



A Personal Farewell to Aidsmap from the Activist Who Was There

Long-term survivor and HIV journalist Gus Cairns brings personal insight — and great stories — to news of the closing of [aidsmap.com](#).

July 18, 2024 By [Mark S. King](#)

The abrupt [closing of aidsmap.com](#), the stalwart HIV/AIDS information and resource site in the United Kingdom, has sent a mortal shudder through the ranks of those with a history in the HIV arena. The loss is incalculable.

It is also a very personal milestone for people like [Gus Cairns](#), an HIV survivor and journalist who discovered his powers of activism, and his identity as a leader, through his work with aidsmap and the groups that preceded it.

Gus is a master storyteller, and his remembrances on social media about his years in the thick of HIV drama, triumphs and losses are dishy and fascinating. His behind-the-scenes tales literally chart the history of HIV treatment, PrEP, and U=U and bring a lot of its most important figures to life.

Why am I talking? Gus should tell you himself. Here is the posting Gus shared on social media about his life in the movement and the role aidsmap played in it. Enjoy.

From Gus Cairns:

I'm so, so sad – and angry – about the demise of aidsmap. Sad to lose an organization that served as a nexus of HIV activism, joining together academics, physicians, policymakers, activists, and patients in a channel they all read and relied on (I have the emails to prove it).

And sad to see the sunset of one of the most significant chapters of my own life, with an accompanying feeling of loss of contact and identity. And not just for me.

Angry because Aidsmap was a shining example of the patient-led organizations that grew out of activism and Made a Difference, and we still don't seem to have a way of sustaining those beyond the emergency phase of HIV.

The AIDS crisis was the first time in history that the fight to tame a violent plague was initiated by its targets, by people like me, instead of health professionals. But, like much of the rest of the HIV

movement, it remained reliant on pharma money too much for too long, and we should perhaps have taken steps to wean ourselves off it many years ago. Too late now for Aidsmap, I hope not for others who need to take note of our demise.

Aidsmap changed my life. It helped turn me from someone who might have muddled-along being an occasional helper into someone who helped bring about change himself, in league with some brilliant colleagues.

Please excuse the following bit of autobiography.

Pre-Map

Back in 1998, when it became clear I wasn't going to die of AIDS after all, I volunteered at the UK Coalition of People Living with HIV and AIDS and ended up editing Positive Nation, the UK's HIV magazine. I'm still proud of Pos Nation; it was not *about* HIV but *for* us. It propelled me from being a worker with homeless youth into the stratospheric and, yes, seductive world of global HIV activism where I discovered, to use a cliché, a global village.

But I left the UK Coalition in 2002. Partly because I could see it was going to have its own demise and I didn't want to be there when it happened. But also because I was tired of just being a Shouty Activist.

The ACT-UP model of being V. V. Angry about your condition was still working, spreading a new epidemic of civil society activism where it went. But even as I used righteous entitlement as my pass to grill the Directors of the WHO and the Global Fund, to ask awkward questions of Bills Clinton and Gates, I started encountering an old enemy, impostor syndrome. I wanted to upgrade my bludgeon of outrage to an Armalite of science. I knew I was going to need it.

Aidsmap seemed to me to be the place where I could do that. I already relied on them. I'd subscribed to AIDS Treatment Update as soon as it started in 1992 and knew that Edward King and Keith Alcorn, with their calm certainty, would never, ever let me down by selling me quackery and false hope (even if, at times, I did the opposite of what they said, like take AZT). So I was thrilled to be appointed as Editor of that same newsletter in 2008.

Knowledge = power

Science helps you make life saving decisions. Because it's based on evidence, not belief, it enables you to turn on a dime when that evidence compels a change of mind. I remember reading about the results from triple combination HIV therapy in 1995. I'd previously kept myself going with Chinese herbs, positive thinking and Shamanism (and they probably helped); but when I read about Dr David Ho's results I remember thinking "Oh, that's it then" and by 1996 I was one of the first people in the UK to get protease inhibitors from a clinic, not as part of a trial.

My guru during my new-agey phase, the late Cass Mann, dubbed me The Survivor. Well, I did survive, unlike some friends who went off to their deaths still believing that Belief was enough.

Aidsmap allowed me to pair information with activism, and join them together. We gave readers the facts and then used the facts – but just the facts – to compel change in order to save people.

Knowledge is power, and Aidsmap understood that better than almost any other organization I know of.

But it also understood its own need to survive to spread that knowledge. In that respect, I'd pay tribute to Caspar Thomson, the Executive Director at the time I joined. Caspar quietly kept the SS Aidsmap engines running, nurturing its crew through the turbulent seas of finance while the wild-eyed Darwins on deck steered towards whatever new Galapagos of fact loomed on the horizon. (Matthew Hodson, his successor, was more the Admiral on the bow deck.)

Aidsmap and U=U

My first experience of Facts That Make a Difference was with what was then known as treatment-as-prevention. I'd known from as early as 1999 that people with low viral loads probably didn't transmit HIV; I'd written an edgy essay about it; by 2008 it had become a fully fledged cuckoo in the comfortable safer-sex nest, with the Swiss Statement that 'undetectable equals uninfected' causing a big row at the Mexico AIDS Conference.

Bruce Richman (Prevention Access Campaign) and Gus Cairns in 2016

A lot of the HIV activist community were deeply suspicious and even scared of any perceived

dilution of the 'Condom condom every time' message. Partly because not everyone had the chance of getting HIV drugs. Partly because yes, condoms work, if used properly (which was always the snag).

But partly because, I sensed, that the corrosion of stigma was undermining the foundations of activism. Too many worried that if HIV positive people started being informed that they were uninfected and telling others, they'd be damned as doubly irresponsible (once, for catching HIV in the first place; twice, for passing it on).

I got so tired of the dissidence on the subject that with Caspar's blessing, and the collaboration of fellow-cheerleaders like AVAC and HIV i-Base, we issued, in July 2016, the first multi-agency, collaborative statement that treatment was prevention.

This wasn't based on conviction, but on science. The statement came out midway between PARTNER 1, the first study to show zero transmissions of HIV from people with undetectable viral loads, and PARTNER 2, which proved that zero transmissions really did mean zero chance of transmission.

It was Aidsmap's insistence on accuracy that impelled me to bone up on statistics so I could say how precise and how compelling those findings were.

The rest of it, as they say, is history. In early 2016, around the time the last drafts of the Consensus Statement draft were zooming round the mailing lists I was contacted by New Yorker called Bruce Richman, a former celebrity public relations man, who'd got very cross being told about treatment-as-prevention only after he'd caught HIV himself, and wanted to tell every HIV+ person in the world about it.

He met me at the Subway just outside the CROI Conference in Boston - I'd assumed he was a delegate but no, this was his first-ever stab at HIV activism. What do you think we should call the campaign, he asked. I drew two letter U's connected by an equals sign on a Subway napkin. "Means Undetectable equals Uninfectious, or something" I said, "But what everyone will remember is the two U's."

Well, that was it. Bruce took those two U's and used his marketing genius to create a global brand to prevent two diseases, HIV and HIV stigma. Nothing to do with me. But I wish I'd kept that napkin!

Aidsmap and PrEP

And then there was PrEP. I first heard about it in 2002 but in the years that followed it made all the wrong headlines and not purely because of stigma. The first trials were misconceived, dreamed up by scientists who thought that if you told a lot of women in poor countries that there was a 50/50 chance they'd avoid HIV if they just took this HIV pill, they'd take it.

Events since have shown us that women in poor countries have minds of their own.

It wasn't until 2010 that the iPrEx study, led by the wonderful Dr Bob Grant (quote: "The indication for PrEP is that the person asks for it") showed that PrEP worked, by first researching and educating the community from which it drew its participants, largely poor Latin queer men and trans women. This stopped a bit less than half of HIV infections. A year later the Partners PrEP study proved PrEP stopped three-quarters of infections in pos/neg African heterosexual couples. This was enough for the US Food and Drug Administration, who authorized its use in July 2012.

But not for its counterpart in Europe, the European Medicines Agency.

Maybe they recognised it would mainly be used by gay men and the 44% protection offered by iPrEx wasn't good enough. Maybe because Truvada was still on patent at the time and would be prohibitively expensive. Maybe because they feared it would unleash a new wave of HIV and STIs if gay men stopped using condoms. Maybe they just feared the wrath of politicians and preachers who thought gay men should damn well get what they deserved for being pervs. Who knows?

Anyway, a charismatic scientist called Sheena McCormack approached me in 2011 after she'd spoken at an EATG meeting I'd put on about biomedical prevention and asked if I'd sell the idea of a new PrEP trial among gay men in the UK.

It was a modest venture, not powered to prove PrEP worked, but just to find out if PrEP really did lead to more STIs. But she knew there was a lot of anti-PrEP suspicion among the UK gay community. Could I get together a couple of meetings with gay community leaders and persuade them to back it?

The people I invited to the meetings included people I knew were hostile to the whole idea. I only remember the one we held at Dean Street STI clinic. I was so nervous. It went on for hours. I combatted accusations that PrEP would downgrade the hard-won public image of the gay community by enabling irresponsibility. The hard-core skeptics left in silence.

Manuel Battegay, Nathan Clumeck, Jens Lundgren, Jürgen Rockstroh, Gus Cairns, and Bernard Hirschel at a 2013 HIV conference.

So a study called PROUD went ahead and I was invited to be co-chair. One day in October 2014, Sheena McCormack phoned and said "We've got efficacy" - meaning that, even in this small

study, PrEP had been so effective that the result couldn't possibly have been due to chance. The efficacy was 86%; it stopped 17 out of every 20 HIV infections.

"Don't tell anyone," she said, so I had to sit on the news for four months till it was presented the following February.

In fact, I told two other people. One, my Aidsmap colleague Roger. The other, a guy called Emmanuel Trénado, my French counterpart in another small PrEP study called IPERGAY that was underway in Paris. "We'd better get our data monitoring committee to look at IPERGAY too," he said.

A few weeks later I was at a conference in Cape Town when Emmanuel approached me. "We have efficacy too," he said. What is it, I asked. "86%", he said.

I felt a shiver down my spine. For two radically different study designs to produce an identical result felt, to me, not just like good news, but as if we'd tapped into some deep layer of fundamental truth. It was the Higgs Boson moment of PrEP.

Back in London, I bumped into the doyen of English HIV physicians, Dr Brian Gazzard. "Well, that's it, then" he said. "They'll have to approve it now." Hah!

The torturous story of PrEP licensing in England and how the National AIDS Trust took their government to court to force it to supply PrEP is something I observed with admiration from the sidelines.

But I wasn't finished with PrEP quite yet. While vibrant grass-roots campaigns like PrEPster agitated for it in England, from European colleagues I could see that its availability in some other parts of Europe was disastrous. We needed the thing Aidsmap and its sister European organizations like EATG did so well, of putting together all stakeholders - users, HIV activists, physicians, researchers, civil servants - to prove this thing was needed, speak with a united voice and demand its availability.

My part in this was to get together a partnership of organizations we called PrEP in Europe and hold two meetings - in Amsterdam in 2018 and Warsaw in 2019, inviting everyone from the HIV directors of whole countries (hello, Dr Julia) to gay nuns running clinics in their hometown (hello, Sister Mary) to talk about how best to get PrEP to more people.

Aidmap's part in this, now captained by Matthew, was to give me my head and let me run with it, hoping that I wouldn't wildly bust the budget (I didn't).

These meetings, though modest, were among the proudest achievements of my professional life, not least because they were funded without a penny of pharma money. It is possible. We were thinking of having the third one in Kyiv but then, well you know, history....

PrEP was always going to be a harder sell than U=U because its potential user base was vastly

bigger, and also because it's harder to convince politicians to fund a medicine to protect people from what they intend to do, rather than what they've already done.

But if you can show people that PrEP, like U=U, prevents two diseases – firstly, HIV and secondly, the terror of HIV – they may come to understand why the world needs it. Now, with vast programs of provision spreading across Africa and PrEP injections being developed that come closer to being an HIV vaccine than anything yet, ending HIV as a disease of millions is tantalizingly within our grasp. If only we could sort out the cost.

The monks of AIDS

About 2000 words ago, I launched into My Brilliant Career but I swear it's not just about me.

Other Aidsmap colleagues have played crucial roles in the HIV story too. I'd especially pay tribute to Roger Pebody for nurturing and mentoring other writers from all over the world to equip themselves with the scientific literacy and eloquence to be mobilisers of change too.

At the time I was offered the Aidsmap job, I was offered another one – running HIV support groups at an HIV organization in London. I had therapy training: I'd loved that too, and would have had direct contact with people I helped rather than indirect. There were times when working at Aidsmap was lonely and even, dare I say it, boring. Like when I was finishing a story at 2am in the press room at an HIV conference when everyone I knew was out boozing. I felt like a medieval monk, illuminating the Word in my lonely scriptorium.

But the discipline Aidsmap's mission demanded had its own reward. I was given a key to a huge and ever-growing mound of information, ready to fish out a gem from the hoard for anyone who needed it. Maybe the most painful part of Aidsmap's demise is the feeling that that corpus of knowledge, and its chance to make new changes in the response to AIDS it has compelled, has ceased to grow.

There are other sources like i-Base, but Aidsmap did a near-unique job of gathering them together in one place, and over such a long period. I hope it will remain as an archive (including, please, the PrEP in Europe pages!), but even that is not currently assured. It will be a huge loss – one I already feel but haven't, I think, fully come to terms with yet. I'm honored to have been one of the Monks of AIDS, one of the chroniclers of the story of How We Beat AIDS.

([Gus Cairns](#) is a longtime HIV survivor, activist and journalist, and as prominent a figure in the UK HIV/AIDS arena as one is likely to find.)