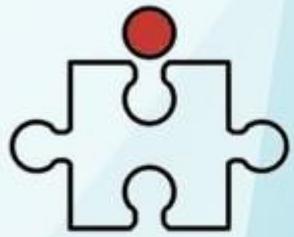


# Annual Report 2016



Herpes  
Viruses  
Association

Your charity – helping people  
with genital herpes, cold sores,  
chickenpox and shingles

# **Herpes Viruses Association Annual Report March 2015 to April 2016**

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# Letter from the chair

Welcome to the Annual Report for 2015/16 which showcases our work and our achievements.

First, a few words about herpes simplex – the nature of the problems it can cause and why it is misunderstood.

## The herpes conundrum

We help people who have been diagnosed with genital herpes, which has been called the second most stigmatised of all diseases (Harris Interactive USA poll, 2007). Yet the viruses that can cause it - herpes simplex, types 1 and 2 - are common. The infection is rarely serious and most of us have caught at least one of them. In 2015, the World Health Organisation stated that 66% of adults worldwide under the age of fifty have one type of herpes simplex virus (HSV-1) and more than 13% has the other type (HSV-2). These two viruses cause genital herpes and facial cold sores. So why are they feared?

A partial explanation is ignorance - only one person in five of those who are infected is aware of it – the rest get minimal symptoms and are usually not diagnosed. Most people catch it on the face, where it is called a cold sore, not on the genitals, where it is stigmatised – and because there are different names for the same infection, depending on location, many people fail to make the connection.

So herpes lives in most of us, yet the misconception that it is an unsavoury problem affecting a reckless minority, continues largely unchallenged. The Herpes Viruses Association works to educate patients, medical professionals, journalists and the wider public about this reality – see page 10.

People approach us for support and we help them in several ways. In recent years, the HVA's website has become the first point of contact for many patients, particularly the newly diagnosed. It is recommended by many clinics and doctors. The unexpected collapse of our web hosting company meant our website was unavailable for a short time during August 2015. However, a temporary site was soon up and running. This will be upgraded in the coming year. Visitor numbers continue to grow and our online information is now being accessed by 1.3 million people a year.

Our helpline continues to be popular. For many people there is no substitute for a sympathetic voice. As well as taking helpline calls themselves, our staff train volunteer helpliners. We are very grateful to these volunteers and would welcome more!

We continue to produce the quarterly online journal, Sphere, for HVA members and we run the very popular Study Days, where members gain a deeper understanding of how the virus works and how to talk to partners about it. We are setting up a private Facebook group where members can interact and staff can deal with queries. This will complement the public facing Facebook page that has been running for several years.

Lobbying and campaigning continues to be a priority. Our involvement with the All Party Parliamentary Group on Skin and with the All Party Parliamentary Group on Sexual & Reproductive Health gives us a voice at Westminster, where we can raise the concerns of patients and argue for effective and responsive healthcare.

Our other main activity is advising patients on the treatment of post shingles pain (PHN) caused by herpes zoster. Our director Marian Nicholson is a trustee of Pain UK and of Pain Alliance Europe. This enables her to work with other charities both domestically and across the EU to raise awareness of the problem of chronic pain – see page 13.

Our work and survival is only made possible with the financial contributions from our members and supporters, which this year included a grant from the Monument Trust. Thank you to you all, for contributions large and small.

In this report, you will read more about our activities and our successes. Thank you to our wonderful staff and volunteers: their passion, talent and commitment enables us to achieve all that we do.

The HVA is well managed and efficiently run and is well able to meet the challenges that face it.



Rakel Perez

# Who we are

The Herpes Viruses Association (HVA) was founded in 1981 to counsel and advise patients with genital herpes and to counter the herpes stigma, created to accompany the launch of the first successful and widely available antiviral drug, Zovirax (aciclovir).

The HVA is a patient support charity, run by patients, for patients. It was registered in 1985 and now provides information on all the human herpes viruses with emphasis on herpes simplex (genital herpes and cold sores). Since 1996, we have run a sub-group, the Shingles Support Society, to give information and advice on shingles (herpes zoster) and the frequently accompanying problem of post herpetic neuralgia – see page 12.

## Why we are needed

### Herpes simplex is complex

Sexually transmitted infections (STIs) are mainly caused by viruses or bacteria. Herpes simplex (like chickenpox and glandular fever) are viruses that can be treated but not eradicated. In the case of herpes simplex this fact is used by pharmaceutical companies and complementary therapy manufacturers to exaggerate its importance, by calling it 'incurable'. Patients may then adopt a psychological burden as they believe themselves to be disease carriers with a high risk of infecting future partners; a concern that is not shared with the majority of carriers (up to 75%) who are not diagnosed at all. Some patients make heavy demands on the counselling services of the HVA (by phone, email or in person) instead of – or as well as - making repeated visits to sexual health clinics.

People with herpes simplex are referred to our services by:

- medical staff at GUM clinics
- Sexual Health Line
- the Terence Higgins Trust helpline
- Brook Advisory Services
- NHS Direct helpline
- GPs
- sexual partners, family or friends
- and of course, Google...

### Increased number of cases

Public Health England reported that 32,139 new cases of genital herpes were identified in sexual health clinics in 2015 – no change over the previous year. 1,079 were diagnosed in other settings. However this does not include GP surgeries: one survey reported that each GP diagnoses an average of 1.8 new cases a year. This could account for a further 56,000 (approximately) new cases.

#### Our charitable objects:

1. To promote good health by advancing public education about herpes viruses and the means by which these conditions may be most effectively prevented and treated.
2. To promote, or assist in promoting research into the prevention and treatment of herpes simplex and its effects on the persons who contract it, and to disseminate the useful results of such research for the benefit of the public.
3. To relieve persons with symptoms of herpes simplex.

#### Our charitable activities:

Patient-run: website, booklets, a helpline run by trained volunteers who can answer medical questions and counsel people with any psychological worries.  
For subscribers: quarterly journals, leaflets on all aspects of the virus, meetings, seminars.

For shingles and neurogenic pain, we supply a 19-page information pack. This pain is especially severe in the elderly and is difficult to treat.

## The herpes stigma means that there is continued need for the specialised reassurance and information that our services provide.

This year for the first time, we have seen other websites quoting from our article on the creation of the stigma:

[www.herpes.org.uk/stigma/](http://www.herpes.org.uk/stigma/) In order for the stigma to be dismantled, the fact that it was created in the first place had to be acknowledged. Before 1980 it did not exist.

Our former Wikipedia page has been copied and pasted to other sites such as

<https://honeycomb.click/topic/41150-how-the-stigma-was-invented-by-a-drug-company/>

It has appeared on the website of US based ProjectAccept.org here: <http://projectaccept.org/herpes-stigma-the-origin/>

This year on March 3<sup>rd</sup>, Vice (an influential and growing news organisation) published [https://broadly.vice.com/en\\_us/article/did-big-pharma-create-the-herpes-stigma-for-profit](https://broadly.vice.com/en_us/article/did-big-pharma-create-the-herpes-stigma-for-profit) quoting the HVA and others and this was quickly followed by <http://www.teenvogue.com/story/herpes-stigma-is-a-lie> less than a week later.

The bottom box on the right shows the only press headline that we have seen which suggests it is not appropriate to use 'herpes' as a derogatory term.

'Good news' is not newsworthy, the internet allows misinformation to be repeated on every blog and forum. Comments from the US are repeated elsewhere. Anyone doing a search for 'herpes' can stumble across this kind of cyber-bullying.

As this stigma is still so strong, our aims include:

- educating the people who are diagnosed with genital herpes with the real facts instead of scare stories so that they can have normal, healthy sex lives;
- educating the wider public to know more about sexual health and herpes simplex;
- helping the media to understand that this is not a rare, unusual and peculiar condition – it is a common, but often hidden, skin complaint which can affect the genitals.

### Examples of 'herpes' used as term for 'something bad', contributing to the stigma:

[The \\$600 million Edmonton train that snarls traffic](#) - National Post

Taken together, the whole project is the equivalent of a candy company releasing a new chocolate bar called 'Herpes Al-Qaeda'. I struggle to ... Jan 2016

[Bromance alert! Ed Sheeran, James Blunt talk herpes, big 'schlongs', and getting engaged ...](#)

Now Magazine Online

Responding in a hilariously inappropriate manner, James joked: 'That's where you got herpes from me,' to which Ed delivered the sharp comeback: 'It ... November 2015

[Mal Brough and Peter Slipper affair like a bad case of herpes: James Ashby](#)

Sydney Morning Herald

Former political staffer James Ashby says the \$200,000 Clive Palmer claims he was asked for to help bankroll a case against Peter Slipper would ... November 2015

[GOP Strategist: Trump Like a 'Hangover and Then Herpes' For Republican Party](#) - Mediaite

GOP consultant Rick Wilson, who works for a pro-Rubio superPAC, said Trump's candidacy is like "a hangover and then herpes" for the Republican ... November 2015

[Amnesty And Illegal Aliens: Still About As Popular As Genital Herpes](#) - VDARE.com

Writing in April, 2004 about a recent conference organized by Pat Buchanan, Jared Taylor included his impressions from the talk given at ... August 2015

[SORRY MOM & DAD: Unpaid parking tickets are like herpes](#) - The Weekender

Herpes are a lot like unpaid parking tickets. Just because you ignore them, doesn't mean they'll go away forever. I first realized this on a

What's different about this headline? In this, it is actually suggested that it is not P.C. to be rude about herpes:

["How Tim Allen's 'Last Man Standing' Gets Away with Politically Incorrect Humor" seen in the Hollywood Reporter](#)

All the other stories report it the way we have sadly come to expect: 'Tim sounds off on Trump (he likes him) and Hillary: "The Clintons are like herpes: Just when you think they're gone, they show up again."

## What we do for the public

## **Website - [www.herpes.org.uk](http://www.herpes.org.uk)**

Our website is updated monthly. Explaining and rebutting inaccurate coverage about 'herpes' is a regular part of this process.

In a web search for 'herpes', [www.herpes.org.uk](http://www.herpes.org.uk) is the first site listed on Google UK. Our ranking is assisted by use of Google 'adwords', an advertising service that is provided free to charities. This means that the HVA is often the first or second promoted site that appears in search results in addition to its non-promoted placing.

In a search for 'cold sores' the HVA website comes second. Visitors to the site find it very different from other websites. They send in unsolicited testimonials:

*I've been wanting to write to thank you for running such an excellent and supportive organisation. I read so much scaremongering and upsetting things on the internet when I first got herpes I became disgusted by my body. Your website gave such sensible calm and practical advice I just hope that everyone who gets herpes finds it.*

*Also, I was amazed when I called your helpline at 11 pm expecting just to find out the opening hours and was answered straight away by a very kind woman who had an excellent knowledge and understanding of my problem. 6<sup>th</sup> November 2015*

*Thanks so much for all this info/insight, and for the speedy reply. Really appreciated. Feb 9<sup>th</sup> 2016*

*I've enjoyed reading this article [on the website]. I was diagnosed with genital herpes earlier today and if I'm honest I've always thought it was the worst thing I could ever catch and I did cry in my doctor's office when she told me. [Your website] makes me feel much better that it's not actually as bad as it seems. Although it just goes to show what a well thought out lie can do. I still feel quite embarrassed and don't think I'll tell anyone but at least it will stop me stressing out over it, which will hopefully mean fewer outbreaks. (website comment) 10<sup>th</sup> Feb 2016*

## **Emails - [info@herpes.org.uk](mailto:info@herpes.org.uk)**

Despite the comprehensive information provided on the HVA's website, we also personally answered 340 emails, many of which had detailed questions about transmission and required further reassurance. The personalised replies frequently elicit 'thank yous'.

*"I just want to thank you so much for your extreme patience with all of my questions! You have been truly wonderful. I feel bad for emailing so much. You have been so helpful ... I have just appreciated your feedback more than you know. Thank you so much again for everything your organisation does and how much you have done for me. 11<sup>th</sup> May 2015*

*Thank you so much for your prompt reply. Your answer was really helpful and has allayed my fears." 16<sup>th</sup> November 2015*

## **Helpline - 0845 123 2305**

Our helpline volunteers have genital herpes themselves and can use this personal experience to reassure callers. They are also armed with data about prevalence and are well informed about treatments. They take calls every weekday and sometimes at weekends and on bank holidays too!

The helpline service is available for over 60 hours a week, with core times of 12.00 am to 8.00 pm on weekdays. At times when volunteers supplement the service, more callers can

get through. This means that the number of person-hours available can reach 80. Anyone can call to get help and support. Commonly callers are:

- people newly diagnosed with herpes simplex;
- people whose new partner has told them that they carry the virus;
- people with too many outbreaks;
- worried people who want advice on how to inform a new partner;
- pregnant women, who tend to phone our helpline in the last weeks of pregnancy to ask about childbirth.

Calling our helpline from a landline costs the same as a local call; it does not generate income for the charity.

- Callers can talk for as long as they wish.
- Each helpliner takes an average of 12 calls per session
- Calls average 10 minutes – which includes some calls lasting over an hour.
- Callers may be crying or mention suicide so our volunteers need to be strong emotionally as well as being trained with 'all the answers'.

"Thank you for the reply and for talking to me today. It has helped me a lot just speaking to you and hearing a voice of someone who knows exactly what I am asking and why. I now feel like I can stop worrying and move on with my life and stop worrying about the past. I am also glad that I have subscribed and I know that all information I receive from you will also help." 4 Jan 2016

"I spoke to a helpliner this afternoon and he was extremely helpful. He, you [via email] and your website have made me feel a lot clearer and more positive about everything so I thank you for that." 17th November 2015

"I just got more useful advice from you in ten minutes than everything I have been told by everyone else since I was diagnosed two years ago." 14 October 2015

## Meetings

In London, office staff and volunteers host support meetings in a central London venue. Details of these are shown on the 'What's New' page of the website and updated every two or three months.

Experience has shown us that talking to others with this condition is immensely valuable in helping people to see that genital herpes is something that normal people have (and not the only the imaginary 'promiscuous individual'). We have found that people discover how sharing stories helps them to envisage possible futures.

Sadly, the stigma deters some people from attending such events: they are afraid that they will be recognised – ignoring the obvious fact that the other people attending would also have genital herpes and would not be in any position to be judgemental. We know that this can be a real problem, because staff and helpliners often have to persuade members and callers that they can attend a meeting without drawing attention to themselves.

There were 31 such events in London (approx. 120 people attended in total).



London meetings are hosted by Nigel Scott or Marian Nicholson, who may also travel to meetings that are held elsewhere.

# Additional services for members

## Leaflets

Leaflets are available on every aspect of concern to people with genital herpes. Popular titles are "Transmission", "Tips to Prevent Recurrences" and two that deal with "Talking to a New Partner".

We are an Information Standard certified organisation. The Information Standard is the NHS's quality mark for medical information for patients. Any organisation achieving it has undergone a rigorous assessment of the information production process to check ensure that the information they produce is high quality, evidence based, balanced, user-led, clear and accurate. Leaflets, as well as other materials such as booklets and web pages are all subjected to the process – a referenced version is available on request. They are tested by people with genital herpes to ensure that they are unambiguous and readily understood. They are then validated by a relevant medical expert.



## Journal - Sphere

Sphere is a quarterly journal, which provides updates on research, trials and changes to drug regimens. Articles tackle psychological trauma and anxiety which can be caused by diagnosis, suggest ways of controlling thoughts, relieving stress, etc.

It always includes personal stories and tips from readers.

"Sphere is worth more than a £25 subscription. It's something I budget to save for throughout the year as its so important to me. Please keep up the brilliant work. You help so many more people thank I think you are aware." Anita - 12<sup>th</sup> February 2016

"Thanks for these leaflets – brilliant! Thanks also for the reminder to renew [my subscription] ... I have been a very quiet/invisible member but I always feel heartened and calmed by the information you chaps send. It's such a help. Thank you so much. It's surprising how quickly one can allow

worry to overtake all the sensible and factual messages you've read. It needs reaffirming at times!" Joan - 16<sup>th</sup> June 2015.

## Meetings

Members and the London-based office staff organise a variety of types of meetings around the country for members and non-members. This enables patients to recognise the 'normality' of other people with genital herpes which is something that quite often comes as a surprise.

In the year 2015:

- 27 people attended four "Study Days". These events provide the information and confidence to talk about genital herpes with new partners, which is one of the most frequently repeated fears. These events were scored by the attendees, and averaged >4.6 out of a possible 5 points.

Other events:

- 31 sharing/talking events in London (with approx. 120 people attending) – as mentioned above in the section on public events
- 2 purely social events such as clubbing, in London
- 8 social events hosted by members in other cities nationwide

*What did you think of the Study Day?* "Undoubtedly invaluable. Everyone who is bothered by their diagnosis should be directed to this programme by the doctor/clinic. It is a no brainer that details of your organisation should be given out at the very start."

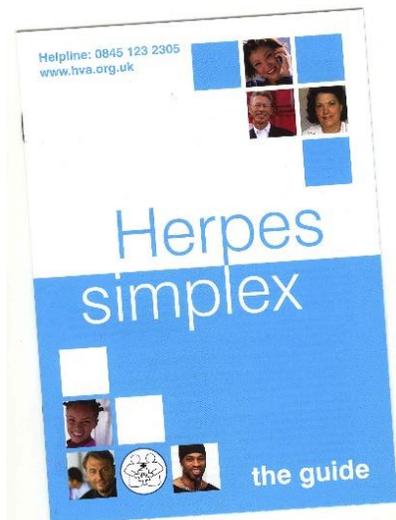
## 'Herpes Simplex - The Guide'

9,250 copies of *Herpes Simplex – the Guide* were distributed through sexual health clinics in the year ending March 2016. *The Guide* is a 16 page, 6,000 word, A5 sized illustrated booklet. It has been written and updated by people with herpes simplex for their peers and is revised for each new edition. The information in the current 12th edition is endorsed by doctors working in Sexual Health and carries the Information Standard logo.

***"Their booklet is just fantastic. We've had hundreds of them"*** said Dr Colm O'Mahony, consultant at the Countess of Chester Hospital and media spokesperson for the British Association for Sexual Health and HIV (BASHH).

***"This booklet is so good, I don't know why they didn't give it to me as soon as I was diagnosed. It was only when I went back for the third time that the health adviser got this out and gave it to me. Can you tell them how important it is that we see this as soon as we are diagnosed and not just because we go and hassle them? It would have saved me ages of heart ache when I couldn't see a future. Thanks for giving me hope."***

November 2015



# How we educate

## A. Medical professionals

The HVA helps medical professionals in their dealings with patients:

- For medical professionals in departments of sexually transmitted infections or dermatology, herpes simplex is considered to be an occasional nuisance but seldom a danger. They know it is extremely common and that most people who catch it never have symptoms. Because they know it is unimportant, they may be taken aback by the emotional reaction from a newly diagnosed patient.

*“The clinic handed me your card as an after thought when they should have been saying ‘Look I simply don’t know the answers to your questions, but these people will.’ They need to sound more enthusiastic because ‘that phone call’ [to the HVA helpline] changed my life. It was the start of my way back to normality.”* Email to the HVA, Vikki – March 2016

- GPs and other non-specialists may have little knowledge of appropriate treatment or even of the basic facts – e.g. that herpes simplex can appear years after infection, that sex will re-infect the other:

*“We were told by the GP that every time we have sex we will reinfect each other [we both have it]. Surely we don’t have to use condoms when we have been together six years.”* Caller - September 2015

This year, we have encouraged and supported a woman who lost her baby because she had never had herpes simplex virus and therefore this infection was not thought of when her newborn became unwell. The infection had most likely come from a visitor who kissed the child. Without appropriate treatment the baby died at three weeks. To try to prevent this happening to another mother, she has given talks to many different medical groups, asking them always to treat ‘floppy babies’ with intravenous aciclovir, a safe treatment, on the off-chance that the cause is herpes simplex, from a cold sore. We helped her to ensure that her talks were medically accurate so that her message would not be dismissed by the professionals she was addressing.

### **Training the frontline staff:**

The HVA offers talks on “*Counselling Patients with Herpes Simplex*”. This offer is taken up by Sexual Health Clinics for their training days. Several clinics regularly invite Marian Nicholson to repeat her talk when staff turnover necessitates it.

### **Consulting on other organisations’ leaflets:**

We are acknowledged as an organisation with the ability and experience required to advise other providers on the appropriate way to explain herpes simplex for the lay reader without being alarmist. A representative from this charity is an active member of the panel set up by the British Association for Sexual Health and HIV to pilot the new range of leaflets for patients and has attended all three of their meetings this year.

## B. The public

We aim to normalise the way that herpes simplex is described to the public – on websites and in other media. In particular, we try to dispel alarming myths associated with genital herpes. Some common ones are: “it can be spread around the body”, “you can pass it on

via towels/ toilet seats/etc." "it will necessitate a Caesarean-section for childbirth", "it turns into HIV".

## Newspapers, magazines and websites:

We seek publicity both for the condition – to improve knowledge - and for the Association – so that people are aware where to come for information. However magazine and newspaper editors usually require case histories to secure coverage. The herpes stigma means that very few people with herpes simplex will talk to the press.

"Dear Deidre" in The Sun (circulation of 3,100,000) regularly answers readers' letters about herpes simplex problems. Her team always refer her suggested replies to the HVA before publication. We frequently suggest edits, which are accepted. She consulted us again in 2015.



Candis magazine (circulation 243,836) printed our comments on treatment options for cold sores including herbal substances that we have trialled on our members. Lomaherpan (active ingredient *melissa officinalis*) has been thoroughly trialled in Germany. We import it and sell it through our website. Sales increase year on year.



## NHS Choices video:

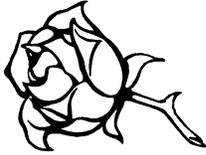
NHS Choices website uses videos to improve understanding: a patient talks about their condition or a doctor explains it. In the case of genital herpes, it is difficult if not impossible to find a patient willing to 'go public' about their condition. Marian Nicholson, the HVA's Director has voiced her own personal journey for the NHS Choices website. This 5-minute video clip is also on [YouTube](#).

It has been praised by viewers:

*"I was so very glad to watch your video on the NHS Choices page which went a long way to alleviate my immediate concerns. You sounded so normal, and confident. And thank you so much for your email, which did a lot to put my mind at rest. As I'm sure you can imagine, when I Googled lumps in the genital region I got back some worrying horror stories and quite frightening images. Claire 15-11-14*

## Adding to and correcting websites:

If we learn of incorrect or misleading information on any UK-based website purporting to be authoritative, we ask for this to be changed. This requires emailing the 'webmaster' and asking for misinformation to be corrected, or for badly written posts to be reworded. In some cases, our emails are ignored. Websites are constantly being revised so misinformation can reappear after it has been corrected.



# Shingles Support Society

Sub-group recognised by the Charity Commission

Our sub-group, the Shingles Support Society (SSS), was formed to allow people suffering from herpes zoster to find support for the treatment of post-herpetic neuralgia (PHN), a pain created by the chickenpox virus when it reactivates and which in older patients frequently continues long after shingles blisters have healed.

We send out a 19-page information pack for sufferers to share with their GPs explaining medical treatment. The first line treatments for PHN are generic tricyclic antidepressants and anti-epileptic drugs, and some GPs remain unaware of how useful they can be. Sometimes patients given these drugs do not take them as it has not been explained to them how 'the wrong drug' could actually be very helpful.

The pack includes two pages of self-help suggestions, and a "contact list" to allow sufferers to get in contact with others for mutual support.

Since September 2013, Zostavax, the long-awaited vaccine to prevent shingles, has been offered by NHS. Although the Joint Committee for Vaccination and Immunisation has approved its use to vaccinate all 70-79 year olds in England, it is being introduced slowly. This year the Department of Health offered the vaccine to people who were 70, 71, 72 or 78, 79 on the 1<sup>st</sup> September 2015.

The complicated allocation of the new vaccine caused confusion and many people got in touch to find out if they qualified for it – and what the rationale for the year's allocation was.

Private individuals are helped directly and personally:

- 245 helpline conversations. Topics included transmission, treatment of PHN and the new vaccine.
- 102 people received the 19-page information pack as well as personalised information
- 28 people had their problems dealt with only via email communications

We gave interviews on radio and quotes for press to explain shingles, how it can cause PHN, how PHN can be treated and how the new vaccine can prevent cases.

- BBC Radio Oxford
- FUBAR radio
- 'HEALTHY' magazine for pharmacies
- 'YOURS' (circulation 545,206)

Our shingles and post herpetic neuralgia work led to the charity's involvement with other organisations that campaign for improved treatment for people suffering from long term pain. We take part in many activities which aim to raise awareness of long-term pain. These include:

- Chronic Pain Policy Coalition events in the House of Commons
- Pain Summit follow-on meetings: four times a year

Our director, Marian Nicholson, has volunteered to be a trustee on the boards of two umbrella groups for pain charities:

- Pain UK - there are 30 pain charity members
- Pain Alliance Europe – five meetings in Brussels where we are the representative from Pain UK - including the launch of the EU's special interest group on Brain, Mind and Pain. PAE includes 33 charity members from all over Europe.

## Working with other associations

We work with other organisations in the interest of herpes simplex patients to maximise our reach and effectiveness. This process benefits sexual health patients in general and those with other skin conditions.

This year we have co-ordinated with Dr Katharine Looker. She is responsible for the World Health Organisation's epidemiology studies on the prevalence of herpes simplex worldwide. We supplied her with patients for a focus group to ascertain the levels of efficacy that a vaccine would need to provide in preventing outbreaks, viral shedding and transmission, in order to be acceptable to infected patients.

The British Association for Sexual Health and HIV (BASHH) gave us a free delegate place at their three-day annual educational meeting, in Glasgow.

# BASHH



We have a representative on:

- BASHH patient panel – the panel does a critique of all BASHH leaflets as well as advising on other aspects of BASHH's outward-facing activities
- British Federation for Sexually Transmitted Infections

We attend meetings of:

- All Party Parliamentary Group on Sexual and Reproductive Health
- All Party Parliamentary Group on Skin

As well as the organisations listed above, we are members of:

- British Association of Dermatologists' Patient Support Groups – this enables us to 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 (Health and Social Campaigners' Network International)
- and other appropriate umbrella groups.

## Who does what: staff and volunteers - monitoring and training

Two full-time staff work staggered hours and have overlapping duties.

Marian Nicholson, director, works from noon to 8pm. Nigel Scott, administrator and information officer, works 10am to 6pm. This schedule allows for a more comprehensive service. The advantage to the public is that on days when volunteers are not available

Marian and Nigel are available to answer helpline calls during an extended period giving callers a wider choice of times when they can call. They also volunteer and answer calls in their own time. An advantage for the staff is that by taking helpline calls they are kept aware of the public's topical concerns.

Volunteers are essential to our service. Over the year, we have had help from ten helpline and other volunteers.

- One new helpliner this year, Sally, was given training and joined the roster. We need new volunteers all the time to replace volunteers who are no longer able to

- offer their services.
- Helpline volunteers are given support by telephone from their original trainer.
  - Emails are sent out regularly to keep them up-to-date with factual information and suggestions for counselling.
  - A helpliners' get-together is organised every year for sharing ways of explaining, learning about new medical developments, etc.
  - Monitoring of helpline services continues at all levels.
  - The volunteers fill in a report sheet (helpline log) to enable supervision of the information provided and to target appropriate training or information.
  - Around the country there are 'local contacts' and organisers of group meetings who are supported by the office staff but do not receive formal training.
  - Six volunteers have provided useful office help from time to time.

## Executive Management Committee

The Executive Management Committee is elected at the Annual General Meeting from the membership and reflects its diversity. Committee meetings are normally held monthly to oversee the work of the association, direct its future and approve exceptional expenses. There are currently eleven members, one of whom is not a service user. Ages range between 30 and 63 years old. Two are male.

The Charity Commission allowed us the option of keeping the names of the HVA's committee members confidential, so they do not appear on our website or on any published document.

## Funding for 2015-2016

The charity's continued existence is dependent on the financial support it receives from patients and families who have been helped by our activities: proof of the vital role that the HVA continues to play, in meeting a genuine need for countless people and that this need is not met by other bodies.

### **Regular sources:**

A survey found that, each year, about one third the members who choose not to renew state that this is because they are now in a relationship and therefore "having herpes" is no longer an issue for them.

Membership fees brought in £10,225 and the number of members continues to decline, and is now around half its previous maximum. This reflects the increased availability of useful advice and information on our website which is provided free of charge as a public service in order to counter the large amount of badly written web pages and outright misinformation about genital herpes that is now online.

This year, we have increased the 'ask' to our members and service users (helpline, website) and have had donations totalling £26,835 – which includes the amount donated via MyDonate, mentioned below.

- Profits from selling booklets, and the creams and supplements (therapeutic materials which we have trialled and found useful in preventing herpes simplex outbreaks) amounted to over £17,000 gross profit – that is before we take into account the cost of writing/designing the booklets and administering these sales.
- Responding to our appeals, over fifty of our members have set up regular monthly donations by standing order of £2-£20.

## **Corporate donations** in the year 2015-2016:

- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £1213 this year.
- A link on our website goes to MedExpress, approved by the Care Quality Commission to sell antiviral drugs. These sponsored links raised £3556.

## **Trust donations and legacies:**

Through working with other charities in the field of sexual health, we were informed that the Monument Trust, which funds HIV charities, would look favourably on an application: we were extremely grateful the trustees of the Monument Trust who awarded us £10,000.

THE · MONUMENT · TRUST

## **Fundraising**

### **Challenges:**

Consultations with fund-raising specialists have indicated that the HVA is hard to place as a charitable cause with a large company: there is no PR gain as the herpes stigma will not create a favourable impression with customers. Similarly, organisations such as the Round Table, Rotary and Freemasons are unwilling to encourage their volunteers to fundraise for a 'herpes' charity because of the stigma associated with sexual disease.

Many charities encourage their members or their beneficiaries to assist with fundraising. This is something that our members find difficult because it would require them to 'go public' about their status. Therefore, community fundraising activities like running marathons or undertaking sponsored challenges are off our agenda. Nevertheless we acknowledge the generosity of many of our members who make extra individual donations and set up monthly standing orders.

### **Fundraising activities**

The public is invited to donate via several links to MyDonate on the HVA's website – MyDonate is a free service from BT. Donations amounted to £1886 this year – plus a single donation of £5250 from a member of the Association.

We ask all contacts use [www.EasyFundraising.co.uk](http://www.EasyFundraising.co.uk) when they access 'online shops'. This is a web portal includes 2,700 online shops including many well-known companies (including Amazon, Asda, ASOS, InterFlora, M&S, Travelodge, Zizzi). A percentage is donated to the charity nominated by the shopper. We ask people to nominate the Shingles Support Society as their designated charity. This year we have received £235.

### **Trusts**

We have an expert fundraising volunteer giving us advice and will continued to apply to secure funding from appropriate grantmaking trusts and charitable foundations.

We are optimistic that this avenue may prove productive in 2016-17.

# About accounts for 2015-2016

The accounts for 2015-2016 were signed by an Independent Examiner: Josh Botham of Josh Botham Tax & Accounting Services Ltd.

**Income: £118,369**

**Expenditure: £121,440**

## **Recognised gains and losses**

The HVA had no recognised gains or losses other than the surplus or deficit for this financial year.

## **Exceptional receipts**

We successfully applied for a grant of £10,000 from the Monument Trust.

The claim made for tax which is returned to us under the Gift Aid Donation scheme includes some claims for previous years, as we incorporate donations made up to four years ago.

## **Continuing operations**

None of the Association's activities were acquired or discontinued during this financial year.

## **Donated items**

Volunteers have donated their time and expertise to the charity.

## **Legal requirement**

The trustees confirm that there are no serious incidents or other matters which need to be brought to the attention of the Charity Commission.

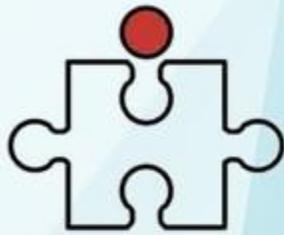
## **Taxation**

The HVA is exempt from income tax by reason of its charitable status. Our deposit account interest is paid tax-free as it is in an account created for charities.

## **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 levels of predictability of the various income streams. We aim to hold a contingency reserve as a buffer to cushion us against an uncertain future. Strategic reserves are to enable the charity to continue with no further support for a period of up to six months and to cover redundancy payments to staff. Therefore the target for this fund is increased each year in line with increased running and redundancy costs. For the year 2015-2016, the target of £79,200 has been met00 short.

REGISTERED CHARITY NUMBER: 291657



Herpes  
Viruses  
Association

Report of the Trustees and  
Unaudited Financial Statements for  
the Year Ended 31 March 2016  
for  
Herpes Viruses Association

Josh Botham Tax & Accounting Services Ltd  
Archer House  
Britland Estate  
Northbourne Road  
Eastbourne  
East Sussex  
BN22 8PW

Herpes Viruses Association

Contents of the Financial Statements  
for the Year Ended 31 March 2016

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	Detailed Statement of Financial Activities 11 to 12

## Herpes Viruses Association

### Report of the Trustees for the Year Ended 31 March 2016

The trustees present their report with the financial statements of the charity for the year ended 31 March 2016. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005.

#### **REFERENCE AND ADMINISTRATIVE DETAILS**

##### **Registered Charity number**

291657

##### **Principal address**

41 North Road  
London  
N7 9DP

##### **Trustees**

Trustees are elected from the membership at the Annual General Meeting. The Charity Commission has given permission for their names not to be shown.

##### **Independent examiner**

Josh Botham Tax & Accounting Services Ltd  
Archer House  
Britland Estate  
Northbourne Road  
Eastbourne  
East Sussex  
BN22 8PW

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

The charity is controlled by its governing document, a deed of trust, and constitutes an unincorporated charity.

##### **Organisational structure**

Trustees are elected from the membership at the Annual General Meeting. They hold monthly meetings. There are currently eleven, only one of whom is not a service user. They range between 30 and 63 years old. Two are male.

##### **Risk management**

The trustees ensure that available resources are used appropriately to fund work priorities and when necessary curtails activities when funds are not available. The Trustees consider ways of ensuring income levels for all aspects of the work of the Herpes Viruses Association. The trustees identify and review the risks to which the charity is exposed and ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

#### **OBJECTIVES AND ACTIVITIES**

##### **Charitable objectives**

The principal objective of the Association is to promote good health by advancing public education about all aspects of herpes viruses and the means by which the symptoms they cause can be effectively treated. The Herpes Viruses Association is a non profit-making organisation and a registered charity.

## **OBJECTIVES AND ACTIVITIES**

### **Charitable activities**

This is a charity run by patients for patients. There were approximately 88,000 new cases of genital herpes last year.

The charity hosts a website which received 1,300,000 visitors this year, it provides a helpline answered by trained volunteers, and individual answers are provided by email. Meetings are held in London and other towns around the country.

Almost all the daily activities carried out by the Association's staff are done in pursuit of its charitable aims. The purchase and sale of therapeutic items, guides and leaflets, although profitable in themselves, are primarily undertaken to assist patients and members in treating and managing their medical conditions.

### **Volunteers**

A number of volunteers have helped in the office on various tasks including publication mailings. Volunteers also log on from their home numbers to answer helpline calls which are switched through to them.

## **ACHIEVEMENT AND PERFORMANCE**

### **Financial Status**

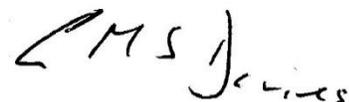
In the current year, the Herpes Viruses Association was extremely grateful to the trustees of the Monument Trust who awarded us £10,000. There were no extra corporate donations or legacies. There was little change in the charity's regular income streams: subscriptions, donations and sales of therapeutic materials.

## **FINANCIAL REVIEW**

### **Reserves policy**

In line with the recommendations of the Charity Commission, the Management Committee has formulated a Reserves Policy to ensure medium term security, taking into account the different level of certainty of the various income streams. Strategic reserves are to enable the charity to continue with no further support for a period of up to six months and to cover redundancy payments to staff. Therefore, the target for this fund is assessed each year in line with running and redundancy costs. For the year 2015/16 the target of £79,200 has been met.

Approved by order of the board of trustees on 12<sup>th</sup> December 2016 and signed on its behalf by:



George Davies  
Trustee

Herpes Viruses Association

Independent Examiner's Report to the Trustees of Herpes Viruses Association

I report on the accounts for the year ended 31 March 2016 set out on pages five to ten.

Respective responsibilities of trustees and examiner:

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under Section 144(2) of the Charities Act 2011 (the 2011 Act)) and that an independent examination is required.

It is my responsibility to:

- examine the accounts under Section 145 of the 2011 Act - to follow the procedures laid down in the General Directions given by the Charity Commission (under Section 145(5)(b) of the 2011 Act); and - to state whether particular matters have come to my attention.

Basis of the independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view and the report is limited to those matters set out in the statements below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that, in any material respect, the requirements

- to keep accounting records in accordance with Section 130 of the 2011 Act; and - to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Josh Botham Tax & Accounting Services Ltd  
Archer House  
Britland Estate  
Northbourne Road  
Eastbourne  
East Sussex BN22 8PW

Date: 10/12/2016

Herpes Viruses Association

Statement of Financial Activities  
for the Year Ended 31 March 2016

		31.3.16 Unrestricted fund £	31.3.15 Total funds £
	Notes		
<b>INCOMING RESOURCES</b>			
<b>Incoming resources from generated funds</b>			
Voluntary income	2	69,533	62,470
Activities for generating funds	3	48,526	57,525
Investment income	4	<u>310</u>	<u>310</u>
<b>Total incoming resources</b>		118,369	120,305
<b>RESOURCES EXPENDED</b>			
<b>Costs of generating funds</b>			
Fundraising trading: cost of goods sold and other costs		15,042	29,774
<b>Charitable activities</b>			
Activity Necessary for Therapeutic Materials		37,298	14,528
Charitable Activities		65,191	66,206
Governance Costs		<u>3,909</u>	<u>3,282</u>
<b>Total resources expended</b>		121,440	113,990
<b>NET INCOMING/(OUTGOING) RESOURCES</b>		(3,071)	6,515
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>		<u>84,927</u>	<u>78,412</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>81,856</u></u>	<u><u>84,927</u></u>

The notes form part of these financial statements

Herpes Viruses Association

Balance Sheet  
At 31 March 2016

	Notes	£	31.3.16 Unrestricted fund £	31.3.15 Total funds £
<b>FIXED ASSETS</b>				
Tangible assets	8		682	149
<b>CURRENT ASSETS</b>				
Stocks	9		22,313	14,046
Cash at bank and in hand			<u>63,204</u>	<u>73,433</u>
			85,517	87,479
<b>CREDITORS</b>				
Amounts falling due within one year	10		(4,343)	(2,701)
			<u>81,174</u>	<u>84,778</u>
<b>NET CURRENT ASSETS</b>				
			<u>81,856</u>	<u>84,927</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>				
			<u>81,856</u>	<u>84,927</u>
<b>NET ASSETS</b>			<u>81,856</u>	<u>84,927</u>
<b>FUNDS</b>				
Unrestricted funds	11		<u>81,856</u>	<u>84,927</u>
<b>TOTAL FUNDS</b>			<u>81,856</u>	<u>84,927</u>

The financial statements were approved by the Board of Trustees on 12-12-2016 and were signed on its behalf by:



Rose Slayden, Trustee

The notes form part of these financial statements



## Herpes Viruses Association

### Notes to the Financial Statements - continued for the Year Ended 31 March 2016

#### **2. VOLUNTARY INCOME**

	31.3.16	31.3.15
	£	£
Gifts	(1)	(1)
Gift aid	8,794	9,264
Subscriptions	15,814	19,298
Member & service user donation s	28,973	28,952
Shingles Donations	1,180	1,350
Corporate Donations	4,773	3,607
Trust Grant	<u>10,000</u>	<u>-</u>
	<u>69,533</u>	<u>62,470</u>

#### **3. ACTIVITIES FOR GENERATING FUNDS**

	31.3.16	31.3.15
	£	£
Elagen, cold sore cream, etc.	40,406	48,678
Sales of 'Herpes Simplex the Guide'	<u>8,120</u>	<u>8,847</u>
	<u>48,526</u>	<u>57,525</u>

#### **4. INVESTMENT INCOME**

	31.3.16	31.3.15
	£	£
Deposit account interest	<u>310</u>	<u>310</u>

#### **5. SUPPORT COSTS**

	Management	Finance	Human	Totals
	£	£	resources	£
			£	
Activity Necessary for Therapeutic				
Materials	23,193	1,123	3,159	27,475
Charitable Activities	55,667	424	9,100	65,191
Governance Costs	<u>2,957</u>	<u>573</u>	<u>379</u>	<u>3,909</u>
	<u>81,817</u>	<u>2,120</u>	<u>12,638</u>	<u>96,575</u>

#### **6. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 March 2016 nor for the year ended 31 March 2015.

#### **Trustees' expenses**

There were no trustees' expenses paid for the year ended 31 March 2016 nor for the year ended 31 March 2015.

Herpes Viruses Association

Notes to the Financial Statements - continued  
for the Year Ended 31 March 2016

**7. STAFF COSTS**

	31.3.16	31.3.15
	£	£
Wages and salaries	66,388	64,410
Social security costs	<u>3,349</u>	<u>5,393</u>
	<u>69,737</u>	<u>69,803</u>

The average monthly number of employees during the year was as follows:

	31.3.16	31.3.15
Management	<u>2</u>	<u>2</u>

No employees received emoluments in excess of £60,000.

**8. TANGIBLE FIXED ASSETS**

	Fixtures and fittings £	Computer equipment £	Totals £
<b>COST</b>			
At 1 April 2015	18,076	-	18,076
Additions	<u>-</u>	<u>909</u>	<u>909</u>
At 31 March 2016	<u>18,076</u>	<u>909</u>	<u>18,985</u>
<b>DEPRECIATION</b>			
At 1 April 2015	17,927	-	17,927
Charge for year	<u>149</u>	<u>227</u>	<u>376</u>
At 31 March 2016	<u>18,076</u>	<u>227</u>	<u>18,303</u>
<b>NET BOOK VALUE</b>			
At 31 March 2016	<u>-</u>	<u>682</u>	<u>682</u>
At 31 March 2015	<u>149</u>	<u>-</u>	<u>149</u>

**9. STOCKS**

	31.3.16	31.3.15
	£	£
Stocks	<u>22,313</u>	<u>14,046</u>

**10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	31.3.16	31.3.15
	£	£
Trade creditors	1,001	1,001
Taxation and social security	1,311	1,400
Other creditors	<u>2,031</u>	<u>300</u>
	<u>4,343</u>	<u>2,701</u>

**11. MOVEMENT IN FUNDS**

	At 1.4.15	Net movement in funds	At 31.3.16
	£	£	£
<b>Unrestricted funds</b>			
General fund	84,927	(3,071)	81,856
	<u>84,927</u>	<u>(3,071)</u>	<u>81,856</u>
<b>TOTAL FUNDS</b>	<u>84,927</u>	<u>(3,071)</u>	<u>81,856</u>

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
<b>Unrestricted funds</b>			
General fund	118,369	(121,440)	(3,071)
	<u>118,369</u>	<u>(121,440)</u>	<u>(3,071)</u>
<b>TOTAL FUNDS</b>	<u>118,369</u>	<u>(121,440)</u>	<u>(3,071)</u>

Herpes Viruses Association

Detailed Statement of Financial Activities  
for the Year Ended 31 March 2016

	31.3.16	31.3.15
	£	£
<b>INCOMING RESOURCES</b>		
<b>Voluntary income</b>		
Gifts	(1)	(1)
Gift aid	8,794	9,264
Subscriptions	15,814	19,298
Member & service user donations	28,973	28,952
Shingles Donations	1,180	1,350
Corporate Donations	4,773	3,607
Trust Grant	<u>10,000</u>	<u>-</u>
	69,533	62,470
<b>Activities for generating funds</b>		
Elagen, cold sore cream, etc.	40,406	48,678
Sales of 'Herpes Simplex the Guide'	<u>8,120</u>	<u>8,847</u>
	48,526	57,525
<b>Investment income</b>		
Deposit account interest	<u>310</u>	<u>310</u>
<b>Total incoming resources</b>	118,369	120,305
<b>RESOURCES EXPENDED</b>		
<b>Fundraising trading: cost of goods sold and other costs</b>		
Opening stock (Note that in 2015 we recorded the wrong closing stock amount)	14,046	-
Purchases	33,132	29,774
Closing stock	<u>(22,313)</u>	<u>(14,046)</u>
	24,865	15,728
<b>Support costs</b>		
<b>Management</b>		
Wages	66,388	64,410
Social security	3,349	5,393
Insurance	198	270
Telephone	1,666	1,636
Postage and stationery	5,205	6,406
Accountancy	360	360
Volunteer's expenses	252	247
Rent AGM + experts talks	377	259
IT Costs	3,646	109
Carried forward	81,441	79,090

This page does not form part of the statutory financial statements

Detailed Statement of Financial Activities  
for the Year Ended 31 March 2016

	31.3.16	31.3.15
	£	£
<b>Management</b>		
Brought forward	81,441	79,090
Depreciation of tangible and heritage assets	<u>376</u>	<u>145</u>
	81,817	79,235
<b>Finance</b>		
Bank charges	2,120	2,338
<b>Human resources</b>		
Rent and Rates	<u>12,638</u>	<u>12,266</u>
<b>Total resources expended</b>	121,440	113,790
	_____	_____
<b>Net income/(expenditure)</b>	<u><u>(3,071)</u></u>	<u><u>6,515</u></u>

This page does not form part of the statutory financial statements