Vital Signs

10 POZ treatment stories that shook our world

May 1, 2004 By Tim Murphy

For a newly diagnosed person with AIDS," wrote *POZ* founder Sean Strub in our first issue, "information is a more important first step than any pill, potion or prayer." That's why we've aimed to replace the stigma and medical confusion surrounding HIV with good information—lots of it—often through HIVers' own voices and experiences.

Ten years and 101 issues later, we're still doing that—even as HAART, for better *and* worse, has come to dominate HIV treatment. We've probed nearly every HIV-related misery, from lymphoma to lipodystrophy. Despite the almighty "cocktail," we've peered down other potential roads to Well-ville, from immune-based therapies to acupuncture. And sometimes, one of our stories has spotted a sea change, struck a nerve or even saved a life. Like these:

1. "What This Means" By Sean Strub / June/July 1994:
In our second issue, Strub tossed this lifeline to HIVers befuddled by their often inscrutable lab results. He published his own—and had four top doctors weigh in to interpret them in plain language—to help HIVers participate fully in our own treatment decisions. Since then, he has surrendered his labs many times—as did *POZ* It Boy Stephen Gendin (until his 2000 death) and as have New Yorkers Marlene Diaz, her HIV positive daughter, Margaretha DeJesus, and Chardelle Lassiter (see "Checkup Check-In").

2. "Women on the Verge**"** By Carol Keeley / August/September 1995:
Here *POZ* tackled the disparities faced by women with HIV: gross underenrollment in clinical trials, dangerously late diagnoses from clueless doctors (leading to earlier deaths) and a phalanx of challenges (children and poverty were only two) to distract them from their own survival. HAART didn't change this: "Even if you were a woman with all the money in the world and David Ho was your doctor, you still wouldn't know how HIV medicine work[s] in your body," said HIVer activist Mary Lucey in the December 1997 *POZ*. Let's hope the massive, decade-old Women's Interagency HIV Study (WIHS) will yield some useful data this year.

3. "It Takes IL-2 to Tango**"** By Elinor Burkett / October/November 1995:
This was *POZ*'s first major story on the manufactured version of IL-2 (a natural body protein), which has boosted CD4s in small trials but fell off the radar somewhat with the advent of combo therapy. Today, two international trials are adding IL-2 to antiretrovirals to see whether it's worth it. But with its flu-y side effects at all but the lowest doses, IL-2's prospects remain cloudy.

Meanwhile, research into immune-based therapies like IL-2 lags behind the push for more HAART.

4. "Trials by Fire**"** By Scott Williams / February/March 1996:
Here readers met regular folks taking unorthodox research into their own hands—like Boston PWA David Stokes, who got 500 HIVers to add the alleged antiviral SPV-30 (boxwood-tree extract) to their regimens. Unfortunately, any effect SPV-30 might have had was lost amid the imminent triumphs of combination therapy. But it was one of many brilliant examples of AZT-weary PWAs organizing to meet their own clinical needs, rather than drug companies' wishes—and, coming as it did on the eve of HAART's debut, one of the last. "It's a different world today," sighs Project Inform's Martin Delaney. "That urgency is gone."

5. "The Morning After**"** By Mike Barr / February 1997:
A few months after 1996's euphoric World AIDS Conference—where David Ho, MD, famously suggested that protease-powered combos could permanently "eradicate" HIV— Barr wrote this sobering prophecy of the HAART future. He predicted renewed health and prolonged life for many, offset by miserable side effects and crippling cross-resistance. He foresaw the new drugs failing many AZT/ddI veterans—and long-term–treatment confusion courted by jumping willy-nilly from one combo to another in search of "the near-mythical allure of undetectable virus."

6. "A New Kind of Waisting**"** By Denny Smith / February 1998:
This was the first of many pieces we'd do on those strange humps and bumps showing up on HIVers taking protease inhibitors (PIs)—replacing the old-time AIDS wasting as the latest body-image (and health-challenging) woe. It marked the *POZ* debut of the now odious terms "Crix belly" and "buffalo hump." (*Lipodystrophy*, the scientific name, appeared in *POZ* four months later.) "Are drug cocktails causing ugly fat deposits?" we asked. No one knew—and six years later, infuriatingly, we still don't, even if studies suggest that, as far as drug culprits go, PIs, nukes or a combination of the two are the likeliest. To repeat this first lipo lament: "Research is urgently needed."

7. "Here Comes the Cure**"** By Martin Delaney / January 2001:
"I didn't write that headline!" recalls Delaney. Still, five years after 1996's "eradication" dream faded, this manifesto redefined *cure*: a treatment strategy that would "allow you to live out a normal lifespan without day-in, day-out drugs"—in part by "creating a robust...immune response," but also by "sustain[ing] the immune responses once HAART is stopped." *If only*. Harvard's Bruce Walker, MD, recently reported that within his much-watched study of 14 patients who started HAART in early HIV infection, stopped it and initially controlled their virus, all but one later "lost control" upon subsequent drug breaks. The impasse frustrates Delaney: "Why does the immune system fail to respond to this [virus]?" He's also frustrated that nobody demands a cure anymore: "If you stop asking for it, you're never gonna get one."

8. "Gimme a Break!**"** By Mike Barr / August 2001:
By 2001, the much-maligned but *POZ*-championed "drug holiday" had morphed into the research-approved "structured treatment interruption" (STI), and *POZ* took the first serious look at a clutch of "ragtag studies" to see whether HIVers could go off their meds. Since then, we *have* come a

long way, babies: Last year, at least three studies showed that people whose pre-meds CD4s had never gone below 200 could ditch meds safely for six to 18 months–plus! The massive SMART study (www.smart-trial.org), which pits staying on meds vs. going on and off (depending on CD4 count), has shown no reason to stop or change the STI side—a good sign that regular breaks may well be a part of many HIVers' future.

9.“The Way We Die Now**”** By Tim Murphy / September 2001:
More than debuting an exciting new *POZ* writer (heh-heh), this story detailed the reasons HIVers were dying five years into HAART: far fewer cases of PCP, KS and other killer infections from the era of “full-blown” AIDS and far more heart, kidney and hepatitis-related liver failure—not to mention progression to AIDS in people with severe drug resistance. I most remember the case of a bright African-American girl, born with HIV, who had died of AIDS-related staph pneumonia shortly after her high school graduation. I wrote this piece four months after my own HIV diagnosis and remember how it scared me.

10. Publisher's Letter By Brad Peebles / January 2004:
Some of *POZ*'s most insightful treatment writing is by POZ publisher Peebles, who, since 1998, has shared his deep knowledge and deeper skepticism about HIV treatment and trends. Even more, he has detailed the doubts and fears inherent in taking responsibility for your own health-care decisions—which, for him, often means taking risks, challenging convention and, not least, *keeping interested.* Here, Peebles wrote about his “combo-lite” of Videx (ddI) and the “poorly understood cancer drug hydroxyurea (HU)”—which, he proudly noted, “the federal…guidelines say ‘Should Not Be Offered At Any Time.’” Although this experimental approach wasn't a spectacular success, it kept him healthy and conserved options—a most *POZ*-like reminder that, even in this day of designer combos, it still pays to think outside the box.

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