Annual Review

2025

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Established 1985

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Herpes Viruses Association
Annual Review
April 2024 to March 2025

Providing medical information:

Our services:

Letter from the Chair

Welcome to the Annual Report for 2024-2025 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 paradox
We help people who have been diagnosed with genital herpes, a condition hugely stigmatised in popular culture. See page 6.

Yet the two viruses that cause it - herpes simplex, types 1 and 2 - are common. In 2015, the World Health Organisation stated that 66% of adults worldwide under the age of fifty have one type of herpes simplex virus (herpes simplex type 1) and more than 13% have the other type 2. Both these two viruses may be the cause of genital herpes or facial cold sores.

So why does the word ‘herpes’ frequently provoke dread?

Partly, it is ignorance. As well as not knowing how common it is, people do not realise that only one person in three who catches it will notice. The others get minimal symptoms so are not diagnosed. In most cases it is caught on the face, where it is called a cold sore. But when it is caught on the genitals it is called ‘herpes’ and stigmatised. Because of these different names for the virus, depending on where the symptoms appear, many people fail to make the connection.

Herpes lives in most of us, yet the misconception that it is an unsavoury problem affecting a reckless minority, continues largely unchallenged.

The medical view
The staff of sexual health clinics are aware of the fact that this virus is rarely of any medical importance. However, they admit that it takes up a disproportionate amount of their time, having to counsel people who become distraught, or even have thoughts of suicide, on hearing the diagnosis.

Many clinics routinely add this charity’s contact details to the text they send out to patients with their herpes diagnosis. In this way, the charity has become very important to the sexual health service of the nation, but it is not funded by government or NHS.

Recognising over 30 years dedication
Medical staff value the time and expertise of the charity, its staff and helpline volunteers. As a result, when our trustee Nigel Scott asked consultants to support an application for the charity’s director Marian Nicholson to receive an award, they were pleased to submit their supporting letters.

In June, Marian was awarded an MBE in the King’s Birthday Honours and received the medal from Princess Anne – more page 17. The initials MBE after the name of our director confer more authority on our messages to normalise this common but highly feared condition.

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.

People approach the HVA for support and are helped in many ways. The website is now the first point of contact for many newly diagnosed patients. Sexual health clinics recommend it to their patients.

Combatting stigma

Marian Nicholson, our director, was invited to speak at BASHH Bournemouth, 2024, on Stigma. Her talk was well received with delegates approaching her later to discuss it. Under Conferences and Training Professionals – read more on page 9.

The stigma prevents our members 'going public' about their diagnosis and helping to normalise it as the common skin condition that it is. However, in the recent past, we have noted that brave young people, mostly women, have taken up the challenge on TikTok and other platforms to tell their followers about their own 'herpes journey' and share sensible messages.

Evaluation of our work

Many charities are able to give accurate results about the value of their services from users' feedback. The stigma means we are asked "Is this service confidential?" and "Are products sent in discreet packaging?" We do not ask for any contact details from the people who use our phone service.

Our website visitors are invited to fill in a survey via a link at the foot of every page.

Our helpline continues to offer callers the chance to talk to a sympathetic, knowledgeable, friendly voice. The link to a survey about the helpline is shown on the 'contact us' webpage. Graphs from these surveys are shown below.

Virtual support

Our twice-monthly Zoom chats, available to everyone and started during the lockdown, have proven to be very popular and are continuing. The monthly in-person meetings in London are also well attended:

"It's been amazing talking to everyone, I feel so much lighter!" Lady, 1 February 25*

* We promise anonymity to everyone who contacts us.

Helpline calls are answered by the office staff or trained volunteers. We are very grateful to all our volunteers and would welcome more!

Emails are answered promptly, so that people have less time to 'google' herpes and find worrying and inaccurate information online.

Services for members

Members are sent a monthly print or e-journal with research and motivational messages.

Some numbers:
15 training sessions (medical staff)
1 medical conference presentation
2 advising on medical guidelines revision
6 training sessions (patients)
290,000 website visitors
2216 phone call sessions
1070 email 'conversations' with patients
24 Zoom support sessions (for patients)
14 in-person support groups for patients
5 helpline volunteers

We host a full-day session on 'Talking to a New Partner' on Zoom every quarter. This interactive tuition can be life-changing for the participants and has empowered many to overcome the hopelessness that sometimes follows diagnosis, enabling them to resume dating and find a life partner.

Our private Facebook group allows members to interact and ask questions which our staff can answer. This complements our public-facing Facebook pages.

We continue to monitor health and news websites for inaccuracies or poor wording. Years of experience has given us an insight into how people can misinterpret what they read if it is unclear. We then offer a clearer wording for them to use.

Help for shingles patients

Our other main activity is advising patients on the treatment of post shingles pain (PHN) caused by herpes zoster, another herpes virus, via our subsidiary charity, the Shingles Support Society.

Our work and survival are 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.

Nigel Scott

Nigel Scott
Chair

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 with the Charity Commission in 1985. Six of our seven trustees have personal experience of the virus, and we have obtained a dispensation from the Charity Commission not to publish a list of their names.

The HVA provides information on all the human herpes viruses with emphasis on herpes simplex (genital herpes and cold sores). A sub-group, the Shingles Support Society, was established in 1996. It provides information and advice on shingles (herpes zoster) and on treating the pain of post-herpetic neuralgia – see page 16.

Why we exist

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

Genital herpes, like the other herpes viruses such as chickenpox and glandular fever, can be treated but not eradicated from the body.

This fact is used by pharmaceutical companies, complementary therapy manufacturers and dating websites 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 so 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 – this is increasing, as cuts are made to these services around the country
- National Sexual Health Line (Public Health England)
- Terence Higgins Trust helpline
- Brook Advisory Services
- GPs
- Sexual partners, family or friends
- And, of course, Google and other search engines…

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 genital herpes diagnoses made in sexual health clinics for 2024.

The number of new diagnoses this year has risen: 27,167 in 2023 and 27,867 in 2024. However, these figures are still well below the 34,464 diagnosed in 2019. We attribute this to the fact that patients are still finding it difficult to access clinics because staffing for clinics has not returned to the pre-pandemic level.

The NHS's self-testing kits for STIs, sent out by post, do not include herpes simplex. Unlike most other sexually transmitted infections, diagnosis of genital herpes requires a swab being taken at a sexual health clinic while symptoms are visible. A reduction in access to clinics will translate into a reduction in cases diagnosed, which does not reflect the true picture.

We help patients to understand the psychology of herpes

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

The stigma regarding 'cold sores on the genitals' coincided with a US advertising campaign to encourage patients to ask doctors for a prescription when the new drug was marketed in 1970s [Cuatrecasas, 2006]. Treatment is usually optional as skin heals on its own. The US-based campaign spread to other English-speaking countries.

What they find when they 'Google'

Stigma is self-perpetuating. New patients routinely turn to the web for information. Most of what they find is either wrong or overblown. Websites selling "treatments" exaggerate the symptoms and highlight the most severe cases in order to promote sales.

Dating websites, just for people with genital herpes, exploit the concerns that newly diagnosed individuals may have about future relationships.

The internet allows misinformation to be repeated on every blog and forum.

The stigma is firmly embedded and dangerous:

Man seeks justice for death of UK-based daughter - The Sun 28/5/2024
"...herpes, which the daughter saw as a stigma that should not be exposed ... Her boyfriend, who did not stop at threatening her with the exposure of the herpes, also broke into her phone; ... and started using the information he got to blackmail her...

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.

'Good news' is not newsworthy. However, we are now beginning to see some useful headlines - see box next page.

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 often used in the media as a synonym for 'something really bad'. Google 'herpes': here is a sample of what you find.

12/4/25
Slugga: Domestic snooping bill dealt a setback but 'like **herpes**, it'll be back' - BizPac Review
BizPac Review

22/5/24
'My songs spread like **herpes**': why did satirical genius Tom Lehrer swap worldwide fame for ...
The Guardian

17/7/24
Coleslaw definitely just called slaw now - NewsBiscuit
…due to coleslaw sounding a bit like cold sore, which then makes people think of herpes, which then makes people think of the joke: *What's the difference between love and herpes? Herpes is forever.*

8/9/24
Trump as an infection - a 14-line poem in Iambic Pentameter - Daily Kos
Your tribe you hold in your deathly squeeze, On our nation's body blighted **herpes**
Full of foolish sight, a comic dancer,
On the soul of the nation

20/9/24
Jimmy Kimmel Says Trump Was Endorsed By "The Babadook, Bill Cosby and **Herpes**" After ...
Decider
Jimmy Kimmel Says Trump Was Endorsed By "The Babadook, Bill Cosby And **Herpes**" After Republicans Back Harris with "Scathing" Letter About Him…

12/10/24
Daily Mail
Elon Musk is mocked for his bizarre pronunciation of 'Robovan' - as one Tesla fan claims he **'makes it sound like a herpes medication'**

9/12/24
The vocalist of Green Day criticizes Psy - Telegrafi
Green Day star Billie Joe Armstrong has hit out at pop sensation Psy, calling him the '**herpes**' of music

22/12/24
Virus causing gut infections could play role in development of Alzheimer's: Study
ET HealthWorld
Most humans are thought to have been exposed to cytomegalovirus, one of the nine viruses known to cause **herpes** (painful blisters on the skin)… [They muddle two different illnesses].

2/3/25
An idiot's guide to Artificial Intelligence is - PressReader.com PressReader.com
It appeared almost out of nowhere and **like a nasty case of herpes,** shows no sign of leaving in a hurry…

Medical facts - for the public

We are known as a trustworthy resource on herpes simplex. 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 the 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.

We seek publicity both for the condition, to improve knowledge about herpes simplex, and for the Association, so that people know where they can find good information.

In general, getting stories in the consumer media is complicated by the fact that journalists require personal stories to humanise and contextualise medical information. The herpes stigma means that very few people with herpes simplex will talk to the press. Many journalists make it plain that they need to describe "the emotional journey." This, we know, is how people learn to be miserable about herpes simplex - by hearing others' bad experiences/thoughts. We have to turn down such interviews as it would not contribute to our stated aim of relieving the stigma.

NHS Choices video – our video clips on YouTube and embedded in HVA 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.

On our YouTube channel, this 5-minute video clip is joined by a 6-minute video **"What doctors *should* tell patients."** Also shown, 5 other short videos answering the most frequent questions, filmed to a professional standard. They are embedded in our website as well as YouTube. They complement other shorter clips giving personal comments on aspects of living with this condition. People have commented positively on these:

> "I must first THANK YOU, THANK YOU, THANK YOU for what you're doing and the information you are providing! Your videos really made me feel normal again..."   Lisa, 24/9/24

British Dermatological Nursing Group and TalkHealth have uploaded their interviews with Marian Nicholson, director, as a leading advocate for a sensible view of the condition, posted on www.youtube.com/results?search-query=talkhealthmedia+herpes

Rising numbers of anti-stigma campaigners

The daily Google alerts we have received for years, now include stories about people who have decided to be 'out' and tell the digital world why 'having herpes' should not be so stigmatised.

These influencers are very helpful to people who are feeling that 'their sex lives have ended.' This negative message will have been absorbed from the many jokes and slurs about herpes that abound in the media.

It is only by being open about herpes, that people can start to believe the medical fact that by age 35 over 85% of women and 77% of men carry the virus. (Cunningham, 1998)

Expert calls for end to **herpes** stigma: 'No need for fear or shame' | Newstalk 28/6/24

Breaking the stigma: Why open communication about STIs is crucial for healthy relationships News24, 21/11/24

"Herpes" in a positive light as a vector for treating cancer

Such Google alerts also include headlines saying that 'herpes saves lives.'

This is the media's simplistic way of announcing trials using modified herpes simplex virus to carry cancer-treating molecules into the centre of the cancers.

Adding to and correcting websites:

Explaining and rebutting inaccurate coverage about 'herpes' is a regular part of our work. When we find incorrect or misleading information on any UK-based website purporting to be authoritative, we ask for this to be changed. Our requests always include detailed instructions for the correct wording to be used. Two examples this year:

"NHS Choices" acted on our re-wording of two pages pregnancy and whitlows. These had been set out in an alarmist manner and used scary wording. In summer 2024, these pages were updated: https://www.nhs.uk/conditions/genital-herpes/
https://www.nhs.uk/conditions/herpetic-whitlow/

Free prescriptions

We are providing the information patients need to get free prescriptions for STI treatment from their GPs. Treatment from clinics is free, by law, so now, GPs can endorse prescriptions with FS (for Free Supply) and the patient will not need to pay a prescription fee at the pharmacy. However, this was made law only in 2020 and it is not widely known. We show the link to the government page that explains this. Patients can direct their GPs to the webpage.

What a bumper edition!! [Of the subscriber magazine, Sphere] More congratulations for the scholarship and the new guidelines.

During pregnancy and as a new mum I constantly worried (11 years ago). Knowing that you have been consulted and are co-author of this new literature gives me great comfort when thinking of women going through it all now.

I liked the section "Woman says" "Man says" and as a 48-year-old woman, I can add that I don't pay for my acyclovir repeat prescription.

I followed the advice provided in a previous Sphere and **invoked the FS code**. So, I enjoy all the relief the medication brings me without paying a penny. It's a true gift in every sense of the word. Zoe, 6/1/25

The medical angle for health professionals

No legal requirement to disclose (but it makes sense)

The Crown Prosecution Service states:

> "There is no legal requirement to disclose any sexually transmitted infection or HIV."

Despite this legal fact, newly diagnosed patients are still being told that they must disclose by medical staff.

We certainly encourage people to talk about this with new partners for many reasons. For instance, it has been shown that when a partner has been informed, the rate of transmission decreases 10-fold. However, since two out of three people with herpes are unaware that they have it and suffer no ill effects, there is no rationale for forcing the few who have had the misfortune to be diagnosed to disclose their status, as long as they behave responsibly.

Research - we help find candidates for medical and psychological researchers

Researchers approach charities for specific medical conditions, because we have contact with large numbers of people who would be appropriate for their research.

We can show 'adverts' for researchers on Facebook pages, both ours and others set up for people with the same condition. The latter will reach large numbers of people, not just our members. People are invited to contact the researcher directly, so we cannot know how many have responded: except when we get 'thank you' emails from them telling us that we can remove the announcement.

Conferences & training for health professionals

Medical conferences

Each year, a representative of the charity attends the annual conference of the British Association of STIs and HIV (BASHH) and reports back in detail to our subscribers. More general news from the conference is added to our website.

At the BASHH conference in Bournemouth this year, we had a research report "poster" accepted for display: *"Patient perception of relative STI significance. Is prosecution for transmission justified?"* This report showed some of the results of the YouGov survey that was run earlier in the year.

For the session "Sex, Stigma and…" Marian Nicholson, our director, provided slides showing how the stigma of herpes can contribute to suicides. She gave clear instructions to the medical professionals ono what they can do to prevent this, and lesser psychological harms.

"Sex. Stigma and Herpes Simplex":

Marian explained that she has, so far, identified three ways to get stigma reduced or removed in society:

Pay: a huge PR budget can pay for a campaign – The charity SCOPE is the result of one such.

Openness from the bottom up: individuals have to challenge stigmatising comments in social situations, heckle in comedy shows, speak up at a script meeting when a script suggestion adds 'the trigger word' as a term of abuse, derision or 'otherness.' – Racist jokes are an example of this.

Top-down: the AIDS campaign. People in the public eye were open: movie stars, musicians. However, since owning up to having herpes is considered such a social taboo, and the person is not about to die as was the case at the start of the AIDs era, none of the many celebrities we have communicated with have responded – even when the media has reported that they are known to have the virus.

Training the frontline staff - now virtual meetings

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, so they can be taken aback by an adverse emotional reaction from a newly diagnosed patient.

We gave 15 training talks this year – an increase on the 10 last year. One was for the NHS psycho-sexual therapists of Kent. The others are for the staff of NHS sexual health clinics. Our talk on "*Counselling Patients with Herpes Simplex"* reached hundreds of individual healthcare professionals. The feedback scores from clinic staff always average around 95%.

One of the introductory slides of the PowerPoint presentation we use at these events states:

> "**How the very first consultation is handled is crucial to the patient's future well-being.** A bit of time, a lot of empathy and a clear explanation *minimising* the future consequences is necessary."
> Dr Colm O'Mahony MD FRCP BSc DIPVen.

Because staff understand how we can help their patients, more clinics are referring patients directly to our website or helpline. 10% of helpline callers mention that they have been referred to us by the clinic that diagnosed them. Clinics can receive free supplies posters, the leaflet 'True or False' or 'patient cards.'

There is still work to be done. Patients tell us that the clinic staff were unable to answer specific questions or gave wrong answers (i.e. that it is a legal obligation to 'disclose' the diagnosis with a new partner.

A caller said that: "The man I am with says he doesn't have it, and the clinic told me that a person will know when they catch it as it will be so painful …"

The helpline volunteer was able to explain that usually it is caught from a person who doesn't know they have it because their symptoms are so mild. But also, that she could have caught from someone else, long before she met the current partner.

Providing information sessions for patients of other organisations

Twice a year, we provide one of the six sessions in a programme for women who have psychological issues arising from their diagnosis of genital herpes. Run by the Psychology Dept, UCL, this event at the Holloway Sexual Health clinic includes lively discussion.

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 as well as those with other skin conditions.

The most relevant of these is British Association for Sexual Health and HIV (BASHH). As in previous years, we were provided with a free place at their annual conference. This year, as mentioned above, we were paid to make a presentation to a plenary session.

This year BASHH published revisions of two guidelines. These are aimed at general medical personnel: '*Management of anogenital herpes*' and, together with the Royal College of Obstetrics and Gynaecology '*Management of herpes in pregnancy.*' Marian Nicholson, our director, is on both writing groups.

We are also active members of: British Association of Dermatologists' Patient Support Groups. This enables us to work with other professional bodies, e.g. British Dermatology Nursing Group, the British Skin Foundation, pharmacists, and pharmaceutical industry.

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 ensure patient engagement in their activities and services and has attended all four of their meetings this year. This panel provided comments on their new range of leaflets for patients on various aspects of sexual health.

What we do for the public – our services

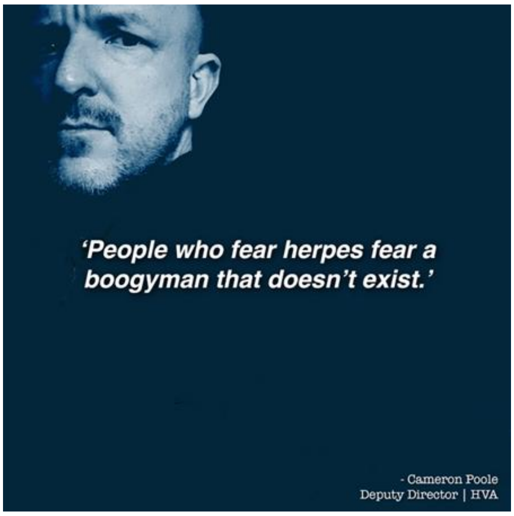
Twitter (now X)

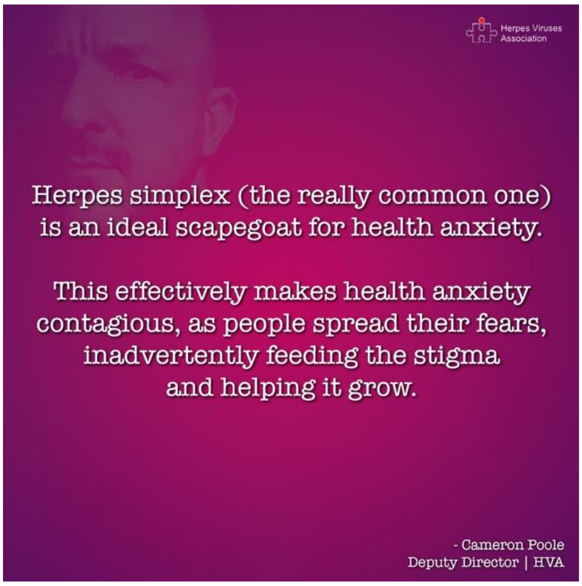
Our long-standing page **@HerpesUK** was set up to inform the health community.

We also have an account on X aimed at the public, which debunks myths: **@DebunkedHerpes**, we post as appropriate through the year.

Instagram

We run an Instagram account, **@HerpesAdvice,** which promotes good information about this virus.





Herpes simplex (the really common one) is an ideal scapegoat for health anxiety.

This effectively makes health anxiety contagious, as people spread their fears, inadvertently feeding the stigma and helping it grow.

- Cameron Poole
Deputy Director | HVA

Facebook

There are many herpes-specific Facebook pages for people with herpes. Most of them are ‘semi-public’. We have joined four of these and regularly correct misinformation being shared and offer sensible advice. For our signed-up members, we run a totally secret Facebook page, which has over 280 members. This provides a safe space for members to ‘talk’ to each other - a boon since so many people choose not to mention herpes to any friend or family member.

Meetings for anyone

Monthly meetings, on a Saturday afternoon, are held at a central London venue. These are free, with no need to book (which might reveal an identity). Details on the ‘Events’ page of the website are updated monthly. Meetings are hosted by office staff or a trained volunteer.

> Thank you, Marian, for your help the other day, it’s reassuring to not feel alone in this situation. Stu (the ski instructor) with £10 donation, 6/2/25

We held a summer picnic and two evening ‘social’ events in Central London bar which were advertised on various Facebook pages reaching thousands of diagnosed patients.

Since Covid lock-down, we have also been hosting two meetings a month on Zoom: one on a weekday evening and one on a weekend morning. These are open to the public: they request a Zoom link to be sent.

Virtual events are very popular because distance is no longer a barrier: people from anywhere can join in. We average 8 people requesting the link for each event, which is a suitable number - too many and it becomes difficult for people to ‘have their turn.’

Before Zoom, the ‘herpes stigma’ meant that people would tell us they did not dare attend in person. At our virtual meetings, attendees rarely show their faces, and some do not speak at all. They wish to passively experience the answers given to questions provided by the bolder participants. Occasionally we can encourage participants to talk amongst themselves - but usually these are seminars with the host providing the standard facts and answering questions they ask or type in the ‘chat’ feature.

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 imaginary ‘promiscuous individual’). People discover how sharing stories helps them to envisage possible futures.

Thank you for running the welcoming, friendly and informative free Zoom session this Sunday. It's really appreciated that you provided a genuine 'safe space' for open discussions, a place to learn more & to also ask open questions. It was off-loading to share experiences, our mixed feelings (let's face it, we've all had them!) and listen to others knowledge. While most importantly being given kind guidance, good advice and accurate facts!

Well done, keep up the great work & thanks again - I'm feeling much lighter having chatted to & listened to others in the same boat #thefactsarekey CA 7/7/24

Website – https://herpes.org.uk - 290,000 visitors

With the assistance of Google AdWords (free to charities), our website generated 1,800,000 impressions. As well as 'herpes' Google Analytics shows that 'cold sores' is the third most common term that visitors have used in their search. Last year, we had a free session with the website experts of a major corporation, who assured us that our website was well configured to achieve visitors: it has a good SEO rating.

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 support', https://herpes.org.uk is the first site listed on Google UK.

Visitors to the site find it very different from other websites. They send in unsolicited testimonials:

Thank you for all the guidance your organisation gives to us. I love your website; it has been a lifesaver more than you know. Kind regards, Anna, with £50, 5/2/25

Thank you for the work you do. Going through the information on your website was hugely reassuring and helpful. Christina 31/10/24

Emails – info@herpes.org.uk - 1070 email threads.

Despite the comprehensive information provided on the HVA's website, we also individually answered 1070 people by email. Many of these were long series of questions and answers with detailed responses re transmission or the risk of rejection and required a great deal of reassurance. These personalised replies frequently elicit 'thank yous.'

HVA is an amazing resource that's helped me many times and I'm so grateful for your response. Karen 7/10/24

I feel better informed, and more able to discuss this with the doctor tomorrow. So, thank you again for your time and reassurances! Jane, with £10, 20/9/24

Thank you so much both of you. The support was so low in Belfast I don't know what I would have done without HVA. Talking to you both helps so much more than the therapy and antidepressants combined! Emma 3/7/24

Thank you so much for your reply and for your opinion – it really has given me peace of mind. I really appreciate it, and you are doing more for HSV reasoning and education than anyone worldwide (I'm in Australia and its nothing but fear mongering down here).

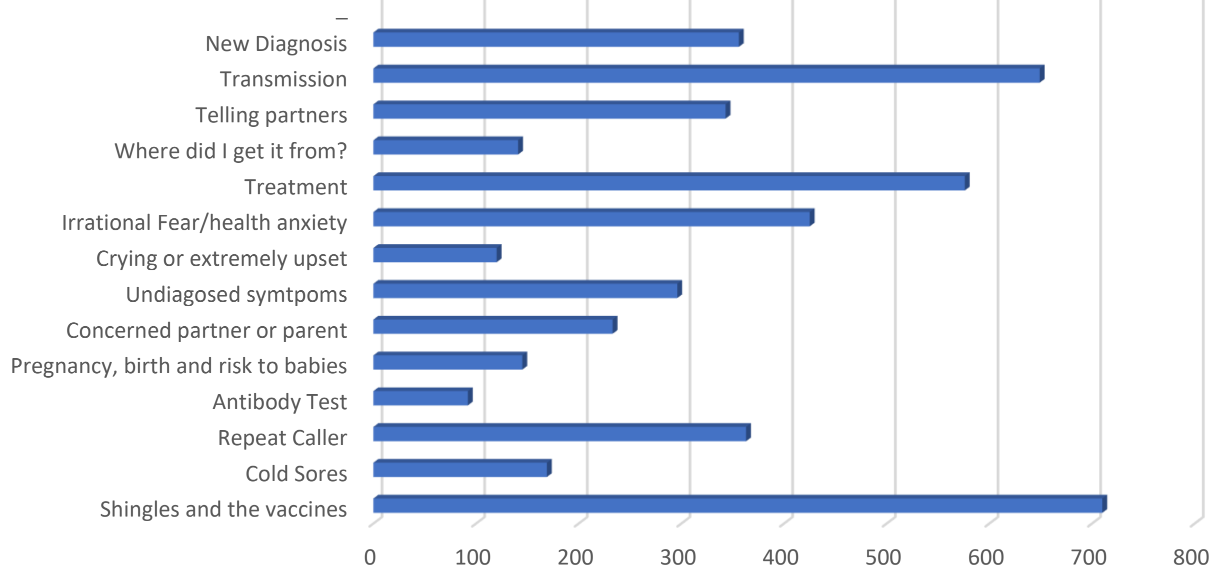
Thanks again and have a great day! Mike 8/5/24

Helpline (0345 123 2305) – available 60 hours a week

More than 2200 callers this year.* An average of 8.5 callers each weekday. The majority are female. The calls can last as long as the caller wishes, with an average of 13.6 minutes. So far, the longest is 112 mins. 5.4% of callers are crying as they speak to us. Although we do not ask, around 16.3% of callers self-identify as a 'repeat caller.'

* Our helpline volunteers are asked to complete report sheets, but not all are diligent about this, and as they are volunteers, we do not insist.

Chart: topics covered April 24 to-March 25: one call can refer to several topics



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 can talk for as long as they wish.
- Callers are anonymous. They are not asked any identifying questions.
- Callers feel able to talk frankly, as volunteers are not 'an authority figure.'
- Callers hear that we are answering calls because the helpline volunteers care.
- Callers can be inspired by our experiences: "You can transcend the diagnosis!"

Just wanted to say a massive thank you to Cameron for helping me today. I feel a lot calmer and so much better after talking to him. I was feeling distraught and like my life was over. He was lovely and now I feel like I can get back to me again after hearing the truth about it.
The videos and your website are also brilliant and very reassuring, unlike google, which sent me down a black hole. Pru, 5/9/24

Thank you for all your help and support earlier this week. You are doing a fantastic job! Eleanor 2/1/25, with £50

Thank you so much for taking the time to talk to me Cameron. It made a huge difference to my state of mind. Leanne 29/10/25, with £50

Thank you for your time and for speaking to me so kindly. It's remarkable how relaxed I feel about herpes now, compared to last month when I was newly diagnosed. Reading all the information on the HVA website was so helpful when I was first adjusting to the news. The work of the HVA really helps people. Abi, 23/9/24

- 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 80 (these ages are volunteered: we do not ask) with the average being 38.8 years.
- Callers may be crying or mention suicide, so our volunteers need to be strong emotionally as well as being trained with ‘all the answers’

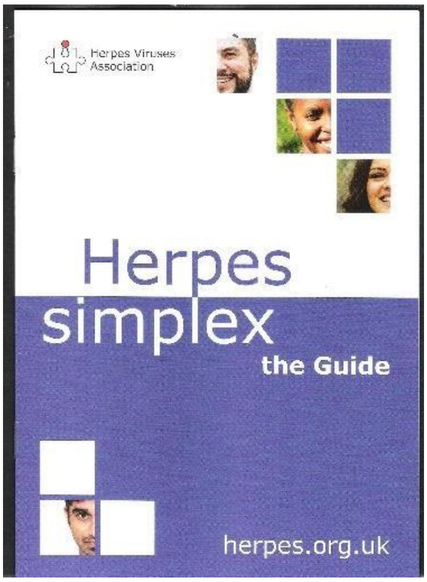
Herpes Simplex - the Guide

Our 16-page, 6000-word A5-sized booklet is now in its 14th edition - with a preface by our patron Dr Phil Hammond. It is endorsed by two other expert doctors working in NHS sexual health clinics.

It is written and updated by office staff with input from the helpline volunteers and members. This ensures it is relevant to what patients need, and easy to understand.

People can buy this on our website shop in two formats: posted or e-version.

Mainly, it is sold to sexual health clinics who to give it to their new patients. After a huge drop in sales, the orders from clinics are now rising towards previous numbers.



Herpes Viruses Association

Herpes simplex

the Guide

herpes.org.uk

Additional services are provided for members

Leaflets

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

Health & care information you can trust

The Information Standard Certified Member

Although the Information Standard (TIS) has now been discontinued, along with other charities we continue to display this as it was 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 of any item is available on request. All materials 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.

Journal - Sphere and mini-SPHERE

Sphere is a quarterly journal, 16 A4 pages for print version, and separately formatted for email recipients. It 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.

Since June 2021, we have added a ‘mini-SPHERE’ that is sent to members on the 1st of the months when we do not publish the journal. This email publication includes ‘flash news’, for instance about research trials, and articles that may not be specifically about herpes simplex such as on ‘dating’ or ‘talking about STIs with your children.’

Thanks, looking forward to reading all the material - keep up the good work! You're doing a great job, much needed. Doug, 11/10/24

I just became a member! I really appreciate all of the advice you've given to my partner and me, so "Thank you!!!" Sarah, 1/6/24

Thank you for getting back to me so quickly - Happy to continue my support for as long as HVA keeps going - which I hope is for many years to come!
I’ve been a member for a long time, and I want to say thank you to you all - I have been helped by you and the team and had my eyes opened to understanding what Herpes is and how to best to manage it. Jemma, 28/5/24

Meetings just for members

As well as the secret, members-only Facebook page mentioned on page 12, we have more services for members:

Annul seminar: a talk from sexual health doctor

This yearly event is offered on Zoom so that members anywhere in the country can attend. Each year, a consultant from a sexual health gives a talk based on their clinical activities with people who are diagnosed with genital herpes.

We record the talks to share with the members who cannot attend on the day – and the talk is reported in detail in the members’ SPHERE journal, so that everyone can benefit from the event.

Our members are always very glad to hear directly from doctors in the sexual health medical profession.

Study Days

“The Assurance Day” is a full-day’s seminar and is provided virtually. Over the year, we offer four of these. They are limited to 16 attendees so that people can have the individual attention they need.

I was touched by your kindness to strangers, and you have probably no idea just how impactful your Saturday Zoom-day has had on me.
Thank you for your service. Best wishes
Patrick, with £1000, 4/2/25

I just wanted to say a massive thank you for everything yesterday. I found the whole day so helpful, and I really appreciated the opportunity to speak so freely with you and gain such clear and kind assurance! Laura 19/5/24

The aim of the events is to provide the information and inspire the confidence that members need so that they feel able to talk about genital herpes with new partners. This anticipated difficulty is one of the most frequently repeated fears, as is shown on the helpline topic chart on page 13. These events are assessed by the attendees and averaged >4.8 out of a possible 5 points across several measures.

- Continued on page 17

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 can continue long after shingles blisters have healed. We promote vaccination to lessen the burden of ill-health the virus causes.

Shignrix, a vaccine to help prevent shingles, continues to be provided to people from age 70 to 80. From September 2023, a new age group has been added to the vaccine programme: people who reach 65 after from September 2023 are eligible. This caused much confusion and had to be explained repeatedly.

Research

- The ATHENA trial continues to ascertain if post herpetic neuralgia (chronic pain) is less likely when newly diagnosed people are given amitriptyline before onset of pain. We are on the steering committee for this UK study.
- We are also on the trial steering committee for the ZosterFluCOV trial, to see if giving more than one vaccine at the same time is acceptable.
- We sent a mailout to 186 shingles contacts to invite them to take part in "Global Patients Collaboration."
- Researchers contact us regularly to advertise for people with pain to take part in their surveys. We post these on Facebook pages, and they reach over 2.5K people.

We send out a 17-page information pack setting out treatment options, including details of medical treatment 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, do not 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 above information is available on our www.shinglessupport.org.uk website.

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

> Thank you so much for the info pack which is really helpful and gives me information to share with my GP.
> I will be giving a donation as your society gives invaluable support.
> Victoria, 20/9/24

Private individuals are helped directly and personally. The numbers are very much higher this year:

- 707 phone conversations, mostly re-treatment of PHN, and vaccine eligibility.
- 124 print and 61 email versions of the information pack were sent out.
- 59 people had their problems dealt with only via emails, often a long series of messages.
- West Hampstead Women's Group were given a talk on "Shingles and the Vaccines"

> I'm so impressed that you replied almost by return. Thank you very much. I can see there is a wealth of help and advice on the website. Margaret, 11/10/24

Our director, Marian Nicholson, is also an active trustee on the board of an umbrella group for the pain charity:

- Pain UK - with 46 pain charity members and over 1,200 individual members. Marian co-ordinates the news alerts and newsletters.

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Who does what: staff and volunteers, monitoring and training

< Marian Nicholson with her newly awarded MBE and Cameron Poole after the award ceremony in St George's Hall, Windsor.

The HVA has two full-time staff who work staggered hours and have overlapping duties.

Marian Nicholson works from noon to 8 pm. Cameron Poole works 8 am to 4 pm. This schedule allows for a more comprehensive service to the public: when volunteers are not available Marian and Cameron are available to answer helpline calls over an extended period.

They are the usual hosts for the three 'chats' each month, in London and on Zoom.

They also answer calls and responding to Facebook Messenger enquiries - sometimes in their own time. This also helps to keep them aware of the current patient concerns.

Volunteers are essential to our helpline service. They work from home and log into the switching service for their 'shift'.

- Our helpline volunteers are trained and then join the roster which covers weekdays 9 am-8pm.
- One new volunteer, with a total of 5 over the year
- Helpline volunteers are supported by telephone with their original trainer.
- Email updates containing facts and helpful suggestions are regularly sent to our helpliners, keeping them abreast of news, and giving them ideas for how to explain the condition and minimise its impact on life.
- Monitoring of helpline services continues at all levels.
- Helpliners complete a log to feedback the topic covered (see page 13) and to enable supervision of the service as well as providing pointers to further training.

In the office, five volunteers have assisted with various admin tasks at different times over this year.

Executive Management Committee

The association was registered with the Charity Commission in 1985. The Executive Management Committee (trustee board) is elected from the membership at the Annual General Meeting. Trustees meet monthly to oversee the work of the association, direct its future, and approve exceptional expenses. During the year, three trustees resigned so that there are currently seven members, two of whom are male.

A Charity Commission dispensation permits us to not show the names of the HVA's committee members on their website. Neither are they shown on the HVA's website, this Annual Review, nor in the Annual Reports and Accounts.

Patrons

We have seven patrons. Six of them are sexual health doctors:

Professor M W Adler, CBE, MD FRCP FFCM
Dr David Barlow, MA BM FRCP
Dr B A Evans, FRCP
Dr Raj Patel, FRCP
Professor Colm O'Mahony, MD FRCP BSc DIPVen
Professor Simon Barton, MD FRCOG FRCPEd FRCP

And one is a 'media' doctor as well as a GP/paediatrician:

Dr Phil Hammond, MB BChir MRCGP

Funding for 2024-2025

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.

Regular sources:

A survey found that, each year, about one third of our members who are 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.

Membership fees raised £17,253.69, a £1,300 decrease on the previous year. We have had declining membership in recent years, so we will be focussing on recruitment as this is a sustainable source of income. People subscribe for an average of two and a half years. This may be improved as we have been sending monthly email updates (as well as the previous quarterly journal;) to encourage member-retention. Over fifty of our members have set up regular monthly donations by standing order of varying amounts between £2 and £30.

The first year's subscription fee is £30, with renewal costing £25. Membership numbers were higher before the internet age. The lower total today reflects the increased availability of useful advice and information on our website which is provided free of charge because it is needed to counter a torrent of badly written web pages and outright misinformation about genital herpes that is found online.

Donations were satisfactorily improved from last year: £23,000 We continue to encourage service users (on phones, emails, website) to be generous with donations.

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 £21,000 gross profit – that is without making allowance for cost of writing, designing the booklet and sales administration.

> I just wanted to leave some feedback for a couple of the products in your store. I have suffered with cold sores for most of my life and vividly remember the agony of my first breakout when I was an adolescent. I have tried multiple products to reduce and ease the pain of subsequent reoccurrences both over the counter and prescription.
>
> I stumbled upon HVA quite by chance one evening and immediately purchased both the LomaProtect balm and Lomaherpan cream. I have been using the LomaProtect daily as a lip balm for 5 months and only had one cold sore (very soon after at the beginning of October). At the first sign I applied Lomaherpan and was amazed. The cold sore stopped developing, it did not blister, burst, or scab. It dried out and healed completely painlessly within a week and a half. I cannot quite express the gratitude and relief I have for having found this. I have not had a recurrence for four and a half months and counting. Thank you for all the work that you do, it is most valuable and necessary. Tom 10/1/25

> I just wanted to thank you for introducing me to Lomaherpan. It has made a huge difference to the horror of cold sores.
>
> Long story short, I’ve been getting cold sores for 40 odd years. My whole bottom lip swells, … I have to take a week off work. The pain goes under my jaw and down my neck! But now, the moment I feel the cold sore start I use the cream and that stops the cold sore in its tracks. No swelling, no weeping and no scabbing, and I don’t have to take time off work. Again, thank you for your help. Patti 27/10/24

Corporate donations/payments:

We continue to have two regular sources:

- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £700 this year.
- A clearly identified advertisement on our website links to MedExpress, approved by the Care Quality Commission to sell antiviral drugs. This sponsored link raised £10,800.

We arranged for another advertisement on our website:

- A mention on the ‘treatment page’ links to a second such online licenced antiviral drug source, DrFox pharmacy, raised £2,500.

Trusts

We received unsolicited and unrestricted donations of £1,500 from Druces LLP and £2,000 from The Aitchison Charitable Trust. We will continue to ask for grants from charitable trusts and we are optimistic that this avenue may prove productive in 2024-25.

Fundraising challenges because of the stigma associated with genital herpes.

Fund-raising specialists we have consulted (when they are offering free advice) have agreed that the HVA is hard to place as a charitable cause with a company: there is no PR gain as the herpes stigma will not create a favourable impression with their investors or customers.

Similarly, organisations such as the Round Table, Rotary and Freemasons have, so far, been unwilling to encourage their volunteers to fundraise for a ‘herpes’ charity because of the associated stigma.

Charities are expected to encourage beneficiaries/members to assist with fundraising. Our members are not willing to do so because it would require them to ‘go public’. Theis means that the usual community fundraising activities such as undertaking sponsored runs or other kinds of challenges are not going to happen.

Therefore, we are very glad of 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 via several links on the HVA’s website. This year, these donations were up by about 18%.

- All donations amounted to £22.671.
- Specifically, ‘DONR text-giving’ raised around £111. People can donate on their phone.
- Donations also include funds raised via www.EasyFundraising.co.uk. This is an online portal that will take users to over 7,000 online shops including many well-known companies (including Asda, InterFlora, M&S, Travelodge, Zizzi). A percentage is donated to the charity chosen by the shopper. We ask all the people we help to nominate the Shingles Support Society as their designated charity when shopping This year we have received £263.

About the accounts for 2024-2025

The accounts for 2022-2023 were signed by an Independent Examiner: Josh Botham of Josh Botham Tax & Accounting Services Ltd.

Gross income: £ 162,826
Expenditure: £165,649

Income is £9K more than last year, expenditure is £9K less.

We are still benefitting from a £76,518 legacy received in 2022.

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

Exceptional receipts
The claim made 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 HVA'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 bought 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 four months and to cover redundancy payments to staff.

Our reserves figure is updated annually in line with inflation and changing redundancy costs. For the year 2024-2025, the target of £86,320 has been met.