How to identify AIDS fraud

Project Inform’s HIV Health Infoline receives many calls about mysterious treatments that claim to cure HIV or AIDS, but are not approved by the Food and Drug Administration (FDA). Our generic name for these treatments is *cures-of-the-month*. They promise miraculous improvements beyond the power of standard treatments and with usually few or no side effects.

Evaluating treatments is not easy. Very rarely can anyone predict which experimental treatment may someday be used as standard therapy. But, in dealing with *cures-of-the-month*, what’s often only 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 products.

**Questionable evidence**

If the following kinds of evidence are offered about a treatment, you can be pretty sure something is wrong.

**ANECDOTAL INFORMATION**

Case reports or anecdotal evidence are observations backed by personal testimony, mostly from true believers of the treatment. It’s impressive to hear from a person that this treatment works, and most people find this compelling.

But how is this possible, if that treatment is actually phony? One reason 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 actually took a dummy sugar pill (placebo). Likewise, people who think they’re getting a beneficial drug often get better, at least for awhile, even though the drug was proven to have no effect or also was a placebo. This is called the placebo effect. It’s a very real phenomenon and because of it, complex procedures are used in studies to separate it from the actual effects of treatment.

**CHANCE MIRACLES**

Another reason is chance. No one fully understands or can predict the natural course of HIV disease. Symptoms come and go; CD4s rise and fall. Simply put, HIV disease varies greatly from person to person.
Inexperienced people often think a miracle has occurred the first time they give someone their elixir and some lab values or their health improves. That appears to be the direct result of their treatment — a miracle breakthrough. Like many, they expect HIV to be a state of constant decline in health. As any long-term patient will attest, 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.

**OTHER GOOD THINGS ARE INSIDE**

Another source of confusion is that even if a treatment doesn’t do what it claims to do, it might do something. Therapies containing vitamins or herbs may — while having no special anti-HIV effect — improve deficiencies in some people. It does nothing special that couldn’t be achieved through standard care; but it may happen.

While there are a few outright con artists, most promoters believe fervently in their own products. They focus on any 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 in developing countries. It is no fault of doctors in some parts of the world that they may not have the medical resources available to researchers. Certainly, serious research has been done in these places.

But all too often, these “studies” are just treatment observations done under uncontrolled conditions with inferior facilities. They’re often sponsored by entrepreneurs more concerned about making money rather than evaluating their product. These people prey upon medical staff and patients in these developing countries.

**Using common sense as a guide**

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

But a moment’s clear thought will tell you that a nurse practitioner who wants to infuse you with a mystery substance in a questionable lab somewhere has probably not solved the great medical puzzle of our time.

The most dangerous thing about **cures-of-the-month** is the harm they do to people who could benefit from more mainstream treatments but who let their health run out by pursuing these fly-by-night cures. People may go off their regular meds to try something that has no chance of producing a cure only to find they’ve risked a decline in their health.
Profile of a fraudulent promoter

- Superficial knowledge of the disease s/he treats.
- 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.
- Attacks the integrity of all who question him.
- May or may not be “True Believer”.

Red flags

HIGH PRICES
Anyone charging excessive and unexplained prices for a treatment that’s not undergoing serious scientific study is suspect. In general, the more a treatment costs, the more evidence you should demand that it works. If no studies have been done or are underway, find out why. Any variation on “it’s too much trouble,” “we don’t have the resources,” “we can’t wait,” or “we’re too busy saving lives” is suspect.

KEEPING SECRETS
Anyone keeping secrets or holding back information is highly suspect. Also suspect are products promoted solely on personal testimonials and second-hand reports or on studies that will happen “any day now”. There’s no real reason why patients can’t be told exactly what’s in the product and how it’s supposed to work.

WORKS FOR MANY DISEASES
Any treatment is suspect that claims to work equally well for many major diseases, especially both AIDS and cancer. Simplistic, unusual theories of AIDS, medicine or biology are often given to explain why the same treatments work for radically different diseases. These are not miracles of science. Other claims to beware of include those that are “miraculous”, “foolproof” or “boosting the immune system”.

SPECIALTY NOT IN HIV
Anyone claiming an HIV cure but whose area of specialization is far removed from AIDS is suspect. The average doctor 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.

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.

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 alarms.

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