. In the case of HIV, and other infectious conditions, the neutrophil is the most important of the granulocytes. Neutrophils are the commandos of the immune system, aggressively attacking bacteria and other invaders. They use the granules contained within themselves to chemically rip open the skin of their targets, after attaching on in swarms. Neutrophils are, in good part, the reason that all the millions of kinds of bacteria that we encounter every day don't colonize us and set up housekeeping. Neutrophils make up the majority of white blood cells in healthy persons, and when the white count goes up in response to a bacterial infection, often the increase is mainly neutrophils.

HIV itself rarely harms the neutrophil response significantly. That's one of the main reasons that persons with AIDS get the very specific OIs (opportunistic infections) that we do, as opposed to picking up every bacteria that we encounter all day, having every cut get infected, and becoming compost heaps.

Unfortunately, as is so often true with AIDS, what the virus doesn't harm, the treatments will, and treatments like AZT, ganciclovir, and various chemotherapies like those used for KS and lymphoma can cause bad granulocytopenia. The loss of neutrophils caused by these drugs is why you will sometimes see persons who are receiving chemo or transplants having to wear surgical masks. They have lost the ability to resist all the garden variety bacteria that fills the air we breathe.

Although this problem is caused by the neutropenias that such people are suffering, very often the term granulocytopenia is used almost interchangeably. This is for two reasons. The various kinds of granulocytes are so closely related that the loss of one kind generally means the loss of all three (the same is not true of elevations), but also because the eosinophils and basophils are much more involved in allergic reactions, and have little importance in HIV medicine. One exception to this is an as yet unexplained form of folliculitis which is an infection of the tiny follicles at the roots of hairs, generally on the limbs and torso. In this form of aseptically (no particular germ implicated) folliculitis, eosinophil levels are high in the skin, but not necessarily in the blood count. In any case, eosinophils and basophils make up a tiny proportion (one percent or less) of the white blood cells in healthy persons, and are mostly a problem only when elevated.

## Lymphocytes

Next come the lymphocytes, so named because they are really more at home in the lymphatic system than in the circulatory system. The lymphatic system, connecting all the lymph glands and lymphatic organs (like the thymus and tonsils) is sort of like the body's sewer system. Not that it's necessarily "dirty", but the lymphatic system is used to clean out all kinds of invaders, debris and toxins from the blood and organs. The lymph glands actually filter the blood, as it passes through them, and with the help of various white blood cells, remove objectionable materials for destruction and elimination. This is done with the help of a variety of different cells, some of which move back and forth from the lymph to the blood, and so are part of the CBC. Others, like dendritic cells stay mostly in the lymphatics, and are not part of the CBC.

### B-cells

Lymphocytes are divided into two main types, T-cells and B-cells, and then each of these major groupings is further divided into other subtypes. B-Cells make antibodies, which are very special chemicals. Antibodies are specially shaped, like jig-saw pieces, to perfectly fit their targets. Each germ or other invader has particular antibodies that match it perfectly. A clone, or family descended from one particular B-cell makes only the antibodies for one type of invader. Other invaders are attacked by antibodies from other B-cells that are specific to that invader.

Once the antibodies have locked onto the particular germ or other invader, they mark that target for destruction through a variety of different means. The coating of an invader by antibodies is called opsonization, which, believe it or not, comes from the Latin word for "buttering", like buttering a piece of toast. Once a cell or foreign protein has been attacked by antibody, a number of different things can occur. The antibody can attract killer T-cells or CD8+ lymphocytes (more on these later). These, once locked on, actually drill holes in invading cells, popping them like balloons.

Or the antibody can attract other chemicals in the blood called complement proteins, which latch on like more and more perfectly fitted jig-saw pieces, eventually surrounding their target and crushing it. Finally, antibodies can also screw up invaders all by themselves, by chemically changing them, or blocking key ligands, which are merely more jig-saw-like proteins that are used by attackers to attach to their specific target. All of these different activities of antibodies are called neutralizing. So one of the intents of vaccine research is the development of neutralizing antibodies. Strangely enough, in some circumstances various germs have evolved methods to trick the antibody system, and actually use the antibodies to better stick to or enter human cells. Such antibodies are called enhancing antibodies, and there are at least some strong theoretical concerns that HIV uses some antibodies to enter some kinds of cells. Clearly, even if this turns out not to be true, there are still concerns about using vaccines that rely entirely upon causing the production of antibodies. The human body already makes lots of antibodies to HIV (as are measured in the "HIV test"), yet these don't seem to stop the infection. A lot of recent research is looking at using other immune responses beyond the antibody one in making HIV vaccines.

B cells make antibodies in response to instructions from T-cells, which instruct them as to which antibodies are needed. B-cells are divided into three main types (these are not distinguished between by the CBC, which lumps all the kinds of B-cell together with all the T-cells, but there are other tests that can tell the difference). Resting or naive B-cells are not yet primed for their particular target. They float through the blood stream, looking for invaders. Once these have been found, the B-cell takes a sample to a T-cell, looking to the T-cell for further instructions. The T-cell, if it agrees that the protein presented to it is a danger, gives chemical signals to the B-cell that cause it to mature into a plasma cell. Plasma cells are antibody factories, pouring out incredible amounts of these very carefully shaped chemicals. Finally, after the threat is cleared,

some of the B-cells stick around as memory cells, which are ready to rapidly begin antibody production again if the invader returns. The antibody component of the immune system is called humoral immunity.

## T-cells

Everything that the B-cell does, it does in cooperation with T-cells, which give all of the important instructions. T-cells are divided into two main kinds, although research done in the last couple of years suggest that there are really four main kinds. T cells are divided among CD4 and CD8 cells, which are named for particular proteins that they show on their surfaces. CD4 cells, or T-helper cells are the ones that are lost in AIDS. They are the ones measured by the "T-cell count". These are incredibly important cells: If the immune system is an army, these are the commanders. They are the ones that tell the B-cells to make antibody, and they also give instructions to the other kinds of T-cells, the CD8s.

The CD8 cells are further divided amongst killer and suppressor cells, Earlier in the epidemic, we knew far less about the essential killer functions of these cells, and thought that high CD8 counts were bad. We thought that CD8s were primarily suppressor cells, which turn off the immune response, generally after the threat is gone. In the last decade, however, we have learned much more about how important the killer function of these cells is. They are one of our main weapons against invaders hiding inside our cells, where neither neutrophils or antibodies can get at them. This type of immune response is called cell-mediated immunity, and it is carried out by CD8 lymphocytes, natural killer cells, and others. More and more researchers are coming to believe that not only are CD8s very important for protection against HIV itself, but also that the immune defects seen in AIDS are as a result of the CD8s not working right, rather than just because of the loss of CD4s. A lot of this work hinges on breaking down the T-cell family into two further groups, Th1 and Th2. Although still very theoretical, a lot of this work holds great promise in understanding AIDS, and we will dedicate a column to it in a later issue.

We have taken a long detour into the various sorts of lymphocytes, because these white blood cells are so important to AIDS. These various kinds of cells are not broken out separately in the CBC and diff, where they are all lumped together under "lymphocytes", or Lymph. A further test, the differential lymphocytes separates out the B-cells and various T-cells. The T cell test that is often performed in persons with HIV is a subset of the complete differential lymphocyte count.

## Monocytes/Macrophages

The word macrophage means "big eater", and that is what exactly these cells are. Monocytes and macrophages are very closely related, just like the different kinds of B-cells. These cells start out as monocytes, which cruise the blood stream, kind of like avaricious teen-agers. Later, when they grow up into macrophages, they settle down into the tissues, where they remain fixed. Monocytes ramble all through the blood system, munching up debris and foreign invaders. When they eat a pest, a very intricate chemical factory inside them goes to work. They break down the proteins on the outside of the invader into manageable lengths, and then carry these fragments of protein (called peptides) out to their surface. They then hightail it to the nearest T-cell, who they "present" these peptides to. It's kind of like they bring the coat of the invader, with "gang colors" stitched into it to the T-cells, so that the T-cells can recognize exactly what the invader looks like, and give proper instructions to other T-cells and to B-cells. Macrophages do very much the same function, but in a fixed locality.

Unfortunately, the greedy appetite of these cells can get them in trouble. A number of different germs have figured out how to take advantage of this whole system, and once eaten will take up housekeeping in the macrophages. MAI is an example of a germ that is pretty comfortable inside

a macrophage/monocyte. MAI is able to resist the digestive process that would break other bacteria down, and adopts macrophages/monocytes as a new home. Intercellular parasites of this sort use their home inside the body's own white blood cells as a very cunning way to hide from the rest of the immune system. HIV does this as well. When HIV takes up residence inside a monocyte/macrophage, the macrophage/monocyte survives just fine, unlike T-cells, which are eventually killed by their unwelcome guest. Now HIV not only turns the macrophage/monocyte into a little HIV factory, using it to pump out more virus, but it also is able to use the macrophage/monocyte as a "Trojan Horse". Remember that the job of the macrophage/monocyte is to bring foreign peptides to the T-cells, which it bumps right up against in doing so. When it does this, HIV has a perfect ferry ride to these T-cells, all the time shielded from the rest of the immune system. This mechanism is thought to be an important way that HIV spreads around the body.

Macrophage/monocyte counts are rarely low in HIV disease: As a matter of fact, often sites of infection (like the lungs, during PCP) are cluttered with monocytes/macrophages. Unfortunately, they seem to be functionally impaired, and often don't do their job properly. Exactly how much of this is due to problems with the macrophages/monocytes themselves, and how much is due to problem with the T-cells that command them is still unclear.

Well, that's it: that is all the tests that make up the CBC and diff, along with some side comments on other tests. Clearly, the CBC and diff is a powerful panel, but as we have seen, it is rarely specifically diagnostic. Nevertheless, it is an important monitor of over-all health, and can serve as first warning for all kinds of hematological and other problems. AIDS is often thought of as a viral disease, but it's important to remember that it is also an immune disease, and a hematological condition. It is incredibly rare for OIs or other major health complications of AIDS to occur before blood abnormalities. The only real exception to that rule is Kaposi's Sarcoma (KS), which can occur in persons who appear hematologically normal. Recent research has shown that even these cases of KS in persons who have normal blood counts, there are still abnormalities in cytokine levels (chemicals produced by T cells), but those tests are uncommon, and of unknown clinical usefulness.

For all other HIV related conditions, generally at least the CD4 T-lymphocyte count is depressed, and other hematological variations may be seen. Perhaps even more significant are hematological abnormalities associated with various treatments, such as AZT, Ganciclovir, and various antibiotics and anti-neoplastic (anti cancer) chemotherapies. Regular and thorough hematological monitoring is an essential part of HIV/AIDS care. Get to know your normal blood test results. Don't let little variations freak you out: they're normal. But big changes can often be an important indicator that something is going on, and should trigger further diagnostic investigation.

#### Footnote to "Prudent Pariah: Blood tests"

One of the most confusing aspects of a lot of sciences is getting the "units" in which various quantities are expressed correctly. Just like there are gallons, quarts, pints, and liters in day to day life, there are variety of different units in which various medical values are expressed in. Lab slips are no exception. Although the most common units for cell counts, like those in a CBC, are total cells per cubic mm (cells/mm<sup>3</sup>), other units are also used. Your lab slip, for example, might say something like "normal range is 4.0x 10<sup>9</sup>-11.0 x 10<sup>9</sup> per Liter". No sweat. One thing that is very convenient for conversions is that a cubic centimeter of water (or blood) happens to be exactly a milliliter. There are a thousand millimeters to a centimeter, so there are 1,000,000 cubic millimeters to a Liter.

I hear you say " Wait a minute! There are ten millimeters to a centimeter!". Indeed there are. But these measurements of volume are expressed in "cubic" amounts. Imagine that you have a cubic

block that is 1 inch on each side. If you wanted to make a cube ten inches on a side, you would need not ten, but a thousand one inch blocks. You would have to have ten blocks for the height, times ten blocks for the length, and ten for the depth. So there really are 1,000 cubic millimeters to a cubic centimeter. It's pretty simple: when you convert from squared units (which are used for area) to other squared units, you use the difference between them squared. If, as in this case, you are converting cubic units (used in volume, or three dimensional area) you cube the difference.

Going back to the lab slip. Another common way of writing cell counts, as noted above, is like this:  $4 \times 10^9$  cells per liter. When you see a number like  $4 \times 10^9$ , or any number of that form, which is written like A times ten<sup>B</sup>, that is in what is called "scientific notation". The whole meaning of scientific notation is just "multiply A by ten B times" or "multiply A by 1 with B zeros after it" (because  $10^1=10$ , or 1 with one zero after it,  $10^2=100$ , etc.). It looks intimidating, but it's actually really easy to convert. We use a "base ten" system, so multiplying by ten means moving a number to the left, and filling in blank space with zeros. So to solve  $A \times 10^B$ , all that you need to do is take the number one, but "B" number of zeroes after it, and then multiply by A

Another way of looking at it, using the example  $A \times 10^B$  : if A is a single digit, you can just add B zeros to the right of it. So, if you saw, for example  $3 \times 10^2$ , you would add two zeros to 3, and get three hundred. It gets a little trickier if you get a number like  $4.2 \times 10^4$ , which has a decimal part. Obviously, adding zeros after the .2 onto the decimal doesn't make sense, so you move the number to the left, and then add one less zero. So for example, using  $4.2 \times 10^4$  first you would add three zeros to 42. If there are two numbers after the decimal point, you move them both left, and then add the zeros, minus two (you used up these two by multiplying the number to get it all left of the decimal point). This way of doing it is really the same thing. You just end up "using up" some of your multiplications by ten in shifting digits from one side of the decimal point to the other. All you are really doing, for  $4.2 \times 10^4$  is multiplying  $4.2 \times 1$  with four zeroes after it, or multiplying  $4.2 \times 10,000 = 42,000$ , which is the same as multiplying  $42 \times 1,000$  (notice that the zero you lost off the 10,000 now makes the 4.2 into 42) One really nice thing about scientific notation is that adding one to B means you are multiplying by ten. Adding two means you are multiplying by a hundred. Subtracting one is dividing by ten, etc.

So you see this " $4 \times 10^9$  to  $11 \times 10^9$  cells per liters" is the normal range on your slip. We already know that there are a million millimeters to every liter. A million is 1 with six zeroes after it, or  $1 \times 10^6$ . If we wanted to compare this lab slip to an earlier one, that gave a white blood count in cells per cubic millimeter, we would first divide the numbers by 1,000,000, so that we could get from liters to cubic millimeters. As we noted above, one nice thing about scientific notation is that you can do any number of multiplications by ten simply by adding to B (also called the exponent). So to get cells per cubic millimeter, you would divide  $4 \times 10^9$  and  $11 \times 10^9$  each by  $1 \times 10^6$ , which could then be expressed as  $4 \times 10^{(9-6)}$  to  $11 \times 10^{(9-6)}$  or  $4 \times 10^3$  to  $11 \times 10^3$ . Proceeding on,  $10^3$  equals one with three zeroes after it, or 1,000. So our range becomes  $4 \times 1,000$  to  $11 \times 1,000$ , or 4000 to 11,000, which is a realistic range for a WBC.

Once you get scientific notation down, the other thing that you need for conversions is a knowledge of the prefixes, and the multiplications or divisions that they denote:

Deci	means	Divided by ten
Centi	means	Divided by a hundred
Milli	means	Divided by a thousand
Micro	means	Divided by a million
nano	means	Divided by billion

Deca	means	Multiplied by ten
Kilo	means	Multiplied by a thousand
mega	means	Multiplied by a million

Giga means Multiplied by a billion

When you know these simple rules, virtually any conversion in the metric system is a piece of cake. This is because of a very useful and sensible fact. The inventors of the metric system wanted to make things simple: remember I told you that a cc (cubic centimeter) was the same as a mm (millileter)? Well, the whole metric system uses water as a reference. For example, one liter of water weighs exactly a kilogram. One CC weighs exactly a gram. Blood and water are close enough in weight and density that you can just use the conversions based on water in calculations involving blood, unless you need to be very precise. So as long as you remember that a CC weighs a gram, and is also a millileter, you can go back and forth all you like between volume, capacity, and weight.

Sorry to abandon you, but if you want to do conversions in the english (non-metric) system, you are on your own. I hope that you have a good calculator.

Terms used in this article:

anemic: A condition of decreased red blood cells, low hemoglobin levels, or poor RBC function

antigen A specific immunogenic protein; generally foreign

anisocytosis Variation in size, generally of cells

antibodies: Antigen specific and binding chemicals produced by B-cells; the main component of humoral immunity

anticoagulant: A compound that prevents the clotting of blood serum, used either to preserve specimens, or in the body as a therapy

aseptic: sterile; not caused by a pathogen

autoimmune: When the body reacts to it's own proteins as though they were foreign antigens

B-cells: White blood cells of lymphocyte lineage that produce antibodies. So called because they were once thought to develop in the bursa.

basophils: Granulocytic white blood cells involved in allergic reaction.

CBC with diff : Complete blood count with differential lymphocytes; a panel of the most common hematological tests

CD4: The protein marking the outside of specific T-lymphocytes, of the helper and inducer varieties

CD8: The protein marking the outside of specific T-lymphocytes, of the killer and suppressor varieties

cell-mediated immunity: That branch of the immune system that is mediated by antigen specific cellular responses.

clone: A genetically identical individual or family

coagulation: clotting, as in the blood.

colonize: For bacteria or other microorganisms to take up residence; not always pathological

cytokine: Chemical used for signaling or regulation, generally produced by a white blood cell

cytopenias: Defects in the number of various cells, usually of the blood

cytotoxic: Poisonous to cells; used to describe the cell killing activity of lymphocytes and NK cells.

dendritic cells: A class of antigen presenting immune cells; the follicular dendritic cells within the lymph nodes are a fine comb-like network that filters the blood.

differential:

enhancing antibodies: Those antibodies that facilitate the binding of a pathogen to it's cellular receptor, rather than interfering

eosinophils: Granulocytic white blood cells involved in allergic reactions and immune responses.

erythrocytes: Red Blood Cells

ferritin: A protein that the body uses to store iron in.

folate: A kind of B vitamins; an essential nutrient for hematopoiesis; the target of certain antibiotics which deplete the folate in bacteria. Sometimes leucovorin (folinic acid) is given to rescue the human body from such the effect of such antibiotics.

folliculitis: An infection of the follicles of the hair, often on the torso or extremities

granulocytes: White blood cells containing vesicles of granular matter, comprised of the neutrophils, basophils, and eosinophils

granulocytopenia: Deficiency in the granulocytes, a kind of white blood cell

hematocrit: The percentage of blood cells in a sample that are red blood cells

hematology: The study of blood, and its constituent cells,

hematopoiesis: Making new blood cells

hemoglobin A protein used to transport oxygen through the body

humoral: Derived from the antiquated notion of "bodily humors"; the antibody portion of immunity

idiopathic: Of unknown origin

idiopathic thrombocytopenic purpura: A platelet deficiency thought to be autoimmune

immunogenic: Capable of eliciting an immune response

immunological : Pertaining to the structure or function of white blood cells; pertaining to the recognition, processing, and elimination of foreign antigens

infectious (disease) A disease state caused by a transmissible pathogen

Intercellular: Inside of a cell

leukocytes: White blood cells

ligand The specific fragment of a receptor-binding protein that is the binding surface; something that attaches to other cells

lymphatic system: A system of organs and circulatory elements that is used in immune responses and the cleansing of the blood

lymphocytes: A type of white blood cell that participates in antigen processing, presentation, or cell lysis.

macrophage: A type of white blood cell that digests invaders, and cleaves surface proteins for antigen presentation.

mean corpuscular hemoglobin: The percentage of a red blood cell that is hemoglobin.

mean corpuscular volume: The average three dimensional size (or displacement) of red blood cells;

memory cell The final stage in the development of the B-lymphocyte; memory cells remain antigen specific, and ready to rapidly re-initiate an immune response

methemoglobin: A form of hemoglobin that will not function as an oxygen carrier

monocyte: A type of white blood cell that digests invaders, and cleaves surface proteins for antigen presentation.

morphology: Shape

natural killer cells: Cytotoxic white blood cells that do not require antigen presentation or processing to initiate a response.

neoplastic: Of, or pertaining to, cancer.

neutralizing antibodies: those antibodies that effectively help in clearing foreign cells or antigens.

neutropenia: a deficiency in neutrophils; a form of granulocytopenia

neutrophil: A granulocytic white blood cell that directly kills foreign cells

normal range: Expected values, as in a test or assay.

OIs: Opportunistic infections; infections due to pathogens not normally pathogenic in an immunocompetent host

opsonization: the coating of an invader by antibody and/or complement.

pernicious anemia A form of anemia caused by deficiency of, or inability to process, Vitamin B-12

panel: A collection of tests, generally performed together.

partial prothrombin time: A test of clotting ability

peptide: A fragment of a protein; a string of amino acids (generally less than ten, although the line between small proteins and large peptides is fuzzy)

plasma cell: a stage in the development of the B-lymphocyte where antibody production is optimized

Platelet: A blood cell that is an early participant in the process of coagulation.

poikilocytosis Variation in the shape of cells

prothrombin Time: A test of clotting ability

protein: a long string of amino acids; proteins have very particular shapes and functions that allow them to perform a range of activities in the body, from structural, to regulatory, to metabolic.

RBC: Red blood cells, or red blood cell count

Red blood cell distribution width; the coefficient of variation of the volume distribution width for red blood cells: a measure of the degree of variance in size of RBCs

sickle cell anemia A form of hemolytic anemia prevalent amongst persons of African heritage.

T-cells: That family of lymphocytes that mature in the thymus and Peyer's patches

T-helper cells: T-lymphocytes that process antigen, and prime antigen specific immune responses by other blood cells

T-killer cells: T-lymphocytes that lyse other cells in an antigen specific manner.

T-suppressor cells: T-lymphocytes that downregulate the immune response

thrombocytes: Platelets

thymus A small lymphoid organ in the chest; the thymus starts shrinking at birth, and by adulthood has become minuscule; functional changes are less clear cut.

tonsils Lymphoid organs guarding the throat.

vesicles: an internal tubular pocket or chamber

Step up and Try your Luck: Pharmaceutical Companies Devise innovative Program, Deprive thousands of Treatment

We all want to win the lottery. I know I absolutely relish fantasies of meeting with the little man in the gray suit, and trying to decide whether to take tens of thousands weekly, hundreds of thousands monthly, or just a cool mil or two every year. But when the lottery is for my health care and potential survival, the whole thing suddenly becomes a whole lot less amusing and diverting.

On June 21st, the Hoffman la Roche Company announced a lottery for expanded access to their new drug Invirase (Saquinavir), the leading protease drug in the race to market. Merck Sharp Dohme, right on the heels of Roche, also announced a lottery for expanded access to their drug, Crixivan. Bizarrely enough, the activist response to this callous raffling off of people's lives was for the most part positive. Roche, Merck, Abbott (maker of another protease drug) and other companies did such a good job fanning fears that there might be no expanded access for the proteases that the lottery was welcomed as the lesser of two evils.

Nobody stepped back to realize that accelerated approval, as has been implemented to date, has traditionally been tied to, and relied on, expanded access. There has never been accelerated approval for any AIDS drug without an accompanying expanded access program. The large toxicity database that is accumulated by the expanded access program is extra insurance to offset the relative paucity of safety information if clinical trials are cut short before approval. The implicit deal was always that the companies reciprocated for being let partially off the hook for expensive and lengthy clinical trials usually needed for drug approval. In return for having the skids so greased for them, they in turn had to cut loose a supply of drug for humanitarian relief. Really not such a bad deal with the seven year patent life ticking away during trials, especially considering the public relations aspect, and the desire created for the drug. Come approval, companies



supporting expanded access have tens of thousands of repeat customers already lined up to buy. All of these facts, which are well known, but somehow unconsidered, made industry's bluff that they would pursue traditional approval before considering expanded access all the less believable.

But an unfortunate precedent was set in the context of multiple sclerosis. Beta-Interferon, a moderately effective treatment for MS was made available pre-approval through a lottery, The MS community, who had never previously enjoyed true expanded access actually made more of a fuss at that time than people with AIDS have so far about the Roche lottery. Unfortunately the MS community has nowhere near the coordinated activist resources of the AIDS community. A couple of enraged PWMS gave angry sound bites to the news, but by and large the fuss died down quickly. Few AIDS activists got involved, despite the obvious implications for our community. And the pharmaceutical companies got away with it.

So now only 2280 persons with CD4 counts less than 300 will be able to access the Roche PI, with tens of thousands of potential applicants. Pharmaceutical companies have claimed product shortage and manufacturing difficulties, both for beta-interferon and the protease drugs. For the most part these claims are unproved and unverifiable. The worst part of the whole situation is how poorly our community has pursued any kind of rational long term goals. Even if product shortages were inevitable, alternatives to the lottery could have substantially advanced our knowledge of these drugs, while still providing access. To understand the whole story of how this comes to pass, we have to go back to the end of last summer.

#### The History of the Protease Disaster

Roche finished their initial safety and preliminary efficacy testing almost a year ago. ACTG 229, a clinical trial of Saquinavir in combination with nucleosides showed antiviral activity (although nowhere near as dramatic a benefit as people had hoped). It was right that time that Roche also began discussing their alleged manufacturing difficulties, and started shedding crocodile tears that they didn't think a full expanded access program was in the cards.

At that point, the Treatment Action Group (TAG) came up with an innovative proposal. If there wasn't going to be enough saquinavir to supply everyone who qualified for expanded access, the drug that was available could be used to supply a large, simple trial (LST). LSTs are a relatively new methodology that have primarily been used in cardiovascular medicine. Virtually no restrictions are imposed on participants: rather than some rigid, restrictive comparison of drug vs. placebo in a tightly controlled population, LSTs take virtually all comers, and test "standard of care" plus or minus the new drug. Unlike the "Bells and Whistles" data collection that is common to most AIDS clinical trials, a typical LST collects even less data than expanded access programs. LSTs cultivate the diversity of people and practices that a drug will eventually be used in, and seek to answer well a question of indisputable relevance. The classic LST design asks if people taking the drug live longer.

An LST could look a lot like the lottery that is about to open, with one small, but critical difference. Information would be collected on all applicants, not just those who received drug. It could be as simple as having a physician send in a postcard once a year, verifying which applicants were still alive. Or the National Death Index, a database of all deaths in the U.S. could be queried, imposing absolutely no burden on busy HIV clinicians. Using an LST rather than a lottery would have also opened the possibility of negotiating for more drug. Right now, with only 2280 slots, and with more than 8,000 applicants entered into the Roche lottery, only one in four get drug. An LST would offer sound grounds for arguing for a much more equal treatment allocation ratio; and the benefits could be enormous.

Despite a decade of clinical research, there is virtually no information on the survival benefits of any antiretrovirals in most populations, including the widely prescribed nucleosides. Plainly put,

we don't even know if AZT, ddI, ddC, or d4T extend life in most of the patients who take them. An LST would give PWA's and the doctors who treat them crucial information for making real world treatment decisions. With no drugs shown to lengthen survival, new treatments like the proteases should be available to anyone who believes they might help them. But access without information is useless – an ill person could have access to an entire pharmacy, and still get no effective treatment if there was no information on what to use and how to use it. An LST could have provided those answers, and made the best of a bad situation.

## The massacre

But TAG made a big tactical error. Rather than bringing these ideas to the community, and educating community members about these issues, they went straight to Roche and the FDA with a specific proposal. TAG already accumulated some distrust in the community, with a perception that they had gotten too big for their britches. Careful education was necessary to diffuse the anxieties of persons expecting constrictive, non-care focused ACTG-style clinical trials when they hear the word "research". People thought TAG was trying to trade expanded access for trials that would disempower patients, and eliminate their choices. Shortly after TAG made their proposal, Ron Baker of BETA, an AIDS treatment periodical, wrote a scathing editorial, accusing TAG of attempting to subvert and destroy the expanded access process for ill defined, but surely nefarious goals. Others quickly jumped on the bandwagon, including Bill Bahlmann of ACT-UP NY and Martin Delaney of Project Inform. Representing themselves as the "true" voice of the community this ad-hoc coalition piously declared that they would have no tolerance for anyone tampering with expanded access. Ironically enough, when all the dust had cleared, these same individuals and organizations ended up being the primary architects and endorsers of the lottery. Which just goes to show how little the whole brouhaha was about authentic principles. TAG had accumulated a lot of bad feeling, with their integral involvement in the NIH revitalization act that created the office of AIDS research and 24-hour access to various NIH staff. The protease battle was an opportunity for less connected activists to bring TAG down a notch. And the "tampering with expanded access" rubric made the perfect battle cry. TAG might have just as well spit on mom, the flag, and apple pie.

## The battle heats up

The smoldering dispute burst into flame at a special meeting of the FDA antiviral advisory committee. Even before the meeting some really ugly politicking began. Bill Bahlmann of ACT-UP NY acted behind the scenes, attempting to keep TAG members off the panel, and preventing them from getting on the agenda to speak. Despite these underhanded moves, worthy of Tammany Hall, TAG retained a presence, as did many doctors and researchers who wanted to see the accelerated approval process optimized to provide the most useful information possible.

I went to testify at that meeting, presenting alternative clinical trials methodologies that maintained the maximum in patient choice while providing clinically relevant answers. I was amazed at the degree of hostility that was directed toward me. people repeatedly accused me of being a "TAG member" in tones reminiscent of McCarthyite accusations of communist party membership. More heat than light was generated at that meeting, although the presentations made by Industry were very interesting. Merck, Abbott, and Roche were all there, and adeptly manipulated the proceedings. Some of the more radical proposals made by community members amounted to fully licensing drugs with no real proof of efficacy and minimal safety data. Such proposals are pharmaceutical company wet dreams. Effective clinical trials are lengthy and expensive: careful scrutiny brings with it the risk that a drug for along in the development process may get yanked if it doesn't really work (as indeed has been the case with many potential AIDS drugs). Unfettered, deregulated accelerated approval would put thousands of PWAs on drug, and probably eliminate any opportunity of promptly recognizing harmful or useless drugs. A guaranteed return on investment.

It seemed clear to me that the pharmaceutical companies had made a careful study of AIDS activist pronouncements, carefully deconstructing the rhetoric and unearthing the proper "buttons" to push to make the AIDS community dance like puppets. Catchy phrases like "immediate access", "acceptable risk", and "unconscionable delays" could have been lifted from any AIDS community publication. Except this time they were coming out of the mouth of pharmaceutical company employees. This appropriation of community rhetoric is nothing new. Burroughs-Wellcome, the maker of AZT pioneered this appropriation of discourse with the phrase "chronic and manageable". This battle cry, lifted from Michael Callen and other "surviving and thriving" PWAs was supposed to represent the condition AZT would provide to its consumers. Hey, it's advertising, not critical analysis.

Anyway, in the relatively innocent 1980's, when it was still possible to believe the cure was around the corner, when one could hope that AZT, Ampligen, A1-721, Dextran-sulfate, etc. might make AIDS "chronic and manageable", a certain tone was prevalent in community communications. It was very much an "open the floodgates" stance. The AIDS community had not yet had its heart broken by the failures of antiretroviral treatment, and the insistence of FDA and academic researchers that drugs should be adequately tested seemed like perverse obstructionism. Since then, of course, findings like the demoralizing Concorde trial, plus the simple observation that one's friends and neighbors kept dying, tempered the euphoric enthusiasm. The community attained a much more nuanced, sophisticated understanding that merely gobbling untested pills was unlikely to produce miracles, and solid research was as important as unfettered access.

### The legacy

But a legacy of those days is the deregulationist rhetoric, that with complete access somehow physicians (through divine illumination?) would miraculously keep their patients alive and healthy. As previously noted, such deregulationist approaches serve industry better than anyone. And a new drug development tactic was born. Companies now release all kinds of provocative and promising pre-clinical and early clinical information, like a drug's effect on viral levels in cell cultures (Just knocking viral load down in the test tube is relatively easy to accomplish: if that was all that was required, we'd have hundreds of effective drugs now). Companies whip up community interest, and then put on their best compassionate face, and gravely intone that it would be "unethical" to withhold the drug from the community one second longer. Never mind that there isn't any evidence of clinical benefit. After winding the community up with their own words, they let them go, to act as well directed pit bulls, coercing FDA to do what, coincidentally enough, maximizes the company's risk/profit ratio. In my opinion, industry played the community like a violin. First they convinced people that LSTs or any other means of robustly proving clinical benefit would slow approval down unacceptably, then once the dust had cleared said that it was a lottery or nothing.

### The Aftermath

So now all of us are in the unenviable position of going to industry, cap in hand, and begging for a chance of trying their drug, while the companies may get off receiving genuine approval without showing their drugs extend life or improve health. How did it come to this pass? These are not the first drugs to have product shortages. Earlier in the century, very much the same situation arose with respect to tuberculosis. Streptomycin was the first drug truly active against TB. Initially there was no way to provide enough to everyone who needed it, and there was much discussion at how best to use limited stocks. There seemed no fair way to judge people more or less worthy. Branford Hill, often called "the father of the modern clinical trial", came up with an answer. Since everyone couldn't have the drug, the most ethical thing was to use the streptomycin available to do research, and learn as much as possible to benefit all patients. I think Branford Hill would have been aghast at the idea of randomizing patients (as in a lottery) with no greater good being

served. A pity we are not as wise as our predecessors. I don't know what the solution is. I do believe that the Protease drugs are unusually difficult and expensive to make. Maybe some initial product shortages are inevitable. But I would be willing to bet all my co-pays for a year that the second the drugs are fully licensed, and can be sold for a profit, all talk of shortages will disappear. During that interval, I would like to see the greatest good come to the greatest number of us. And there is no way I can accept that a lottery will provide that. Randomizing people, arbitrarily deciding who can and who can not have a potentially life extending treatment always feels cruel, at best, to those seeking new options. It's excusable when it serves the greatest good, as in a clinical trial that provides essential answers. Without that rationale, it's simply abhorrent.

## Requiem For Michael

Well, it's the second decade of AIDS all right. We have met the mainstream, and it is us. We have a PWA in the white house, there's a country music AIDS benefit album, and Suburban matrons, fresh from seeing Philadelphia, vie to have an honest-to-goodness PWA ornament their cocktail parties. This outpouring of long desired cuddlability is a little tainted though. All in all, it was a bad year for hope.

No, I'm not talking about the debunking of the AZT-hype machine, or the abysmal failure of the non-nucleoside drugs. I'm not even talking about the fact that all of the trials of prophylaxes and antivirals to date shows that we may be able to delay some OIs, but nothing seems to lengthen survival. All of these are just little deaths of hope, where one potential option among many turned out not to be the viable one. Special cases, single promises: we're used to seeing those turn to dust.

For me, at least, the most significant piece of 1993 AIDS history was the death of Michael Callen. Long-term readers of this magazine need no introduction to Michael. Much to his dismay, he had been our poster boy, our embodiment of promise. For those who did not know of Michael, I hope that I can do justice to why he was so important, and why his death is the bitterest blow yet, amongst all that we have endured.

Beyond who Michael really was in his personal , the idiosyncratic, feisty brilliant man, he had another identity, his symbolic one, as "the PWA who stayed alive". As long as he survived, he demonstrated the potential that any of us might make it out of this inferno alive. Michael got his official AIDS diagnosis in 1983, not long after AIDS was first named. Public health officials constructed a consensual object to explain and contain the mounting death toll of gay men, hemophiliacs, and IDUs, and Michael fit their criteria. So by that measure, Michael lived ten years with AIDS, a supposedly impossible task. And to my knowledge, he was the only one to do it, unless you believe the assertions of those new age hucksters who charge \$35 lecture fees, and claim to have become HIV negative by virtue of their own patented brand of snake oil and positive thought (some of these escape artists claim to have tested HIV positive long enough ago that the date actually predates the isolation of HIV and the invention of the test...sure proof of their miraculous status! Pointing out these trivial little discrepancies marks you as having negative thoughts, and presumably unfit to share in such miracles)

Ten years is remarkable enough. But Michael actually had a couple of the infections that qualify one for an AIDS diagnosis in the late seventies, long before these illnesses carried the somber significance of being AIDS-defining. He had AIDS before it existed, and lived to tell the tale until this year. On the bell curve of survival, he was an infinitesimal speck on the horizon, a far star. And for many (certainly including myself) that was so important. It's selfish, I know, but as long as Michael stayed alive, I could ignore all of the others who have died, and think "if him, why not me?". For a long time, it was anathema here at PWA Live to get too graphic or specific about the

fact that AIDS killed people. We were "People Living With AIDS", "Surviving and Thriving" (a term coined by Michael)

But reality has a nasty way of destroying dogma, and despite all of our affirmations, Louise Hay seminars, and positive thoughts, we have been (not to put too fine a point on it) dropping like flies. Especially under such horrible, incomprehensible circumstances, it is natural to seek comfort where it can be found, and painfully earnest testimonials of "living with AIDS" have persisted, despite the charnel evidence. In trying to keep alive that ember of hope, Michael was a point of undwindling life, I don't know why he lived so long. Neither did he. When pressed, he would attribute it to "Diet Coke and the love of a good man". In more serious moments, he would cite his minimal and judicious usage of medication as a likely factor. But nobody knows for sure. There was some mysterious "Factor X" that kept Mike alive. And as long as that was true, all of us could hope that whatever Factor X was, we might have it too. Well, the market in factor X crashed this year. Whatever kept Michael alive dwindled out, and left yet another hero gone, a 38 year old man dead before his time.

Not that everyone was delighted in the face of Michael's perverse survival. That survival, combined with Michael's extremely assertive personality, and unflinching commitment to speaking what he believed to be the truth threatened many "experts" and "community members". Especially when he preached skepticism of the then-adored AZT, and remained amazingly healthy while ignoring the treatments du jour, There was so much bitter gossip and slanderous claim that he was pretending to have AIDS, he was forced to publish biopsy results in the PWA Coalition Newslines. But even then, in making a gesture that might have appeared petty or defensive from another, Michael managed to make fools of his assailants, and gain in dignity and credibility.

One of the best things about Michael as a symbol was his refusal to be constrained by the meanings others had attached to him. He, probably better than we, knew the significance of his survival, but he adamantly refused to let the mere feat of surviving define who he was. He had a personality impossible to summarize. I hardly knew him, save through some infrequent correspondence, but the richness and texture of his sometimes paradoxical personality clearly emanated from his writings and speeches. We was irascible and sweet. Unbelievably opinionated, yet willing to learn. Uncomfortable with being the AIDS messiah, yet urgent in communicating what he believed worked for him. Totally committed to AIDS, yet able, in the last few years of his life, to walk away from the battleground, and to reclaim an uninfected lifestyle.

One of Michael's most important messages (I think) was skepticism. He was involved in bringing the first truckload of AL-721 (a stone age alternative treatment) to New York, yet one of the first to declaim it when it was obvious that it wasn't keeping people alive. What a remarkable contrast to all the hucksters, alternative and mainstream, who so fear being "discredited" and ridiculed that they deny the evidence of their own eyes! It seems as if people keep loudly proclaiming the virtue of their own panacea long after doubt sets in, trying to eke the con out just a little longer.

But then again, Mike had no agenda in regards to treatments. He was risking nether tenure nor profit, and his renunciation of the crown that the community kept trying to bestow on him made it clear how he felt about being the "AIDS expert". All he was trying to do was keep himself and his friends alive.

Mike and his doctor, Joseph Sonnabend of New York, created the prototype for the empowered PWA-doctor relationship. Equally as opinionated and forthright as Michael, Dr. Sonnabend is also universally loved or despised. A visionary, Dr. Sonnabend, with Michael as his all star patient, implemented many innovations in ADS treatment that are now finally being accepted and widely used. It hardly seems genius to recognize that the drug Trimethoprim Sulfa, which has a long history of use in leukemic children to prevent PCP pneumonia, might be equally beneficial in persons with AIDS. Yet Sonnabend went out on a limb in 1983 when he recommended it's

universal usage in those who could tolerate it. The tide of opinion only caught up this year, when the institute of Medicine recommended the usage of Trimethoprim-Sulfa in all persons with CD4 counts of less than 200 who can tolerate it.

Dr. Sonnabend was flying blind in the early years, shooting from the hip, and hoping that the clinical judgments that he was making based on little more than common sense were correct. What was needed was knowledge, not good guesses. So Michael, Sonnabend, and others put in motion plans to get the AIDS community the quality research that it needed and deserved. Federal research efforts seemed to move glacially slow, gorged with mediocre treatments and old ideas. Michael and Sonnabend started the first community based clinical research consortium, CRI-NY. Later, Michael's testimony before Congress was widely credited with being the deciding factor in the eventual funding of the CPCRA, the federally funded community based clinical research program. Ironically, once the feds had decided that community based research was a good idea, they then froze out CRI, and elected to not allow CRI to participate in the program that Michael lobbied so hard for.

But CRI was hardly Michael's only project, or even his only "first": Besides being involved in the creation of the first community based clinical research effort, he also helped to found the first PWA Coalition in New York, and was editor of their Newslite. He was part of the team that wrote the first safe sex guidelines, long before HIV was discovered (it should be noted that Michael never accepted the idea that HIV was necessarily the cause of AIDS, but the safe sex guidelines arising from his "multi-factorial" concept of AIDS etiology probably saved many lives, regardless of what the real cause turns out to be).

Michael and "firsts" just seem to go together. Part of it, of course, was due to his early diagnosis, and being on the scene from the beginning. But that simply is not adequate to explain his impact. Many of the things that we now take for granted as PWA empowerment or activism came about because Michael and others totally reinvented what the role of a "sick" person was, and the role of the community in dealing with an epidemic, as opposed to surrendering authority to the professionals. They wrote the paradigm that made being a PWA a cultural and political identity, not just an epidemiological one. He was part of the group that drafted "The Denver principles" which are as much a touchstone to the PWA movement as Stonewall has been to the gay community. It is from those principles that the word "PWA" comes, as well as the idea of living with AIDS. He was a plaintiff in the first AIDS discrimination law suit. He founded the first buyer's club.

This was a man who would not accept anything less than the best and most respectful treatment for himself and his community. And he was willing to take that fight anywhere it needed to go, from the halls of Congress to the soundstages of TV networks to the streets of NY, where Michael was a regular participant and instigator in many demonstrations.

If Michael's whole life had been constructed and molded by AIDS, he would have ultimately been a less interesting and admirable character. It was precisely because he refused to turn his life over to AIDS that he ascended from merely enduring to heroic. In 1989, Michael walked away from the battlefield, and reclaimed his life. An incredibly gifted singer, he spent the last years of his life performing with the Flirtations, his a cappella group. This was perhaps the most significant victory of all over AIDS: He stopped letting AIDS run his life, and got on with living as he chose.

In Michael's own words, from his book *Surviving and Thriving with AIDS*, Vol. I  
"...Basically, follow your mythical grandmother's advice. All things in moderation. Listen to your body. Eat right. Get plenty of sleep. Be good to yourself. Love yourself, and find somebody to love you. Love somebody back. Love is very healing.

I encourage appropriate skepticism about what you read and what you're told. AIDS has become a cottage industry, and everyone has an opinion. Anyone who keeps up with the media knows that you can find an "expert" to say anything about AIDS, most of it contradicting last week's expert. So try and find a quiet place above the maddening roar.

If you can possibly manage it, become political. Write your congresspeople. Join the PWA coalition or the local PWA group in your area. If there isn't one, form one! Speak up and speak out. Insist that this country mount a better response to AIDS. Make America value your life as much as you do. Life in general, and your own life in particular, is worth fighting for....Time is short, and life is precious, and there's much to be done if we're to get on with this business of living"

Michael is survived by his long time partner, Richard Berkowitz.

Also featured in this issue are excerpts from letters Michael wrote to Udo Schucklenk, and lyrics from some of his songs

CDC finally changes AIDS definition

That's great...or is it?

Several issues back, we ran a feature on the proposed new CDC surveillance case definition for AIDS that was supposed to go into effect last year. Long term activist pressure had finally coerced the CDC into considering changes in the list of conditions that made up the formal diagnosis of AIDS, and we collected a number of eloquent local opinions. As everybody connected with AIDS probably knows, the definition didn't change at that time, but there will definitely be a new case definition that may be in place by the time you read this magazine. It's unlikely, in our opinion, that this alteration will successfully solve the problems that prompted the revision.

The CDC, or Centers for Disease control, with main offices in Atlanta, is the arm of the US public health service (PHS) chartered to track disease and illness prevalence and transmission in the US. Any time you hear any statistics about disease in this country, odds are good that CDC investigations provided the data. CDC also works extremely closely with local health departments, like our own beloved MDH, who often act as the local "eyes and ears" . It was investigators with the CDC who first described AIDS as an entity in itself, gave it a name, and "wrote the rules" as to who qualified as a PWA, Their entire purpose in creating this category "AIDS" was to be able to count cases, and chart transmission.

Having given birth to this problem child, like many parents, they soon saw their creation take off on it's own, taking up residence in strange places, and behaving quite unexpectedly. AIDS took on a life of it's own, becoming one of our most powerful and intricate cultural symbols. "AIDS" became an identity for many people, a threatening nightmare for others, a microcosm of all society's ills for some, and a path to spiritual transformation for yet others. Perhaps most pertinent, the social Security Agency, another far-flung arm of our government adopted the CDC definition, lock, stock and barrel. AIDS was deemed a "presumptive disability", and those people whose illness fit neatly within the confines of the CDC definition found their path to access to social security benefits well greased, and drastically shortened. After some confusion and intrasingence in the first few years, people with AIDS Were eligible for social security, and all the benefits associated with it. End of sentence.

For those unfortunates whose illness wasn't exactly described by the case definition, the road was a lot harder. Tremendously ill people were denied benefits repeatedly, despite multiple appeals,

because they didn't have the courtesy to have the proper diagnoses that could be neatly checked off on the right form. In particular, as repeatedly noted by the activist community, women, people of color, IV drug users, (and basically all of the people with AIDS who weren't gay white men) tended to not fit those categories so well. These people had enormous difficulties getting benefits from SSA, because SSA had adopted the CDC definition.

And so the activists began exerting that uniquely pressure that has become the hallmark of AIDS activism. Die-ins, letter-writing campaigns, prominent speaking engagements and media appearances. Virtually all directed at the CDC, and not the SSA. And, as so often before, the community got it's way. It's pretty hard to hold your ground against thousands, if not tens of thousands of people fueled by the rage created by having their freinds, lovers, and family die. Not to mention the righteous indignation of those PWHIV's who weren't technically PWAs, but were sicker than hell. And Mohamed moved the mountain.

As of January first, the following conditions will be added to the list of AIDS-defining conditions: Cervical cancer; repeated bacterial pneumonias; Pulmonary tuberculosis (extra-pulmonary has been on the list since 1987); and a T-cell count of less than 200.

I am definitely going against the prevailing mood in the community when I say this, and even contradicting some statements I have previously made, but I'm not so sure that this is the best idea. Hindsight is always easier, but I think that we should have gone up against the SSA in the first place, and not the CDC. Rather than changing the definition of AIDS, maybe our efforts would have been better spent to de-couple SSA criteria from the CDC definition. Before I am summarily lynched by ACT-UP, Project Inform, Test Positive Women, and the whole PC patrol. let me explain why I say this.

As the AIDS definition today stands, it gives us a rough idea of how many people there are whose immune systems are truly torched. It does not give an idea of how many people are debilitated. There are many people with AIDS who stay pretty healthy, and there are many people who aren't even HIV-infected who are pretty sick, and definitely deserve public assistance. Immune status and illness are not in absolute one to one correlation. I think there are pretty strong arguments for adding some conditions like Microsporidia, which like it's better known cousin cryptosporidia, needs a depressed immune system to get a good foot-hold. And I think that people with TB, regardless of their HIV status, deserve social security. The same holds true for cervical cancer, and for repeated pneumonias. These people are really, functionally, sick. If anyone deserves help, it's them. They are sick enough that working for a living will be hard, if not possible and that's true whether or not they are HIV infected.

On the other hand, there are tons of people with T-cells under 200 who are fine, and stand a good chance of remaining so for a while. Their risk of getting sick is certainly higher, and that's a very real fact that would be cruel to ignore. But resources are limited, and if I had the choice of whether to subsidize a healthy person with T-cells of 150, or a person with TB, whether or not they were HIV-infected, I personally would not have a hard time deciding.

That's the inherent problem. The newly added conditions ( T-cells excepted) are nasty, life-compromising things in their own right. Even in the complete absence of HIV, a humane society should help these people. And there are many, many people who suffer from these conditions who do not have HIV. Unlike PCP, CMV, Toxo, and the others from the old list, your immune system doesn't have to be that bad off to contract the new diseases. So any list we make will not tell us much about the rates of severe immune damage, which is what the AIDS definition was intended to do. We will be collecting a hodge-podge of persons whose immune systems range from "normal", all the way to AFU (all fucked up) . Any utility the definition had for epidemiological studies will be secerely compromised.



On the other side of the coin, by restricting ourselves to yet another little list, we are still ignoring many people who really are having a pretty hard time. Ask somebody with peripheral neuropathy so bad that they can't walk. We've created a weird brew of immune damage and functional sickness that certainly doesn't approach solving the service access question. Simultaneously, by changing the rules of the game in the middle, we've crippled our ability to study the patterns of AIDS growth. How can you compare the number of cases in 1991 to those in 1993, when the definition of case has totally changed? Without exhaustive chart review, and other investigative efforts, we have no way of separating out the people with the new conditions from those with pre-1993 AIDS. It will be a lot like comparing apples with apples and oranges. There's no question that in the first year, cases will go up drastically. But we've lost our ability to tell if cases are really going up, at least for several years, when a new equilibrium will form. A similar, although less drastic problem occurred in 1987, the last time the definition was changed. As a result, we have no valid comparisons between years before 1987 and years preceding. Now we are going to compound the confusion.

The whole thing is the most classic possible case of "confusing the map for the territory", except that it may even be worse. It's more like confusing SSA's map of CDC's map for CDC's map itself.

So what's the answer? I certainly don't know. It seems to me that disability should be functionally determined, correlating perhaps with the Karnofsky scale (a widely used scale of ability, mobility, and functionality). There is of course, a real catch-22 there. Any time that you give real world functional tests to disabled persons, gauging the difficulty of the test, and the required degree of proof becomes enormously problematic. If it's too easy to appear disabled, and if anyone can get away with it, they probably will. Many able-bodied people who are used to "working the system" will soak up the tragically limited resources. On the other hand, if you make the test of disability too difficult, involving multiple examinations, forms filled out, testimonies, and other proof of illness, you also have made it that much more terrible for the sick person, who doesn't want to deal with any of this in the first place. If you "put the hoops too low" that people have to jump through to get social security, hordes will use up a limited pot. If on the other hand, you set them too high, the whole thing will end up being too exhausting for the person who really needs the help.

I guess this is kind of an eternal dilemma that has probably existed since the very first public assistance program. But the important thing to remember is that we have to try to always keep the onus of effort off of the backs of those who are disabled. Persons in need of help should be exerting the minimum of effort in receiving that help. Whether the new rules are good or not, it is to our nation's pronounced shame that the effort had to have come from the sick people first: that those who needed help were forced to be the ones to review and revise the system that is supposedly there for their benefit. Personally, I think that persons with TB, cervical cancers and bacterial pneumonias should be eligible for public assistance if they want it. Likewise, people with HIV, and no dramatic symptoms except profound fatigue and malaise, who are likely to have T-cells less than 200 should also be assisted. As long as we're being humane and reasonable about it, how about people with crippling peripheral neuropathy? And what about people with chronic fatigue syndrome, regardless of their HIV status? "in their head" or not, these folks have a real tough time dealing with day to day life. So it's not always so easy to come up with an exhaustive list.

But bureaucracies need lists. They need guideposts, and benchmarks, and standardized criteria. When the SSA adopted the CDC definition, they were taking the easy way, and just copying the list from another agency. And that did have its good points. Ask anyone with AIDS who got their check as fast as the system works, which is still five months. Just taking another list for the new definition is not a solution. And you can bet that the SSA won't do that this time. The new conditions have been sneered at by many "experts", simply because anyone can get them. It doesn't require a significant lack of immune function. This completely ignores the functional

reality that persons with these conditions don't feel so good. Nonetheless, the SSA is likely to be a lot less impressed with these fairly common clinical conditions. They simply don't have the frightening exoticism of, say, PCP or MAI. You can bet that SSA will not be reaching as quickly for the checkbook the second they hear the word "AIDS". Let's hope that whatever new rules do come down the pike are fair, easy to assess, and relatively quick to process.

Sure. What are the three big lies again? "Checks in the mail"; "I won't do anything unsafe" (updated for the 90's); and the "we're the government, we're here to help".

## DHS Thumbs its Nose at Chemically Dependent PWAs

The Chemical Dependency Division of the Minnesota Department of Human Services (MNDHS) has enjoyed a glowing national reputation for its innovative and aggressive attention to the issues surrounding the intersection of HIV and chemical abuse. Projects initiated by Carol Falkowski and Earl Pike set new standards for quality and originality, carefully characterizing gaps in existing services, crafting new programs, and providing technical expertise to care providers in a variety of disciplines.

This incredible track record makes the DHS CD division's ongoing and progressive withdrawal from AIDS issues all the more troubling. Over the last six years, DHS produced two comprehensive guides for the humane and appropriate chemical dependency treatment for all people with HIV, incorporated "HIV-readiness" into the licensing qualifications for CD programs, and trained non-stop across the state. The AIDS and substance abuse partnership (ASAP) was widely utilized as a community-based advisory panel, directions for activities coordinated by DHS.

However, in the last year Earl left DHS, and Carol has been pushed far into the background. With the departure of these two leaders, the CD division seems to have lost all momentum. All AIDS issues have been relegated to only part of a half-time position (Nick Vega Puente dedicates half of his time to AIDS, Tuberculosis, and other health issues in CD treatment facilities). The long standing flow of innovative effort has slowed to a mere trickle, with no major projects of any kind on the books. It appears as if the sum of DHS's commitment will amount to little more than the distribution of pre-existent materials, and assurance of minimal compliance with licensing requirements. There is little sense of the vision and ambition that once graced all the CD department's efforts.

It appears that more and more of the responsibility is being passed off to ASAP, an organization that has a long history of productive collaboration with the CD division. This winter the steering committee of ASAP requested a meeting with Cindy Turnure, head of the division. ASAP members expressed concern about what they perceived as DHS's dwindling commitment to AIDS/CD issues, and pressed Ms. Turnure for specifics on what ASAP and the community could expect in the future from the CD division.

ASAP members left that meeting depressed and angry. Many felt that although Ms. Turnure was not very forthcoming on specifics, the message came through loud and clear that DHS would be substantially pulling back from leadership on AIDS/CD issues. The only specific Ms. Turnure was willing to commit to was some minor administrative support to ASAP. It seemed absurdly clear that the CD division would be blazing no more new paths, but if they were very lucky, those who took this role on might get some mailing list support.

This is completely unacceptable. The HIV epidemic is moving more and more into drug using and abusing populations. Now is the time for increased focus on these groups. As mentioned earlier

in this article, the contrast is only heightened by DHS's previous leadership in these areas. Chemically dependent people and those at risk need a comprehensive range of services, from targeted prevention efforts to AIDS-friendly CD treatment and individualized relapse prevention. The range of issues is staggering: harm reduction, pain management, sexuality education and rehabilitation and integrated care plans are only the tip of the iceberg.

It's not up to DHS to provide all of these of course, but the division is uniquely situated to initiate and coordinate such initiatives. By virtue of the program accreditation process, DHS has arguably the most frequent and ongoing contact of any agency with CD programs across the state. Other branches of DHS license health care facilities, supervise medical assistance, and administer AIDS drug reimbursement. The CD division of DHS is perfectly positioned to pull together these varied resources and begin to address the world of need out there.

If you believe that the chemical dependency division of the Department of Human Services should continue to provide leadership on issues of CD and HIV/AIDS, and to expand its efforts in reaching communities increasingly beset by AIDS, please write to Maria Gomez, MN Commissioner of Human Services, Let Ms. Gomez know your concerns with respect to all the challenges created by the twin epidemics of drug abuse and HIV/AIDS. These two plagues twine together like serpents. It's critical that the contribution of drug abuse to HIV not be swept under the rug. Equally important is guaranteeing that drug users and those in recovery, or seeking recovery, have available a continuum of culturally sensitive, clinically relevant, and empowering services. Write the Commissioner and urge that DHS maintain and expand its programs in chemical dependency and AIDS.

Maria Gomez Commissioner,

MN-DHS

444 Lafayette Road

St. Paul, MN

### Remembering David

David Lindahl (or "Daisy" to his Faerie friends) was an essential and beloved part of PWALive dating back to our beginnings. He was one of our first board members, a tireless contributor, and perhaps most importantly, he gave a lot of his unique personality to the overall spirit of PWALive. He was always present and active, and certainly participated in editorial meetings and other such decision making, but before and above all of that, David helped prepare the soil in which PWALive was to grow.

It is not hyperbolic to say that David's activities as an artist and activist shaped a significant part of Twin Cities history, and that the flavoring dispersed by his personality lingers on in many diverse communities. His activities with Tom Young in the early days of the James White Review advanced the cause of gay and lesbian literature as a major thematic thread worthy of archival and dissemination. His loving and enthusiastic support of the Radical Faeries helped to build the Kawashaway Faeries into the tight knit family it is today. His poetry and art touched many who never had an opportunity to meet him.

David's impact was clearly manifest as he became sicker. The loving and skilled support team that coalesced around him represented a broad cross section of humanity, all different sorts of people whose common bond was their love and respect for David. He had a care team like few have seen

before: twentyfour hour a day care by people who felt it was their privilege to give something back to David. I don't think anybody felt it to be a burden. I know friends who looked forward all week to their shift "sitting with Daisy". Even sick, he was more welcoming, funnier, more entertaining and personal than most people get to be at their peak. An invitation to Daisy's bedside was an invitation to gossip, to dish , and to bask in the love for life David radiated.

I don't mean to intimate that David was some kind of pollyanna or denial queen. He could gripe about the unfortunate turn his life had taken after his encounter with a "danger penis" (as the staff of diseased Pariah news so delicately put it) with the best of them. But he was never bitter, never pathetic. He clearly articulated what was making him feel cruddy, and that it was a terrible thing that was happening, and then he let it go. Often after turning the whole thing into an acerbic joke that was a larger commentary on life at large.

His willingness to live fully with AIDS was the stuff legends are made of. He gave performances and readings up through the last months of his life. There's a story I heard from his doctor, Frank Rhame, who is also my doctor. At one point, David was having a bad patch, and was in the hospital terribly sick. Some horrid little resident positively strong armed him, trying to get him to sign a DNI/DNR (Do not intubate/do not resuscitate, a document authorizing physicians not to use 'extraordinary means' to keep one alive) She obviously felt that there was so little hope for people with AIDS, and particularly for David that she wanted to make sure no resources went into keeping "a hopeless case" alive. Fortunately, sick as he was, David had enough strength to fight off this ghoul, and to live over a year and half more, writing a very funny account of this hospital stay for PWA Live. Frank wanted to give this doctor a book of David's poetry that was written and published after this hospital stay, just so that she could be aware of the light that she almost snuffed out.

An even more epic saga is the story of Daisy's last trip to Kawashaway, the Minneota Radical Faerie's campground. He had been bed bound for the better part of a year, and was going down pretty rapidly. But his community and loved ones were gathering, and he wanted to be there, to give of all that he had to offer, and to get back all the love that his Faerie brothers and sisters had for him. So his care team packed up the IVs, the pills, the dressings, and all the impedimenta of the PWA life, and trundled up to Kawashaway, in Northern Minnesota. He made it through the gathering with flying colors, but it took a lot out of him, and he checked into the Duluth hospital for a couple of days on the way home. He died shortly after. Now he was not in good shape when he went to Kawashaway. He had experienced many different OIs, lost a lot of weight, was unable to walk, and in general was pretty fucked up physically. Here come the great part of this story, though: can you imagine the look on the doctor in Duluth's face when David's friends told him that they had just taken this emaciated, mortally-ill person camping? I know David must have enjoyed that.

One of the things I loved most about Daisy was that humor: he took the story of the murderous resident , and other events that heppened during this stay, like hallucinating angels on the light switches and eating his journal, and turn it into hilarious AIDS slapstick. He was such a gossip queen, with an arch word for (or about) anybody, but I never, ever heard him be cruel or insensitive. He knew so clearly where the line between funny and catty lay, and always made fun with compassion and wit. He had an unerring instinct for the absurdities that make life so amusing. He and I could spend hours laughing about the indignity and discomfort of medical procedures, something that few would ordinarily find funny. But you work with what you got.

Others, who got to spend more time with David and knew him better will do a better job than I in describing his mercurial and joyous personality. I am writing this brief memento to talk about what a valuable piece of PWA Live we lost with him, and how much this magazine will lose with his passing. His dedication was remarkable. The last board meeting he made it to, he lay on the floor all meeting, too sick to even sit up. But he wanted to be there. He felt a loyalty to this community,

which along with his other families, including the gay community, the arts community, and others received rich benefits from his participation. I can't sum up his work in this brief piece. Buy his book, read the pieces he published here. But I hope I can communicate how much we respected and admired this quirky, multi-talented and unique man. Our loss, and that of all the others who loved David, is profound. But we are so much richer for having had him briefly, to light up the night with his phosphorescent trajectory.

## AIDS Activists Vs. Peta

Activists from ACT-UPs around the country and other AIDS activist groups such as ACT UP, the AIDS Action Council, the National Association of People with AIDS, Treatment Action Group and Project Inform clashed with the animal rights group PETA over the last week in an escalating war of sound bites and press conferences, culminating in ACT-UP protests at PETA's annual conference

Nine AIDS activists from ACT UP Washington and ACT UP Golden Gate were arrested outside of the Animal Congress at the US Air arena in Prince Georges County, Maryland, while protesting the destruction of AIDS research facilities and other violent tactics which animal rights activists are using to obstruct AIDS research.

Protesters were arrested when they staged a peaceful sit-in, blocking cars filled with PETA conventioners from entering the arena. ACT UP members involved point out that their protest was peaceful and non-violent, despite attempts by conventioners to hit them with cars and provoked physical altercations. During the protest, ACT UP Golden Gate member Jeff Getty, whose controversial transplant of Baon bone marrow enraged many animal right activists was allegedly deliberately struck by a PETA member's car.

Thousands of people attended the five-day event Animal Congress, billed as the world's largest animal rights event ever. "The fundamental goal of the week is to unite, for the first time in history, the international animal protection community " said PETA director Peter Gerard. But in a break from the past, AIDS activists joined scientists and other patient advocates to argue that opposing the use of animals in medical research threatens progress toward curing AIDS and other diseases.

The strategy is sure to disconcert the celebrities scheduled to participate in the animal rights events, many of whom are also avid supporters of AIDS research. "It's heartbreaking to see this attack on a movement which is based on compassion," said Chrissie Hynde, lead singer for the Pretenders and one of the scheduled guests at a celebrity dinner.

PETA has targeted various high profile celebrities, discouraging their contributions to AIDS charities. A number of animal rights groups, including Peta, are seeking to end the use of laboratory animals for life-saving medical research.

ACT UP spokesperson Steve Michael, who is HIV positive, comments, "Our lives are more important than a bunch of lab rats. People with AIDS need housing, health care, and nutrition. We're trying to stay alive until there's a cure. These people have too much time on their hands and too many T-cells." Many people with AIDS are staying healthy longer because of medications

developed through animal testing. However, attacks on AIDS research by animals rights groups have severely hampered efforts:

\* Two laboratories at the University of Arizona were burned and over 1200 rats, rabbits, and mice were stolen by the Animal Liberation Front (Alf), destroying years of research to develop a treatment and vaccine for Cryptosporidium, a bacteria that causes deadly diarrhea in people with damaged immune systems. There remains no treatment for Crypto.

\* Another animal terrorist group, Paws, shut down a project at the University of Washington studying mother-to infant transmission of SIV (the monkey version of HIV). Researchers are still seeking answers to how HIV is passed-on from mother to infant.

\* Objections by animal supremacist groups to a groundbreaking experimental procedure transplanting baboon bone marrow to an AIDS patient caused expensive delays and came close to derailing the project altogether. The patient, ACT UP's Jeff Getty, is alive and well, and scientists are learning invaluable information about the immune system.

ACT UP joined with researchers, scientists, and other patient advocates (such as breast cancer and diabetes) in several events, including press conferences, pickets, and acts of civil disobedience. In particular, ACT UP will be targeting the celebrity fund-raisers of animal rights groups. "The Hollywood crowd needs to realize that by supporting groups like Peta, they are killing people with AIDS," adds Michael. "They can't wear a red ribbon and support groups that oppose our efforts for a world without AIDS."

" Their actions play into the very hands of right-wing extremists. The Pat Robertsons, Pat Buchanans and Ralph Reeds of the world relish the message of Hollywood's 'politically correct' liberal establishment: Lab rats and mice are more important to the world than Gay men, people of color, injection drug users and Lesbians.' Said ACT UP Washington in a press release.

In the past, AIDS activist groups have been silent or splintered on the issue of animal research, in part because they've relied on the good will of Hollywood, a stronghold of animal rights sympathies. But now these and other groups have signed a consensus statement, to be released on Monday, voicing support for "compassionate" and "humane" treatment of animals but giving unequivocal backing to their use in medical research.

"Animal research is essential to progress in the study, treatment and prevention of HIV/AIDS, including the development of new approaches that may ultimately lead to a cure," reads a draft of the statement obtained by the Washington Post. Activists said they plan to disrupt the convention and celebrity dinner with leaflets and acts of civil disobedience.

"Wherever (they) set up their tables, there will be counter-leafletting," said Jeff Getty. Also planning to speak out next week is Wise Young, a researcher at the New York University School of Medicine, who helped prove that a drug called methylprednisolone can reduce paralysis in people with spinal cord injuries.

"In five years of research we used 150 cats," Young said. "Now this drug benefits 10,000 people a year in the United States alone," as well as countless animals that are hit by cars.

But Awareness Week participants said they would not be dissuaded from the moral imperative of protecting all animals.

In an unusually mean spirited and petty attack, David Wasser, communications director of Physicians Committee for Responsible Medicine, a group that advocates animal rights and vegetarianism said "They play the violins and pull the heat strings and say, 'Look at this poor man

who has AIDS". Groups such as PETA (People for the Ethical Treatment of Animals) have actually stated that they would oppose any cure for AIDS that involved research with animals. However, other animal rights groups have backpedaled and denied the fact that they want to stop animal testing in AIDS.

Asked for evidence that medical research could progress without animals, Wasser said the antidepressant Prozac was 'designed and tested entirely in humans. No animals were used at all.'

But a spokesperson for Eli Lilly & Co., Prozac's manufacturer, said Prozac was "extensively" tested in animals. In reality, every single AIDS drug, and virtually every other prescription drug has undergone animal testing. Without this vital research, safety and toxicology profiles could never be established and important life-saving drugs would never reach humans. The thalidomide tragedy, which occurred in the late 1950's would have never occurred had there been appropriate animal teratogenicity studies.

Linda Lange, manager for the international grass-roots campaigns of People for the Ethical Treatment of Animals (PETA), said more effort should go into preventing disease. Even if animal research develops a cure for AIDS, "we'd be opposed to it anyway because we always take the animals' side of the case." Lange stated.

Linda Blair, whose medical qualifications include spitting up pea soup in the movie "The Exorcist" said she believed animal research held little medical promise. "We have been doing research on animals, which do get cancer, for 30 years with no cure in sight," she said. "Why would anyone think that a cure for AIDS can be found in testing on animals when they do not get HIV?"

Speak for me? Thanks anyway. .

(Dedicated to R.H., & A.U. M.)

I was at a meeting recently of a group whose Raison d'etre is AIDS activism. They even have the word "AIDS" in their name. And I have to confess that I completely lost it. I fell prey to a rage so encompassing that I could hardly breathe, let alone speak, let alone empower myself to calmly and systematically take constructive action against my oppressors. One of the luminaries of this little group made a pronouncement to the effect that the group had a "gay" agenda, because AIDS was primarily a "gay" issue.

Over the years I have heard all the possible variations on this kind of blatant power play, this forcible hijack of the moral high ground. AIDS is appropriated as an issue of people of color, or of women, or of Native Americans, or of straight teenagers. Almost inevitably, those who seek to monopolize whatever moral legitimacy the word "AIDS" possesses in the name of their particular agenda are themselves HIV negative. And unfortunately often, that agenda, while perhaps pertinent or involved with the issues, concerns, and concepts important to HIV infected people or those at risk, is one that the speaker espoused long before they hitched their wagon to the AIDS gravy train.

The overwhelming and sobering tragedy of hundreds of thousands of deaths in this country alone is used to give a patina of respectability and urgency to the speaker's own endeavors. Often, persons who have exhausted the gamut of legitimate organizations working in their field of interest come to roost in the AIDS community. Those activist or advocacy organizations closer to the offender's core agenda have either found them too difficult to work with, or have not elevated them to superior positions quickly enough.

And so they have struck off on their own, wrapped an AIDS label around their product, and are off merrily peddling it to the masses, co-opting the moral imperative and urgency surrounding AIDS to justify a precedence over groups who have similar or overlapping agendas. Often these agendas, as exemplified in priorities, objectives, and actions have only the most tenuous connection to AIDS.

Obviously I am painting a picture in the broadest possible strokes here, and a majority of the people working in the constellation of issues abutting or tangential to AIDS are legitimately integrating AIDS concerns into their curriculum. This is more than just important, it's essential if we hope to see the day where AIDS is legitimized, and destigmatized, taking its place among the myriad of woes facing the human race as a universal concern of the human community. The observations in this piece were triggered by a specific incident involving a specific organization, who have shown a consistent propinquity for demagoguery nominally justified by AIDS. The reason that I don't identify the group by name is not for fear of reprisal, or even of alienating those involved. Unfortunately, they are not alone in this exploitation. Although as I previously indicated, I would not want to tar everyone who invokes AIDS as a concern with the same brush, this particular group is by no means unique, as I referred to in the first paragraph. This particular incident catalyzed my desire to write about it, but obviously there is nothing unique in exploiting an already beleaguered group in the name of helping it. The hordes of phony foundations and fundraising groups who have preyed on the cancer community for years, and recently have expanded their activities into the AIDS sphere are only the most blatant example of this. President Bush kissing "AIDS Babys" while refunding NIH at less than the rate of inflation is another example that springs to mind.

It's critical that to confront this unscrupulous cynicism. The problem is to do so without fanning the flames of discord or avaricious competition. Obviously, fomenting divisiveness or infighting amongst those whose agenda includes AIDS does no one a service, especially those who truly are infected or affected. Unfortunately the importance and dignity of the struggle for gay rights (or those of people of color, or of women's rights, Native American rights, etc.) is only compromised by such dubious and parasitic tactics, and not truly advanced. It's always problematic to make an inflexible, black and white assertion about whether the ends justifies the means or not, but descending to systematic oppression has never helped any liberation movement.

Gay rights (or any other civil liberties issue) is phenomenally important for a civilized society. And that's why there are organizations with that specific focus. The AIDS struggle is inextricably bound with the fight for gay rights, and with feminism, compassion for those afflicted by addictions, and anti-racism efforts. Coalitions have to be built, and the various disenfranchised must be mutually supportive of each other's efforts in order to hope to confront the juggernaut might of the hegemony. Progress will have to be made in parallel.

No matter how strong a supporter of gay rights I might be (and I am), I will never know the oppression of growing up gay in modern America. I will never know the incremental agony of doors being shut in my face, opportunities missed, and my very personal worth being repeatedly devalued. I will never know what it feels like to have "faggot", "homo", "cock-sucker" and "sissy", words created to describe me, being used as the most common insults in our society. I will never know exactly what that means, or what kinds of hopes, angers, fears, dreams and griefs that might engender. And so it would be enormously condescending and patronizing of me to "speak for" the gay community, or pretend a right to set its agenda. No matter how strongly I sympathize or empathize, no matter how important I feel the fight for liberation might be, I do not have the right to determine the course of the struggle. Even though I am a person with AIDS, and thus my fate is inextricably tied in myriad ways with that of the gay community, I am still a supportive outsider, and I must yield to the affected community's self-determination. I may pass ammunition, but not pick the targets.



So where does this HIV negative gay man get off claiming the right to dictate the terms or parameters of the AIDS struggle? How dare he invoke my suffering, and that of my comrades, living and dead as justification for decisions he has made as to what is best for our community? Yes, many, many of us are gay. Many of us are also blonde, or wear size ten shoes. I realize that that analogy is a little oversimplified, as the separate persecutions feed off each other, and AIDS was permitted to spread out of control just because it was gay men who were the first to start dying. And those of us who are gay are doubly burdened, in sharing the difficulties faced by both groups. But the seronegative gay man does not automatically understand the trials and torments of a gay man with AIDS any more than a seronegative straight does with a straight PWA. Gays are oppressed, PWAs are oppressed, and there are unique flavors to both of these experiences, for all that they often blend together.

We welcome your help, your support your commitment. We welcome being brought back into the human community on the whole, and not being treated as some bizaare, sinister "other". We welcome the support, and advocacy, and activism coming from the community level, gay and straight, that has furthered our causes and improved our lot. "battlefield camaraderie" has actually done much to heal the wounds of divisiveness, of homophobia, racism, and sexism, among those who have struggled together. But you don't speak for us. Do things in the name of "gay men who are concerned about AIDS", or people of color, or women, etc, but do not usurp our name and our identity.

AIDS, when you come right down to it, is about loss. Health. life, mobility, financial security, independence, appearance, dreams: Virtually everything is eventually taken away from us. Do not steal our name, and our voice, and our anger.