

Facial Wasting Treatments

– A Patient’s Perspective

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Credits for photographs:
Patient records, Medical Illustration, University Hospital Birmingham Foundation Trust

What is facial wasting? Basically, it is a depletion of fat from the cheeks and temples, a common form of lipodystrophy, clinically termed ‘lipoatrophy’, which is related to certain antiretroviral drugs most typically the ‘D’ drugs: d4T, ddI, ddC but it has also been connected with AZT and HIV itself. Nowadays with improved forms of HIV medication, it is a problem that people recently diagnosed with HIV should not have to confront. However, for many long-term survivors of HIV, it has been and remains, for some, a distressing issue: what is the point of living well with HIV when you look as though you were dying of AIDS? The adverse impact on mental health is clear. What follows is a brief account of one person’s experience of benefiting (and suffering) from the treatments for facial wasting currently available in the UK.

Newfill

The first time I noticed that something was wrong was when in 1999, I saw photos of myself and I was horrified by my image. Let me be clear, I have never been mistaken for Brad Pitt or John Barrowman, but neither do I normally look like a survivor from the Holocaust: that was how bad it seemed. Fortunately, in 2001 I was at North Manchester General Hospital under the care of Dr Ed Wilkins who offered me a place on a study with Newfill, a polylactic acid water gel com-



June 2006 before treatment with Bio-Alkamid



July 2006 after treatment with Bio-Alkamid

monly used in plastic surgery as an anti-wrinkle device and in surgery in other situations. Needless to say, I jumped at the chance.

Looking back over the Patient Information sheets I was given, I noticed that it said that I would have three injections into the skin in both cheeks, each two weeks apart and that local anaesthetic was not usually necessary. The reality, however, was quite different. The three sets of single injections turned out to be five sessions of multiple injections (around 16 in each cheek) in a grid over the affected area, which were painful and bloody. After the first session, I understood why I had been advised not to wear old clothes and nothing white! From the photographs taken before and afterwards, you can’t really detect a marked change; but there was indeed a measurable increase in the thickness of skin. More important, I knew my looks had improved. When people began to say how well I looked; that also made me feel better. The major drawback was that Newfill didn’t last very long.

Bio-Alkamid

My second chance for facial wasting treatment came when I transferred my care back to North Staffs University Hospital. Patients with facial wasting were

being referred to Birmingham University Hospital, Selly Oak, where Miss Ruth Waters was using Bio-Alcamid. In 2006 I had my first set of injections. A preliminary injection of local anaesthetic numbed the entry for a larger needle to insert the implant in each cheek. Regrettably, the pain of positioning Bio-Alkamid was not dulled in the least; if anything, I found the experience even more painful than Newfill. On the positive side, there was only a single injection into each cheek and there was no mess. It took two operations about a year apart to achieve the desired effect. After the first implant I had no side effects, but after the second, I had a post operation infection that caused the left side of my face to swell up like a balloon! Thankfully, a short course of antibiotics from my helpful GP swiftly remedied the situation to produce a result that I am still pleased with three years on.

Aquamed

Having had two painful experiences of ‘extreme botox’, you can imagine how envious I felt of my New Zealand and Australian comrades when I discovered that the Aquamed treatment they were being offered was painless! Aquamed seems to be very similar to Bio-Alkamid in substance and in the way it is implanted. Moreover, the results appear to be just as

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good – the big difference is the absence of pain during surgery. People who have had the treatment told me that apart from the tiny prick of the local anaesthetic, it was truly a painless operation.

For my part, I don't regret the discomfort of either of procedures I underwent. Apart from countering the physical disfiguration of facial wasting, I believe the operations have helped me to develop greater self-confidence. What saddens me is that the pain of the treatments currently available here in the UK is a real deterrent for some people. Wouldn't it be wonderful

if Aquamed was recommended by the British HIV Association to become the preferred option for facial wasting treatment in the future?

I would like to acknowledge the help given by individuals with their personal accounts of facial wasting treatments in the UK and New Zealand as well as the kind assistance of Bruce Kilmister Director of Body Positive New Zealand for giving me comprehensive information about Aquamed including a video of surgical procedure that I passed on to Selly Oaks Hospital.

BINGO

BODY POSITIVE FUNDRAISER & AFTERNOON TEA

Sunday 11th October
2pm
Body Positive House

BYO - Plate of food for afternoon tea
 Tea & Coffee Supplied.

* Refer to email or website www.bodypositive.org.nz for more details.

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"Empowering People, Strengthening Networks" — 9th ICAAP opens

9th International Congress on AIDS in Asia and the Pacific (ICAAP) this year took place in Bali, Indonesia from 9-13 August under the theme "Empowering people, strengthening networks".

The President of the Republic of Indonesia, H.E. Hj. Dr Susilo Bambang Yudhoyono has officially opened the 9th International Congress on AIDS in Asia and the Pacific (ICAAP), which this year took place in Bali, Indonesia from 9-13 August under the theme "Empowering people, strengthening networks".

At the opening ceremony, Mr JVR Prasada Rao, Director, UNAIDS Regional Support Team, Asia and the Pacific, has delivered a speech on behalf of UNAIDS Executive Director, Mr Michel Sidibé calling for the establishment of enabling environments and supportive social norms necessary to deliver a future generation free of HIV.

The Congress has drawn thousands of people together for five days of discussion around the AIDS response in the Pacific and across Asia. Together they discussed a wide range of issues and contexts for the AIDS epidemic in these regions including mobility and migration, injecting drug use, human rights as well as gender.

According to Mr Rao "There will be evidence-based discussion on whether Universal Access can be an achievable goal by 2010 for many countries in Asia and the Pacific. Every facet of the epidemic and the region's responses are featured in the wide array of session and activities."

Mr Rao continued, "What is really impressive is that the conference will showcase the immense progress made by community groups, working together and in partnership with government and other partners, in spearheading the response in many countries in the Asia Pacific region."

Congress Programme

The event, which takes place every two years, is broad in scope as it includes 24 symposia, 32 skills-building workshops, and 75 satellite meetings. Some 349 abstracts have been accepted by the programme committee for 64 sessions of oral presentations, and 1932 abstracts accepted for poster presentations.

The other main goals of the event are to empower individuals and strengthen networks in the regions to effectively respond to AIDS.

Young people and women

The Bali Youth Force (BYF), a coalition of youth networks and organizations that has collective representation in all Asia &

Pacific countries, encouraged significant youth participation in the 9th ICAAP.

UNAIDS Secretariat and its Cosponsors will participate and lead a wide number of events including the launch of a new report, HIV Transmission in Intimate Partner Relationships in Asia, that highlights the increased risk of HIV infection by women engaged in long-term relationships.

HIV epidemic in Asia and Pacific

According to the Independent Commission on AIDS in Asia (2008), AIDS remains the most likely cause of death and loss of work days among people aged 15 to 44.

An estimated 5 million people in Asia were living with HIV in 2007 according to 2008 report on the global AIDS epidemic. The several modes of HIV transmission present in the region, via sex work, injecting drug use, and unprotected sex between men; make Asia's epidemic one of the most diverse in the world. The Pacific region's epidemics are relatively small with an estimated 74 000 people living with HIV across Oceania in 2007.

Unfortunately Body Positive has not been able to send a representative to the conference. Each conference provides a number of "scholarships" which meet travel and accommodation costs for representatives of HIV / AIDS groups and individuals throughout the Pacific. Body Positive applied for a scholarship to send one person and unfortunately this was declined. Usually scholarships go to third world countries. However we are pleased to confirm the NZ AIDS Foundation did send their Executive Director – Rachael Le Mesurier and Simon Hager-Ford. We further believe Positive Women had a representative at the conference so we are asking them to provide us with a report so we may bring relevant news to you.

USA Move, One Step Closer

Fifty-four churches and Christian organizations, networks of people living with HIV and individuals have sent a letter to the United States' Department of Health and Human Services welcoming a proposed revision to current US regulations that ban people living with HIV from entering or transiting through its borders without a special waiver.

The US currently is one of 13 countries that essentially bar people living with HIV from entering their borders. In July 2008, the US Congress requested that the Department of Health and Human Services remove HIV from an official list of communicable diseases that disqualify foreigners from entering the country.

Hepatitis C virus infections among HIV-infected men who have sex with men: An Expanding Epidemic

Abstract

Background Since 2000 outbreaks of sexually transmitted hepatitis C Virus (HCV) infections have been reported among HIV-infected men who have sex with men (MSM). We studied the prevalence and determinants of HCV-infection among MSM attending a large sexually transmitted infection (STI) clinic in the Netherlands.

Method In 2007-2008, 3125 attendees of the STI clinic Amsterdam, including 689 MSM, participated in an anonymous biannual cross-sectional survey. Participants were interviewed and screened for HIV and HCV antibodies. Additionally, all anti HCV positive and HIV-infected individuals were tested for HCV RNA. Using phylogenetic analysis, HCV strains of the STI clinic attendees were compared with those isolated from MSM with acute HCV in 2000-2007. Determinants of HCV-infection were analysed using logistic regression.

Results Two of 532 (0.4%) HIV-negative MSM and 28 of 157 (17.8%) HIV-positive MSM were infected with HCV. Over the study period, HCV prevalence among HIV-infected MSM increased (14.6%-20.9%). Seven of 28 (25.0%) HIV/HCV coinfecting MSM had acute HCV infection. Only five of 28 (17.9%) HIV/HCV coinfecting MSM ever injected drugs (IDU). HIV-infection, IDU, fisting and gamma hydroxy butyrate (GHB)-use were significantly associated with HCV-infection. Phylogenetic analyses revealed a high degree of MSM-specific clustering.

Conclusion We found a high and increasing HCV prevalence in HIV-infected MSM. Though not statistically significant, this trend, and the relatively large proportion of acute infections suggest ongoing transmission of HCV in HIV-positive MSM. Regardless of IDU, rough sexual techniques and use of recreational drugs were associated with HCV-infection; phylogenetic analysis supported sexual transmission. Targeted prevention, like raising awareness and routine testing, is needed to stop the further spread among HIV-infected MSM, and to prevent possible spillover to HIV-negative MSM.

FREE Condoms of Every Kind

Body Positive is pleased to announce a new contract allows us to provide free condoms to people living with HIV. This is particularly important for positive people in serodiscordant partnerships (where one partner is positive and the other partner is negative) Although Body Positive has previously provided condoms free this is the first time we are able to offer a variety of the different types manufactured to tailor for personal preference.

Call in or telephone if you are not resident in Auckland and we will post to you your choice.



Remember Jock?



Well he is alive and well and working for the Auckland District Health Board. He took up a new position as the Smokefree Systems Facilitator and as is his usual style he has buried himself in work. He hasn't forgotten his old workmates and the almost first communication from him tell any positive smokers to amend their ways.



Jock says:

Apart from the already known fatal diseases of smoking, now researches show its association with an increased risk of acquiring HIV infection. A study from the Food and Drug Administration (FDA) provides preliminary evidence that at least in the test tube, constituents of cigarette smoke induce HIV production in chronically infected cells.

People with HIV disease are now living longer. But, smoking can easily interfere with long term quality life of HIV people.

Smoking greatly weakens the immune system of the body, and an increased risk for certain infections in both HIV-negative and HIV-positive individuals, including the sexually transmitted infection (STI), human papilloma virus (HPV), which is associated with genital and anal warts and cervical and anal cancer.

How smoking affects HIV patients?

- People with HIV who smoke are more likely to suffer complications from HIV medication than those who don't. For example, they are likely to experience nausea and vomiting from taking HIV medications.
- Smoking causes HIV drugs and medications not to work as well as they should.
- HIV-positive smokers develop AIDS faster than non-smokers.
- People with HIV who smoke are more likely develop osteoporosis and it may lead to fractures.
- HIV treatment in smokers increases the risk of a heart attack.
- HIV positive individuals who smoke have a significantly increased risk of dying from lung cancer.
- Tobacco smoking increases the risk of chronic lung disease for HIV positive smokers. It also interferes with the processing of medications by the liver.
- People with HIV disease who smoke are more likely to develop several Opportunistic Infections related to HIV. These include:
 1. Thrush
 2. Oral hairy leukoplakia (whitish mouth sores)
 3. Bacterial pneumonia
 4. Pneumocystis pneumonia

We wish you well in the new job Jock!

Treatments Update:

Kaletra

Once daily dosing:
Previously treated patients can achieve good outcomes with once-daily lopinavir/ritonavir (kaletra), and boost their adherence.

In the USA, Kaletra is approved for once-daily dosing in combination with other antiretrovirals for individuals starting HIV treatment for the first time.

Researchers wanted to see how well this treatment strategy performed in patients with previous experience of antiretroviral therapy.

The study involved 600 people currently taking HIV treatment, but with a viral load above 1000 copies/ml. They were randomised into two equal groups, one taking the standard twice-daily dose of Kaletra (lopinavir/ritonavir 800/200mg).

After 48 weeks, equal proportions of patients in the two arms (52% vs 55%) had an undetectable viral load (below 50 copies/ml), the goal of antiretroviral therapy. Increases in CD4 cell count were also comparable between the two groups.

An advantage of once-daily dosing was better adherence.

Abbott Laboratories (NZ) Ltd advise the single daily dose is not yet approved in New Zealand. Currently the Australian body equivalent to NZ's Medsafe are considering approval for Australian customers and if approved New Zealand should follow. We hope to see this through for next year.

Rilpivirine

Gilead Sciences and Tibotec have announced that they will collaborate on a new fixed-dose combination HIV pill that will include Gilead's Truvada (tenofovir and emtricitabine) and an experimental Tibotec drug called Rilpivirine (TMC-278).

Rilpivirine is a once-daily second-generation non-nucleoside reverse transcriptase inhibitor in the same class as Tibotec's Intelence (etravirine). Early data published thus far indicates that rilpivirine, when combined with two other drugs, might have similar efficacy and tolerability as a combination including Sustiva (efavirenz).

Gilead stated that it will have exclusive rights to manufacture and sell the new combination pill in the developed world, while Tibotec will be responsible for marketing it in developing countries.

GSK-522

Glaxo SmithKline's experimental second-generation integrase inhibitor GSK-572 has performed well in early clinical trials.

In a phase 2a, ten-day, study, 35 HIV-infected, treatment-naive people were randomised to receive either monotherapy with the drug or a placebo.

Significant falls in viral load were observed in patients taking all doses of the drug.

Especially good results were achieved by individuals taking the 5mg dose, with 70% having a viral load below 50 copies/ml at the end of the study, and 90% had a viral load below 400 copies/ml.

The most commonly reported side-effects were diarrhoea, tiredness and headache. With the exception of headache, these were more common in the placebo arm.

The 50mg dose will be studied in a phase 2b trial starting later this month.

Isentress (Raltegravir)

The new drug produced by Merck Sharp and Dohme will be funded by Pharmac for New Zealand patients from 1st October this year. Already 60 New Zealand positive people are on this drug under compassionate supply. Merck ceased compassionate supply once they applied to Pharmac for funding. This left anyone needing the drug to go without until it was funded. Body Positive lobbied Pharmac and a number of physicians were concerned as more and more people seemed to be denied this option. The drug is particularly good for people with "resistance" issues. For more information contact Body Positive.

Isentress without a protease inhibitor is effective for treatment experienced patients

It might not be necessary to combine the integrase inhibitor Isentress (raltegravir) with a protease inhibitor (PI) in treatment experienced people with HIV, according to a study published at the Fifth IAS Conference on HIV Pathogenesis, Treatment and Prevention in Cape Town.

High Rate of Vitamin D Deficiency in HIV-Positive Men

Nearly half of a group of HIV-positive men in New York City had abnormally low levels of vitamin D—potentially leaving them at risk for developing bone problems, according to a study presented at the Fifth IAS Conference on HIV Pathogenesis, Treatment and Prevention in Cape Town.

Open House

Saturday 26th September

Open from 5pm to 10pm.
Light supper provided.

Meet other people in a safe, comfortable environment.

For more information, contact Body Positive:
Phone: (09)-309 3989
office@bodypositive.org.nz

Thank You!

<p>CENTURIAN SAUNA gold coin collection \$ 142.10</p>	<p>ALLELUYA for the coin box in your cafe \$ 92.20</p>
<p>QUIZZ NIGHT at Naval & Family \$ 419.10</p>	<p>STEFAN for generously cutting hair at Body Positive.</p>

Diary

Tues	08	Counsellor	
Wed	09	Pot Luck Dinner	
Thurs	10	Counsellor Massage for members	
Fri	11	Pot-Luck Lunch	

Tues	15	Counsellor	
Thurs	17	Counsellor Massage for members	
Fri	11	Pot-Luck Lunch	

Tues	22	Counsellor	
Thurs	24	Counsellor Massage for members Straight Arrows Dinner	
Fri	25	WINZ Clinic	
		Pot-Luck Lunch	
Sat	26	Open House	

Tues	29	Counsellor	

OCTOBER			
Thurs	01	Counsellor Massage for members	
Fri	02	Pot-Luck Lunch	

Tues	06	Counsellor	
Thurs	08	Counsellor Massage for members	
Fri	09	Pot-Luck Lunch	
Sun	11	BINGO - Fundraiser	

Tues	13	Counsellor	
Wed	14	Pot-Luck Dinner	
Thurs	15	Counsellor Massage for members	
Fri	16	Pot-Luck Lunch	



K'Road Clinic

For general medical consultation
Free for HIV+ people on a benefit



HIV RAPID TEST

The 60-second HIV Rapid Test is now available at Body Positive House. A simple pin-prick is done, to test the blood with a 99.7% accuracy. It's always better to know your status early, so you can keep healthy, if you become HIV positive.

Call **0800 HIV LINE** to book a **FREE** no-hassle Rapid Test.



WINZ Clinic

Remove the anxiety you experience in dealing with WINZ. Body Positive operates a monthly WINZ Clinic for anyone at our premises with qualified, sensitive, understanding and supportive WINZ staff.



Psychiatrist

An experienced, qualified psychiatrist operates a clinic at Body Positive on a monthly basis. *Access is by medical referral.*

Contact Body Positive for more information.



FOOT DOCTOR

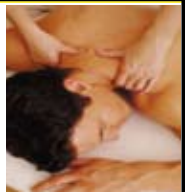
A professional podiatrist runs a clinic here at Body Positive House on a monthly basis. Next clinic date - 28th Sept 2009 (Monday) from 1pm-5pm

Phone now for an appointment 09-309 3989



MASSAGE

Both Swedish (Therapeutic) or Sports massage are available at Body Positive on every Thursday. A minimum koha of \$10 is requested from each client, making the service within reach of most Body Positive members. Phone 09-309 3989 and book an hour to pamper your body.



6 ON 6

The next **6 on 6** will start in Sept/ Oct. This facilitated peer support group is for anyone who has issues around their HIV status. It is particularly useful to recently diagnosed people and is open to men and women. If you would like to register your interest in attending or want more information, call us on 09-309 3989



Friday Pot-Luck Lunch

Members please note Body Positive will be hosting a drop-in lunch every Friday at mid-day. Members are welcomed to bring a pot-luck plate.



QUIT SMOKING

Apart from adhering to your medication regime, quitting smoking is the next most significant improvement HIV+ people can take to improve their health and life expectancy. Smoking increases the risk of brain, heart and lung diseases, various cancers and opportunistic infections. If you would like to quit smoking, we can help. Phone 0800 HIV LINE.



Budgeting

Need help with your money. Body Positive has developed a computer software programme that helps you to identify concerns and issues with your personal budget and recommend ways to help.

Contact in complete confidence.



RECYCLED MEDICATION

If you have unused medication or no longer need left-over medication, please either return your unused medication to your prescribing physician or drop it into us or send it to:

Body Positive Inc
P.O. Box 68-766
Newton, Auckland



We will pass it on to physicians.

VITAMINS

Body Positive has fantastic *Swisse brand vitamins* available to members for only \$15.00! (Usually over \$30) *Swisse Women's Ultivite Multi vitamins* & *Swisse Men's Ultivite Multi vitamins*. Both with the highest quality ingredients that will give you a kick!

Drop by BP House or call **0800 HIV LINE**



TRAVEL INSURANCE

Buy your Travel insurance from **Mike Henry** Agent Body Positive, whether you are Positive or Negative, travelling to Sydney or the Seychelles just call 0800 HIV LINE for a travel insurance quote. (When you buy from us you help support our work + you get a good deal!)



Facial Lipodystrophy treatment

A fantastic facial filler treatment is available through Body Positive.

Please contact *Body Positive* on (09) 309 3989 for more information.

