

Annual Report 2019



Herpes
Viruses
Association

41 North Road
London
N7 9DP
020 7607 9661
<https://herpes.org.uk>

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

Herpes Viruses Association Annual Report April 2018 to March 2019

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Letter from the Chair

Welcome to the Annual Report for 2018-19 which showcases our work and our achievements.

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

The herpes enigma

We help people who have been diagnosed with genital herpes, the second most stigmatised of all diseases after HIV (source: Harris Interactive USA poll, 2007).

Confirmation of this surprising statistic came in 2017 when Seth Stephens-Davidowitz published "Everybody Lies: Big Data, New Data, And What The Internet Can Tell Us About Who We Really Are." In this analysis of Google searches he revealed that one of the most common diseases that triggers a suicidal search is herpes.

Unfortunately, this is not news to many of our helplineers who frequently have to reassure desperate callers that what they have is "a cold sore in a different place."

Common but terrifying

The two herpes simplex viruses, types 1 and 2 - are common.

The infection is rarely serious and most of us have herpes, often without being aware of it. 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% have the other type (HSV-2). Either of these two viruses



may be the cause genital herpes and facial cold sores. So why are they feared?

Ignorance and embarrassment

A partial explanation is ignorance. Only one person in three of those who are infected is aware of it, the others 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.

Our mission and activities

The Herpes Viruses Association works to educate patients, medical professionals, journalists and the wider public about the reality of herpes, instead of the myths – see pages 6 and 7.

People approach us for support and we help them in a number of ways. The HVA's website has become the first point of contact for many patients, especially the newly diagnosed. Clinics and doctors recommend it. The free for not profits Google AdWords service helps people to find it.

Our helpline continues to offer callers the chance to talk to a sympathetic, well-informed peer. Our staff take helpline calls themselves – partly to keep themselves informed of services users' concerns – and train the new volunteers.

We are very grateful to all these volunteers and would welcome more!

Services for members

We continue to produce the quarterly online journal, Sphere, for HVA members and we run the very popular 'Study Days', enabling members to gain a deeper understanding of how the virus works and how to broach the subject with partners.

We offer a private Facebook group where our members can interact and where staff can deal with queries. This complements the public-facing Facebook page:

I love the group, honestly it has taught me so much, ... not only about the condition and other health issues but also it has taught me so much about myself, others' views, ... and it's helped me grow as a person.

A survey found that, each year, about one third our members choosing 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.

Working with others

Lobbying and campaigning continues to be a priority. Our involvement 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 more 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 two umbrella charities: Pain UK and Pain Alliance Europe. This enables her to network both domestically and across Europe to raise awareness of the problem of chronic pain – see page 14.

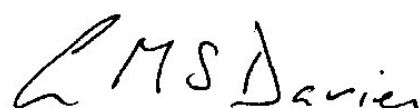
All support is valued

People are invited to donate through a button on the website. Helpline volunteers are encouraged to solicit a donation at the end of a call, when the caller is expressing their thanks.

Donations can be made with a text donation (maximum £20), an anonymous donation through NoChex, or on the shop page of our website.)

Our work and survival is only made possible with financial assistance from our members and supporters. 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.



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, which appeared alongside 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). The Shingles Support Society, our sub-group, established in 1996, gives information and advice on shingles (herpes zoster) and on treating the pain of post-herpetic neuralgia. This mostly affects people over 60 and is often more severe in older patients – see page 14.

Why we exist

Herpes simplex viruses are complex – and a diagnosis can be psychologically troubling

Genital herpes (like the other herpes viruses such as chicken-pox and glandular fever) can be treated but not eradicated.

This fact is used by pharmaceutical companies and complementary therapy manufacturers to exaggerate its importance, by calling it 'incurable'. For many patients this becomes a psychological burden: they believe themselves to be disease carriers with a high risk of infecting future partners. This view is incorrect. The majority of carriers (around 66%) are not diagnosed at all because their symptoms are mild. They escape this psychological burden. Some patients make heavy demands on the 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 genital herpes are referred to our services by:

- The staff of NHS sexual health clinics – increasingly as cuts are made to services around the country
- National Sexual Health Line (Public Health England)
- the Terence Higgins Trust helpline
- Brook Advisory Services
- NHS 24 hour helpline: 111
- GPs
- sexual partners, family or friends
- and, of course, Google...

Our charitable objectives:

1. To promote good health by improving public education about herpes virus infections, their prevention and treatment.
2. To promote, or assist in promoting research into the prevention and treatment of herpes simplex and its effects on patients, and to publicise the useful results of this research for the benefit of the public.
3. To relieve persons with symptoms of herpes simplex.

Annual statistics for the diagnoses made in sexual health clinics for 2018 - these are the most recent figures available –

- There has been a slight rise in the diagnoses of genital herpes (33,867 in 2018, compared to 32,737 in 2017, 33,040 in 2016). Fluctuations may be because it is becoming more difficult to access the services. Herpes simplex can only be diagnosed when symptoms are visible, so if access is delayed, diagnosis cannot take place.
- In two groups the level of diagnosis has risen: females in the 25-34 age group up 2%; and men and women over 65 up 15% to a total of 359.

We help patients to understand the psychology of herpes

Herpes stigma means that there is continuous need for the specialised reassurance and information that our services provide.

As mentioned on the previous page, a stigma regarding 'cold sores on the genitals' was created when medication first became available. The reason for this is that treatment is usually an option, not a requirement, as sores heal without intervention. Advertising was required to persuade patients to ask their doctors for prescriptions. The US-based campaign spread to other English-speaking countries.

What they find when they 'Google'

Once the stigma had been created, it became self-perpetuating. Newly diagnosed patients routinely turn to the internet for information. Most of what they will find is either wrong or wildly exaggerated. Websites are created to sell potions and lotions: these exaggerate the symptoms and highlight the most severe cases in order to promote sales.

Dating websites were created for people with genital herpes. These play on concerns that newly diagnosed patients may have about relationships.

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

Headlines in the box – right – are typical of the way that the word 'herpes' has become a synonym for 'anything bad that will not go away'. The word is used in totally inappropriate settings.

To try to mitigate the stigma, our aims include:

- educating those who are diagnosed with herpes with 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 asymptomatic, skin complaint which can affect the genitals.

'Herpes' is used as a synonym for 'something really bad'. People find these comments when they google 'herpes':

25-3-19 Daily Mail - and many other media sources:

["... saying "\[Cardi's\] just a Grammy-nominated prostitute running around spreading her herpes..."](#)

13-3-19 New York Post

[Stormy Daniels ... says Cohen is 'dumber than herpes' at DC event](#)

8-1-19 Celebrity websites

["Shaniqua fought back by accusing the New York rapper \[50 Cents\] of having genital herpes, ..."](#)

17-12-18 VanityFair.com

["THREE IN FOUR C.E.O.S TREAT TRUMP LIKE A BAD HERPES OUTBREAK"](#)

25-11-18 Time.com - and others

[Fox News Host Apologizes After Guest Compares Hillary Clinton to Herpes: "She won't go away. She's like herpes." Paulina responded.](#)

31-8-18 Mirror.co.uk

[X Factor is the herpes of the TV schedule - it's impossible to get rid of, says Polly Hudson](#)

27-8-18 Advocate.com

[Fox News Is Like Racist Herpes](#)

21-8-18 WomensHealthMag.com

[Tiffany Haddish Just Made A Herpes Joke At The VMAs, ...](#)

2-7-18 USA Today - and many others

[Michelle Wolf compares Ivanka Trump to herpes: 'Very unpleasant, totally incurable'](#)

29-6-18 HuffingtonPost.co.uk

[Trevor Noah: Trump 'Giving America Judicial Herpes'](#)

9-4-18 Daily Mail - and others

[The 32-year-old quickly became a scene stealer ... 'You can't get rid of me... Like herpes or something...'](#)

Medical facts - for 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 errors 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". These are all false.

Adding to and correcting websites:

Explaining and rebutting inaccurate coverage about 'herpes' is a regular part of our work.

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 we have previously obtained a correction.

Examples of websites that 'get it wrong' in box >

TV, radio, newspapers, magazines

We seek publicity both for the condition – to improve knowledge – and for the Association, so that people know where they can get information from.

Magazine and newspaper editors usually require personal stories to secure coverage. The herpes stigma means that very few people with herpes simplex will talk to the press.

We placed a story via the Press Association from a mum who did not have herpes. Her baby Kelly was kissed by someone with a cold sore with fatal results. She wanted the dangers of 'stranger kisses' to be spread in order to save others babies from this fate. This became a major news piece as it was picked up by the Mail online, Scottish Sun and others...

Our information/interviewees were used in pieces about genital herpes:

- BBC Radio 4 Woman's Hour - two members and our director were interviewed and the piece was selected by BBC to use again on the Saturday. round-up and to be included on Sounds podcasts.
- "Living (and dating) with herpes" on BBC THREE - the man who presented his own story on the radio was briefed by us in advance.
- Metro on-line quoted Marian Nicholson in their article about dating with genital herpes.
- Patient.info on-line quoted us about genital herpes

And about cold sores:

- Patient Magazine ran our information.
- Country Living quoted us.

Factually incorrect 'information' provided on the internet:

NHS Choices - neonatal herpes <https://www.nhs.uk/conditions/neonatal-herpes/states>:

"Cover up any cold sores to avoid accidentally touching your mouth and then breast – this is enough to transfer the virus"

The British Association of Sexual health and HIV guidelines for doctors, states that this does not happen.

British Association of Dermatologists – patient 'information leaflet' <http://www.bad.org.uk/for-the-public/patient-information-leaflets/herpes-simplex> states:

- Use tissues when washing to dry the area, and dispose of them by bagging or burning, to prevent others from becoming infected.
- Do not use a communal towel.

In fact, these are unnecessary actions.

NHS Choices video - and video clips embedded in the website:

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 the 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 really felt that my life was over when I got this diagnosis. I thought there was no point and I might as well kill myself. For ages I just felt miserable and thought I had no future. But when I saw your video, it felt like a light had been turned on.
You cannot imagine how down I was and seeing the bravery of the woman who was talking about herpes made an enormous difference – a load fell off me!
I really wish I had seen the clip months earlier, it would have saved me months of being miserable.
WOMAN October 2018

This year, further shorter clips giving personal comments on aspects of living with this condition have been placed in the website itself - where the text is appropriate. People have commented positively on these as well.

I want to thank you for your video talking about your experiences. I have watched it many times. Whenever the thought of this gets on top of me, I watch it again. Thank you for putting it up and for being so honest about it.
MAN March 2019

The doctor who diagnosed me looked so disgusted I have felt "dirty" ever since... And the information online keeps saying "Incurable disease, and stigma". Your story was so different and so sensible – it made a huge difference.
WOMAN March 2019

The medical angle - for health professionals

Patients may be given inaccurate statements by medical staff:

Thank you beyond Thank you for this site! I recently got diagnosed with genital herpes and was devastated because I had such a lack of knowledge over it. The doctor (GP) scared the hell out of me and I had such a negative outlook on contracting an STD.
WOMAN March 2019

Training the NHS clinic staff:

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. Staff know it is extremely common and that most people who catch it never have symptoms. Because they know it is unimportant, sometimes they are taken aback by the emotional reaction from a newly diagnosed patient.

The HVA offers training talks for the staff at NHS sexual health clinics on "*Counselling Patients with Herpes Simplex*". This offer is popular and this year Marian Nicholson addressed more than 200 staff at their clinics, with a satisfaction score of 92%. Several clinics invite us to repeat the talk when staff turnover necessitates it.

Clinics can receive free supplies of the leaflet 'True or False' or 'patient cards'.

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, and be diagnosed, many years after infection.

My GP said I had to have caught it in the last few weeks. But I have been celibate for 3 years now!
WOMAN, February 2019

Consulting on other organisations' websites and leaflets:

We have the ability and experience required to advise other providers on the appropriate way to explain herpes without causing alarm.

A representative from the HVA is an active member of the panel set up by the British Association for Sexual Health and HIV to pilot their new range of leaflets for patients and has attended all three of their meetings this year.

Reviewing reports and responding to consultations:

We submitted our evidence/opinion to Parliament's committee on Health and Social Care on the provision of sexual health services, since responsibility for these has been devolved to local councils. We were able to tell them from our constant contacts with patients that access for diagnosis and to get treatment has become much more difficult and in some cases the service is no longer provided or is fragmented.

We responded to the UK National Screening Committee's consultation on antenatal screening for HSV-1 and HSV-2. We were pleased with their decision not to screen for herpes simplex viruses because the unreliable nature of the antibody tests that are currently available would cause confusion rather than clarification.

What we do for the public – our services

Website – <https://herpes.org.uk> - 450,000 unique visitors this year

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', <https://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 Google 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 just wanted to message to thank you for this website. I have recently been diagnosed and thought the worst but this website has been a godsend. Thank you.
WOMAN March 2019

Hello I just wanted to say a massive thank you for the website. It has really been so helpful having the lemon balm and so nice to hear all your Herpes news. I'm a sufferer who is really anxious and depressed about my condition and I really can't help but think there won't be a cure.
WOMAN Oct. 2018

Guys. I love you. I really love you. The last week was perhaps one of the worst weeks in my life. The information online is misleading, confusing and many times written by insensitive people who doesn't have a clue about this.

You really helped me to feel good again. I loved one line "Don't allow this to define you". Just perfect, that's exactly the key of all this.

What you are doing is amazing. Thanks a lot!

MAN June 2018

Emails – info@herpes.org.uk

Despite the comprehensive information provided on the HVA's website, we also individually answered 875 emails, many of which had detailed questions about transmission and required a great deal of reassurance. These personalised replies frequently elicit 'thank you's'.

Thank you Marian you have been helpful I wished I had come across your site and emailed you four months ago rather than getting myself in to a state like I have. WOMAN March 2019

I've been in touch with you a few times over the last 12 months and you are always there with the support and answers. WOMAN November 2018

Thank you so much for coming back to me. That is such a relief, I have been worried sick. Thanks. WOMAN November 2018

Helpline (0845 123 2305) - 2,796 callers this year - 11.1 callers every day.

Our helpline volunteers and current office staff all have herpes themselves and use their own experience to reassure callers. They are also armed with data about prevalence and treatments. The value of this peer support is especially useful when dealing with such a stigmatised condition.

- Callers don't feel judged.
- Callers feel able to talk frankly, as volunteers are not 'an authority figure'.
- Callers hear that we are doing it because the helpline care.
- Callers can be inspired by our experiences: "You can transcend the diagnosis!"

The helpline service is available for over 60 hours a week, with core times of 10.00am to 8.00pm on weekdays, sometimes at weekends and on bank holidays too. When there are multiple volunteers, 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 are between 17 and 74 (ages are volunteered, we do not ask) with the average being 36.95 years.
- Callers can talk for as long as they wish.
- Each helpline answers an average of 11 calls per session
- Calls average 10.21 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'.

I would just like to say thank you ever so much for starting this initiative and for your help. I was diagnosed last year and found this website and your services so useful and encouraging. I called the helpline for advice and regularly check the resources online for my reference. I have even recommended it to friends! WOMAN February 2019

I phoned the helpline a few weeks ago and I spoke to yourself. I cannot describe how much better I felt after that call. After I was on the sofa laughing at myself for how out of proportion I had blown the whole thing up to be. Thanks so much for that conversation! MAN October 2019

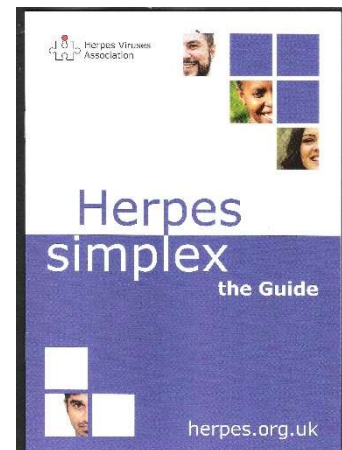
I spoke to a woman yesterday who was wonderful and told me that I needn't worry. She was very well-spoken and I really hope this gets to her. The story goes I had oral sex with a guy who I didn't inform that I had herpes. I told him the following day and he went mad. He threatened me with court and made me feel like the worst person alive even though he had previously had 40 sexual partners. After not eating for two days and after being called a whore and dragged through the dirt by this man, I called this helpline. Now, he is long gone and I would like to thank the lady on the phone, I donated £10 because you honestly helped so much. I think this charity is wonderful and actually want to specialise (I'm a microbiologist) in STIs and reducing their stigma. Have a fantastic day, you're all wonderful.

WOMAN August 2019

'Herpes Simplex - The Guide'

5,670 copies of *Herpes Simplex – the Guide* were distributed through sexual health clinics in the financial year ending March 2018. *The Guide* is a 16 page, 6,000 word, A5-sized booklet with cartoon illustrations. It has been written and updated by people with herpes simplex for their peers and is revised for each new edition. The information in this 13th 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, former consultant at the Countess of Chester Hospital and previous media spokesperson for the British Association for Sexual Health and HIV (BASHH).



Meetings for the public

Office staff and volunteers host support meetings in a central London venue: details are on the 'Events' page of the website and are updated regularly.

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

There were 24 such support/counselling events – open to the public - in London last year attended by approximately 112 people.

Sadly, the stigma deters some from attending: they fear recognition – ignoring the obvious fact that the others attending would be there for the same reason so would not be in any position to be judgemental. We recognise the scale of this problem, because staff and helplineers often have to persuade callers that they can attend without drawing attention to themselves.

I just wanted to say thank you for everything and for all that you do. You guys really do make a difference to people's lives. ... After meeting 'others' like me I'm feeling less alone and more positive about the future. It's actually done me the world of good being able to talk about things freely and in a safe environment. I'm feeling much lighter within myself too. I know it's not always going to be plain sailing but I do feel hopeful.

WOMAN December 2018

I felt such a huge sense of relief that I had gone to see Marian because I really did leave that meeting fearing absolutely nothing about herpes! My whole view of the virus had changed. I had been reassured. My life was going to continue, and it was going to be great. I had nothing to be worried about. Yes, I may have another outbreak, yes, I may have to have a conversation about it with my future partner but the whole thing was so normalised for me by Marian, that I wasn't worried about it anymore. I thank the HVA massively for the support and knowledge they have

given me. Without them I really do think I would still be having a really terrible time coming to terms with being diagnosed with HSV-1. I couldn't recommend their services more to anyone struggling with having HSV-1 or HSV-2.

WOMAN October 2018

It was lovely meeting you on Saturday. What you and Nigel are doing is amazing ☺

WOMAN October 2018

Additional services are provided for members

I don't know if I can explain what a huge difference you have made. After several years of suffering in silence, I decided I needed more support and given that the HVA's website was the only one I found that remotely made any sense of it all for me, I decided to become a member. I received my first Sphere journal along with leaflets on the topics I had wanted more specific information on and read intently. I was soon understanding the virus a lot more and how to manage it physically and emotionally.

But still, I couldn't shake, the now slightly reduced, sinking feeling when I reminded myself that I had genital herpes. I decided to go to one of the London meetings to chat with Marian. Nervous and inexplicably somewhat embarrassed, I entered the Atrium Lounge and soon saw Marian and went to introduce myself. I chatted to her about the type I had contracted, my outbreak, future outbreaks, how to speak to a partner about it, what treatments were recommended and soon realised that this is not the end of the world. This skin condition is incredibly common and not actually something that is going to stop me living my life the way I want to.

I felt such a huge sense of relief that I had gone to see Marian, because I really did leave that meeting fearing absolutely nothing about herpes. My whole view of the virus had changed. I had been reassured. My life was going to continue, and it was going to be great. I had nothing to be worried about. Yes, I may have another outbreak, yes, I may have to have a conversation about it with my future partner but the whole thing was so normalised for me by Marian, that I wasn't worried about it anymore. I thank the HVA massively for the support and knowledge they have given me. Without them I really do think I would still be having a really terrible time coming to terms with being diagnosed with HSV-1. I couldn't recommend their services more to anyone struggling with having HSV-1 or HSV-2.

Many thanks,

WOMAN October 2018

Leaflets

Leaflets are available on every aspect of genital herpes. Popular titles are "Tips to Prevent Recurrences", "Transmission" 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 ensure that the information produced 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. All the information products we produce are tested on people with genital herpes to ensure that they are unambiguous and readily understood. They are then validated by a relevant medical expert.



Thank you both for this so helpful association! Thank you for the leaflets. You have no idea what a weight has lifted of my shoulders.

WOMAN August 2018

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 the diagnosis, suggest ways of controlling thoughts, relieving stress, etc. It always includes personal stories and tips from readers.

[I looooooves this issue!!! \[about the quarterly magazine for members\]](#)

WOMAN July 2018

Meetings just for members

As well as open meetings mentioned on page 10, members and the London-based office staff organise various types of meetings around the country just for members. This enables patients to recognise the 'normality' of other people with genital herpes which is something that quite often comes as a surprise to them.

Expert talks: once a year, members are invited to an afternoon of talks from experts. This is attended by about 30 people each time. They are subsequently summarised in SPHERE journal for members, so that everyone can benefit from the event.

44 people attended the four "Study Days" offered held this year. These events deliver the information and confidence required for members to feel able to talk about genital herpes with new partners. This anticipated difficulty is one of the most frequently repeated fears. The events are assessed by the attendees, and averaged >4.6 out of a possible 5 points across several measures.

What did you think of the Study Day? What would you say to others thinking of coming?

[I feel safer with the virus now and can understand how low risk transmission actually is. Attend! It's liberating to understand how to approach getting into my next relationship](#)

MAN February 2019

[I learned extremely useful facts and for me the role play with others was priceless. Definitely attend as soon as possible after diagnosis - it will help immensely.](#)

WOMAN February 2018

Other events:

- 24 sharing/talking events in London (with approx. 112 people attending) – as mentioned above in the section on public events
- 2 purely social events such as clubbing, in London
- 12 social events hosted by members in other cities nationwide: Bristol, Carlisle, Newcastle, Birmingham and Bury.

Working with other associations

We work with other organisations to further the interests of herpes simplex patients by maximising our reach and effectiveness. This process benefits sexual health patients in general and also those with other skin conditions.

Each year, we are provided with a free place at the annual conference of the British Association for Sexual Health and HIV (BASHH) for a member of our staff.

We have a representative on the BASHH Patient Panel. This panel does a critique of all BASHH leaflets as well as advising on other aspects of BASHH's outward-facing activities

We attend meetings of the following APGs where we can make comments from the patients' perspective:

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



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 (shingles) to find support for the treatment of post-herpetic neuralgia (PHN), a pain that sometimes accompanies this condition. In older patients, this pain frequently continues long after shingles blisters have healed.

We send out a 17-page information pack setting out treatment options, for sufferers to share with their GPs. The first-line treatments for PHN are usually generic tricyclic antidepressants and anti-epileptic drugs, which also have pain-block benefits. Some GPs remain unaware of how useful these can be. Sometimes, patients who have had them correctly prescribed fail to take them because they were not told that what appears to be 'the wrong drug' is likely to be helpful: we are able to explain.

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

There is a vaccine, Zostavax, that helps to prevent shingles, which has been phased in by NHS during the last decade. Many people contact us to find out if they qualify for it. It is now available to all patients from age 70 and the somewhat complicated allocation catch-up process for those between 70 and 80 is largely complete. This process has confused many GPs and practice managers. Take-up has recently been falling and we are now working to reverse this trend.

Private individuals are helped directly and personally:

- 331 phone conversations. Topics included transmission, treatment of PHN and the new vaccine to prevent shingles.
- 89 people received the information pack as well as personalised information
- 25 people had their problems dealt with only via email communications

We were interviewed on radio and also provided quotes for the press about shingles, how it can cause PHN, how PHN can be treated and how the new vaccine can prevent cases. Marian Nicolson was interviewed on the impact on this pain for Merck's "Shingles Vaccination Best Practice Videos" for staff training.

To help with research into treatment of PHN, we found volunteers to contact three research centres around the UK for the pharmaceutical company Novartis. We publicised the link to an on-line questionnaire for an MSc Psychology student with the University of Derby.

Cochrane, an independent organisation doing meta analyses of trials, treatments, etc. requires 'consumer referees' for protocols and final review/meta analyses. This year, we volunteered to review a protocol for using 'Pregabalin for neuropathic pain in adults'.

Post herpetic neuralgia causes chronic pain. There is a worldwide campaign to increase awareness of this problem. This charity works with other organisations that promote the improvement of treatment and a holistic approach for people suffering from long-term pain.

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

- Pain UK - there are 29 pain charity members and over 1,100 individual members who receive alerts and newsletters.
- Pain Alliance Europe - she attended four meetings in Brussels where she was the representative from Pain UK - including the launch of the EU's special interest group on Brain, Mind and Pain. PAE has 41 charity members from all over Europe. She is also involved in the steering group for the Societal Impact of Pain

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.
- 'HealthUnlocked' and other appropriate websites and umbrella groups.

Who does what: staff and volunteers - monitoring and training



The HVA has two full-time staff who 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 when volunteers are not available Marian and Nigel are available to answer helpline calls over an extended period. They also volunteer by answering calls and responding to Facebook Messenger enquiries in their own time. This also helps to keep them aware of the current patient concerns.

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

- Some members around the country organise group meetings. They are supported by the office staff who attend when possible but they are not formally trained.
- Our helpline volunteers are trained and then join the roster: weekdays 9 am-8pm
- Helpline volunteers are supported by telephone by their original trainer.
- Emails updates containing facts and helpful suggestions are regularly sent to our helpliners, keeping them abreast of news.
- Monitoring of helpline services continues at all levels.
- Helpliners complete a log to feedback on the topics covered and to enable supervision of the service as well as providing pointers to further training.
- Four volunteers have assisted in the office at various times.

Executive Management Committee

The association was registered with the Charity Commission in 1985. The Executive Management Committee is elected from the membership at the Annual General Meeting. Committee meetings are normally held monthly to oversee the work of the association, direct its future and approve exceptional expenses. There are currently ten members, only one of whom is not a service user, three of whom are male.

The Charity Commission has agreed not to publish the names of the HVA's committee members on its website. Neither are they named on our website.

Funding for 2018-2019

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

Income: £ 135,870

Expenditure: £ 132,152

Regular sources:

Membership fees raised £20,269, a slight increase on the previous year. The first year's fee is £30, with £25 for renewals. Membership numbers were higher before the internet age. Today's lower number of members reflects the increased availability of useful advice and information on our website which is provided free of charge. This is needed to counter the torrent of badly written web pages and outright misinformation about genital herpes that is found online.

Donations totalled £21,520. We continue to encourage members and service users (on phones, emails, website) to be generous with donations. Over fifty of our members have set up regular monthly donations by standing order of varying amounts between £2-£30.

Profits from selling booklets, and the creams and supplements (therapeutic materials which we have trialled and found useful in preventing herpes simplex outbreaks) generated around £13,600 gross profit – that is without making allowance for cost of writing and designing and sales administration.

Corporate donations/payments in the year 2018-2019:

- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £1621 this year.
- A link on our website goes to MedExpress, approved by the Care Quality Commission to sell antiviral drugs. This sponsored link raised £10,800.
- We received three educational grants totally £3825 for producing leaflets and manning a stand at the annual conference of the Royal College of GPs.

Fundraising

Challenges because of the stigma associated with genital herpes:

Charities routinely encourage members and beneficiaries to assist with fundraising. Our members are not able to do so because it would require them to 'go public'. 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 to the HVA in many ways (see page 4) Also, we routinely ask contacts to use www.EasyFundraising.co.uk when they are using 'online shops'. This web portal includes over 3,700 online shops including many well-known companies (including Amazon, Asda, ASOS, InterFlora, M&S, Travelodge, Zizzi). A percentage is donated to the charity chosen by the shopper. We ask people to nominate the Shingles Support Society as their designated charity. This year we have received £322.

Trusts

We received an unrestricted donation of £2,000 from Druces LLP. We will continue to ask for grants from charitable trusts and we are optimistic that this avenue may prove productive in 2019-20.