

# HOW TO IDENTIFY AIDS FRAUD

things to consider  
when dealing with questionable  
treatments and “cures”

A PUBLICATION FROM

PROJECT  
*inform*

Information,  
Inspiration and  
Advocacy for People  
Living With HIV/AIDS

JANUARY 2007



AIDS, like cancer, is a disease that is seen as having no cure, with standard treatments that are viewed as having many side effects. In response to these uncertainties in cancer, a thriving underground has evolved offering “cures” and treatments based on unproven (often disproven) and conflicting theories. They all promise miraculous improvements beyond the power of standard treatments and usually promise few or no side effects.

In AIDS, at least two types of underground have evolved. One is the familiar *buyer's club*—community-based groups which strive to improve access to legitimate treatments. But a second underground has emerged. It's quite similar to the one found in cancer, offering the same sort of things—and sometimes the exact same things from the exact same practitioners.

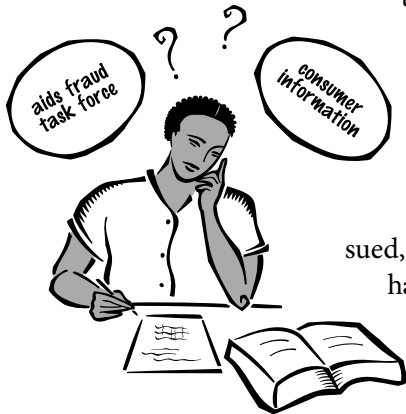
Project Inform's Treatment Hotline receives a steady stream of calls about mysterious treatments that don't have Food and Drug (FDA) Administration evaluation or approval. Nonetheless, they're being sold to the public with claims of being effective. Our generic name for these treatments is “cures-of-the-week.” Over the years, Project Inform has looked at hundreds of these claims and products, ranging from interesting medicines to formulas purportedly delivered from the flight decks of flying saucers.

Assessing such magical *cures*—separating the truly crazy from the plausible—is more difficult than it may sound. Most offer some evidence of satisfied users, typically AIDS patients who feel they have benefited. We hear claims from sincere people who saw their CD4+ cell counts rise, who “felt much better,” or who “recovered miraculously” from some infection or condition.

These people are hard to argue with, as they truly believe that their treatment discovery is responsible for their newfound well-being. The last thing they want to hear is someone questioning their experiences. Project Inform respectfully sees these individuals as “true believers.” Sincere “true believers” help support almost every kind of treatment, reporting similar kinds of improvements. However, our long-term experience with hundreds of products is that few if any of these experiences ever predict the real value of the treatments.

## Using resources as a guide

Ideally, some authoritative and unbiased agency would investigate all these treatments and the practitioners who make unfounded claims. Several states have established AIDS Fraud Task Force groups to help address this issue in a way that's sensitive to the community. Of course, the FDA has authority to control the sale of products and the claims made about them. Various state and local agencies have some responsibility in this area as well.



Information sources, like Project Inform, try to offer some consumer guidance since we're often the first to hear of new therapies. Rarely, some charlatan is arrested or sued, but in recent years this problem has grown out of control. This is perhaps because standard treatments are rife with problems, which include side effects and difficulty of use.

No one has the resources to respond to every new claim and product. Many patients assume that if these practitioners aren't shut down by law, they must be legitimate. It's a bit like believing that the things we read in newspapers and hear on TV must be true. In fact, it just means that the issues are complex and regulatory resources are spread very thin.

Evaluating treatments is not easy. Very rarely can anyone predict which experimental HIV treatment may someday be used as standard therapy. Even among treatments in FDA-approved studies, researchers differ greatly about what's promising and what isn't.

But, in dealing with *cures-of-the-week*, judgments are sometimes easier to make since precise evaluations aren't necessary. Often, all that's needed is a general sense of whether something is rational or not. What follows is a short guide to what sort of evidence matters and what doesn't in evaluating these treatments, as well as a guide to the warning signs of possible AIDS fraud.

## questionable evidence

The following forms of evidence are considered questionable, if not misleading. If these are the kinds of evidence offered about a treatment, you can be pretty sure that something is wrong.

### Anecdotal information

The most common, of course, are case reports or anecdotal evidence. These are observations backed by personal testimony. It's always impressive to hear from a live person that a treatment works, and most people find this compelling. If it worked for him or her, then why not me?

But reports of success, which are often fleeting, unfortunately don't help much. In fact hardly ever has there been a treatment in the history of the epidemic that some people didn't claim to do well on. No matter how unlikely, unscientific or transparently mercenary the marketing for the treatment may be, there is always a group of true believers who are evangelical in their enthusiasm for it.

How is this possible, if the treat-

ments are phony? There are some obvious, and some subtle, reasons why everything seems to work for somebody. One is the power of the mind. People in studies who think they're getting a toxic drug often experience its side effects, even though they took a placebo (a dummy sugar pill). Likewise, people who think they're getting a beneficial drug often get better, at least for awhile, even though the drug may later be proven to have no effect or it was a placebo.

These are not imaginary events—people often have measurable changes. But they are not always due to the treatment. The so-called *placebo effect* is very real. Because it is such a powerful force, complex procedures are used in studies to separate it from the

actual effects of treatment. Sometimes, perceived benefits are proportional to cost. People who have made a big investment in a questionable treatment, emotionally and financially, may at a minimum feel increased energy and well-being—for awhile.

### Chance miracles

Another reason is chance. No one fully understands or can predict the "natural course" of HIV disease. In treated and untreated people, CD4+ cell counts rise and fall, symptoms come and go, and there are long periods of stabilization and steep declines. All this happens without any definitive explanation or cause. Simply put, HIV disease varies greatly in people.

Inexperienced practitioners often think a miracle has occurred the first time they give a patient their elixir and some lab values improve or the patient goes on to live a fairly normal life for awhile. To them it appears to

## Using common sense as a guide

Probably the most important thing to keep in mind, in looking at *cures-of-the-week*, is not to lose your common sense. Of course there are people in genuinely desperate circumstances who feel they have nothing to lose. Unfortunately, desperate situations don't tend to bring out common sense.

But a moment's clear thought will tell you that a nurse practitioner who wants to infuse you with an expensive mystery substance in Tijuana has probably not solved the great medical puzzle of our time. People go from one questionable treatment to another like playing the lottery—but with less chance of winning.

The saddest and most dangerous thing about *cures-of-the-week*, however, is not the money they take from dying people. It's the harm they do to people who could benefit from more mainstream treatments but who let their health run out by pursuing fly-by-night cures.

There is at least one *cure-of-the-week* that is given away to patients and has no particular side effects; so it is said that people have nothing to lose. In fact, if they go off their regular medications to try a treatment that has virtually no chance of producing any benefit, they're

risking a decline in their health. There are people who've exhausted everything that can be done with current anti-HIV therapy, but there are far more people who, in a futile search for home-run drugs with no possible side effects, neglect the available options with some evidence of benefit.

Obviously, there is no "cure" for AIDS now—only treatments and combinations of them that buy time until a cure can be found. In the meantime, the *cures-of-the-week* come over the hills in waves, beyond anyone's capacity to keep track of them. People will go on running to Mexico, Kenya, Bavaria and shady practitioners all over America, lured by the promise of miracles. Money is the least important thing they will lose.



be the direct result of their treatment. To someone new to AIDS treatment (patient or practitioner) simple stabilization looks like a breakthrough. Like much of the public, they expect HIV infection to be a state of constant, obvious decline leading to death. As any long-term patient will confirm, it is not.

Controlled studies are the only known means for accurately separating the results of treatment from the general ups and downs of HIV infection and the placebo effect. We have yet to hear of any "miraculous" improvements that haven't been duplicated on standard anti-HIV therapy or no treatment at all.

### Other good things are inside

Another source of confusion is that even if a treatment doesn't do what is claimed, it might do something. Therapies containing vitamins, herbs or food supplements may—while having no special anti-HIV effect—improve

deficiencies in some people. It's a process that's sure to miss a lot more often than it hits. It achieves nothing that couldn't be achieved through standard care; but it *may happen*.

Personal testimony by itself and however sincere isn't a good basis, on its own, for making decisions. Similarly, the sincerity of the practitioner tells us little. While there are a few outright con artists, most practitioners believe fervently in their own products. They focus on the results that can be interpreted as positive, and they dismiss failures as unimportant. Their sincerity isn't in question—their competence is.

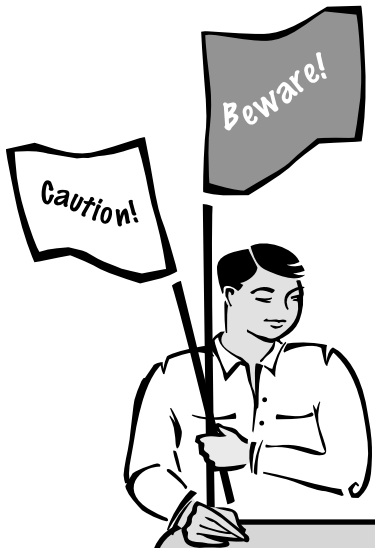
### Studies in developing countries

A final common source of misinformation is reports of studies or proposed studies in developing countries. It is no fault of doctors in Africa, Latin America or the Caribbean that they may not have the medical resources available to

researchers in developed nations. Certainly, serious research has been done in these places.

But all too often, these "studies" are just treatment observations done under totally uncontrolled conditions with inferior facilities. They're often sponsored by white middle-class entrepreneurs more concerned about making money and promoting products rather than evaluating them. Such people prey upon medical practitioners and patients in the developing world after they have been booted out of the developed nations.

The track record of research in developing countries is not good, and it has not led to promising HIV treatments now under study in developed countries. These treatments are promoted in both developed and developing countries. But in most developed countries, research must meet rigid standards, making it harder for promoters to make false claims.



## profile of a fraudulent practitioner

- Usually male, middle-aged, in second or third career, sometimes charismatic.
- History of failure or rejection in previous careers, including other scientific careers not related to HIV.
- Claims to solve what everyone else missed.
- Claims he's "too busy" saving lives to keep records.
- Superficial knowledge of the disease he treats.
- Attacks the integrity of all who question him.
- May or may not be "True Believer".

## red flags

Here are some warning signs of questionable treatments or practitioners.

### High prices

Anyone charging excessive and unexplained prices for a treatment that's not undergoing serious scientific study is suspect. Careful thinking is needed here to separate the genuinely promising yet expensive therapies from those that are expensive but unwarranted.

In general, the more a treatment costs, the more evidence you should demand that it works. If no actual studies have been done or are underway, find out why. The explanation had better be good. Any variation on "it's too much trouble," "we don't have the resources," "we can't wait," "we're too busy saving lives," or "the system is biased against us" should set off an alarm. Similar statements, word for word, have been the war cry of medical con artists for nearly a century.

Valid processes exist for determining what works and what doesn't. Sometimes you'll see products that are based only on test tube, animal or pre-clinical studies. Treatments that never enter or even try to enter normal drug development (with all its flaws and delays) will never be proven, widely accepted or available. So why would any ethical doctor leave a genuinely hopeful treatment in this limbo?

### Keeping secrets

Anyone keeping secrets or holding back information about the offered treatment is highly suspect. Also suspect are products promoted solely on personal testimonials and second-hand reports, while studies that will happen "any day now" never come around. We know of no real reason why patients can't be told exactly what's in the product and how it's supposed to work. A researcher can quickly and easily obtain patent protection for a legitimate treatment. Failure to do so smacks of snake oil at its most blatant.

### Works for many diseases

Any treatment is suspect that claims to work equally well for many major diseases, especially both AIDS and cancer or auto-immune diseases. A few may turn out to affect some cancers by improving immune function; but claims of multi-disease benefits are almost certainly bogus. Others to beware of include those that claim to be a "cure" or

render patients HIV-negative or ones that are promoted as *miraculous, foolproof* or *boosting the immune system*.

AIDS and cancer are entirely different diseases—there's no reason to expect that a single product works for both. Simplistic, unusual theories of AIDS, medicine or biology are often given to explain why the same treatments work for radically different diseases. These are seldom more than fantasies or simply the product of marketing—not miracles of science.

### Specialty not in HIV

Anyone claiming an HIV cure but whose area of specialization is far removed from AIDS is suspect. The average heart specialist or general practitioner didn't learn about AIDS in medical school, let alone people without medical degrees. People without achievements in the field of medicine are very unlikely to unravel the complexities of HIV disease. Project Inform often receives miracle "cures" sent by electricians, physicists, spiritualists and flying saucer contactees.

### Travel to other countries

Anyone offering a treatment that requires travel to foreign countries is suspect. Normally, the reason is to do something that isn't allowed here. Legitimate studies in other countries are usually filled by local people, and are free as studies must be. Promising treatments approved overseas can often be imported for personal use. There's no reason to believe that high-priced treatments from Switzerland or Peru are any more promising than the magical "cures" offered here. Often, these products come from little known doctors or "researchers" whose credibility can't be verified.

### Obscure sources

Anyone who cites articles in obscure publications or research done in obscure institutions is suspect. *Vitamin Magazine*, whatever its virtues, has no competency in HIV research questions. References to foundations or centers with impressive titles that nobody has ever heard of should set off alarm bells.