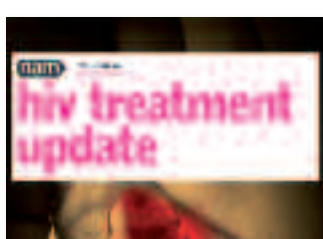
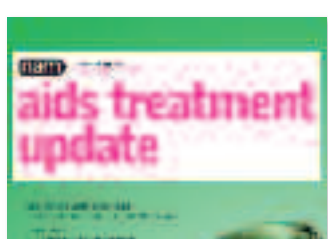
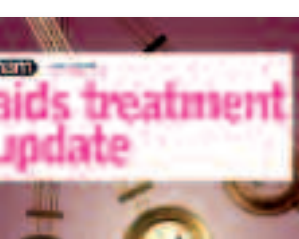




back to the future

Edwin J Bernard looks back over five years as editor of this newsletter



Back in October 2003, when I edited my first edition of *AIDS Treatment Update* (as it was known then), interest rates were 3.5% (they are currently 1%) and the average house price was just over £135,000 (currently £203,500 and also falling).

Although the number of drugs available and those prescribed have changed dramatically over these five years, some things, as we have just discovered in our treatment survey, have not changed at all. Back when I began as editor, the greatest concern for someone about to start treatment was how to avoid side-effects, notably lipodystrophy, and in particular facial fat loss (lipoatrophy).

Today, it seems, many people with HIV are still concerned about side-effects. Until not that long ago, one of the most popular strategies for people on treatment who were, quite literally, sick and tired of their side-effects was to take a 'treatment holiday', called a structured treatment interruption. The concept was discussed in July 2004 (*ATU* issue 138) and discredited following the early termination of the SMART study in early 2006 (*ATU* 154). Treatment interruptions were revisited, albeit cautiously, in December 2008 (*HIV Treatment Update* 182).

This is not the only example of the cyclical nature of HIV treatment strategies. The debate over when to start treatment has been reported many times in *ATU* over the past five years, beginning in October 2005 (*ATU* 150). By May 2006 (*ATU* 156) the old concept of 'hit hard, hit early' reappeared but it wasn't until March 2007 (*ATU* 164) that US guidelines (followed by European and UK guidelines later that year) finally recommended starting treatment before CD4 counts hit 350 cells/mm³.

What does this tell us? That what we may consider to be 'state of the art' today could be 'old hat' in a couple of years, and that in the world of HIV treatment, there are few absolutes.

So many drugs...

In October 2003, HIV treatment choices were far fewer than they are today, particularly for people who had previously been exposed to several previous treatment regimens, as I had been.

Once you were on 'salvage therapy' – a term that smacked of desperation – you just

hoped for better drugs to come along, and preferably more than one at a time. This involved recycling drugs from the three current classes – NRTIs, NNRTIs and PIs – and possibly adding the revolutionary new entry inhibitor, T-20 (enfuvirtide, *Fuzeon*) that requires reconstituting from powder and injecting twice a day.

No wonder, then, that we heralded a new era in our December 2006 issue (*ATU* 162) with the headline, 'From salvage to salvation'. New drugs arrived in the clinic in quick succession, starting with the PI tipranavir (*Apitvus*), approved in October 2005, and darunavir (*Prezista*) approved in February 2007, and followed by the new NNRTI, etravirine (*Intence*), approved in September 2008.

"They're not perfect," I wrote, "but these better drugs have now arrived, and the term 'salvage' really is no longer appropriate for the vast majority of highly treatment-experienced individuals in the UK."

Even more exciting were the new drug classes, CCR5 antagonists and integrase inhibitors, which meant that entirely new NRTI-, PI- or NNRTI-sparing combinations were possible. However, the approval of the first CCR5 antagonist, maraviroc (*Celsentri*) in late 2007, and the first integrase inhibitor, raltegravir (*Isentress*), in early 2008 also came with the realisation that the drug development pipeline had slowed considerably. There may well be a handful of new drug approvals in the next five years, but they are unlikely to be as revolutionary a development as we have just witnessed.

Interestingly, it was another innovation, the belated arrival of *Atripla* – the first modern potent combination of three drugs in one pill, and taken just once a day – that captured most mainstream imagination. *Atripla*, which contains the drugs efavirenz, tenofovir and FTC, was finally made available in the UK in December 2007, eighteen months after its US approval. "Is it the 'holy grail' of anti-HIV drugs; the treatment we've all been waiting for?" we asked in May 2007 (*ATU* 166). "If *Atripla*'s components are right for you, and the drug becomes available in your clinic, it's obviously worth considering," we concluded. "However, another potent, tolerable once-daily regimen consisting of more than one pill – or even a twice-daily regimen – may still be preferable."

...so little time?

Those of us who are well informed about HIV treatments know that someone diagnosed with HIV in a timely manner is now expected to live a relatively 'normal' lifespan. The concept was first expressed in *ATU* by one of our longest-standing medical advisory panellists, Professor Brian Gazzard of London's Chelsea and Westminster Hospital. "My personal view is that most people on HAART will have a normal lifespan," he told us in January 2005 (*ATU* 143).

It took a while to sink in. In 'Great expectations' (*ATU* 162) published at the end of 2006, we asked more experts, "Can people with HIV really expect to live a normal lifetime?" and we noted that "it is becoming increasingly likely that if you live in the UK, and are diagnosed and under care, that HIV/AIDS will not be the cause of your death." The latest data currently suggest that the gap is narrowing between the average lifespan of an HIV-negative and HIV-positive individual.¹ Another recent study² calculated that a 35-year-old diagnosed between 2002 and 2005 with a CD4 count above 200 cells/mm³ could expect to live well into their 70s.

However, the concept that someone with HIV might live close to a normal life – both in terms of quality and quantity – is one that has developed slowly over the past five years. Some might argue there's still a long way to go.

Certainly, the best prognoses are for those with the luxury of an early diagnosis. As I noted in 'Rethinking when to start' (*ATU* 156; May 2006), "in the real world many people are not being diagnosed HIV-positive until their CD4 counts have fallen below 200 cells/mm³, making the debate about whether to start earlier something of a moot point... Perhaps more time, money and effort should be spent trying to overcome the many obstacles that prevent people from testing for HIV in the first place, and making sure that treatment guidelines are followed uniformly across the UK. After all, what's the point of life-saving treatment, and guidelines for their use, if so many people are falling between the cracks?"

One of the things that hasn't changed in five years are the numbers of people who are diagnosed too late to make the most of the latest advances in HIV therapy: overall 33%³ of new HIV diagnoses in the UK and Ireland continue to be made when an

individual's CD4 cell counts are already below 200 cells/mm³ – the percentage is even higher in black Africans.⁴

However, as we reported in November 2008 (*HTU* 181) new HIV testing guidelines⁵, issued in September 2008, “urge healthcare workers of all specialities to consider HIV testing in a wide range of situations and settings. It is part of a package of recommendations to reduce the number of late and undiagnosed HIV infections in the UK.”

In a move that could be just as significant for HIV in the UK as the life-saving treatments that have been developed in recent years, the guidelines aspire “to put an end to ‘AIDS exceptionalism’ – which suggests that HIV testing could not be handled by mainstream health services, and that specialised pre- and post-test counselling is required.” It remains to be seen, however, whether these aspirations are followed through and make the difference we all hope for.

New directions

In so many ways, life for people with HIV has changed remarkably over the past five years, which is why NAM decided, in January 2008, to change the name of this newsletter. “Today, HIV infection is treatable,” I wrote in the first *HIV Treatment Update* editorial. “If you are diagnosed before you have an AIDS-defining illness, you’re now unlikely ever to receive an AIDS diagnosis. In addition, some of us who received AIDS diagnoses in the past are now in better health than ever before.”

The name change was, however, just the icing on the cake when it came to changes in the look and feel of NAM’s treatment information. In October 2006, we undertook a major redesign of the newsletter after in-depth research revealed that many people who would find the information it contains valuable were put off by the old design which they found too daunting, too medical, and too difficult to get into.

One of my proudest moments as editor was revealing results of our post re-launch readers’ survey that found that the new design had a very positive impact on how the newsletter is read and rated. Of those respondents who had been readers prior to October 2005, and who expressed an opinion, 99% found the new look easier to navigate; 96% found it more appealing; and 94% found it to be more trustworthy since the redesign (*ATU* 160, October 2006).

My Top Five Significant Events for People Living with HIV, 2003 to 2008

What	Why	Where
1 New salvage options, 2005-2008	A cornucopia of new drugs has led to a substantial increase in treatment options as well as an increased life-expectancy for people at all stages of HIV infection.	<ul style="list-style-type: none"> ● <i>ATU</i> 162 (December 2006) ● <i>ATU</i> 164 (March 2007) ● <i>HTU</i> 173 (January/February 2008) ● <i>HTU</i> 174 (March 2008) ● <i>HTU</i> 180 (October 2008)
2 Swiss statement, January 2008	Rocked the foundations of the status quo for prevention, criminalisation, reproductive rights and stigma.	<ul style="list-style-type: none"> ● <i>HTU</i> 175 (April 2008) ● <i>HTU</i> 179 (August/September 2008)
3 SMART study, January 2006	Showed that drug side-effects are much less harmful than uncontrolled HIV; points to role of inflammation in HIV-related disease; suggested earlier treatment is better.	<ul style="list-style-type: none"> ● <i>ATU</i> 154 (March 2006) ● <i>ATU</i> 156 (May 2006)
4 Criminalisation of HIV transmission, 2003-2008	Established that HIV transmission without disclosure can be a criminal offence; led to concerns over impact on doctor-patient confidentiality and miscarriages of justice; increased stigma.	<ul style="list-style-type: none"> ● <i>ATU</i> 131 (November 2003) ● <i>ATU</i> 148 (July/August 2005) ● <i>ATU</i> 159 (August/September 2006) ● <i>ATU</i> 160 (October 2006) ● <i>ATU</i> 164 (March 2007)
5 NHS changes, 2003-2008	Cost increasingly an issue, first affecting non-EU migrants; and now, with increasing numbers living with HIV and stagnating budgets, could affect all of us.	<ul style="list-style-type: none"> ● <i>ATU</i> 150 (October 2005) ● <i>ATU</i> 158 (July 2006) ● <i>ATU</i> 163 (January/February 2007) ● <i>HTU</i> 177 (June 2008) ● <i>HTU</i> 181 (November 2008)



An archive of *HIV Treatment Update* (and *AIDS Treatment Update*) is available in the Treatment and Care section of our website, www.aidsmap.com.

NAM continues to evolve the way it delivers treatment information, becoming increasingly more creative in its design to help people get the most out of life with HIV. Back in December 2004 (*ATU* 142), NAM launched the first edition of the book, *Living with HIV*, which epitomised the concept of living well with HIV that *ATU/HTU* has also tried to embody. A second edition, launched in 2006, was even more of a success, leading to the launch on 1 December 2008 of namlife.org – a new online, interactive portal containing all of the information in the book, and more. The launch of NAM’s news-digest email for

HIV-positive people, *HIV Weekly*, in the same month as the *ATU* redesign, was another example of innovative content delivery, and *HIV Weekly* now has thousands of subscribers all over the world.

Future challenges

There really isn’t enough space here to detail all of the changes – many, but by no means all, improvements – in the way we live with HIV.

As we live longer with HIV – and with around 7500 more of us being diagnosed each year – HIV clinics all over the country

have had to cope with increasing numbers of patients in the face of stagnating (or even reduced) funding. Some of the solutions have been creative, and even positive – annual CD4 counts are now a possibility for those of us who are on stable, successful treatment, suggesting we are becoming less medicalised than ever before (*HTU* 177, June 2008). On the other hand, the cost of treatment, which eats into most of the NHS HIV budget, is becoming more of an issue. Now that the government has announced the removal of its ban on patients paying for drugs deemed too expensive for the NHS⁶, will there come a time when we have to pay top-up fees to access more expensive antiretrovirals than the NHS will pay for?

Even now, access to treatment and care remains an issue for some of us – those who attempt – and fail – to seek a knowledgeable and trustworthy GP to prescribe non-HIV medications (*ATU* 158: July 2006); those who are unable to find a dentist because of discrimination against HIV-positive patients (*ATU* 161; November 2006); and, most sinister of all, those of us who are perceived to be a ‘treatment tourist’ and denied any NHS care (*HTU* 181; November 2008).

When I first started editing *ATU*, the idea of ageing with HIV, and of facing the kinds of non-HIV illnesses experienced by our older HIV-negative counterparts – particularly cardiovascular disease, non-AIDS cancers, as well as liver, kidney and bone disease – was in its infancy. Today, these are some of our greatest health concerns and challenges.

And as the length of our lives increases, so do concerns about quality-of-life issues, notably around mental health. These issues have featured heavily in the newsletter over the past five years. In ‘Understanding depression’ (*ATU* 168: July 2007), Dr Pepe Catalan, consultant psychiatrist at London’s Chelsea and Westminster Hospital, told us that: “Although we find that HIV often is a trigger, it’s not always the main problem: often HIV-positive people have all types of unresolved issues.” The longer we live, and the less we focus on simply staying alive, so those issues come to the fore. I know this only too well from (quite recent) personal experience!

The importance of our sexual and reproductive health has also been highlighted in recent years. I’m proud to have represented the HIV community

during the development of the first-ever British HIV Association (BHIVA) guidelines on the *Management of sexual and reproductive health (SRH) of people living with HIV infection*, which were finally published in September 2008.

They come at a time when gay men with HIV are also facing additional sexual health concerns, notably syphilis, LGV and sexually transmitted hepatitis C – all of which have been covered here in depth over the past five years. The guidelines also finally recognise that many men and women with HIV want to be parents and to have reproductive rights, although accessing assisted-conception services is still not easy.

Increased conception options are one of the reasons why Swiss HIV experts issued their vitally important statement in January 2008 about the effect of treatment on HIV transmission, which we examined in depth in April 2008 (*HTU* 175). The impact of the ‘Swiss statement’ is only just being felt, but the idea that treatment can be used as a prevention tool has already gained support at the highest levels (*HTU* 179, August/September 2008).⁷

Many other areas of living with HIV aside from HIV treatment – notably around money and work issues and HIV and the law – still require much more attention. Despite hard-won protection against discrimination in the provision of goods and services (thanks to the revision of the *Disability Discrimination Act* to include HIV from the point of diagnosis, in 2005), the stigma of HIV continues to haunt us, deeply affecting our relationships with ourselves, those around us, and society in general.

Treatment for life

I feel confident that NAM, and *HTU*, will continue to provide the most up-to-date, relevant, accessible and impartial information about life with HIV in 2009 and beyond. As *HTU*’s new editor, Gus Cairns, wrote in an article examining whether HIV treatment was now a lifelong prospect, following the termination of the SMART treatment interruption study: “Perhaps there are worse things than popping a few pills every day. Maybe ‘treatment for life’ is just what it sounds like – a good thing.”

This issue of *HIV Treatment Update* marks the end of an important chapter in the newsletter’s history. It is the final issue, after five years, to be edited by Edwin J Bernard.

Edwin joined the staff team in 2004, though he was already well known to us as a regular contributor. He took up editorship at a time when the landscape for people with HIV was changing rapidly. Treatment was becoming simpler, side-effects increasingly manageable; the majority of people with HIV in the UK were living well, resuming full lives, holding down jobs, etc. Edwin successfully steered the newsletter to meet people’s changed information needs.

He worked with NAM’s marketing team on the newsletter’s relaunch in 2005 which introduced a new, more accessible, design and broader content, including greater coverage of issues beyond treatment that nevertheless impacted on the health and wellbeing of readers, such as the criminalisation of HIV transmission. He has ensured that *HTU* remains one of the UK’s authoritative sources of up-to-date information on HIV treatment and health, and we are very grateful to Edwin for what he has achieved.

Edwin will continue to work with NAM on specific projects but, for now, the mantle of editorship passes to Gus Cairns, who we are delighted to welcome to the NAM team. Like Edwin, he’s well known to us and, of course, to you as a reader, having contributed pieces for *HTU* for some time.

Caspar Thomson
Director, NAM