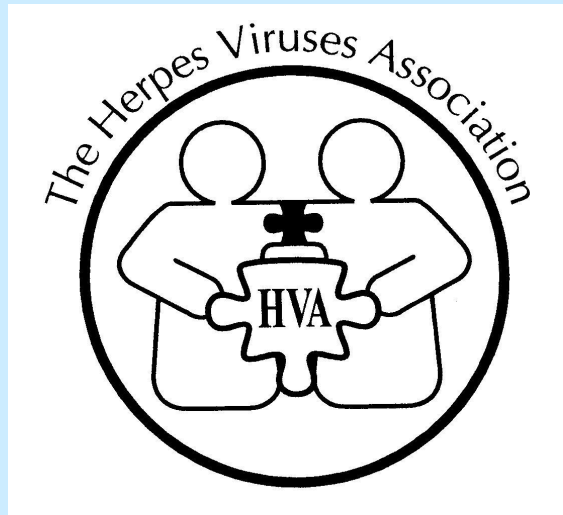


Annual Report 2007



The only charity for people
with herpes viruses:
cold sores, genital herpes,
shingles, glandular fever
and more...

Contents

The need for our services:	
- diagnoses	3
- stigma does not decrease	3
Our aims:	
1. To give information on herpes viruses to:	
- public	3
- medical professionals	5
- the media	5
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 to:	
- public	6
- members of HVA	6
Our strategies to increase awareness include:	
- media, websites, links and directories	7
- talks with – and to - health professionals	7
- articles in professional journals	7
- umbrella organisations and affiliates	8
Shingles Support Society – our sub-group	8
Staff and volunteers - monitoring and training	8
Executive Management Committee	9
Funding	10
Accounts	11
- statement of Financial Activities for Year Ended 31 March 2006	12

Statement:

The Herpes Viruses Association (HVA) continues as a vital support organisation. Increasing use of the internet has made us more effective – it is now easy for anyone to access helpful information on our website. The stigma remains and our busy helpline proves that we are needed.

The need for our services

DIAGNOSES

Diagnoses of all sexually transmitted infections (STIs) recorded at STI clinics around the country are increasing. After several years of very small increases, herpes simplex rose significantly in the year 2006 with a rise of 14 percent to from 18,991 to 21,698.

Patients are also diagnosed by GPs and self-diagnosed. A questionnaire to members of the Herpes Viruses Association (HVA) shows that 34 per cent of women and 42 per cent of men were diagnosed by their GPs, and 3 per cent were self-diagnosed.

- Total new patients diagnosed at GU clinics in England for 2006: 21,698.⁽¹⁾
- The 16 to 19 years women age group experienced a pronounced rise of 16% from 2416 to 2803.
- There was an increase of 10% in 20 to 24 years men age group (1835 to 2016).
- GPs diagnose an average of 1.37 new patients each per year: a further 49,320 per year.⁽²⁾

“If this Association didn’t exist, it would have to be invented. Keep up the tremendous work.”

Dr Colm O’Mahony, MD FRCP, Consultant physician in sexual health, Countess of Chester Hospital, Chester.

“Genital herpes has considerable long-term clinical and psychological morbidity and a crucial part of our management approach is referral on to the Herpes Viruses Association for support... many patients have come back to me to say that their [HVA’s] support has been vital in their coming to terms with the diagnosis. They also have a unique position in public education and raising awareness regarding herpes. This is particular important in de-stigmatising these infections.”

Dr Patrick French Consultant physician in HIV/GU Medicine, MBChB FRCP, Central Middlesex Hospital, London

“Clinicians advise patients diagnosed with herpes simplex to look at the website of the HVA as this has good information unlike others. This association fulfils the need for patient voice in this particularly troublesome and stigmatised clinical disease area.”

Dr Angela Robinson, president BASHH (British Assoc for Sexual health and HIV)

“If the services of the HVA were not available, I have little doubt that this would be translated into increased patient morbidity from these infections and additional accompanying long-term health costs.”

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

“Many patients who I have seen at the Chelsea & Westminster have expressed their gratitude to the HVA for providing clear information, reassurance and support to them. I believe that the seminars and the public information which you produce does reduce the workload of the NHS clinics in supporting patients living with HSV infection.”

Dr Simon Barton, BSc, MD FRCOG, FRCP, Consultant Physician and Clinical Director, Chelsea & Westminster Hospital, London

1. http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/epidemiology/datatables2006.htm

2. Woolley and Chandio, 1996.

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:

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

Public

Website:

- 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

This site saved my life in the sense that it presents a non-hysterical approach to herpes.

Thanks for the most helpful and constructive website I have come across re herpes. Many of them scared me into denial. I may just have acquired HSV2, and will now chase it up at my local GUM.

Hi there, and congratulations on your great site! ... Thank you for your time and expertise.

I really thought that was it as far as my sex life was concerned. But your website has really helped me see it for what it is. I don't feel so depressed about my future. Thank you!

Helpline:

- around five thousand people a year
- answered by trained volunteers
- calls average 13 minutes each, with some lasting over one hour

I just spoke to a wonderful lady on the Helpline number (12-9-2006 at just before 7PM) and simply just wanted to say “thank you” once again. She made my day with frank and positive advice and suggestions for what treatments to follow.

Just a quick email to thank you for the wealth of information that you provided me, especially when I was calling at 11pm at night. It's nice to know that there are people you can turn to and speak to one on one in times of need.

I had to write and say thank you for such a brilliant website and also to the lady who spoke to me earlier on this evening. I was diagnosed with herpes today and had an awful row about it with my boyfriend who drove off leaving me standing in the rain. I found your website in a slight state of shock and felt entirely calmed when I had finished reading. I called your number to ask about the possible treatments and had such a beautifully spoken lady talk me through things that I felt compelled to write.

Medical professionals

- *Herpes Simplex – the Guide* is a 6,000 word booklet written by staff and members of the HVA.
- over a hundred NHS GUM clinics choose to supply this leaflet to their patients since its first edition
- 10,075 copies have been ordered by GUM clinics this year
- leaflets were supplied to delegates at the British Association of Dermatology (July 06)
- talks are given to GUM staff on the topic *Counselling patients with herpes simplex*; two this year at the Blanche Herriot Unit and the Annual Conference of GUM nurses
- our “letter to the editor” was published in British Medical Journal, September 2006

Media

- Journalists require case histories when they write about a medical condition. Interviews were given by staff and/or members of HVA for stories in:

Bliss	130,000 circulation	
Zest	96,000	“
Daily Mail	2,313,900	“
Company	264,000	“
Sutton Guardian (and syndicated papers)	104,000 (or more)	
You (in Mail on Sunday)	2,200,000	“
The Sun	3,209,000	“

- HVA was mentioned in:

Sunday Mirror	April 06
Take a Break	Summer Special 06
Sunday Mirror	May 06
Reveal	15-7-06
I'm Pregnant	Oct, Nov, Dec
Good Housekeeping	September 06 (Ask Viv)
The Guardian	NS's letter August 06
Sunday Mirror	October 06
Sunday Times (Style)	29-10-06
Daily Mirror 'Dear Miriam'	6-12-06
Cheddar Valley Gazette	15-3-07
The Sun	Dear Deirdre 23-3-07
The Sun	Dear Deirdre 31-3-07

- Radio interview on BBC Northamptonshire
- TV production companies asked for our assistance in the early stages of creating their programmes: 'Embarrassing Illnesses', the 'Panel of Doctors' and 'Dating Sites'
- Mentions in connection with cold sores and their treatment:

Sentinel Sunday	18-3-07
Daily Mail	13-2-07
YOU magazine (Mail on Sun)	7-1-07
The Lady	2-1-07
Slough & Sth Bucks Express	24-11-06
Maidenhead Express	24-11-06
Love It	22-8-06
Woman	14-8-06
Bella	11-7-06
Woman's Weekly	25-4-06

2. Encouraging research into prevention and treatment of simplex and its effects on the persons who contract it:

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

3. Providing treatment advice and emotional support to those who are badly affected physically or mentally by a herpes simplex diagnosis to:

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
- more than 260 emails from the public (not including members or medical professionals) were answered during the year
- a talk entitled 'Cold sores, shingles and all the herpes viruses' was given as part of the Skin Information Day in Portsmouth.

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 John Green of BASHH's special interest group "Herpes Simplex Virus Advisory Panel"
- Meetings were held in London, Manchester, Milton Keynes, Leeds, Newcastle-upon-Tyne, Brighton and Glasgow (and Dublin)
- Workshops were offered in May August February
- One-to-one counselling at the HVA office or in a neutral place.

Can I just say that the organisation is fantastic and I have found so much comfort and optimism in the newsletters, advice and experiences of other sufferers. Since joining HVA I have adopted a more positive and hopeful outlook to the future.

I spent a lot of time in 2006 depressed and anxious with really low-esteem connected to my outbreaks. The saddest thing for me was how it affected my relationships with those close to me when I was having an outbreak. I'd be so uncomfortable and in pain and angry that I couldn't even tell my closest friends why I was behaving so strangely around them. The whole thing became a vicious cycle of physical pain, angry behaviour and hating myself. I found the HVA and joined. The leaflets were so helpful, I almost wore them out I read them so often.

A fantastic breakthrough came when I was able to ring the help line a number of times and have you both explain to me logically and calmly what was happening physically and mentally. My self-esteem rose dramatically and one of the effects was that I could separate the issues between my outbreaks and the person with whom I was having a relationship at the time. I had fears which had nothing to do with the outbreaks and a lot to do with what I thought about myself and how I was being treated by this person who I hadn't told – and who was making me anxious anyway.

Our strategies to increase awareness

Media, web, links and directories

- We are alert to stories so that we can comment/amend. On 'I'm a Celebrity – Get Me Out of Here' David Gest said his donation was for "Chinese Girls with Herpes." We immediately acquired a link to this "spoof website" with a request that donations be sent to us.
- We send corrections to any UK site 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

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
- Talks entitled 'Counselling Patients with Herpes Simplex' given at the Health Advisers Conference (Homerton Hospital) and Ashford Hospital,

**Thank you so much for excellent talk and presentation to our clinic staff last week. It produced lots more discussion over the rest of the week and has given us all a better knowledge of the herpes simplex virus and the patient's perspective of it.
Elly [Ms Elly Bittleston, Sister, Ashford Hospital]**

- 10,000 copies of "Herpes Simplex – A 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.

**Just a little note of thanks for the posters you sent to me. We need all the information we can get and your contribution is very much appreciated.
Thank you.
Regards, Helen Griffin, Torfaen Youth Service**

Articles we have written for professional journals

- Nursing in Practice, Nov/Dec 2006; no. 31 "Herpes Simplex, Diagnosis and Treatment"
- Skin Care Campaign News, August 2005, no. 31
- Skin Care Campaign News, February 2006, no. 33
- PULSE, 14 May 2005: "We must work to destigmatise herpes infection"



Reviewing, commenting on and correcting guidelines

- BASHH – Clinical guidelines for genital herpes
- PRODIGY - guidelines for genital herpes, cold sores and shingles/PHN

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:

- 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**

Shingles enquiries received vary according to the number of mentions we receive in the press: 350 this year (the peak was 2002 with 978 enquiries). Donations to the value of £1480 were received.

This year we worked with:

- Chronic Pain Policy Coalition to get 'pain' established as the fifth vital sign
- British Pain Society on guidelines for 'pain in the elderly'
- SanofiPasteur MSD to write a leaflet "What you need to know about Shingles"
- Pfizer Ltd to write a leaflet "Do you often get pain like this – it could be neuralgic"

Radio – seven interviews were given on BBC regional stations and independent radio stations

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, press releases, writing and editing leaflets, *SPHERE* and the Annual Report.
- attends most meetings with external bodies and gives most of the lectures on various 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 head of information, works from 10am to 6pm.

- answers requests for information
- 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 and lectures to the public.

Both:

- write articles for *SPHERE*.
- take 'advice and counselling calls' several times a day, from members of the Association and the general public.

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 helpline users on the telephone from their original trainer. Newsletters 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 helpline users fill in a report sheet to enable supervision of the information provided and give further training or information to the helpline users.
- Questionnaires are sent to people who have been counselled at the office by our paid staff.
- Local contacts and organisers of group meetings all over the country are supported by the office staff but do not receive formal training.

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 approve outgoing expenses. The chair rotates. At year end the Committee included five men and six women aged 25-62 yrs 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 2005/2006 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.

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 up a little on the previous year, as did donations from services users (both members and the public) went down. This is a trend across the sector and is considered to be the result of information being offered freely on our website. Disappointingly, profit on sales of leaflets, creams and supplements also went down.

- Classified advertisements in our journal *SPHERE*: over £1,000. (Ads are only taken for products we are confident about)
- Profits from selling the creams and supplements that we have shown to be useful in preventing herpes simplex outbreaks: this year 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

Alternative Sources:

Fund-raising activities in 2005/6 include:

- Six members ran in the British London Run and raised £750. All of them agreed to wear a T-shirt with www.herpes.org.uk printed on the back – see right.
- A ‘friend of the charity’ ran in the London Flora Marathon and raised £650



Accounts for 2005/2006

The accounts for 2005/06 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 2005/2006 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 2005/06:

:

£ 65,000 represents 6 months running costs

£ 28,000 for redundancy payments for two office staff

Therefore for the year 2005/06, a total £95,000 would be nominated as Strategic Reserves and we are working to achieve this amount.

Herpes Viruses Association

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST MARCH 2006

	Year:	2006	2005
INCOMING RESOURCES were all unrestricted			
Grants Receivable (DoH)		25,000	27,000
Subscriptions		22,340	22,670
Members donations		13,115	13,623
Commercial donations		-	-
Sales of books and sundry		47,961	41,757
Fund raising		1,400	-
Bank interest		2,331	3,442
Sundry income		<u>1,082</u>	<u>47</u>
		<u>113,229</u>	<u>108,539</u>
RESOURCES EXPENDED			
Direct Charitable expenditure		(121,577)	(132,887)
Fundraising and publicity		-	-
Management and administration		<u>(10,110)</u>	<u>(11,680)</u>
Total Resources Expended		<u>(131,687)</u>	<u>(144,567)</u>
NET INCOMING/(OUTGOING) RESOURCES			
		(18,458)	(36,028)
Fund balances brought forward at 1 March 2005		<u>62,721</u>	<u>98,749</u>
FUND BALANCES CARRIED FORWARD AT 31 MARCH 2006			
		<u>44,263</u>	<u>62,721</u>

BALANCE SHEET	Year:	2006	2005
	£	£	£
FIXED ASSETS			
Tangible assets		3,690	4,921
CURRENT ASSETS			
Cash at bank and in hand	832	815	
	<u>42,222</u>	<u>62,700</u>	
	43,054	63,515	
CURRENT LIABILITIES			
Creditors: amounts falling due within 1 year	<u>(2,481)</u>	<u>(5,715)</u>	
NET CURRENT ASSETS		40,573	57,800
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>44,263</u>	<u>62,721</u>
Represented by :			
UNRESTRICTED FUND		44,263	62,721
RESTRICTED FUND		-	-
		<u>44,263</u>	<u>62,721</u>