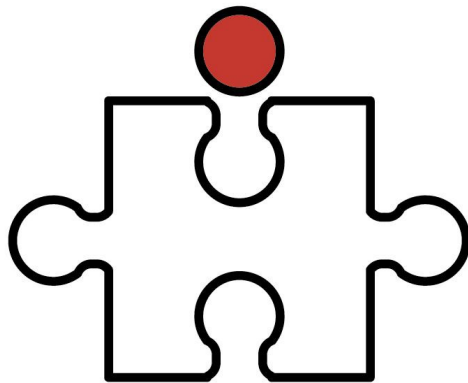


Annual Report ***2008***



The only herpes viruses charity
Registered charity 291657

Statement

The Herpes Viruses Association (HVA) continues as a vital support organisation for people who have herpes viruses. This includes shingles, cold sores, genital herpes and glandular fever.

The stigma associated with genital herpes remains, there is evidence of increasing stigma regarding cold sores. Our busy helpline indicates a considerable need for our services.

**The Herpes Viruses Association
41 North Road
London
N7 9DP**

**Office: 020 7067 9661
Helpline: 0845 123 2305 (local rate)**

Contents

The need for our services is growing

- rise in diagnoses at clinics of Genitourinary Medicine 3
- the stigma does not decrease 3

We have three aims, as stated in our Constitution: 4

1) To supply information on herpes viruses to:

- the public 4
- medical professionals
- the media

2) To encourage research into prevention and treatment of herpes simplex and its effects on the persons who contract it. 6

3) To provide treatment advice and emotional support to those who are badly affected physically or mentally by a herpes simplex diagnosis

Strategies to increase awareness:

- use of the media, websites, links and directories 7
- talks with - and to - health professionals 7
- articles in professional journals 7
- umbrella organisations and affiliates 7

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Staff and volunteers - monitoring and training 9

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The need for our services is growing

Diagnoses are on the increase

More cases of all sexually transmitted infections (STIs) are diagnosed in clinics of genito-urinary medicine (GUM clinics) each year.

Diagnoses of herpes simplex have risen steadily since the 1990s with the most recent figures for GUM clinics showing:

- The total new patients diagnosed at GUM clinics in England for 2006 was 21,698.⁽¹⁾
- There was an increase of 10% in men between 20 - 24 years (1835 to 2016).
- Women between 16 and 19 years showed a pronounced rise of 16% from 2416 to 2803.

GPs diagnose an average of 1.37 new patients each per year: a further 49,320 per year.⁽²⁾

Thank you so much for sending me all the information. I was diagnosed last week and felt absolutely distraught but feel much, much better. Since receiving your email - have even managed not to really think about it today! If you haven't posted it already, it's fine to shred the credit card slip. Many, many thanks, Charlotte

We offer a truly public service:

- The website is seen by three hundred thousand visitors a year (who don't pay).
- The GUIDE is given to twenty thousand patients a year (who don't pay).
- The helpline is used by over a five thousand callers a year (who don't pay).

1. http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/epidemiology/datatables2006.htm
2. Woolley and Chandiook, 1996.

The stigma remains

There is no let-up in the strength of prejudice and stigma. Magazines and newspapers continue to refer to genital herpes simplex as though it were as serious as HIV. In reality it is less serious than a facial cold sore, which may cause herpes keratitis or herpes encephalitis.

Herpes drives epidemic of sexual diseases

By **Jeremy Laurance**
Health Editor

Sexually active young peo-

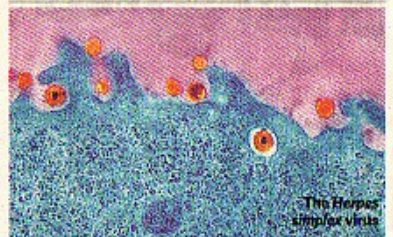
even greater, at 16 per cent. Genital herpes is caused by a virus and is incurable. The virus remains in the body for life and sufferers

almost 150,000 extra cases. Casual sex, an increase in "risky behaviour" and a perception that the diseases are trivial has fuelled the

chief executive of the Health Protection Agency, which published the figures yesterday, said: "We have to tackle all the risky be-

films pulling on a condom." The explosion of infections over the past 10 years had been "very worrying" but there were now some

A ten year epidemic



The Herpes simplex virus

<p>■ SYPHILIS 1996: 162 cases 2006: 2,766 cases Increase: 1,607 per cent</p>	<p>2006: 113,585 cases Increase: 166 per cent</p>
<p>■ GONORRHOEA 1996: 13,063 cases 2006: 19,007 cases Increase: 46 per cent</p>	<p>■ GENITAL HERPES 1996: 16,615 cases 2006: 21,698 cases Increase: 31 per cent</p>
<p>■ CHLAMYDIA 1996: 42,668 cases</p>	<p>■ TOTAL INFECTIONS 1996: 231,185 2006: 376,508 Increase: 63 per cent</p>

STIGMA

In the above example from the **Independent**, 21-7-2007, the headline totally contradicts the figures in the box (right) which show genital herpes increased **least** of the four conditions detailed.

Our 'letter to the editor' detailing the errors in this piece, was the 'feature letter' in the **Independent**, 26-7-2007 see below.

Other letters were published in:

The **Independent** 27-12-07 (shown on page 7)

with downing, y and com-re for y men y wor-psaid, s, the ismit-agen-s and d dif-h ex-ld rise Gon-from 08 to s con-popu-m and tions, d with signs. from lmost eriod more leam.

you can have a major impact on the infection rate. That is harder to do for genital herpes" Mr Hughes said

overall last year, but had cut waiting lists. Latest figures showed 86 per cent of patients were seen within 48

Letters to the Editor

191 MARSH WALL, L4
EMAIL: letters@independent.co.uk (NO ATTACH-
FAX:

PLEASE INCLUDE YOUR FULL STREET
DAYTIME TELEPHONE NUMBER. LETTERS I

Scientists trying to tame the climate

Sir: It is interesting to learn from Michael McCarthy's article (23 July) that a major scientific study demonstrates that global warming is likely to be responsible for the greatly increased UK summer rainfall and concomitant flooding.

A possible route to resolution of this problem is to engineer a controlled global cooling. The Nobel Laureate, Professor Paul Crutzen, has proposed one scheme, involving injection of reflecting sulphur particles into the stratosphere, and Dr Roger Angel has advocated the positioning of mirrors at a zero-gravity point on the line between the sun and the Earth.

A third possibility involves increasing the reflectivity of low-level shallow clouds which cover about a quarter of the oceanic surface. This would be achieved by spraying copious quantities of small seawater particles from

Use of herpes stigma to encourage condoms abuses our rights

Sir: We all want to see more people being responsible about sex, using condoms and having check-ups (report, 21 July). But reinforcing stigma and laying a guilt trip on people with genital herpes is not the way to do it. It simply makes the people who are already diagnosed even more miserable.

The Health Protection Agency's annual report on the nation's sexual health shows an increase in the diagnosis of many sexually transmitted infections, including genital herpes. Professor Pat Troop, the HPA chief executive, said: "It is important to remember that herpes infections are carried for life." Dr Gwen-

da Hughes, also of the HPA, said: "Genital herpes is a lifelong infection; it's not curable." Lisa Power, of the Terrence Higgins Trust, added: "This is a lifelong and unpleasant condition which will require ongoing treatment, and not something to be taken lightly."

Herpes simplex has two names, "genital herpes" when it is on the genitals and a "cold sore" when it is on the mouth. Two-thirds of us carry one of the viruses that causes it. It usually goes undiagnosed because most people who have it either get very mild symptoms or no symptoms.

Chickenpox and glandular fever are also herpes viruses carried by most of us.

They are also lifelong infections; chickenpox can recur as shingles and can be very unpleasant, but no one is made to feel guilty about this.

The main problem for patients with genital herpes is stigma and psychological trauma. "Will I ever have another relationship?" "Will anyone want me again?" The Herpes Viruses Association is the charity that helps these patients put their lives back together. Reinforcing herpes stigma as a cheap way of encouraging condom use abuses the human rights of millions of us. It has to stop.

NIGEL SCOTT
HERPES VIRUSES ASSOCIATION, LONDON N7

parking, either fully open carports or single-skin walkways as a double, treble even quadruple garage and beside it the space to be used as the equivalent of a 'ground floor cellar' recreation room or utility store.

There must be no boilers, electricity meters, gas meters or

is no agency, human or divine, to give us a copper-bottomed guarantee that disaster will never strike us or our loved ones.

The first truth should lessen our arrogance so we do not act as though the universe was designed for our benefit. The sec-

which only concentrate the flow and pressure to be released downstream, perhaps the solution is to dig canals. Unless we have a huge increase in sea levels, the Fenland seems reasonably safe.

Here in Suffolk, we find a

mean English, why didn't he say so at the start?

He is not alone. Recently, your columnist Bruce Anderson, who also should know better, wrote that the English are an island race. They are not: England has

Face it, can is here to stay

Sir: I am increasingly in favour of the idea that cannabis back to will have any impact (letters, 24 July).

I agree that so-called cannabis can be health problems for children. But this argument is legal for the use of the

As a drug worker arrested for cannabis. The problem is the drug is now grown in poor countries in poor conditions with the crop with Methadone, and other substances. The potency is the cause of the problem. The children do not know are smoking.

Cannabis use is not good for you. You could make use

Our aims

The constitution of the HVA states that it exists to promote better mental and physical health with regard to the family of herpes viruses in the following three ways:

Aim 1. Giving correct information on herpes viruses to the public, to medical professionals and to the media.

The public

Increasing use of the Internet has made us more effective because it's now easy for anyone to access helpful information on our website. **It's important to the public** because it provides a source of unbiased information on the herpes viruses.

Our website provides people with anonymous help and encouragement. The fact that users do not have to divulge their identity is particularly beneficial, because many sufferers are ashamed that they have caught the virus:

Our website is a busy place

- quarter of a million visitors a year
- frequent emails reporting how "this website saved my life"
- updated several times a month
- top of the list on Google UK search, in the top 10 on a Google World search

I just wanted to say thank you for this website. I am waiting on some results and I was getting so scared. It really calmed my nerves and made me realise that I can cope with it if my results are positive.

I have had this virus for 21 years now and have kept it mostly to myself. I still struggle with the shame... about 6 years ago I started getting infections on my face as well. Day to day I am doing okay, but whenever there is a breakout I generally have a meltdown and become depressed... My family do not know why this happens – and I am distracted at work. All this to say, it was so nice to read through your website. I really feel that there is light at the end of the tunnel. A big THANK YOU!

Our helpline is another, equally appreciated support tool available to the public:

- it receives around five thousand calls a year
- it's answered by trained volunteers
- calls average 13 minutes each, with some lasting over one hour
- support for repeat callers with long-term problems offering life strategy and advice

Medical professionals

- *Herpes Simplex – the Guide* is a 6,000 word booklet written by staff and members of the HVA.
- 110 NHS GUM clinics are supplying this leaflet to their patients
- 12,575 copies have been ordered by GUM clinics this year
- three talks were given during the year to GUM staff on the topic *Counselling patients with herpes simplex*. These took place at East Surrey Hospital, Ashford Hospital and Mayday Hospital
- we wrote the editorial for an edition of Practice Nursing (November 2007)
- we composed the Ten Top Tips feature for Pulse (February 2008) to be signed by Dr Phil Hammond on our behalf

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INDEPENDENT THE
Circulation ('000): 245 Readership ('000): 604 Display Rate (£/sqcm): £9.62
- 1 DEC 2007
Sir: Your article veers close to letting this government off the hook. For example, a tenfold increase in the incidence of syphilis in the last ten years is truly frightening. Yes, in 2004 the Government announced a £300m programme to improve clinics. Unfortunately the allocation was not ring-fenced and this omission resulted in most of the money being used by cash-strapped primary care trusts to balance the books last year. Yes, £50m was earmarked for a safe-sex publicity campaign but last year it emerged that only £4m was actually allocated and a recent parliamentary answer revealed that only £1m of this is being spent this year. The Government is very good at talking the talk, but until it insists that money for improving clinic services is used as intended and until a properly resourced safe-sex publicity campaign is adequately funded, we will continue to be the sexually "sick man" (and woman) of Europe. NIGEL SCOTT HERPES VIRUSES ASSOCIATION LONDON N7

Media

Journalists require case histories when they write about a medical condition. Interviews were given for stories in:

Look
New
Daily Mirror

The charity was plugged in:

Sunday Mirror, Dr Catherine Hood	27-5-07
The Sun, Dr Kate Nicholson	2-7-07
Full House, Christine	2-8-07
Bella, What's New in Health	28-8-07
The People, Dear Rachael	26-8-07
Best, Dr Sally Hope	11-9-07
Bella	13-11-7
The Argus, Dr David Devlin	12-11-07
Sunday Mirror, Dr Catherine Hood	25-11-07

Radio interview on BBC Midlands ??

TV production company asked for our assistance in the early stages of creating their programme: 'Embarrassing Illnesses'

Aim 2. Promoting research into prevention and treatment of simplex and its effects on the persons who contract it. This year we:

- provided subjects for a survey of patients' views on 'quality of life' for the QALYity Project
- provided interviewees for a nurse doing a project on 'patients' attitudes to having herpes simplex'

Aim 3. Providing relief for persons with symptoms of herpes simplex:

Public

- they can call the helpline without charge on a local rate number
- they can talk for as long as they like with a trained volunteer who has been through many of the same physical and psychological traumas
- 300 emails (approx) from the public were answered during the year (not including members or medical professionals)

Members

- 466 women and 113 men joined during the year: the same total as in the previous year (347 women and 230 men)
- On joining they are sent 12 leaflets on aspects of herpes simplex (some self-chosen such as 'Pregnancy & Childbirth' or 'Transmission')
- They get five issues of *SPHERE* (the current one and four more) in the first year
- Annual meeting with lecture from top 'herpes doctor': this year Dr Colm O'Mahony the media spokesman for the British Association for Sexual Health and HIV
- Meetings were held in London, Manchester, Milton Keynes, Leeds, Newcastle-upon-Tyne, Brighton
- Workshops were offered in May August November and February
- One-to-one counselling at the HVA office or in a neutral place.

Strategies to increase awareness

Media, web, links and directories

- We are alert to stories so that we can comment or write responses
- We send corrections to any UK website that misreports on herpes viruses
- We ask for links on relevant sites
- Web links are up by about 255 on last year
- Directories and local resources across the nation list our details and services

– since doctors and other medical professionals routinely do not mention patient groups, the local library listing are often the place where people hear about us.

Working with – and for – health professionals

- Patient representation on the “Herpes Simplex Virus Advisory Panel”, the special interest group of the British Association for Sexual Health and HIV
- Three talks entitled ‘Counselling Patients with Herpes Simplex’ were given to staff at GUM departments in Croydon, Chertsey and Redhill.
- 12,300 copies of “Herpes Simplex – The Guide” distributed through GU clinics this year
- patient cards and posters sent to GU clinics nationwide
- information and posters sent to youth workers, university advice centres, etc.

What consultants in GUM say about *Herpes Simplex - The Guide*:

“It saves us such an enormous amount of time in the clinic for patients to be able to read these books and then come back and discuss sensible issues with us.”

Dr Colm O’Mahony Consultant physician in sexual health, MD FRCP Chester and spokesman for BASHH

“[The HVA] continues to help very many people, not only via its helpline and website, but also through its excellent publications “Herpes Simplex – the Guide” is widely used in GUM clinics.”

Dr GR Kinghorn, MD FRCP, Clinical Director for Communicable Diseases, Hon Prof in GUM Sheffield

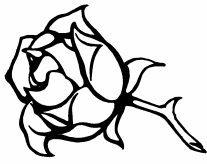
Articles in professional journals

- Practice Nursing
- Pulse (written by the HVA and signed by Dr Phil Hammond, GP)
- Skin Care Campaign News (which goes to dermatologists, GPs with special interest in Skin and members of the All Party Parliamentary Group on Skin)

Umbrella organisations

To achieve more publicity and reach a wider audience as well as addressing wider health concerns we join with other groups. We are members of:

- The special interest group for herpes simplex of the British Association for Sexual Health and HIV (BASHH)
- British Federation against Sexually Transmitted Diseases (BFSTD)
- All Party Parliamentary Group on Skin (APPGS)
- British Association of Dermatologists’ Patient Support Groups - work with many other professional bodies, e.g. British Dermatology Nursing Group, the British Skin Foundation, Pharmacists as well as the pharmaceutical industry.
- Patient View
- Involve – patients in research
- Skin Care Campaign
- Scottish Skin Care Campaign
- Skin Care Cymru
- Cochrane Review Group on Skin



Shingles Support Society

Sub-group recognised by the Charity Commission

We send out a 19 page information pack for sufferers to share with their GPs explaining post-herpetic neuralgia (PHN), a pain created by the shingles virus and which in older patients frequently continues long after shingles blisters have healed. Since the first line treatment for PHN are generic tricyclic antidepressants and anti-epileptic drugs, GPs may be unaware of their usefulness.

Shingles enquiries vary depending on how often we are mentioned in the press. This year we had:

- 450 written enquiries (the peak was 2002 with 978 enquiries)
- over 1000 helpline conversations

Donations to the value of £1,748 were received.

We worked with three pharmaceutical companies:

- Grunenthal whose Versatis plasters with lidocaine are newly licensed treatment for shingles
- SanofiPasteur on advance publicity for a vaccine against shingles for older people.
- Pfizer on a leaflet for patients to be distributed through GPs surgeries, raising awareness of 'neuropathic pain' caused by a range of conditions.

Media: Kate Devine, "Herald" Scotland re Princess H's shingles and treatment for Chat in March – needs young case study for shingles
Swindon Advertiser Shingles Marian quoted

Radio: BBC Three Counties "Drive By" Catherine Boyle

Staff and volunteers - monitoring and training

Two full-time staff on staggered hours and with overlapping duties:

Marian Nicholson (MN), director, works from noon to 8pm.

- responsible for non-routine letters, grant applications to statutory bodies such as the National Lottery and Department of Health, writing and editing leaflets, *SPHERE* and the Annual Report.
- attends most meetings with external bodies and gives most of the lectures on aspects of herpes simplex to medical personnel and the general public.
- answers helpline calls in the evening from members of the association and newly diagnosed patients.

Nigel Scott (NS), administrator and information officer, works from 10am to 6pm.

- answers requests for information
- administrates the membership service
- reconciles accounts monthly
- manages sales of our booklet to GUM clinics
- oversees volunteers who help out in the office
- sits as Vice Chair of the Skin Care Campaign
- sometimes lectures to the public

Both:

- write press releases, articles for *SPHERE*
- run workshops (study days) for members
- take ‘advice and counselling calls’ several times a day from members of the Association, the general public, medical professionals and the media.

Volunteers are essential to our service. Over the year we have help from about 30 people:

- Helpline volunteers are trained and supervised. Continuous support is given to helpliners on the telephone from their original trainer. News sheets are sent out regularly to keep them up-to-date with factual information and suggestions for counselling.
- Monitoring of helpline services continues at all levels.
- Volunteer helpliners fill in a report sheet to enable supervision of the information provided and give further training or information to the helpliners.
- Local contacts and organisers of group meetings all over the country are supported by the office staff but do not receive formal training.

Two “job-seekers” doing three-month placements provided useful help in the office.

Executive Management Committee

The Executive Management Committee is elected at the Annual General Meeting from the membership and reflects its diversity. Committee meetings are held monthly to oversee the work of the association, direct its future and approves outgoing expenses. The chair rotates. At year end the Committee included six men and seven women aged 26-68 years old.

The Charity Commission has issued a dispensation so that the names of committee members do not appear on their website or on any published document – although nine out of the twelve members are not ‘shy’ about being listed.

Funding for 2006/2007 onwards

Core Grant:

The HVA remains a small charity with no investments beyond its deposit account, no property, no assets beyond its office equipment. We rely on a core grant from the Department of Health (DH), which was £25,000 this year but which we are pleased to know will continue for a further three years. Income from service users pays for information material and subscriptions.

Corporate donations:

The only major corporate donation was from £4,000 was received from SanofiPasteur MSD for working with them on shingles awareness.

Regular Sources:

Memberships went down again this year, as did donations from services users (both members and the public). This trend has been recognised across the sector and probably results from information being offered on our website for free.

- Classified advertisements in our journal *SPHERE* raised over £1,000. (Ads are only taken for products we are confident about)
- Profits from selling the creams and supplements we have shown to be useful in preventing herpes simplex outbreaks: this year were approximately £12,000.
- Fees paid to the HVA for talks given: £120.
- Our members have helped by sending us Covenants, Give As You Earn certificates and a few members make regular monthly donations of £5-£10.

Fundraising

- "Walk for Skin" raised £255.55: 3 walkers in London and 3 (anonymously) elsewhere
- Raffle ticket sales, under the auspices of Alexandra Rose Day, raised over £1000



Accounts for 2006/2007

The accounts for 2006/07 were signed by an Independent Examiner: Derek Rothera of Derek Rothera & Company.

Recognised Gains and Losses

The HVA had no recognised gains or losses other than the surplus or deficit for the above two financial years.

Continuing Operations

None of the Association's activities were acquired or discontinued during the above two financial years.

The information given overleaf has been extracted from the Herpes Viruses Association's accounts 2006/2007 upon which the authorised accountant gave an unqualified opinion. Copies of the full accounts may be obtained on request from the Administrator. A copy has been submitted to the Charity Commission for filing.

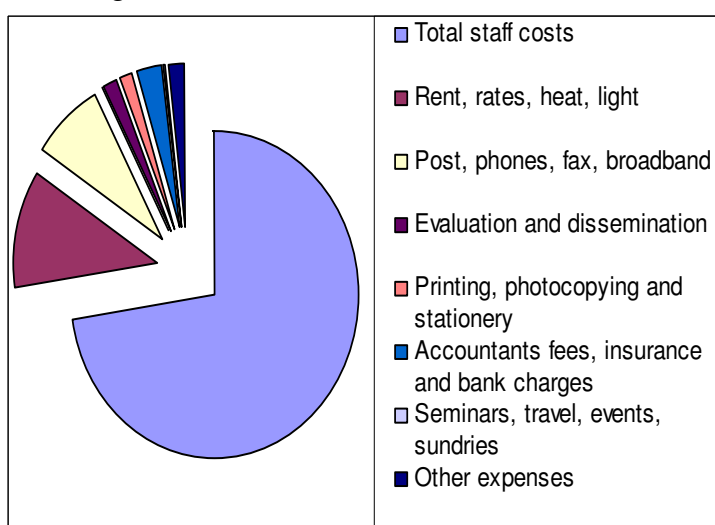
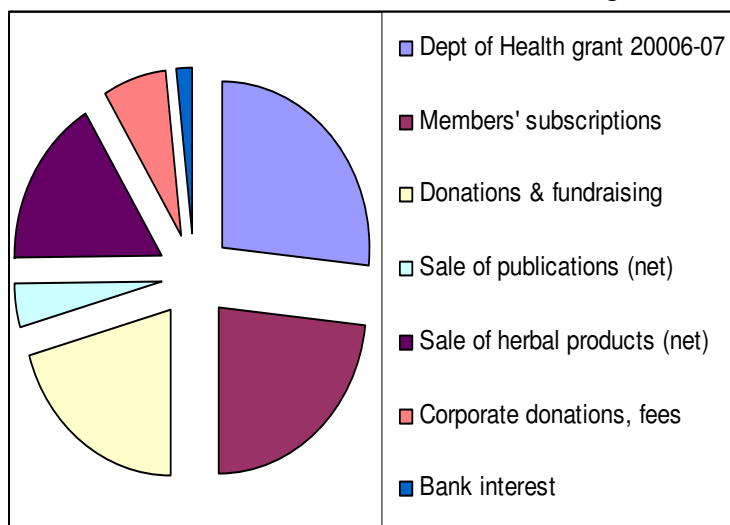
Reserves Policy

In line with the recommendations of the Charity Commission, the Management Committee has formulated a Reserves Policy to enhance our medium term security, taking into account the different level of certainty of the various income streams. The charity had a precarious existence for many years, culminating in a funding crisis between 1993 and 1995. We aim to hold a contingency reserve as a buffer to cushion us against an uncertain future. Each year, the Management Committee will plan to carry forward an amount which will cover 6 months running costs and a Staff Contingency Fund. For the year 2006/07

:

- £ 60,000 represents 6 months running costs
- £ 30,000 for redundancy payments for two office staff

Therefore for the year 2006/07, a total £90,000 would be nominated as Strategic Reserves but we are still working towards reaching this amount.



Herpes Viruses Association
STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST MARCH 2007

INCOMING RESOURCES were all unrestricted	Year:	2007	2006
Grants Receivable (DoH)		25,000	25,000
Subscriptions		20,946	22,324
Members donations		16,063	13,115
Commercial donations		4,256	-
Sales of books and sundry		53,927	47,961
Fund raising		1,289	1,400
Bank interest		1,647	2,331
Gift Aid Donations – tax refund		9,910	-
Sundry income		<u>855</u>	<u>1,082</u>
		<u>133,893</u>	<u>113,229</u>
RESOURCES EXPENDED			
Direct Charitable expenditure		(109,389)	(121,576)
Fundraising and publicity		-	-
Management and administration		<u>(9,044)</u>	<u>(10,110)</u>
Total Resources Expended		<u>(118,433)</u>	<u>(131,686)</u>
NET INCOMING/(OUTGOING) RESOURCES		15,460	(18,457)
Fund balances brought forward at 1 March 2005		<u>44,263</u>	<u>62,721</u>
FUND BALANCES CARRIED FORWARD AT 31 MARCH 2006		<u>59,723</u>	<u>44,264</u>

BALANCE SHEET	Year:	2007	2006
		£	£
FIXED ASSETS			
Tangible assets		2,768	3,960
CURRENT ASSETS		832	832
Cash at bank and in hand		<u>58,479</u>	<u>42,222</u>
		59,311	43,054
CURRENT LIABILITIES			
Creditors: amounts falling due within 1 year		<u>(2,356)</u>	<u>(2,481)</u>
NET CURRENT ASSETS		56,955	40,573
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>59,723</u>	<u>44,263</u>
Represented by :			
UNRESTRICTED FUND		59,723	44,263
RESTRICTED FUND		<u>-</u>	<u>-</u>
		<u>59,723</u>	<u>44,263</u>