



Herpes Viruses
Association

Annual Report 2021

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

Herpes Viruses Association Annual Report April 2020 to March 2021

Welcome from the Chair	3
Who we are	5
Why we exist	5
Providing reassuring and supportive information about genital herpes	6
Providing medical information:	
- to the public	7
- through media	7
- to the medical professionals	8
Our services:	
- for the patients and public – directly	10
- our website, emails, phone calls	11
- extra services for members	13
Working with others	16
What we do for patients with shingles pain (post-herpetic neuralgia or PHN)	15
Who does what: staff, volunteers and trustees	17
Funding and fundraising	18
About the accounts	19

Letter from the Chair

Welcome to the Annual Report for 2020-21 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, which has been called the second most stigmatised of all diseases after HIV [Harris Interactive USA poll, 2007]. Yet the viruses that cause it - herpes simplex, types 1 and 2 - are very common. The infection is rarely serious and 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). 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, rather than on the genitals where it is stigmatised. Because there are different names for herpes, 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.

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 us for support and are helped in a number of ways. HVA's website has become the first point of contact for many patients, especially the newly diagnosed. Clinics and doctors recommend it. Free Google AdWords help people find it. We are becoming increasingly active on social media: Instagram and Twitter.

Our research into patient experience was published in the peer-reviewed professional journal ***International Journal of STD and AIDS***.

Our new Zoom chats, twice a month, are incredibly popular with extra sessions scheduled when the list of attendees gets too long:

May I say how helpful I found the Zoom meeting on 6th February. It was my first time after 20 years of living with this virus and I am only now accepting it and trying to live my life. I'm so grateful that there is a support group for people like me who have struggled and are struggling with their diagnosis. Woman, February 2021*

* We promise anonymity to everyone who contacts us.

Our helpline continues to offer callers the chance to talk to a sympathetic, well-informed friendly voice. Our office staff also take helpline calls – to keep themselves informed of service users' concerns – and they also train the new volunteers. We are very grateful to all these volunteers and would welcome more!

The quarterly online journal, Sphere, is sent to 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 talk to partners about it.

These days can be life-changing for the participants and have empowered many people to overcome the loneliness caused by herpes stigma, 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 the public-facing Facebook page. Ensuring accurate information is

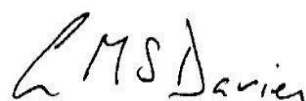
shown on national websites is a priority. The years of experience we have had gives us an insight into how people misinterpret what they read. We constantly check such websites and advise them how to improve wording for the public's comprehension.

Our other main activity is advising patients on the treatment of post shingles pain (PHN) caused by herpes zoster. This is delivered through our subsidiary organisation, the Shingles Support Society.

This year we said 'goodbye' to Nigel Scott who retired in July 2020 after over 22 years of continuous service. His contribution to our literature and lobbying power has been considerable and his reassuring advice to thousands of callers and visitors will not be forgotten. We are grateful that he will remain in contact if we need to call on him.

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.



G Davies
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. Our trustees are nearly all patients, and we have 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 13.

Why we exist

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

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

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 – increasingly as cuts are made to these services around the country
- National Sexual Health Line (Public Health England)
- 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 genital herpes diagnoses made in sexual health clinics for 2019. These are the most recent available:

There has been a 2% rise in the number of new diagnoses (34,570 in 2019, 33,867 in 2018). However, there was 4.7% rise in all diagnoses from 2018 to 2019.

There are no newer statistics from the UK. However, despite the pandemic, several European studies reported an unchanged incidence of STIs for the first half of 2020.

Unlike other sexually transmitted infections, diagnosis depends on access to a sexual health clinic when symptoms are visible. A reduction in ease of access can 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' was a result of a US advertising campaign to persuade patients to ask their doctors for a prescription when the new drug was marketed in 1970s [Cuatrecasas 2006]. Treatment is usually optional as genital herpes heals on its own. This 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. New patients routinely turn to the web for information. Most of what they find is either wrong or overblown. Websites selling potions and lotions 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.

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.

'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 used as a synonym for 'something really bad'.

People find these comments when they google 'herpes':

[INQUIRER.net](https://www.inquirer.net) 19.1.21

Like a **herpes** simplex virus that causes recurring mouth sores, the House of Representatives is again attempting to amend our Constitution.

<https://thehill.com/> 3-12-20

He's like **herpes** — there might be blossoms of him where we have to take Valtrex. We have to take it to keep the Trump blossoms down.

[ScienceDirect.com](https://www.sciencedirect.com) 26/10/20

'I love James Blunt as much as I love **herpes**' – 'I love that you're not ashamed to admit you have both':

<https://www.nerdsandbeyond.com/> 19/9/20

Throughout the entire four minutes of the video, Gubler also drops a few iconic lines of his own, "I'm like **herpes**...but charming **herpes**."

[TheOaklandPress.com](https://www.oaklandpress.com) 21/9/20

Not **herpes**-and-death badly, but, like, very badly. Dejected and drunk, Lucy slumps...

[Breitbart.com](https://www.breitbart.com) 10/9/20

As a curse: "Eat a giant smoking f***ing d**k that has herpes," she said on one video, posted by investigative reporter Drew Hernandez.

[American Council of Science and Health](https://www.acsh.org/news/) <https://www.acsh.org/news/> 31/7/20

Conspiracy theories are like **herpes**. Once a person is exposed, he's infected for life and cannot be cured.

[Mirror.co.uk](https://www.mirror.co.uk) 13/7/20

Brexit isn't mentioned once. It's a dirty word, these days... But like herpes, it hasn't gone away. It's merely quiet, and at some future date an ugly manifestation of the thing we've forgotten about is inevitable.

<https://www.forbes.com/> 29/5/20

40% of Americans incorrectly think herpes is deadly, according to a study (1000 people interviewed). The survey found that a third of respondents overall believed that herpes couldn't be passed on to other people.

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.

A new threat:

Online clinics offer private antibody tests. These purport to show whether a person is 'clean' or carries herpes simplex virus antibodies. Despite the authoritative CDC (in the USA) and NHS stating that this antibody test should be avoided, these clinics' advertising is persuasive - so people pay for it. However, one in ten positive results is wrong and up to three in ten negative results is wrong [De Vries, H. 2016].

The test result is given with no counselling, no explanation of 'what this means.' People then contact the HVA. We explain the inaccuracy of the results, that it cannot tell where on the body the virus might have been caught, and that a positive result does not mean that any symptom the patient is worried about is caused by herpes.

TV, radio, newspapers, magazines, books - podcasts...

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.

Useful stories countering the stigma

Heartbreak, hope and Herpes: What it's actually like to have an STI. [Stuff.co.nz](#) 10/2/2021

"At 43, and knowing what I do now, I'm kind of surprised herpes hasn't popped up in my life before now.... But if I do hear anyone joking about herpes I'll have no qualms gently sharing that it's an infection I have – and they could easily have too."

HSV diagnosis doesn't need to doom love life [Clinton Herald](#) and syndicated widely. 16/9/2020

Everything You Need to Know About **Herpes** and How to Get Tested for It [Shape Magazine](#) 05/06/202

But the worst thing about herpes? The stigma. We've got *Time Magazine* to thank for that. When herpes graced the cover of the August 1982 issue headlined *Today's Scarlet Letter* – it stated:

"...frequently, herpes seems to strike nice, healthy, educated, clean-cut Caucasians of the middle and upper classes" amongst numerous other journalistic malpractices.

"THE HORROR. WHITE PEOPLE GET HERPES! AND NICE PEOPLE TOO!" [sic]

That article, published almost 40 years ago, has played a significant role in how herpes is perceived in popular culture today e.g. badly and falsely.

Since then, herpes just hasn't managed to shake its hideous reputation."

Journalists working in any form of media 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' and 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 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](#). This, and other shorter clips giving personal comments on aspects of living with this condition, have been placed in our website itself - where the text is appropriate. People have commented positively on these - see 'call out'.

This charity was a lifeline when I was first diagnosed with HSV2.

I'd like to thank Marian for her really reassuring, frank and informative video, and for bravely putting her face to a charity few would choose to. I was devastated when the doctor said she thought I had herpes because I was totally ignorant about it. The doctor recommended this video and charity for information, which did much to reduce my anxiety and removed the negative stigma.

Fortunately, I watched it before I got my result. I might well have assumed my partner had been unfaithful but realised by our mid fifties its far more likely that I'd contracted it years before, and that what I thought was a sensitivity to washing powders may have been earlier mild attacks. Its incredibly important not to cast blame or, assume your partner has been unfaithful, or knowingly infected you, the virus can lie dormant for years and be suddenly triggered.

I had two tiny white spots the size of a pin head each, if I had been single, I'd have ignored it. Don't frighten yourself by looking at photos of the rare extreme cases and use this site for correct, reassuring information. For many the symptoms are so slight they don't notice.
Woman March 2021

The medical angle for health professionals

No legal requirement to disclose (but it makes sense)

We encourage disclosure for many reasons. For instance, it has been shown that when a partner has been informed, the rate of transmission decreases 12-fold. However, since two out of three people with herpes are unaware that they have it and suffer no ill effects, we do not believe that those who have had the misfortune to be diagnosed should be forced to disclose their status, as long as they behave responsibly.

As a symposium for sexual health doctors in September 2020, we were pleased to hear a legal expert state that:

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

This has since been repeated by two other legal experts. Despite this legal fact, newly diagnosed patients are still being told that they must disclose by medical staff.



An article we wrote with Dr Nigel O'Farrell was published in the peer-reviewed *International Journal of STIs and AIDS*, Nov 2020.

It details patients' experience based on two surveys we have conducted with the members of the charity, the first in 2015 and again in 2007.

Research - we have helped find candidates for medical research

Since suffering from recurrences is a fact of life for some patients, initiatives seeking to develop treatment alternatives to the current antiviral medication are welcome. We have helped provide the volunteers for two researchers:

Chickenpox vaccine for HSV?

Dr F. LeGoaster, in France, reported her trial which showed that the chickenpox vaccine, Varivax, could reduce the number of recurrences of genital herpes that patients were experiencing. It was a small trial and should be repeated.

We worked with Dr Bret Palmer, Reading Hospital, to recruit patients for his follow-up research, via our Facebook pages as well as directly advertising to our members.

Natural powders?

EBDT powders containing spirulina and colostrum as nanoparticles have been sold by Dr Luc Moudon in Switzerland for several years with excellent results in preventing outbreaks of genital herpes. He had anecdotal reports informed by feedback from over one hundred satisfied customers.

He wished to do a double-blind, placebo-controlled trial and we recruited 100 people to receive either placebo or real powders. The result showed a very small, but significant result.

Virtual conferences and training for health professionals

International Union against STIs (IUSTI) virtual conference, September 2020



Our director (top left) was invited to join Professor Simon Barton MD FRCOG FRCPEd FRCP, (top right) and Ceri Evans, the BASHH health adviser spokesperson (below), to make a presentation about reducing the stigma on herpes simplex. This was well-received by the conference delegates from the UK and Europe.

Training the frontline staff - now virtual:

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.

The HVA offers training talks for the staff at NHS sexual health clinics on “*Counselling Patients with Herpes Simplex*”.

One of the introductory slides of the accompanying PowerPoint presentation 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.

This talk is popular and doing the session on Zoom has meant that we are able to address more clinics that when we were travelling to give the talks in person. The feedback scores from clinic staff are always around 95%.

"Great presentation, and very informative, thank you."
Doctor, after a session organised by Cobridge STI clinic.
"This is very useful. I will be using it with patients."
Health advisor, after a session for Chelsea & Westminster Hospital

Because the staff understand our work, we are finding that more clinics are referring patients 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.'

Phone call to the helpline - May 2020:

"The GP tells us that this diagnosis means that one of us has been unfaithful. But we know that we have not. So, how else could it have appeared like this?"

The helpline volunteer was able to explain that **either** it was caught long before they became exclusive, **or else** it could be caught off a cold sore via oral sex.

When patients are diagnosed by GPs they may be given incorrect advice. For instance, the doctor may not know that, unlike other sexually transmitted infections, herpes simplex can appear, and be diagnosed, many years after infection.

Working with other organisations

We are providing one of the six sessions that form a service for women who have psychological issues arising from their diagnosis of genital herpes which is run by the Psychology Department, UCL. Since the pandemic, this is now a virtual event - but still includes lively discussion.

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

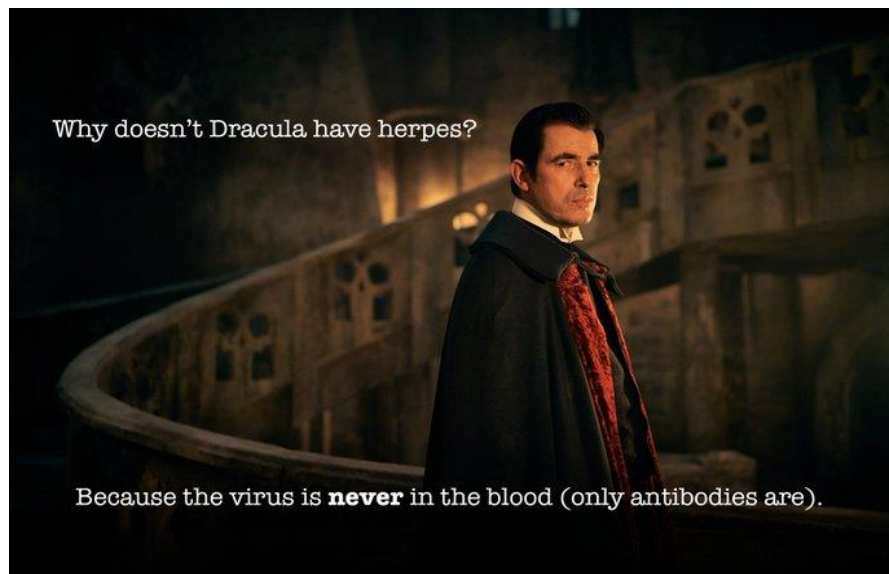
Twitter

Our long-standing Twitter page @HerpesUK was set up to inform medical professionals.

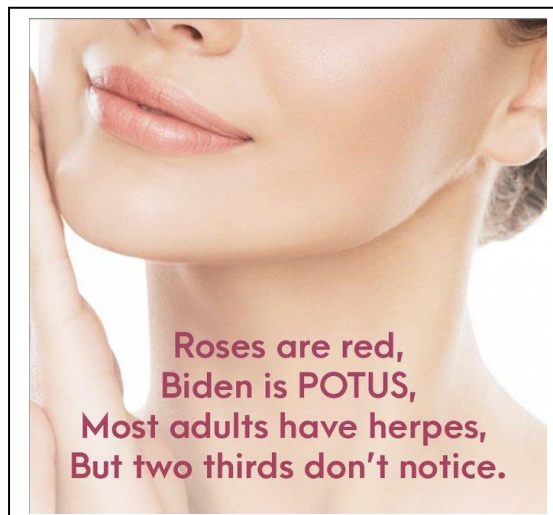
We have now launched a new Twitter account @DebunkedHerpes. This is aimed at the public.

>

October 2020 (one of five tweets that month)



> **February 2021**
(one of six tweets that month)



Instagram

We run an Instagram account @HerpesAdvice which promotes the service and shares articles and a second one @DebunkedHerpes that debunks myths.

May 2021 >



Continued...



^ January 2021



^ January 2021

Meetings for the public and members/subscribers

Previously, support meetings were hosted by office staff and volunteers at a central London venue: details are on the 'Events' page of the website and are updated regularly.

By May 2020, we had learnt how to host meetings on Zoom. We have also been running virtual consultations for individuals and couples.

At first, for the group events, we offered two hours on a Saturday, mimicking the 'social meetings' that we had offered before the lock-down. But by November, there was an obvious need for a two-hour session on a mid-week evening.

These virtual chats are very popular because distance is no longer a barrier: people from anywhere can join in. We average 15 people requesting the link for each event.

I joined the Zoom call last month and found it both interesting and useful hearing from other people in the same boat as me. Am I able to join again for the April meeting please?
Man March 2021

You guys are wonderful! I have never reached out to you, but the moment I did a few days ago for the drop-in meeting, I realized how amazing you are and how reachable! We need you!
Woman March 2021

Really appreciate all of this and the zoom last night too. Looking forward to the next meeting and hearing more experiences and learning more too.
Woman, Dec. 2020

I just wanted to say thank you to you and your team for the zoom session on Saturday. I found it so useful and was really moved by the honesty of some of the members. I really appreciated the session and just wanted to say thank you.
Woman Feb 2021

Previously, the 'herpes stigma' meant that people would tell us they did not dare attend in person. At our virtual meetings, between 30-50% of attendees do not show their

faces and (mostly) 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 it is a seminar with the host providing the standard facts.

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.

Website – <https://herpes.org.uk> - 390,000 unique visitors this year

Our Google Ads (free to charities) generated 8.73 million impressions.

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:

... by exploring the site and found it very interesting. I especially like the research section of the quarterly publications.
Woman, Feb 2021

I really can't show you how appreciative I am for your help and now I have the peace of mind and closure in my head too just get on with my life/relationships, to stop obsessing and being a health freak and realise it's just a poxy cold sore LOL and that the hsv-1 I have is a negligible problem, that it's no difference where it is on my body.
For years I've held back on my life over something so silly, I also am a healthy kid, non smoker and rarely drink alcohol as which seems to be a trigger but I don't want to bore you with my life story, I'll definitely be making a donation and I just want to say God bless to you all and nothing but the best wishes to you, you'd be very surprised how far your words and help go along way in people's life's.. your helps been 5 stars and I wish I reached out to you sooner and not suffered alone, I just hope for other people suffering that they can find your organisation and talk too your self instead of googling all the Bull**** on the web making them suffer even more mentally. Hope I haven't sound like a nutter LOL. No worries for a reply, i just wanted to show you how grateful I am for your help.
Man, Feb 2021

Emails – info@herpes.org.uk - 1345 email threads.

Despite the comprehensive information provided on the HVA's website, we also individually answered 1345 emails, many of which had were long threads with detailed questions about transmission or the risk of rejection and required a great deal of reassurance. These personalised replies frequently elicit 'thank yous.'

Thank you for your reply once again, a huge weight lifted off my shoulder with the relieving information you provided me with... It's not really a risk like you said or important and a state of normality... It's great to actually hear solid information like that from the best providers as of yourselves, I have been looking for the closure for years I guess but I was a bit to embarrassed to reach out to great people like yourselves over something which is harmless. Thank you again Woman, March 2021

... I don't even know what to say. A million thank yous just don't seem enough. I can't describe how much I needed to hear (read) what you wrote in your email. Thank you, from the bottom of my heart for getting back to me. Woman, Feb 2021

Facebook

There are many herpes-specific Facebook pages for people with herpes. Most of them are 'semi-public'. We have joined four of these so that we can correct misinformation being shared and offer sensible advice.

For our signed-up members we run a totally secret Facebook page, which has over 250 members. This provides a 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.

Thank you Marian. I love your answers. I've messaged you before. Woman March 2021

Helpline (0845 123 2305) - over 2,250 callers this year* - averaging 9 callers a day.

* 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.

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 75 (these ages are volunteered, we do not ask) with the average being 35.8 years.
- Callers can talk for as long as they wish.
- Calls average 12.2 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 spoke to you on the phone yesterday and you have really helped me not to feel anxious anymore, I feel like myself again! It's amazing what you're doing to help people move on.
Woman March 2021

I have been meaning to email in regard to a phone call I had with one of your helpers on the helpline the other day. I want to say thank you for your help, having recently been diagnosed with HVS2, I felt my world had ended and now I just want to educate and raise awareness.
Woman March 2021

Just a thank you for providing great advice for my daughter who is suffering from anxiety from her cold sores. I have called twice and the support we have had is second to none. Thank you. I hope this little donation helps.
Woman March 2021

I have since called and spoken to you regarding this. Thank you very much for your advice and for the book recommendation! Have a great day :)
Woman Feb 2021

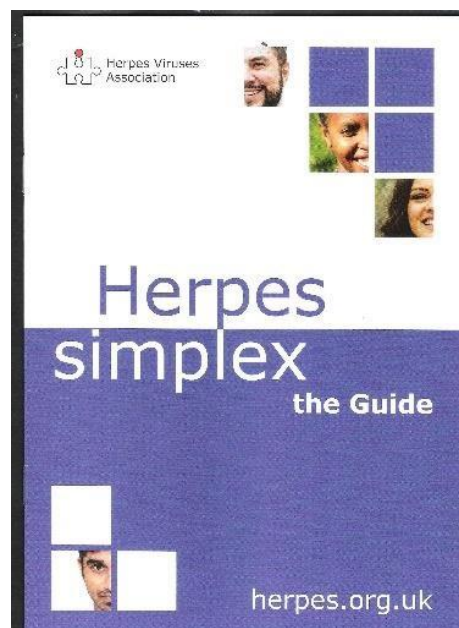
On our anonymous donation platform: Ms X wrote "Your helpline service is invaluable thank you: £50.00"

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, but mainly it is sold to sexual health clinics who give it out to newly diagnosed patients. In the financial year to March 2021, we sold only around 2000 copies as clinics were closed due to the pandemic. (Previous year: 6995 copies.)



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 two that deal with "Talking to a New Partner".

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.

Thank you so much for your fast response, you must help so many people out there like me. I use the cream regularly and I can't recommend it enough, I used it this time around and no sore appeared at all!!
I will try the other remedies on your page [Tips to prevent recurrences] and see how I go.
Thanks for your support, you don't realise how comforting it is to speak to you.
Woman March 2021

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.

Thanks so much for such a friendly email and all of this information!
Woman March 2021

Thank you so much for all the support.
Such a great organisation to help with this diagnosis.
Woman February 2021

Meetings just for members

As well as open meetings mentioned on page 10, we have more services for members.



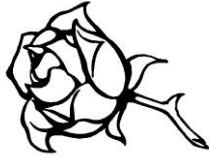
Above: Prof. Colm O'Mahony has just warned us that, when using silicone-based lube, to be very careful, otherwise "you can start making love at the top of the stairs and end up having sex on the door mat!"

Study Days: "The First Day of the Rest of Your Life" workshops moved on-line and over the year, 45 people attended these events. The aim of the events is to 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 >4.7 out of a possible 5 points across several measures.

Expert's talk: This yearly event was even more popular this year as 53 people signed up to attend via Zoom.

We recorded Dr Colm O'Mahony's talk and shared it with the members who did not attend on the day. It was also reported in detail in the members' SPHERE journal, so that everyone can benefit from the event.

I've got up today with a completely different mindset, attitude and outlook so I'm really happy I joined the "Day", already I feel it's helped me, I just wish I'd come across HVA sooner. Woman, October 2020



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 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, 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.

Zostavax, a vaccine to help prevent shingles, is now available to people from age 70 to 80. The catch-up process for those between 70 and 80 is complete. Take-up has recently been falling and we are now working to reverse this trend.

Private individuals are helped directly and personally:

- 205 phone conversations. Topics included transmission, treatment of PHN and the new vaccine to prevent shingles.
- 105 people received the information pack as well as personalised information.
- 57 people had their problems dealt with only via emails, often a long thread.

Thank you for all. Wish that I had found you earlier. I have done a £20 donation on your website. Man, Oct 2021

The information you have sent us is really helpful. I shall take it with me to the GP next time I have an appointment and discuss using this medication. Woman, August 2020

This year we wrote an article about shingles that was published in Northern Ireland Healthcare Review, the Scottish Pharmacy Review and Welsh Pharmacy Review. Two journalists interviewed us in February 2021. Andrew Greaves contacted us for News Associates and Kate Oxtoby quoted us in an article in GM Journal for medical professionals.

Researchers contact us regularly to advertise for people with pain to take part in their surveys. We post these on our Facebook page, and they reach over 650 people.

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 32 pain charity members and over 1,400 individual members who receive alerts and newsletters.
- Pain Alliance Europe – Marian gave a virtual presentation on behalf of PAE at the EFIC pain conference and attended meetings by Zoom. PAE is active with the EU's MEPS' special interest group on Brain, Mind and Pain. PAE has 42 charity members from all over Europe. She is also involved in the steering group for the Societal Impact of Pain.

***What did you think of
the Study Day?***

You really helped me to recover mentally after being diagnosed; I went from thinking it was the end of the world to something that doesn't need to affect my life massively, so I really appreciate that.
Woman March 2021

Fantastic. I should have come years ago! Woman March 2021

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.

As on previous years, we were provided with a free place at the annual (virtual) conference of the British Association for Sexual Health and HIV (BASHH) for a member of our staff.

As mentioned above, we have a representative on the BASHH Patient Panel. This panel met virtually to critique all BASHH leaflets as well as advising on other aspects of BASHH's outward-facing activities.

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

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

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

- British Association of Dermatologists' Patient Support Groups – this enables us to work with many other professional bodies, e.g. British Dermatology Nursing Group, the British Skin Foundation, pharmacists, as well as the pharmaceutical industry.
- '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.

In July, Nigel Scott retired (left with Marian) and was replaced by Cameron Poole (below).

Marian Nicholson, director, works from noon to 8 pm. Cameron Poole works 9 am to 5 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 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 four helpline volunteers. These work from home as they can log into the switching service for their 'shift'.

With the first lockdown, the volunteers who were coming to the office to help with administration tasks stopped and were not available again until November 2020.

However the very important task of being pilot readers for our leaflets when they are created or updated has continued by email.



- Our helpline volunteers are trained and then join the roster which covers weekdays 9 am-8pm
- Helpline volunteers are supported by telephone from 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 subjects covered and to enable supervision of the service as well as providing pointers to further training.
- On pause: 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.
- 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 (trustee board) 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 thirteen members, three of whom are male.

The Charity Commission has given a dispensation so that we do not show the names of the HVA's committee members on its website. Neither are they named on our website.

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 2020-2021

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 choose not to renew state that this is because they are now in a relationship and therefore "having herpes" is no longer an issue for them.

Membership fees raised £25,848.00 - a useful increase on the previous year's £21,627. We can speculate on the cause: on the helpline, we have been encouraging people to subscribe; we have been sending more emails to encourage member-retention; or perhaps it is a silver lining of the pandemic. Over fifty of our members have set up regular monthly donations by standing order of varying amounts between £2-£30.

The first year's 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. This is needed to counter a torrent of badly written web pages and outright misinformation about genital herpes that is found online.

Donations were down £24,622 (from £28,942). We continue to encourage service users (on phones, emails, website) to be generous with donations.

Just a donation for the fantastic ongoing work of the charity. No goods needed. Man Feb 2021

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 £20,000 gross profit – that is without making allowance for cost of writing and designing and sales administration.

Corporate donations/payments:

This year we have two sources of regular payments:

- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £1168 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.

Fundraising

Challenges because of the stigma associated with genital herpes:

Consultations with fund-raising specialists have indicated that the HVA is hard to place as a charitable cause with a large company: there is no PR gain as the herpes stigma will not create a favourable impression with customers. Similarly, organisations such as the Round Table, Rotary and Freemasons have to date been

unwilling to encourage their volunteers to fundraise for a 'herpes' charity because of the associated stigma.

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 via several links on the HVA's website. These include MyDonate, a free service which is popular as donations made via this website can be anonymous.

We 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 we help to nominate the Shingles Support Society as their designated charity. This year we have received £394.

We have an Amazon Smile account too - again using the name Shingles Support Society. This raised £75 in the year.

Trusts

We received an unrestricted donation of £1,500 from Druces LLP. We will continue to ask for grants from charitable trusts and we are optimistic that this avenue may prove productive in 2020-21.

About accounts for 2020-2021

The accounts for 2020-2021 were signed by an Independent Examiner: Josh Botham of Josh Botham Tax & Accounting Services Ltd.

Gross income: £160,835

Expenditure: £144,032

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 brought to the attention of the Charity Commission.

Taxation

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

Reserves policy

In line with the recommendations of the Charity Commission, the Management Committee has formulated a Reserves Policy to enhance our medium-term security, taking into account the different levels of predictability of the various income streams. We aim to hold a contingency reserve as a buffer to cushion us against an uncertain future. Strategic reserves are to enable the charity to continue with no further support for a period of up to 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 2020-2021, the target of target of £86,320 has been met.