

# hiv treatment update

## happy 200th issue!

coming of age  
from paediatric to adult care *page 4*

in their own words  
two young people tell their stories *page 8*

how hiv harms young brains  
the medical perspective *page 10*

don't forget sp  
testing untested children *page 12*

upfront  
hiv – the recession bites *page 3*

news in brief  
women may have high genital levels of hiv despite none in blood *page 14*  
did needles kickstart the hiv epidemic? *page 15*





Gus Cairns

## in this issue

### The next generation

This edition of *HTU* is themed on the subject of HIV and young people. *HTU* hasn't covered positive youth for a long time. Apart from a short piece on the *Don't Forget the Children* conference (see page 12) the last feature on HIV and young people was *Growing Pains* in December 2008 (issue 182).

This is for a good reason, and a bad one. The good one is that, as covered in *Happy Families* two issues ago, babies born with HIV are becoming rare in the UK, thanks to good mother-to-child prevention. What HIV does to kids is becoming less rather than more of a problem (though it may have repercussions in later life: see page 10).

The bad one was that HIV-positive kids didn't fit into our demographic. They weren't the kind of older 'expert patient' that tends to read *HTU*. I think we kind of assumed they wouldn't be interested.

Underlying this was perhaps an assumption about the next generation with HIV, one that you sometimes hear when prevention is discussed. It goes something like:

"Us oldies, we were around in the dark days of AIDS, we had to become politicised and educate ourselves about science and treatments or we'd die. Young people? They don't care, they never think about HIV till it's too late and anyway they're probably more concerned about global warming and [insert current youth cult]."

I maybe even shared this attitude. At least till March this year, when I attended a UK Community

Advisory Board meeting on testing in the African community. One of the people there was a young university student who spoke passionately about the problems of adherence and disclosure (see "How can the world accept us if we don't?" issue 195).

I realised I was wrong: there was a new generation of young HIV-positive people in the UK, many of them second-generation Africans, who had every bit as much energy and fire as the previous generation of AIDS activists. After meeting several I asked two, JD and Max, to write pieces about their experiences and these form the core of this issue. Around it we talk to the professionals involved in their care who are helping them navigate the stormy waters of adolescence and help them turn from 'HIV-positive child' to 'young person thriving with HIV'.

We'll need this new generation. I was reflecting cheerfully the other day that, given the rate of development so far, the chances are I'll be dead before they finally find a vaccine for HIV. Till then (and for some while after) we will need to keep up the pressure on governments and funders to put enough money and enough strategic thinking into HIV prevention, care and research to keep the epidemic contained and stop people dying. Especially when recessions bite and compassion fatigue sets in, as now (see *Upfront* opposite).

I probably won't want to be an AIDS activist in 15 years time anyway. We'll need to support, educate and listen to people like Max and JD to carry on the fight. I'm not sure I can forgive myself for quoting Whitney Houston, but what she sang is true: "The children are our future".



### hiv treatment update

editor Gus Cairns

#### sub-editing & proofreading

Greta Hughson

design Rowena Weedon

printing Cambrian Printers

ISSN 17567890

copyright ©NAM Publications

2010 All rights reserved

charity number 1011220

### hiv treatment update

was founded by Peter Scott

### contact details

Lincoln House, 1 Brixton Road,  
London, SW9 6DE, UK

tel: 020 7840 0050

fax: 020 7735 5351

email: info@nam.org.uk

web: www.aidsmap.com

### medical advisory panel

Dr Tristan Barber

Dr Fiona Boag

Dr Ray Brette

David A Castelnuovo

Professor Janet Darbyshire OBE

Heather Leake Date MRPharmS

Dr Martin Fisher

Professor Brian Gazzard

Professor Frances Gotch

Liz Hodges

Professor Margaret Johnson

Dr Graeme Moyle

Dr Adrian Palfreeman

Kholoud Porter PhD

Dr Steve Taylor

Professor Jonathan Weber

Dr Ian Williams

Dr Mike Youle

For more information about *HTU's* medical review panel, please visit [www.aidsmap.com/page/1445504](http://www.aidsmap.com/page/1445504)

### about NAM

NAM is a charity that exists to support the fight against HIV and AIDS with independent, accurate, up-to-date and accessible information for affected communities, and those working to support them.

For more information, and details of our other publications and services, please contact us, or visit our website, [www.aidsmap.com](http://www.aidsmap.com).

### disclaimer

The publishers have taken all such care as they consider reasonable in preparing this newsletter. But they will not be held responsible for any inaccuracies or mis-statements of fact contained herein. Inclusion in this newsletter of information on any drug or clinical trial in no way represents an endorsement of that drug or trial. This newsletter should always be used in conjunction with professional medical advice.

### supported by

**NHS Pan-London HIV  
Prevention Programme**

## HIV – the recession bites

On 15th September, a man dressed as a bear was being tugged around Red Square in Moscow on a leash by three blonde 'naughty nurses'. Promoting a fetish club? No, a deadly serious demonstration by AIDS activists.

The bear was Russia, humiliated by its inability to deal with HIV. "People with HIV face a choice, to die quietly at home or try to attract the attention of the government," said activist Alexey Yaskovich. He was protesting against the corruption and indifference that has meant only half the people in this increasingly prosperous country who need antiretroviral (ARV) drugs get them.

Next door, in Romania, the situation is at least as bad. Alina Dumitriu of local organisation Sens Positiv told *HTU* that the money for ARVs from the Romanian government ran out in September this year, with no more till January. "Hospitals are prescribing incomplete combinations: patients have to try and buy the rest."

This is not just a European problem. In Zimbabwe, protests have broken out as corrupt, or just poverty-stricken, nurses steal ARVs from hospitals and re-sell them; in Uganda, where still only a third of people who need ARVs get them, people with HIV have started a "no drugs, no vote" campaign ahead of the 2011 general election. We face a global AIDS financing crisis and there is no consensus on how to solve it.

The World Health Organization (WHO) has issued its fourth treatment access report<sup>1</sup> showing that, while the number of people on ARVs went up by 30% last year, still only 52% of people in need of HIV treatment get it. More than 50% is an achievement. But 2010 was supposed to be the year we achieved 100% treatment access, according to the promise made by G8 leaders in 2005.

The WHO is worried that even present levels cannot be sustained: "Without sustained and strengthened financial and programmatic

commitments, there is a significant chance that these achievements may be undone."

The Global Fund for AIDS, TB and Malaria calculates it needs \$20 billion over the next three years. But European countries, mindful of their financial crisis, are reluctant to sustain current funding levels. France, the most generous donor in Europe to the fund, has just given \$1 billion but international health charity Médecins sans Frontières says that Germany and Italy may decide to give no money at all. Totting up even the vaguest pledges indicated so far comes up to 20% of the \$20 billion target.

In the US, activists are furious with president Obama. While campaigning he indicated he would increase support for the other mainstay of HIV treatment – the US-only PEPFAR initiative – by \$1 billion a year. Last year he increased its funding by 10% of that amount – not enough to match medical inflation.

It is not just about money. As the Russian situation shows, you can have plenty but still be unable or unwilling to treat your people.<sup>2</sup>

The 2000s, says the WHO, saw an emergency response to AIDS. Rich countries parachuted in cash to fund disease-specific programmes. They acknowledge that this led to many lives being saved, but also to corruption and inefficiency. They say we need to restructure HIV funding so we don't just pump money into HIV but into the creaking healthcare systems that prevent the money being spent efficiently.

This would also ensure improvement in the other UN Millennium Development Goals (MDGs), such as maternal and child health, progress towards which was reviewed at a summit in September. In a pre-summit debate on "Smart Global Health Policy"<sup>3</sup>, Julian Schweitzer, former Human Development Director at the World Bank, decried the situation of "freestanding clinics that can only treat a particular disease, as well as cars sitting in Ministry of Health garages that can only be used for specific projects." Ex-US

AIDS Ambassador Mark Dybul's solution in this debate was radical: turn the Global Fund for AIDS, TB and Malaria into a Global Fund for Health. Schweitzer, however, warned that this might become a corrupt monopoly in itself.

The search for solutions has split AIDS activists. Traditional treatment activists fear that structural reformers will de-prioritise HIV. In one example, Mark Harrington of the US Treatment Action Group accused Mead Over of the Center for Global Development of 'genocide' for advising Obama that the answer is not to pour money into HIV alone. Over responds that he is just championing prevention and structural reform, pointing out that donors have even refused the relatively paltry sum of \$100 million to ensure the continuation of microbicide trials.

There are many other suggested solutions. One is a patent pool, whereby companies holding patents on drugs that normally command high prices donate the patents to a communally owned pool; this ensures generic versions of new drugs can be manufactured legally. AIDS activists are now branding the EU, rather than the US, as the worst patent enforcers as they try to strong-arm Indian drug manufacturers, who provide 80% of the world's HIV drugs, into signing up to trade agreements preventing their export.

Then there's the idea of the Robin Hood Tax,<sup>4</sup> a tiny levy on every single one of the millions of international financial transactions that happen every day that would go to relieving global poverty and disease.

About the only thing people agree on is that the money must be made to work better. The global response to disease was revolutionised in the 2000s because people realised that HIV could not be met by 'business as usual'. Today the way we fund HIV treatment and prevention has become the new business as usual, and we have found a new way to structure sustainability and permanence into the global fight to defeat AIDS.



Soon, the majority of children in the UK born with HIV will be young adults. Many already are. *Gus Cairns* talks to healthcare workers about helping HIV-positive teenagers navigate to adulthood. On page 8, two young people with HIV talk about their own experiences.

"Dealing with HIV is a responsibility thrust on teenagers at a time any responsibility is a new challenge," says Katia Prime, HIV consultant at St George's Hospital in south London. I'm talking to her about the range of services the hospital offers children and young adults.

"Yet never forget," adds Wendy Majewska, a health adviser, "that the

majority of the young people we deal with are well, at school or university, and somehow they flourish with that heavy rucksack of HIV they carry."

#### **A growing population**

In the UK, only one in 50 people with HIV was born with it or infected as a baby.<sup>1</sup> Thanks to one of the world's highest rates of antenatal testing and prevention of transmission in pregnant

women, only one in 250 HIV diagnoses – about 30 a year – is now in an infant.<sup>2</sup>

Altogether, around 1250 children and young people currently living in the UK and Ireland face the challenges of growing up with HIV. This figure includes children infected in infancy but diagnosed after entering the UK from other countries, mainly in Africa, as well as children infected here. But it excludes

the 100 or so teenagers each year who acquire the virus from early sex or child abuse or, in a couple of cases, from injecting drugs.

Increasingly, children with HIV are now entering their teen years. The Collaborative HIV Paediatric Study (CHIPS) is a collaboration of around 60 HIV clinics, which treat virtually all the children with HIV in the UK and Ireland. The median age of patients in the CHIPS cohort is now twelve; a quarter are 15 or above.

Paediatric HIV clinics have had to set up transitional arrangements to support young people making a precarious journey from being in paediatric care to independence, attending their own appointments. 'JD' provides an account of her own experience on page 8.

It's not just the young patients who have to adjust, but their healthcare workers too.

What about privacy and confidentiality, for instance?

"It's a sliding scale," says Katia Prime. "If it's a one-year-old child, everyone – healthcare workers, social workers, whoever else is involved in their care – is aware of their status and involved in case discussions. By the time they get to be 13, their privacy is becoming a real issue and one has to start asking their permission to share data."

Parents and carers have to step back too, as with all teenagers. But there can be acute worries.

Christina Newbould is a clinical nurse specialist at St Mary's paediatric HIV clinic in London.

She says: "It's really hard sometimes for parents to let go. To have the experience of sitting outside the consulting room for the first time while their 12-year-old is with the nurses. By the time they're 15, when a parent comes to me and says 'I'm so worried about her, is she taking

her meds?' I have to say, 'Well, I can't really tell you any more if she doesn't want me to'."

How well do young people do on treatment? Suppressing viral load may be more problematic in children as they tend to have higher viral loads and may already have been through a lot of HIV drugs (half of the children aged over ten in the CHIPS cohort had taken three or more classes of HIV drugs). CHIPS reveals that 84% of the cohort are on treatment, a bit higher than the proportion of adults, but that only 70% of those had an undetectable viral load at the end of the first year. This compares with 85% of adult patients in London with a viral load under 50 copies/ml after a year's therapy.<sup>3</sup>

Nonetheless, overall the cohort is in a reasonable state of health. Only 4.5% of the CHIPS patients have a CD4 count under 200 and 15% under 350. This compares favourably with the 6% of adult patients in London who have a CD4 count under 200 after a year in care.

### Adherence for teenagers

Adherence seems the number one concern for those working with teenagers.

Caroline Foster is HIV consultant at St Mary's Hospital and chair of HYPNet, the HIV In Young People Network, a multidisciplinary group of health workers and voluntary agencies working with 12- to 24-year-olds, which was set up as a link between CHIVA (the Children's HIV Association) and its adult equivalent, BHIVA (the British HIV Association).

"Many young people do fine," she says. "But for others adherence is very, very difficult. People say 'Oh, maybe they'll sort themselves out' if their adherence gets worse during their teens, but what we find is that a lot of children, often for very complex reasons, haven't had enough support when young and the pattern of adherence you start with in childhood is the pattern you'll have in adulthood."

In a paper on optimising HIV therapy for adolescents, Foster and her colleague Sarah Fidler note that European data show that children are 2.4 times more likely to fail HIV therapy if they start treatment aged 10 to 15 than children who start aged 5 to 9.<sup>4</sup>

Christina Newbould agrees.

"I think if you haven't got adherence licked by 12, your chances of succeeding later are shot. It's very depressing. We sadly still see 20-year-olds occasionally dying of a treatable virus."

A lot of it has to do with family circumstances, she says. "Some parents expect the kids to do it unsupported. More often adherence problems are due to previous bad experiences with AIDS. Kids' adherence is better if they have the experience of parents remaining well; conversely, we struggle with kids whose parents have died as they can't shrug off the feeling it will happen to them.

"And some is about basic self-esteem and stigma. We had a male African teenager from a strict Muslim family, who had acquired HIV after a sexual assault. He could not tell anyone he knew about his HIV and the first thing his parents said after they heard his diagnosis was 'We will not arrange a marriage for you'. This in a culture where, if you are not married, you are no one. He couldn't find any reason to take his pills."

She finds that there are two groups of teenagers who are problematic, for different reasons.

"The medically problematic are the kids infected at birth who may be massively treatment experienced. They have had lots of suboptimal therapy, and may have had multiple bereavements.

"In addition, they often have neurological problems related to HIV and developmental delay – small stature, late puberty, difficulty in concentrating. You find yourself working with a 20-year-old

who has more of the appearance and maturity level of a 13-year-old.

“The socially problematic are most frequently kids diagnosed later, often after arrival in the UK. They may have arrived as unaccompanied minors and are being looked after by parents who don’t really know them, an extended family or ‘aunt’ who is in fact a foster carer. We’ve had to ask carers for DNA tests to prove they’re blood relatives before now.

“This is also the group in which it’s most common for parents/carers to refuse or withdraw treatment, rely on cures through prayer, and so on. When the child is diagnosed late, the parents may only ever have heard about HIV via their church.

“We are conscious that some families don’t really believe in the treatment but give it anyway because they know social services will be involved if they don’t. So what are the chances that the young person in that climate will be keen to take treatment after they are no longer a minor?”

At St George’s, Wendy Majewska says, “Only one in ten of our teenage patients are the problematic ‘did-not-arrive’ type but they’re the ones we worry about.

“We try all sorts of stuff that’s not traditional medicine. We engage the community nurse specialists who will go round and visit them, knock on doors and so on. With their permission, we engage other trusted adults who they have used as supporters: the local pastor, for instance, or a teacher. Between 13 and 17 they attend our teenage clinic and everything is laid out for them, they get the pills in pre-ordered boxes, phone support, and so on. By the time they get to our young person’s clinic (for 18-to 24-year-olds) they have to start asking for adherence help, though.”

### Models of care

The hospitals I talked to operated two slightly different models for the transition from paediatric to adult care, roughly conforming to two different models suggested by CHIVA.<sup>5</sup> At St Mary’s, young people go from the Family Clinic to the 900 Clinic,

**The first reaction I often get from teens who’ve grown up with HIV is “That’s it. I’m never going to have sex!” The burden of responsibility they assume and the fear of infecting their partner is huge.**  
David Cox,  
Health Adviser

specifically for teenagers. St George’s has the Penta Adolescent Clinic (13- to 17-year-olds) and the Penta Young Person’s Clinic (for 18- to 24-year-olds).

“I have a role as the transitional care consultant at St Mary’s,” says Caroline Foster. “My job is explicitly to manage the transition... and to provide continuity of care.”

Paediatric HIV clinics have wide catchment areas – at St George’s, families travel in from as far as West Sussex. This may become a problem for older teenagers and, although most would prefer to stay with their original hospital, some will need help to move to a local clinic.

CHIVA’s model of care slowly introduces children to the knowledge that they have HIV before puberty; they should know the name of their condition by the time they are 12.

This is so that the necessary and sensitive process of sex and relationship education can start before they start having sex.

Christina Newbould explains how it happens at St Mary’s.

“By eight to nine years old, we find, kids often start asking questions such as why they have to take pills or go to hospital when their brother doesn’t. Many parents really can’t find the words so we help them. Initially we start giving the kids more and more information on staying strong and healthy: food, exercise, and their medicine.

“Then, six months later, we’ll check what they remember from our previous talk, and we’ll introduce the idea of the immune system and talk about cells that fight off infection, and maybe tell them that they have a condition that stops them fighting.

“Six months later, we’ll introduce the idea that they have a viral illness, and six months after that, we’ll name it as HIV. At that point, or at the next visit, if they’re with their mother, we’ll introduce the idea that their mother has the same virus.

“I don’t find kids react strongly to the specific name of their infection: remember, they have lived with it since birth, so they don’t face the unknown. Some will twitch and obviously hold back a reaction: they’re the ones who have already guessed.

“The parents are often much more afraid of disclosure. They’re concerned about the child going into the class and talking – and we reassure them that they almost never do – and they’re often consumed by the guilt of infecting their child.

“If they’re really reluctant we emphasise that there are so many ways the child could find out accidentally: what if your home village came up on Comic Relief? What if the name of your medicine came up on TV and they know you take it?”

“We don’t usually at that stage start talking about safer sex: in any case, we often find that teenagers prefer a different professional to talk to than one they’ve grown up with.”

At St George’s, Katia Prime also believes that it’s hard for teenagers to talk about sex with familiar doctors. One

girl said to her: "I've had the same doctor since I was a baby; he's like my parent. I can't talk to him about sex. I don't want to disappoint him."

"A young person's first sexual partner may also be the first person they've ever told about their HIV status," says Caroline Foster (19-year-old Max, relates just such an experience on page 9).

"Some teenagers seem to sail through the complexities of negotiating sex and relationships but for some, especially those who may be more thoughtful and reflective, it can be really difficult. Boys can suffer a lot of performance anxiety and with girls, it's about being sexually empowered enough to even know *whether* the boy has used a condom, let alone persuade him to if he doesn't want to."

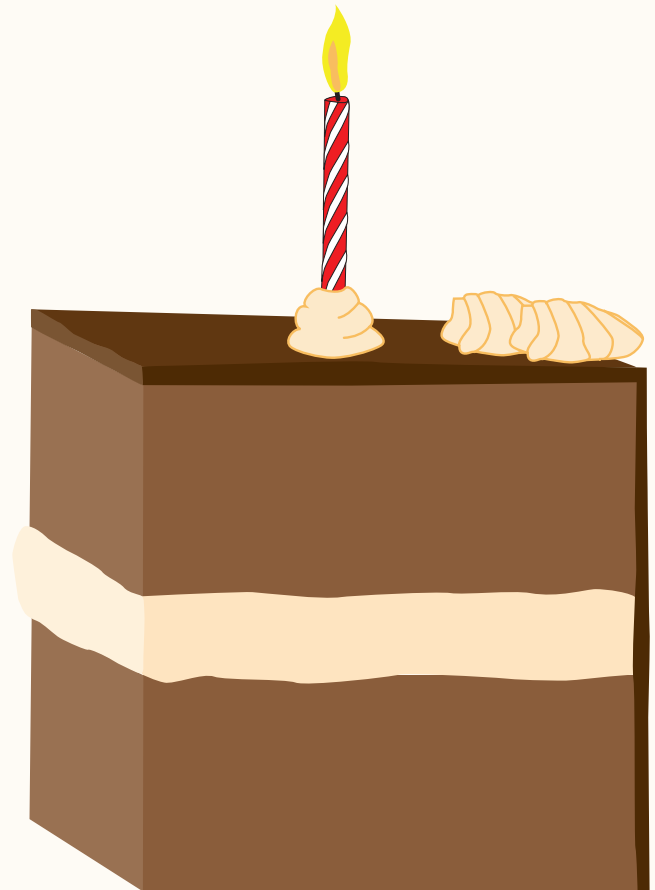
Wendy Majewska comments that difficulties in both disclosure and adherence are often driven by the same anxieties.

"With girls, I find it's about peer pressure, of desperately wanting to forget you have HIV and just wanting to be a normal teenager. So they think 'If I don't take my pills/go to the clinic, I haven't got it'; similarly 'If I don't discuss it, I haven't got it'.

"With boys, yes: terrible performance anxiety: condoms are fiddly enough for teenage boys anyway, but if you're frightened of infecting your partner if it goes wrong, that can be an intolerable pressure. It's terribly lonely telling people.

"We don't go straight from paediatric care to 'Did you have vaginal or oral sex?' in that really clinical way anyway. We'll start with the under-12s in talking about friendships, and about disclosure to friends, asking them to run through ways of disclosing their status, once they know it, in their minds."

David Cox, another health adviser at St George's working with teenagers, says: "The first reaction I often get from teens who've grown up with HIV is 'That's it. I'm never going to have sex!' The burden of responsibility they assume and the fear of infecting their partners is huge.



"Because of that, we emphasise that there are things that we can help with if there's a condom accident or just an impulsive night. Sometimes accidents happen.

"We make sure they know about post-exposure prophylaxis (PEP) and we run through the law on criminalisation of transmission, but in a hopefully positive way – 'As long as you've told them, you've got no reason to fear this' – that sort of thing."

Katia Prime adds: "I have on occasion used the argument that if they have an undetectable viral load on treatment they're more likely to be less infectious as an incentive for adherence, but it can backfire. One boy's girlfriend, who was negative but came along to talk about it, understood it to mean 'He only had a little bit of HIV but he's all right now'.

"Really, I'm surprised how many actually do tell their partners," she adds. "And very often they bring their partners in or ask that we talk to them."

Caroline Foster concurs. "Teenagers may be irresponsible sometimes, but they're dealing with this whole mosaic of new life tasks that don't fit together easily, so I'm not surprised. For instance,

a girl asked me if she could stop her HIV treatment around the time she was taking her exams. She didn't want that extra anxiety.

"Any way we can reduce that anxiety helps. For instance, in the leaflets for teenagers designed for HYPNet and CHIVA we didn't mention HIV on the cover, because the feedback was that they'd be too anxious to carry around something with HIV prominently there in case it fell out of their pocket.

"At the same time they impress me with their responsibility and protectiveness. For instance, I know one young woman who actually told partners she had caught HIV through sex, because she didn't want to 'out' her mum as having HIV."

"The reward for me as a healthcare worker," says Christina Newbould, "is that I've worked as a clinical nurse specialist for seven years and on the AIDS ward before that. At the time I couldn't see how these kids could ever have a normal life if they did survive. Seven years later I have them coming in and saying 'You see? I told you I'd be OK.' It's a privilege to be part of someone's normal, adult life." ■

# JD Bailey\* – female and 20 – reflects on growing up HIV-positive...

The geographical transition from paediatrics to adult care was minimal. In fact leaving the sixth floor of St Mary's to go to their ground floor 900 Clinic was much easier. The emotional transition was somewhat different.

My paediatric doctor had always known about my love of Ribena; every time my blood was taken, he would comment on how much Ribena I must have drunk that morning.

Going to appointments, believe it or not, was fun! The waiting room was exciting, there were rocking chairs and paintings of clowns on the wall with blue and green noses; everything I would have wanted if I had been given a playroom. Everything was fun, even being weighed and measured. All I cared about was whether I'd grown that month or not.

When I was moved to the adolescent/adult clinic I was overwhelmed by how much information I had access to. Previously my mum and I would enter the doctor's room together, we would discuss how I was feeling/doing and then I would have to leave, as my mum and doctor discussed something about me that I was too scared to enquire about on the train journey home.

I guess I took comfort in the saying, 'no news is good news' or, 'what you don't know can't hurt you'. Later at the 900 clinic I found out that they were discussing my viral load, my CD4 count

and when might be the right time for me to start taking medicine.

What I remember was that 'we' liked the CD4s because they were my very own personal soldiers, fighting for my body. The viral load, on the other hand, was the thing 'we' were trying to put to sleep: 'we' couldn't get rid of them, but it would almost be like they weren't there. It's funny, I liked the use of the word 'we' and still do, I felt that I wasn't alone.

The first year I moved to the adolescent clinic my new doctor encouraged me to bring my mum with me, but I wasn't the one to sit outside, she was! The doctor asked her to leave so that I didn't have to. Eventually my mum stopped coming into the room with me altogether until she just didn't come anymore. I don't remember when it was; I think there was one appointment that she just couldn't make. It was clear that I'd handled that one on my own, so she just stopped coming. She recognised that I was growing up and any medical information about me should be told to her by me.

Thinking about it, the transition from paediatrics to adolescents came with lots of information about sex. I went to a Catholic secondary school; I don't know if they are all like it, but mine only discussed the bare minimum when it came to sex.

When they asked me if I was sexually active I was shocked! It had nothing to do with my status, I guess I was just innocent, or naive. Every appointment my doctor and nurse asked if I had a boyfriend and reassured me that if I was to have one, I didn't have to disclose, just to make sure I practised safe sex.

In the first year of changing doctors, I worried a lot about the hardship that might come from disclosure. Would letting people know about my status shut me off from my potential future?

I began daring to think that perhaps my boyfriend wouldn't see me as the 'victim' invaded by things that 'we' wanted to keep asleep. I found solace in the idea that other people usually had something to hide, an extra load, somewhere in their lives – that helped me too. It was comforting knowing that I wasn't always going to be the only 'risk'. Yes, I needed to protect any partner I may have in the future, but I also needed to protect myself.

I've been attending the 900 Clinic for four years now. At first the change was uncomfortable but soon it became empowering. It took time to readjust and get used to going to appointments on my own but that's all part of growing from a child to an adult. I'm not there yet, but it's a start!





# ...and Max\* – male and 19 – discusses the rewards and perils of disclosure

“HIV, HIV, HIV! It seems that ever since I was disclosed to by my father in a hospital waiting room, my life has been all about HIV. Like shackles on my ankles, it has kept me both prisoner and given me the desire for freedom, both educated me in the potential of life and showed me my limitations. Being positive has given me an array of experiences both good and bad. At twelve you could have never told me that, out of the darkness that HIV casts upon your life there would be light piercing its dark spectrum.

When my father first told me of my status my first thought was death and how tragically short my life will be. Instinctively I cried assuming the worst, because like many in society I had bought into the tombstone propaganda pushed by the media. That was it, I had nothing left to live for.

It was hard enough dealing with the fact that my life seemed all but over, it became even tougher when I realised that I could not turn to my friends for support. HIV didn't carry the same sympathies as cancer, a disease people contract "through no fault of their own".

It was shrouded in prejudice, stigma and common misconceptions, the biggest being that you got it because you deserved it for being morally questionable or you had committed a wrongdoing of some kind. Life offered little comfort in its embrace, as it took my father away from me four months after he had disclosed to me leaving my sister, brother and I. As my father was positive too, this reinforced my fears that death was imminent.

Unlike people back in Africa, where I was born, I had the fortune of being able to attend a group for young people infected or affected by HIV at Body & Soul. It fast became my sanctuary, a home away from home where I could strip back the protective layers that kept

secret my true self. I was me wholeheartedly when I walked through those doors. I had left the bigots behind and found friends.

Being around so many people who had endured so much in life but kept a resilient and dignified strength, beauty and compassion about them, gave me the courage to challenge myself and face my demons. It led me to disclose for the first time in my life.

I was 16 years old and my girlfriend at the time was a leggy light-skinned girl, with 'come get me' eyes that all the guys wanted, but she picked me (he laughs at the competition). It was the weekend and we had decided to have sex for the first time. I had been putting it off for a year and a half, something slightly unnatural for a guy my age with raging hormones. She thought I was just being a gentleman, but I was just afraid because she meant a lot to me and I didn't want to lose her.

Despite my efforts the day had finally come. We were in my bedroom and I just started talking about hypothetical scenarios like, "what would she do if she found out I was HIV-positive?" I was trying to gauge what kind of response I was likely to receive. Her reply was that she would shoot me dead, because I had not told her and put her at risk. Not the most encouraging start, but nonetheless I dropped the bomb, I could not dodge time forever.

She became quiet, then asked if this was a joke, I calmly replied no. Silence took over again. Then she shuddered, tears began streaming down her cheek. It felt like I was on Family Fortunes: "What's the most common question asked when people disclose their HIV status...Our survey says: 'Are you going to die?'"

I thought that this may be a red herring thrown out there to lull me into a false sense of security, while unwittingly I was

bombarded with punches from all sides. I said no, and to my surprise she hugged me. I asked her, don't you want to gouge my eyes out or give me a facial tattoo with your fingernails? She just said she was disappointed that I had not told her sooner, but she loved me and didn't want to go anywhere.

The positive experience of my first disclosure gave me the self belief that has led me to disclose to all my sexual partners. Some reactions have not been so smooth, but I have found with a little charisma and education on the facts, you can turn the biggest skeptic into a believer. It may not happen always but it can happen.

Now I am open about my status to all my partners and to my friends basically those who need to know, but I will not let it define my character. That is why I maintain my anonymity in this article. Not because of fear but because the content of my character makes me more than HIV. I am more than my illness, I thank those that have touched my life and given me this power and self belief, notably my father and those at Body & Soul. The strength felt emotionally has also manifested itself physically, I have been undetectable for six years.

HIV has been both the biggest bane and blessing on my existence, it has introduced me to people with both the purest and darkest of hearts, limited my ambition and spurred it further. Now I'm studying at university, and don't feel the pressures of the rat race of life, I don't know what I want to do in the future, just that I want to enjoy it and enjoy the ride. No matter the illness whether it be cancer or HIV, or the hurdle obstructing my progress. I firmly believe, life is for the living.

*\*Names have been changed.*

# how hiv harms young brains

HIV paediatrician *Anton Tan* and clinical psychologist *Diane Melvin* write about the challenges to development and maturity that HIV imposes on children.

The last ten years have seen marked reductions in death and sickness in children infected with HIV from their mothers, particularly for those who live in well-resourced countries like the UK.<sup>1,2</sup> Since more children are now surviving into adolescence and adulthood, we are faced with an increasing need to understand and manage the long-term consequences of growing up with HIV on teenagers' coping abilities, their independence and achievements, and their quality of life and social and emotional wellbeing.<sup>3,4</sup>

Knowledge of their longer-term prospects helps us plan for their future treatment needs and also helps us understand the complex relationship between their past and present health, their treatment and adherence history, and the stresses of life.

In the UK there are, as yet, relatively few published data on longer-term developmental and psychological outcomes in children infected as babies. Although a lot can be learned from other countries, there are big differences in the characteristics and life experiences of different HIV populations, making some comparisons invalid. In the US, for instance, parents of children with HIV infection are more likely to be injecting drug users, while in poorer countries nutrition and access to antenatal and health care will differ from the UK.

The UK cohort is also diverse, with a wide range of health, cultural and social experiences amongst the children. The majority of UK children with HIV have African parents and live with their biological families. But, of these, some were born here, others arrived when young, and an increasing number have arrived more recently as adolescents, often with undiagnosed or untreated HIV and many having experienced extreme disadvantage or traumas.

Social disadvantage, lack of opportunities, family death and ill health, lack of stability, lack of English

and missed schooling can all affect young people's development, making it hard to tease out the causes of developmental difficulties.

We do know, however, that children infected from birth are more likely to have neurological and developmental problems than people who acquire HIV in later life. These problems manifest both as an acute condition in young children and subtle developmental difficulties later on, with a wide range of severity.

## Neurological problems and how they happen

The most common neurological problem is stiffness in one or both lower limbs, similar to cerebral palsy, which can affect mobility to varying degrees. This is associated with damage around the time of birth to the motor areas of the developing brain. Other co-factors such as premature birth, failing to thrive and early AIDS-related infections, like cytomegalovirus (CMV), increase the likelihood of this problem. These motor symptoms often, but not always, occur with other developmental difficulties. Good management of HIV can minimise the impact of damage on the nervous system but will not reverse it.

HIV does directly infect some types of nerve cells, but more importantly it infects immune cells within the brain that in turn cause inflammation that damages nerve cells. We don't know exactly how it crosses the blood-brain barrier; some researchers think it is able to traverse it directly, while others think it smuggles itself in within 'Trojan horse' immune cells that can pass this barrier.

We also don't know if HIV infection in the brain proceeds alongside infection in the rest of the body, with immune cells trafficking between the bloodstream and the brain, or if the virus develops independently within the brain because the immune environment and the concentration of various antiretroviral drugs are different. There's some evidence

the first picture is true of early infection and the second of more chronic infection.

## What is HIV encephalopathy and how common is it?

HIV infection of the brain in a child may lead to HIV encephalopathy. In the 1994 Centers for Disease Control and Prevention (CDC) classification, this is an AIDS-defining illness and is defined as:

- failure to attain or loss of developmental milestones or loss of intellectual ability
- impaired brain growth or acquired microcephaly (= abnormally small head)
- acquired symmetrical motor deficit, in the absence of a concurrent infection other than HIV, persisting for at least two months.

Risk factors for HIV-positive children developing HIV encephalopathy include a low CD4 count, high viral load in both blood and in the brain, and advanced maternal disease.

Because definitions of encephalopathy have varied across studies, reporting on how common brain impairment is in children with HIV is difficult. Early studies looking at untreated children often reported up to 50% of their young cohort with encephalopathy.<sup>5,6</sup>

In these children, delays in early milestones – walking, talking – were common. However, in pre-treatment years, there was already some suggestion of more chronic effects of HIV on the later progress of longer-term survivors, including poorer expressive skills and sometimes difficulties with attention.<sup>7</sup> Cognitive abilities (the ability to think clearly) were in the low average range, a number of children needed support at school for learning, and compared to uninfected children, the HIV-positive children had consistently lower scores.<sup>8</sup>

### The outlook today

The most immune-compromised children may have died in the early years and so the long-term survivors who now predominate in the UK are less likely to have severe difficulties. More recent studies suggest that neuro-developmental problems are now more likely to be in the range of 10 to 15% and that often their severity is less.

The introduction of antiretroviral (ARV) therapy in the mid-1990s changed the outcome for HIV-infected children in developed countries as much as for adults. Their overall survival rate is increasing and their admission rate to hospitals is decreasing. There is also evidence that ARVs can reduce the incidence of HIV encephalopathy.

The important question here is whether therefore we should offer ARVs to all children without delay after diagnosis, irrespective of their age and CD4 count.

Treatments and improved care for children with HIV have resulted in a reduction of severe neurological and motor consequences and progressive encephalopathy is now rare where HIV has been effectively managed.

The Children with HIV Early Antiretroviral Therapy (CHER) study showed that early treatment (within the first three months of life), as compared to deferred treatment, reduced the mortality rate by 76%,<sup>9</sup> and a substudy showed that early treatment significantly improved children's neurocognitive development when assessed at the age of ten to 15 months. It is therefore recommended that all HIV-positive children up to the age of a year should commence ARVs as soon as possible after diagnosis.

Early neurological damage will have lifelong effects, but there are older children in HIV cohorts whose neurological damage occurred early in life but who now have minimal symptoms due to better treatment and increased general wellbeing.<sup>10</sup> In more recent years, we are tending only to see neurological deficits in children

diagnosed late, and where HIV was diagnosed after a catastrophic illness.

With access to careful monitoring and appropriate treatments when needed there has been a reduction in the numbers being reported with severe delays and progressive deterioration and early motor delays are now rare. In studies, the performance of children who took early treatment is similar to HIV-negative children, and further reports are now showing that as they get older children maintain scores within normal limits.<sup>11</sup> Recent research by our team with a group of HIV-positive schoolchildren aged nine to twelve confirmed that most of them had IQ and basic attainment scores in the average range.<sup>12</sup>

### Clinical issues for teenagers

However, the more subtle weaknesses noted in earlier studies are still being recorded and – for some – are becoming more marked as children are getting older. While not all children will have evidence of these weaknesses there is a common profile of difficulties, affecting what are called 'executive functions'. These include dealing with complex verbal material, being able to maintain attention and concentration, memory and the ability to sustain effort.<sup>13,14</sup>

Impairment of executive functions can affect learning and application to tasks, especially at older ages as the demands of life increase, and may also have some associated behavioural consequences such as being over-impulsive or not planning ahead or thinking through consequences – exacerbations, you might say, of normal teenage struggles.

Where MRI or CT scans have been used, it has been found that those children with HIV with evidence of nervous system damage on their scan are also particularly poor on tasks of executive functioning.

In the UK, there are clinical reports that suggest a notable number of children have difficulties with attention and overactivity in the early years and others with remembering, sustaining effort and applying themselves to school learning, even if they have intact thinking skills.

Further, the numbers of HIV-positive children receiving extra learning support in school is higher compared to other children of the same age and ability. This increase in numbers needing support was found for those born in the UK – not just for those more recently arrived – and appears not to be due to adjusting to UK language and culture.

As more children with HIV are living longer, healthier lives there is evidence emerging that some of the more chronic effects of living with HIV are becoming apparent and having some influence on later learning and performance. This pattern of neurocognitive weaknesses can have an influence on behaviour as well as potential to achieve. Adolescence, because of the increased learning, social and emotional demands, may be a particularly stressful time when any underlying difficulties may become more evident. Adolescence is also a time when adherence to medicines may be most difficult and underlying clinical and neurological difficulties may themselves have an influence on remembering to take medicines or sustaining the effort to. This has to be taken on board when planning adherence support.

There is a need to collect more data on developmental outcomes for children with HIV, but in-depth assessments are often not practical due to limited resources, and it may not be appropriate to refer to other services because of concerns both about confidentiality and because they are already over stressed. Subtle difficulties may not meet the criteria for access to such services.

The UK population of children with HIV is growing older and entering adulthood. There is an urgent need to collect more data on the longer-term health outcomes, which will not only guide treatment decisions but may also provide a better understanding of how lifestyle and psychosocial factors will impact on our young HIV-positive patients as they grow up. Enabling more children and youngsters to attain their potential and achieve a fulfilling and independent life is a core aim of good HIV care. ■

# don't forget SP: testing untested children

'SP' (not his real initials) was a ten-year-old boy who died of AIDS in a north London hospital in 2008. He was finally tested for HIV, and found to be positive, the day before he died.

Yet his parents had been diagnosed at the same hospital six years earlier, and his mother had been advised to get her son tested then. She declined at the time, saying finding out about her own status was enough of a burden to deal with. Besides, the boy was a happy, healthy four-year-old – so unlike the pictures she'd seen of dying babies.

Over the next six years SP's health deteriorated, but no consultants he saw ever made the link with HIV and his mum didn't volunteer her status until it was too late. If he'd been diagnosed six years, two years, even six months earlier, he would probably have lived.

This tragic case gave rise to a one-day conference in December 2008 called *Don't Forget the Children*, and a subsequent guidance document<sup>1</sup> with the same title, co-written by BHIVA, CHIVA and BASHH (the British Association for Sexual Health and HIV), suggesting systems to ensure such a case never happened again.

Studies, including one co-written by workers at St George's Hospital, found that, when asked why they did not get their child tested, the most common reason cited by mothers is that they thought it unlikely their child could have HIV.<sup>2</sup>

In many cases they will be right, although as Katia Prime, one of the authors of the study points out, mothers often say their child has been tested but have no proof, frequently because the test was done abroad.

Mothers diagnosed after the birth of a child often assume their child is negative

because they confuse the date of diagnosis with a date of infection. There is a need to help them understand they can have had HIV for many years and so their child may have the virus as well.

The other reason they think it is unlikely that their child has HIV is that the child is well. However it is becoming increasingly apparent that, while one group of children gets very sick with HIV from the start, another group may survive well into adolescence with no symptoms.

Dr Prime had earlier co-authored a study<sup>3</sup> that found 542 UK cases, up to the year 2007, of children born with HIV who had not been diagnosed until the age of 13 (the oldest was 20). Most had spent their earliest years in Africa, and the median age of arrival in the UK was 12; but 30% were diagnosed more than five years after they arrived in the UK and 14% had been born here.

Half of the young people were asymptomatic, but half had a CD4 count under 200 cells/mm<sup>3</sup> and 20% had AIDS symptoms. Some had undoubtedly narrowly escaped the fate of young SP.

Since then, clinics have been urgently revising their protocols and doing 'look-back' exercises to check whether any woman, and in many clinics any man too, who tests positive for HIV and mentions they have a child has had any children tested.

St George's, in conjunction with two other south-west London clinics, has recently undertaken such a study.<sup>4</sup> The researchers found, through prospective interviews and looking through notes, that 30% (254) of the 846 children of patients living in the UK were untested, and that of these nearly a quarter (56 children) were under 18.

As well as not believing their child could have HIV, the other main motivation for

mothers not to have had their child tested was that, with older children, it inevitably would involve disclosure of their own status.

"Mothers feel huge guilt about infecting their child," says Katia Prime, "and the older your child is, the more difficult it is both to have your own status revealed and to face the possibility your child will learn you infected them."

At St Mary's, Christina Newbould explains, they have instituted a much more proactive testing procedure, as have St George's and many other clinics. Any child of a person diagnosed at the HIV clinic, or any sibling of a child diagnosed in paediatrics, is followed up to ensure they get tested too (at St Mary's, children of diagnosed fathers as well as mothers).

From August 2008 to February 2010 there were 39 children referred for testing at St Mary's, of whom two – a 12-year-old and a 15-year-old – turned out to have HIV. All children 12 and over were informed they were having an HIV test, as well as two eleven-year-olds.<sup>5</sup>

Included in the protocols are criteria for deciding when parental refusal to have a child tested becomes a child protection issue: at St Mary's, two cases involved social service referrals. When threatened with procedures, parents in both cases agreed to have the children tested.

"If your kid is 17 and you've had HIV for 20 years and never disclosed to them ... and you are probably right that they don't have HIV ... then testing is a really big issue," says Christina Newbould.

"With younger children, we tell mums that the sooner they do it, the less they'll have to explain. With older teenagers, we explain that we don't have to disclose the mum's status: we can say 'Well,

since you've come over from Africa or are within that community you are more likely to have certain conditions, which could be asymptomatic, such as malaria, TB and HIV: so we're just going to check for them'. No young person has ever refused such a test request."

She cites two cases in which testing brought families closer together. In one, a 16-year-old girl died of an AIDS-related condition at St Mary's and it was realised her 14-year-old sister was untested. The mother consented to HIV testing but adamantly refused that the girl be told it was for HIV.

In the end, with social service intervention, the girl was told the test was for HIV with her mother's consent. She was negative.

In the other case, an eleven-year-old boy had seen his father die of AIDS in Africa and had then come to the UK. Again, the mother did not want her boy to know what he was being tested for.

"However, he was obviously scared his mum had HIV," said Christina: "He kept on asking leading questions: 'Mum, are you all right?' and so on."

In the end she agreed, and we tested him. He was negative too.

"The mum later said 'Our bond is so much stronger now'," says Christina. "He just needed the reassurance that, although his mum had HIV, she was fine." ■

## Further information on HIV and young people



NAM produces a booklet called *HIV & children*, which covers information on treatment and care for HIV-positive children. Copies are available free through clinics and HIV organisations in the UK and copies are also available free to individuals. Contact us to request a copy – or to enquire about joining our free booklet scheme – at [info@nam.org.uk](mailto:info@nam.org.uk) or 020 7840 0050.

Body & Soul is a charity supporting children, teenagers and families living with HIV. It provides support sessions and workshops including Teen Spirit, a project for adolescents living with HIV. Contact 020 7923 6880 or email [info@bodyandsoulcharity.org](mailto:info@bodyandsoulcharity.org). [www.bodyandsoulcharity.org](http://www.bodyandsoulcharity.org)

HYPNet (the HIV in Young People Network) is a group of health professionals and representatives from the voluntary sector, working with young people aged 14 to 24. HYPNet (in partnership with CHIVA) recently produced four short leaflets on key topics - contraception, condoms, transmission and PEP. [www.hypnet.org.uk](http://www.hypnet.org.uk)



CHIVA (the Children's HIV Association) is an association of more than 150 professionals, involved in the treatment and care of children affected by HIV. CHIVA develops standards of care through guidelines and materials. [www.chiva.org.uk](http://www.chiva.org.uk)

CWAC (Children with AIDS Charity) provides financial support through a hardship and respite fund, assists with transport costs and aims to educate people about HIV. [www.cwac.org](http://www.cwac.org)

### references to all articles [continued on page 15]

#### hiv – the recession bites [page three]

- 1 See [www.who.int/hiv/pub/2010progressreport/summary\\_en.pdf](http://www.who.int/hiv/pub/2010progressreport/summary_en.pdf)
- 2 See [www.who.int/hiv/pub/2010progressreport/ch4\\_en.pdf](http://www.who.int/hiv/pub/2010progressreport/ch4_en.pdf)
- 3 See [www.smartglobalhealth.org/blog/entry/a-look-at-our-second-fault-lines-in-global-health-debate/](http://www.smartglobalhealth.org/blog/entry/a-look-at-our-second-fault-lines-in-global-health-debate/)
- 4 <http://robinhoodtax.org.uk/>

#### coming of age [page four]

- 1 Data from the Collaborative HIV Paediatric Study (CHIPS). See [www.chipscohort.ac.uk/documents/CHIPS\\_overall\\_2010.ppt](http://www.chipscohort.ac.uk/documents/CHIPS_overall_2010.ppt)
- 2 Health Protection Agency data tables. See [www.hpa.org.uk/web/HPAwebFile/HPAweb\\_C/1267552587453](http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1267552587453)
- 3 Brown A and Zheng Y *HIV clinical outcome for patients accessing NHS sites in London*. HPA: see [www.hpa.org.uk/web/HPAwebFile/HPAweb\\_C/1267552587453](http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1267552587453), 2010.
- 4 Foster C and Fidler S *Optimising Antiretroviral Therapy in Adolescents with Perinatally-Acquired HIV Infection*. In press.

- 5 Melvin D et al. *Guidance on transition and long term follow-up services for adolescents for HIV infection acquired in infancy*. See [www.chiva.org.uk/publications/2007/transition.pdf](http://www.chiva.org.uk/publications/2007/transition.pdf). 2005

#### how HIV harms young brains [page 10]

- 1 Gibb DM et al. *Decline in mortality, AIDS, and hospital admissions in perinatally HIV-1 infected children in the United Kingdom and Ireland*. *BMJ* 327:1019, 2003.
- 2 CHIPS (2009) *Collaborative HIV paediatric Study*. See [www.chipscohort.ac.uk](http://www.chipscohort.ac.uk)
- 3 Judd A et al. *Morbidity, mortality and response to treatment by children in the United Kingdom and Ireland with perinatally acquired HIV infection during 1996-2006: planning for teenage and adult care*. *Clinical Infectious Diseases* 45:918-924, 2007.
- 4 Patel K et al. *Long-term effectiveness of highly active antiretroviral therapy on the survival of children and adolescents with HIV infection: a 10-year follow-up study*. *Clinical Infectious Diseases*,46:507-515, 2008.
- 5 Brouwers P et al. *Central nervous system involvement: Manifestations, evaluation, and pathogenesis*. in Pizzo PA & Wilfert CM (Eds.) *Pediatric AIDS: The challenge of HIV infection in infants, children and adolescents*. 2nd ed. pp. 433-455, Baltimore: Williams & Wilkins, 1994.
- 6 Willen Elizabeth J *Neurocognitive Outcomes in Pediatric HIV. Mental Retardation and Developmental Disabilities*. *Research Reviews* 12: 223-228, 2006.
- 7 Nozyce M et al. *A behavioral and cognitive profile of clinically stable HIV- infected children*. *Pediatrics* 117, 763-770, 2006.
- 8 Wachslar-Felder JL, Golden CJ *Neuropsychological consequences of HIV in children: a review of current literature*. *Clinical Psychology Review* 22:443-464, 2002.
- 9 Violari A et al. *Early Antiretroviral Therapy and Mortality among HIV-Infected Infants*. *NEJM* 359:2233-2244, 2008.
- 10 Melvin D and Biggs R *A multidisciplinary approach to monitoring neurological & functional outcomes in paediatric HIV infection*. See [www.chiva.org.uk/guidelines/2009/pdf/monitoring-neurological09.pdf](http://www.chiva.org.uk/guidelines/2009/pdf/monitoring-neurological09.pdf), 2007.

# news in brief



## Gay men

### US survey: one in five gay men has HIV and nearly half don't know it

A US survey of men frequenting the gay scene has found that nearly one in five – 19% – had HIV and that 44% of these did not know it, despite the fact that most had previously taken an HIV test.<sup>1</sup>

This survey, plus a recent French one showing that an HIV-positive result is increasingly likely to have been preceded by a negative one,<sup>2</sup> are worrying signs that HIV infection in urban gay scenes in many countries is reaching levels only seen in the worst African epidemics, and shows no sign of abating. While it's important to emphasise that these surveys are of 'gay scene' men and are not necessarily representative of all gay men, they do underline the need for radically new methods of HIV prevention within the gay community.

The US survey, one of a periodic sampling of gay men frequenting commercial venues, pick-up places and community organisations in 21 US cities, found that the HIV rate among African Americans was even higher – 28% had HIV and 59% were unaware of their status.

HIV prevalence varied by city, from 6% in Atlanta to 38% in Baltimore – similar to the general-population HIV prevalence in Swaziland, the worst affected country in the world.

Forty-five per cent of those who tested positive had followed the US recommendations of taking an HIV test at least once a year, suggesting a very high rate of new infections.

Meanwhile, a study in France has found that while the HIV infection rate in

other groups has declined, the infection rate in gay men has remained "high and stable". The researchers estimate that 1% of the gay population of France becomes infected with HIV each year. Whereas in 2003 only a third of men testing HIV-positive had had a previously negative test, by 2008 this proportion was up to nearly 60%.

## Anti-HIV drugs

### CD4 count not related to nevirapine liver damage, study finds

Nevirapine (*Viramune*) may be safe to take at any CD4 count, a three-country study has found.<sup>1</sup> The study found that the risk of severe liver damage was raised in women who already had abnormal liver function, but not in women with high CD4 counts.

Nevirapine is one of the cheapest HIV drugs, may lower rather than raise cardiovascular risk and is generally side-effect free after the first month. However, doctors have been nervous of prescribing it because it can cause life-threatening liver failure and skin eruptions. Previous research appeared to show that these reactions were more common in women with CD4 counts over 250 and men with counts over 400, so nevirapine has generally been withheld from these groups.

However, a survey from Zambia, Kenya and Thailand has now found that the proportion of women experiencing severe liver damage when starting nevirapine was 5%, regardless of CD4 count.

The study found that while 4% of women who had normal liver function before taking nevirapine experienced severe reactions, 12% of women who already had raised liver enzymes did.

Researchers warned that the study did not provide a *carte blanche* for nevirapine therapy: three women (0.4%) died of nevirapine-related liver failure. All of them were on anti-TB drugs, and researchers stressed that nevirapine should not be combined with the TB drug rifampicin.

Meanwhile the European Medicines Agency (EMA) has decided that it is safe for people to switch to nevirapine if they are already on another HIV drug regimen, as long as they have an undetectable viral load. The EMA revised its Summary of Product Characteristics to allow anyone with an undetectable viral load to switch to nevirapine regardless of which regimen they were previously taking.

## Infectiousness

### Women may have high genital levels of HIV despite none in blood

A study has found that some women may continue to have very high levels of HIV in their genital secretions despite having undetectable levels in blood.<sup>1</sup> The study calls into question whether, in women at least, undetectable truly means uninfected.

Fifty-nine women in a clinic in Rhode Island state in the US had their blood and genital viral loads measured repeatedly over the course of a year. They had all had an undetectable blood viral load (under 75 copies/ml) for over six months.

Nearly four in ten women (37.8%) had at least one visit when HIV was detectable in their genital fluids, and at any one study visit an average of nine per cent of women who had an undetectable viral load in their blood had a viral load

## For daily news reports and breaking stories from the international conferences visit [www.aidsmap.com/news](http://www.aidsmap.com/news)

above 3300 copies/ml in their genital fluids. Four of the study participants (6.8%) had at least two consecutive visits when HIV was detectable in the genital fluids but not in the blood.

The highest genital viral load in a woman with no detectable blood viral load was 648,000 copies/ml at the cervix and 480,000 in the vaginal fluid; quite enough to be infectious.

While there was a correlation between blood plasma viral load and genital viral load, the reverse was not true: detectable vaginal or cervical HIV was not associated with detectable HIV in blood and did not predict treatment failure.

The researchers comment that the "episodic and unpredictable" nature of genital shedding of HIV may, in women at least, make it difficult to predict how much risk they run of transmitting HIV to partners.

### Origins

## Did needles kickstart the HIV epidemic?

Canadian scientists have found circumstantial evidence that the HIV epidemic may have been set in motion, ironically, by the use of not sufficiently sterilised needles in campaigns to eliminate other tropical diseases.<sup>1</sup>

It has long been a puzzle as to how a rare, largely blood-borne tropical disease of rural areas in west-central Africa could make the jump to being a sexually spread worldwide pandemic. Although HIV is now largely spread sexually, this is a slow and inefficient method of transmission and needs a high prevalence of HIV to already be in the population, and a large number of interconnected sexual partners, more typical of urban than rural areas.

In addition, history shows that when HIV first arrives in a country the most rapidly infected group are people who pass on HIV in their blood via needles, such as heroin addicts or the recipients of blood products.

Dr Jacques Pepin of Sherbrooke University in Montreal took blood samples from elderly villagers in the areas of Africa that appear to have been the cradle of HIV. From the 19th century to the 1950s, these areas also saw campaigns against malaria and sleeping sickness that featured drugs being given with non-disposable needles that had to be re-sterilised perfectly.

Reasoning that if HIV had been spread in this way, those who had it would be long dead, he studied the prevalence of two somewhat less lethal viruses, hepatitis C (HCV) and the HTLV-1 virus, in the Central African Republic, which now has the highest HIV prevalence in Francophone Africa.

He found that people who had been treated for sleeping sickness before 1951 – when the course consisted of a hard-to-forget series of injections – were three times more likely to be infected with HCV or HTLV-1. In neighbouring Cameroon, he found a similar correlation between previous injected malaria treatment and hepatitis C. He also found that the number of over-65s who had been treated for sleeping sickness and were still alive was six times lower than people who had not – and reasoned that this was because they had died of AIDS.

Suggesting that needles, especially involved in medicine, inadvertently set off the HIV epidemic is still a controversial suggestion and other epidemiologists prefer to blame the urbanisation of Africa, with villagers getting involved in migrant work and what inevitably goes with it, prostitution. Dr Pepin, however, believes that at the beginning of the HIV epidemic "needles played a substantial role that was probably as important as prostitution."

### references to articles [from page 13]

- 11 Malee K et al. *The role of cognitive functioning in medication adherence of children and adolescents with HIV infection.* Journal of Pediatric Psychology, 164-175, 2009.
- 12 Martin SC et al. *Cognitive functioning in school-aged children with vertically acquired HIV infection being treated with Highly Active Antiretroviral Therapy (HAART).* Developmental Neuropsychology: 30(2):633-657, 2006.
- 13 Krechevsky D & Melvin D A case note review of cognitive, learning and quality of life outcomes from a UK cohort of HIV infected school age children. Poster 16, CHIVA conference, Brighton, 2010.
- 14 Brackis-Cott E et al. *The impact of perinatal HIV infection on older school-aged children's and adolescents' receptive language and word recognition skills.* AIDS Patient Care, Vol 23, Number 6, 415-421, 2009.
- 15 Koekkoek S et al. *Neurocognitive function profile in HIV-infected school-age children.* European Journal of Paediatric Neurology 2008, 12:290-297, 2008.

### don't forget SP: testing untested children [page 12]

- 1 BHIVA/BASHH/CHIVA 'Don't forget the children': guidance for the testing of children with HIV-positive parents. See [www.bhiva.org/DontForgetTheChildren.aspx](http://www.bhiva.org/DontForgetTheChildren.aspx), 2009.
- 2 Andrews S et al. *Testing children of mothers with HIV, experience from three southwest London HIV clinics.* HIV Medicine 11 (supp 1), abstract P146, 2010.
- 3 Prime K et al. *First presentation of vertically acquired HIV infection in adolescence.* 14th Annual BHIVA Conference, Dublin, HIV Medicine 9 (Suppl. 1), abstract O2, 2008.
- 4 Andrews, *op. cit.*
- 5 Newbould C et al. *"Don't forget the children": ongoing experience of a paediatric HIV unit in using point of care tests in children born to HIV positive parents – how far have we come?* HIV Medicine 11 (supp 1), abstract P148, 2010.

### news in brief [page fourteen]

US survey: one in five gay men has HIV and nearly half don't know it

- 1 Smith A et al. *Prevalence and awareness of HIV infection among men who have sex with men – 21 cities, United States, 2008.* MMWR 59:1201-1207, 2010.
- 2 Le Vu S et al. *Population-based HIV-1 incidence in France, 2003-08: a modelling analysis.* Lancet Infectious Diseases 2010, in press.

CD4 count not related to nevirapine liver damage, study finds

- 1 Peters PJ et al. *Nevirapine-associated hepatotoxicity was not predicted by CD4 count 250 cells/μL among women in Zambia, Thailand and Kenya.* HIV Medicine, advance online publication, DOI: 10.1111/j.1468-1293.2010.00873.x, 2010.

Women may have high genital levels of HIV despite none in the blood

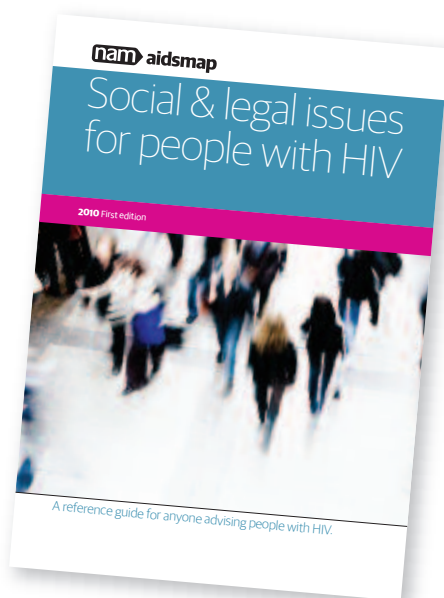
- 1 Cu-Uvin S et al. *Genital tract HIV-1 RNA shedding among women with below detectable plasma viral load.* AIDS 24: advance online publication, DOI:10.1097/QAD.0b013e32833e5043, 2010.

Did needles kickstart the HIV epidemic?

- 1 Pepin J et al. *Iatrogenic transmission of human T cell lymphotropic virus type 1 and hepatitis C virus through parenteral treatment and chemoprophylaxis of sleeping sickness in colonial equatorial Africa.* Clinical Infectious Diseases 51:777-784, 2010.

# New from NAM

***Social & legal issues for people with HIV is your practical guide to the social and legal issues that can affect people living with HIV.***



With straightforward summaries of the most recent developments in social policy and legislation, *Social & legal issues for people with HIV* will get you quickly up to date with the key issues.

## Topics include:

- Discrimination in employment
- Equality Act 2010
- Access to health care for migrants
- Transmission of HIV as a criminal offence
- Confidentiality and consent in medical settings

*“A client-centred approach means we are often called upon to answer questions and understand a huge range of situations faced by people with HIV. Having practical information is vital in being able to support them effectively with the wider challenges they may be facing”*

**David Cox, Health Adviser, Courtyard Clinic,  
St George's Hospital, London**

**The book is currently on offer at £29.95 (usual price £34.95). To order your copy, or for more information, call 020 7840 0050 or email [info@nam.org.uk](mailto:info@nam.org.uk)**

## thanks to our funders

NAM's treatments information for people living with HIV is provided free thanks to the generosity of:

Abbott Laboratories Ltd; Abbott Fund; Allan & Nesta Ferguson Charitable Trust; Avexa Ltd; Boehringer Ingelheim Ltd; Bristol-Myers Squibb Pharmaceuticals Ltd; Caviidi AB; Delphic Diagnostics Ltd; Derek Butler Trust; Government of the United Kingdom, Department of Health; Government of the United Kingdom, Department for International Development; Diana, Princess of Wales Memorial Fund; Elton John AIDS Foundation; Estate of Sidney Klieff; F. Hoffmann-La Roche Ltd; Gilead Sciences Ltd; GlaxoSmithKline PLC; GlaxoSmithKline's Positive Action; Hugh Fraser Foundation; Lloyds TSB Foundation for Northern Ireland; Manchester City Council; Merck & Co., Inc; Merck Sharp & Dohme Ltd; Merck Sharp & Dohme Romania SRL; Miss Agnes Hunter's Charitable Trust; NHS Ashton, Leigh & Wigan; NHS Birmingham East and North; NHS Bolton; NHS Brighton & Hove; NHS Manchester; NHS Norfolk; NHS Pan-London HIV Prevention Programme; NHS Salford; NHS South East Essex; NHS South West Essex; NHS West Sussex; NHS Worcestershire Health Services; Pfizer Ltd; Plumptions Ltd; Roche Molecular Systems, Inc.; Roche Products Ltd; Sanofi Pasteur MSD; Schering-Plough Corporation; Janssen; UNAIDS; World Health Organization.

NAM would also like to acknowledge the generous support of its individual donors.

## donate to nam

Every year NAM provides information resources, like *hiv treatment update*, to thousands of people living with HIV, completely free of charge. To do this we really do rely on the generosity of people like you to help us continue our vital work. You can make a difference today. Please make a donation by visiting [www.aidsmap.com/donate](http://www.aidsmap.com/donate) or by ringing us on 020 7840 0050.

## where to find out more about hiv

- **Find out more about HIV treatment:**  
NAM's factsheets, booklets, directories and website keep you up to date about key topics, and are designed to help you make your healthcare and HIV treatment decisions. Contact NAM to find out more and order your copies.
- **[www.aidsmap.com](http://www.aidsmap.com)**  
Visit our website for the latest news about HIV & AIDS, a fully searchable treatments database and a complete list of sexual health clinics in the UK.
- **THT Direct**  
Offers information and advice to anyone infected, affected or concerned about issues relating to HIV and sexual health.  
**0845 1221 200**  
Mon-Fri, 10am-10pm Sat-Sun, 12pm-6pm
- **i-Base Treatment Phonenumber**  
An HIV treatment phonenumber, where you can discuss your issues with a treatment advocate.  
**0808 8006 013**  
Mon-Wed, 12pm-4pm