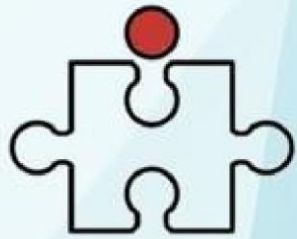


Annual Review



Herpes
Viruses
Association

2023

Registered charity 291657
Established 1985

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Herpes Viruses Association Annual Review April 2022 to March 2023

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Letter from the Chair

Welcome to the Annual Report for 2022-2023 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 many ways. HVA's website has become the first point of contact for many newly diagnosed patients. Clinics and doctors recommend it.

Evaluation of our work

Many charities are able to give accurate results about the value of their services: their users provide feedback. Because of the stigma, we are asked "Is this service confidential?" and "Is posted material 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; there's a link at the foot of every page. We receive 100% "Yes" answers to the question "Did you find this website useful?" Over two thirds of respondents say their initial question took them straight to the answer they needed. One commented "It's the only honest website on this subject."

People who attend our meeting In London or on Zoom are given a link to a survey.

It is rare for helpline callers to fill in the survey. But of the 20 who have this year, 85% said they felt "much better" or "better".

Diversity

The anonymity of the people using our services means that we do not have details of the ethnicity or gender of our users. Helpline volunteers record only if the voice is male or female. Of course, sometimes these details, or the religion of the caller, are divulged by the caller to help personalise the advice they are seeking. This is recorded but it is too rare to be analysed.

Virtual support

Our Zoom chats, twice monthly, available to all, started during lock-down, have proved very popular and are continuing. The monthly 'real' meetings in London are also well attended:

I just wanted to say thank you so much for Sunday's session. Since I've been diagnosed, I'd cried every single day but since coming to your Zoom when I actually learnt about the facts rather than Google, I honestly feel like the old me again. Thank you so much for all your help. Also, I feel like Google is a real issue with making people feel down.
Lady* in January 2023

* We promise anonymity to everyone who contacts us.

Our helpline continues to offer callers the chance to talk to a sympathetic, knowledgeable, friendly voice. The office staff also take helpline calls as well as training new volunteers.

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

Some numbers:

6 training sessions (medical staff)
2 medical conference presentations
2 advising on revisions to medical guidelines
4 training sessions (patients)
2207 phone call sessions
745 email 'conversations' with patients
24 Zoom support sessions (for patients)
11 "in real life" support groups for patients
4 helpline volunteers

Services for members

Members are sent a monthly update on research and with motivational messages based on other people's experiences. The journal 'Sphere' is sent quarterly.

We continue to run our very popular Information Days, on Zoom. They enable members to gain a deeper understanding of how to combat symptoms and talk to partners.

This interactive tuition can be life-changing for the participants and have 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 to ensure that accurate information appears. Years of experience has given us an insight into how people can misinterpret what they read if it is unclear.

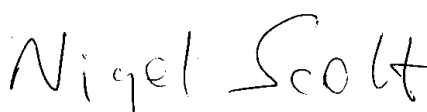
We offer suggestions on improving wording to aid comprehension.

Help for shingles patients

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 charity, the Shingles Support Society.

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.



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. 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 17.

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 2022.

A 5.3% rise in the number of new diagnoses since last year (21,892 in 2021 and 24,910 in 2022). 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 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 often used in the media as a synonym for 'something really bad'. People find these kinds of comments when they google 'herpes':

Jimmy Kimmel on Donald Trump's 2024 presidential bid: "He keeps coming back – he's like herpes"

NME – online 16/11/22

But unlike herpes, Pokerus is actually entirely beneficial.

The Gamer – online 18/11/22

ABC's Q&A guest compares PM Scott Morrison to herpes: Johann Hari

'Well, Scott Morrison seems a bit to me like **herpes**,' Mr Hari said to the shock of the live TV audience

Daily Mail – online 19/8/22

"Fact Check: The BBC has confirmed that monkeypox is an airborne form of herpes that is ..." and:

"The CDC has classified monkeypox as an airborne form of herpes that can lead to paralysis. It claims that the disease has been classified as a variant of herpes and that airborne infection can occur over a distance of 15 feet."

This made up 'fact' was reported all over the internet - 5-8-22

'My cat was slut-shamed by the vet after he contracted "feline herpes"'

Daily Star – online 17-8-22

Feline herpes is a respiratory infection, so the 'slut' slur was all in the owner's mind.

Izzie also receives backlash from people who tell her that her acne is her fault and that she has herpes ...

Techno Trenz - 15-6-22

He's about as funny as a herpes sore," Joy Behar groused in response to Amber Ruffin.

The Daily Beast 27-4 22

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.

NHS Choices video and video clips on YouTube and 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 our [YouTube](#) channel. 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 speech bubbles.

I have just been diagnosed with genital herpes. I watched the NHS Choices video by Marian, and it has made me feel so much better about it all. Thank you, Marian. Lady, February 2023

Thank you for the support & advice you have given to me these last few months - I have called you several times. You have helped me rationalise the situation and have helped me feel hopeful instead of fearful & overwhelmed.

I still listen to Marian's interview on Women's Hour if I feel myself slipping back into doom & gloom & it sets me straight and gives me that reality check that I need. I have also sent it to a few of my nearest & dearest as there is something so comforting about the way Marian says: 'completely normal life'. Also, the part about having unprotected sex for ten years is enormously powerful & at the risk of sounding a bit nuts, it's actually life changing. I honestly can't think of a more powerful myth buster than hearing Marian say that, and I am so grateful to you for sharing that with everyone.

What a fantastic service you are all providing. Thank you so much, you brilliant bunch. Lady, May 22

A new 6-minute video we made, has been posted on YouTube. "**What doctors should tell patients,**" has had 43K views in a year. Three other shorter clips have each had thousands of views.

Rising numbers of anti-stigma campaigners

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

These influencers are so helpful to people who are feeling that their sex lives have ended. This is a message that they will have 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)

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

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

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

This treatment has been used in various research departments for many years, and each time a new use is announced, the publicity shows something positive about 'herpes'!

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. Our requests always include detailed instructions for the correct wording to be used. A few examples for this year:

- "NHS Choices" acted on our request to add the statement that neonatal herpes is very rare to <https://www.nhs.uk/conditions/neonatal-herpes/>.
- They corrected the way herpetic whitlow could be spread: <https://www.nhs.uk/conditions/herpetic-whitlow/>
- And on the cold sore page, NHS Choices removed the warning about spreading the virus via fomites (towels, cups, make-up, etc.) <https://www.nhs.uk/conditions/cold-sores/>

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.

In general, getting stories in the 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' 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.

In August 2022, a journalist who realised she was not a herpes expert, invited us to improve the article that on cold sores that she had drafted. It was published in "Lifespan" magazine.

In September 2022, our director was interviewed on Woman's Hour, BBC radio 4, together with a sexual health doctor from the NHS. A listener emailed:

"Just listened [to your interview] on BBC Sounds - absolutely brilliant. Wish I'd heard this 40 years ago, could have made such a difference to my life - I'm late to the party, but I'm there now, thanks to HVA"

In October 2022, we were quoted in the Daily Mirror and Daily Express articles on cold sores on the lips. This has two benefits, the reader is getting well explained, correct facts and also knows that there is a further resource for more information.

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 this page.

Just wanted to say thank you to you and Marian for all you do. I love receiving your newsletter and invaluable hints and tips. I recently followed up the one regarding the FS endorsement on the prescription for aciclovir. It has worked and I'm now getting the medication for free. My practice group were unaware of FS, so I sent them screen shots from your newsletter and also searched online and found NHS business guidance links to support my claim. They had never heard of it but discovered I was correct and duly added the endorsement. Lady, Dec. 2023

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 particular medication 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 and training for health professionals

Medical conferences

We were invited to present at a plenary session during the Annual Meeting of the British Association for Sexual Health and HIV on “*How to Talk to Patients with Genital Herpes*” in July. We received a fee for this talk.

In June, we had a stand at the annual conference of the Annual Meeting of the British Association for Dermatologists. We presented “*Differential Diagnoses for Genital Herpes*” as one of their 'hot topic' talks. It was such a popular subject that the audience included people standing at the back. The slides were requested by many attendees for future use.

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 7 training talks this year. Five were to NHS sexual health clinic staff on “*Counselling Patients with Herpes Simplex*”, reaching hundreds of individual healthcare professionals. The feedback scores from clinic staff always average around 95%.

Two more were for two medical training days for large audiences of GPs, practice nurses as well as sexual health clinic staff. We received payment for these two events.

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.

Feedback from the organiser, Shonda Powell, West Midlands Association for Contraception and Sexual Health following one of these talks:

Everyone attending thought it most informative and the feedback on the meeting was generally positive. Your evaluation score from feedback of the delegates for 4.8 (out of 5) for your talk on **Herpes** with the overall average for all lectures at 4.45. I have noted below some comments from the audience for your information:

- Fabulous, energetic, no-nonsense speaker, a breath of fresh air!
- Very enthusiastic speaker. Useful resources.
- Some of the myths about herpes that were mentioned were applicable to me as they would be for patients. It was the first I was hearing about the herbal alternatives to antivirals for treatment.
- Very interesting and informative - will certainly be using some of the advice for patients. Increased my professional knowledge around this subject.
- Lively speaker who very much related to the patient. She gave a practical and pragmatic talk with up-to-date information.
- Very engaging speaker. Useful <https://herpes.org.uk> resources
- Fantastic presenter; would definitely signpost patients to herpes.org.uk!
- Very knowledgeable and entertaining. Statistics are very useful to support and "normalise" patient discussions. I enjoyed the historical details as well.
- Excellent speaker, expert in her field, really informative and I will certainly apply few learnt points in my practice.

Because the staff understand how we can help their patients, 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.'

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

Phone call to the helpline - woman, April 2022:

"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. This is run by the Psychology Dept., UCL. Since the pandemic, this is now a virtual event but still 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 and also 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.

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

Currently BASHH is revising two of its guidelines. These are aimed at general medical personnel: '*Management of ano-genital herpes*' and '*Management of herpes in pregnancy*.' Marian Nicholson, our director, is on both writing groups.

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

We are also active 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.

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.

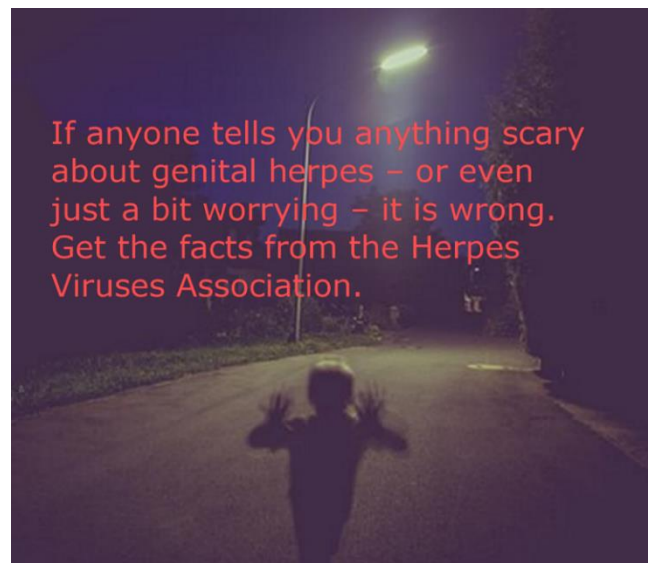
A representative from the HVA is an active member of the panel set up by the British Association for Sexual Health and HIV to ensure patient engagement in their activities and services and has attended all four of their meetings this year. This panel provided comments on their new range of leaflets for patients on various aspects of sexual health.

What we do for the public – our services

Twitter

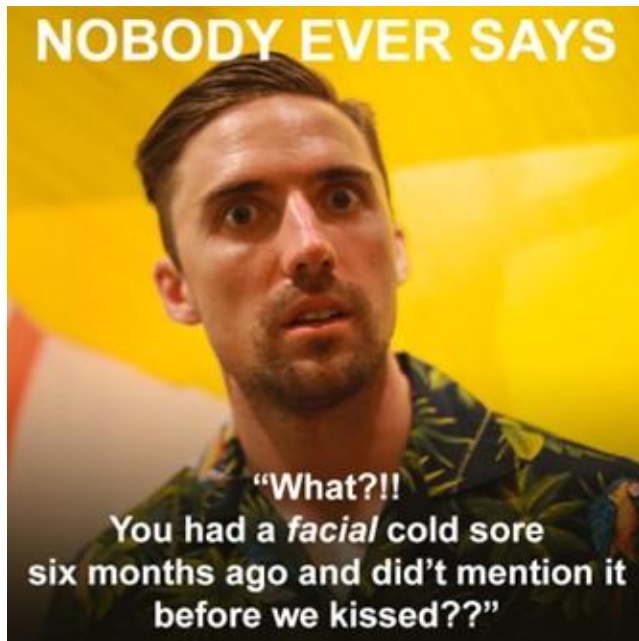
Our long-standing Twitter page **@HerpesUK** was set up to inform the health community.

We have also have a Twitter account 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.



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

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 regularly. These are hosted by office staff or a trained volunteer.

We were able to host meetings in Glasgow, Sheffield and Dublin whilst we were in these cities to present at medical conferences. People are delighted to have the opportunity to meet one of the staff members in their own region.

Since mid-2020, 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.

We also provide private virtual consultations for individuals and couples.

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.'

Look around you: by age 25 years, around seven in ten have herpes simplex (on faces or genitals).



If they are over 35 years old, then even more have the virus.

Having herpes is normal.

Conspiracy creators have said:

"Monkeypox is a form of herpes"

They figure the stigma of herpes will make monkeypox seem worse...

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 it is a seminar with the host providing the standard facts, and answering questions they 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 only the imaginary 'promiscuous individual'). People discover how sharing stories helps them to envisage possible futures.

"Thank you for the nice event yesterday. I received lots of good information about herpes and its treatment. Kind regards. Woman, February

Thank you so much for your very thoughtful and helpful presentation leading to great questions.

You are a STAR 🌟🌟🌟

Woman, March

Website – <https://herpes.org.uk> - 362,000 visitors this year

Our Google Ads (free to charities) generated xx million impressions. As well as 'herpes' Google Analytics shows that 'cold sores' is often the term that visitors have done search on.

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. 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.

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

Thank you again the website has been a life saver to me it's so helpful, appreciate all the hard work you and your team do. Lady, March 2023

I'd also like to thank you for the amazing work you do. When I first got this diagnosis, I was extremely worried, it's a virus with so much stigma and misunderstanding. Your work and website are so informative and reassuring. I will be making a donation for the fantastic work you do! Lady, Oct 2022

Thank you so much for the information. I have found your website immensely helpful over the past several months and truly appreciate you helping to set the record straight on this ridiculously common and totally benign virus. If I had not been told by a previous partner that he had it, I would not even know that my symptoms were herpes. Man, Jan 2023

I don't know if you will see this, but I wanted you to know that your work spreading information on herpes has really saved me. I'm not yet diagnosed with herpes but pretty sure I have it and I have spent the last few days thinking I was disgusting and gross, you've helped me realise how common and normal it really is.

Thank you so much, Kind regards, Man, May 2022

I'm having my first experience of herpes and I was really panicking over it, I found your site and it was the most informative and helpful, I feel a lot calmer about everything now so thank you. X Lady, Aug 2022

Emails – info@herpes.org.uk - 745 email threads.

Despite the comprehensive information provided on the HVA's website, we also individually answered 745 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.'

Thank you very much for the clarification, it really helps.
Please let me know what is the best way to support the glorious work you are doing
Best. Man Dec. 2022

Your email is very much appreciated!

I have stopped taking the suppressive therapy and bloating has now stopped so I'm going to hope that my outbreaks are limited and if they arise will look into the cream you suggest.

Again, many thanks for taking the time to respond. It's wonderful to know there are people out there who know what you're going through and can help from a place of personal experience.

I hope that I can volunteer to help once I have my head around it a bit more! Lady, May 2022

Thank you so, so much for the AMAZING support you provided, and the information shared!
Woman, June 2022

Helpline (0845 123 2305)

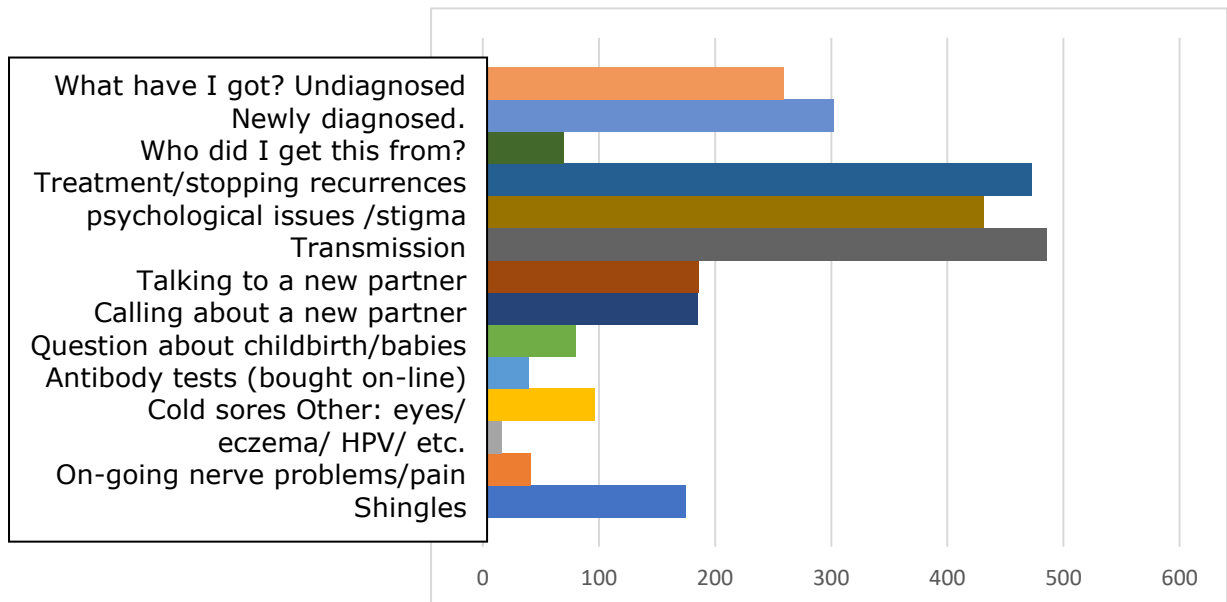
More than 2,200 callers this year* - an average of 8.5 callers each weekday. The majority are female. The calls can last as long as the callers wishes, with an average of 12 minutes. So far, the longest is 112 mins. More than 4% of callers are crying as they speak to us. Although we do not ask, more than 13% 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.

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 helpliner volunteers care.
- Callers can be inspired by our experiences: "You can transcend the diagnosis!"

Chart: topics covered April 22-March23, one call can refer to several topics



The helpline service is available for over 60 hours a week, with core times of 9.00am to 8.00pm on weekdays. Sometimes volunteers are available 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.

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 40 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'.

I am just sending this email to say thank you.

I was diagnosed with Herpes as a seventeen-year-old girl over ten years ago and following that diagnosis, I guess you could say I 'lost my sparkle'. I had always suffered from 'feeling blue', even as a child - of course now as an adult I recognise and am treated for depression. The Herpes diagnosis chipped away at me until I hit rock bottom in January 2021. My diagnosis turned out to be a misdiagnosis - but this is completely irrelevant. I am writing a thank you, as I when I called your helpline hysterical and on the brink of suicide - Cameron somehow managed to make the darkness lighter and even got me to crack a smile. **Cameron saved my life.** From the moment I hung up that call I decided to live again, and my lovely mother cried happy tears.

I have a dear friend who finds herself in the same situation and I am desperately trying to convince her to call your helpline. My heart aches when she self sabotages a relationship when it becomes 'serious' and she tells me that she wouldn't care if she just did not wake up - feelings I know all too well. Lady, May 2022

I called your helpline earlier today and I just wanted to thank you.

I was struggling with opening up to a new partner when a flare up had come on. This is only my first year with the condition so I'm still trying to navigate how, when and if I should open up to someone.

The helpline volunteer, helped me feel comfortable and helped a lot with feelings of self-shaming, he made me feel normal. He helped me find a way I could open up to my new partner which felt right for me. Lady, Jan. 2023

January: I wanted to say that I am extremely grateful to the association for the help offered to me when I called up 2 or 3 times a few years ago. I most prominently remember calling and speaking to a male individual who was patient, kind, and offered practical advice.

Whilst still, at times, I may struggle with acceptance, I am reassured by the fact that I know where to turn should I become overwhelmed.

I sincerely wish you all the best and hope that the association continues to receive the donations/ support that it truly deserves. Lady, May 2022

*You were one of the first places I found when I first caught it, and I was suicidal and felt my life was over. I will never forget how kind and calming Marian was to me back then. She made me feel I could cope and that it wasn't the end of the world.
Kind regards, Lady, Nov 2022*

I am so glad I found this charity. I called the helpline earlier and I cannot tell you how helpful it was to finally get accurate information on the herpes virus. The person I spoke to on the phone was wonderful, I felt safe, relieved and understood. I didn't think twice about subscribing! Lady, Oct. 2022

Thank you for being there our conversation has given me so much comfort I can't tell you and when I do get a bit anxious about things I just remember our chat. Lady, Oct. 2022

Dear Cameron

*I hope you (or someone!) also got my completed survey that I submitted after talking to one of your amazing volunteers. The lady I spoke to was wonderful and has made such a difference to how I feel about my recent, shock diagnosis. I had been catastrophising since last week and she has given me some peace and literally turned me around.
Thank you for such a great service. Lady, May, 2022*

I have called the HVA helpline many times over the past 25 years or so and found the service tremendously helpful. The advisors are so knowledgeable about latest tips and suggestions and always so supportive in their advice giving. I consider them to be the go-to service for help around this tedious virus and would absolutely recommend them as the first port of call for their accuracy on the subject and kind, non-judgemental approach. They have made practical therapeutic suggestions that have helped me on many occasions but also offered invaluable support and perspective for the emotional and mental struggles that I've had around living with Herpes. On my call to them recently I was so relieved to find they were still around after the pandemic. When my lottery win comes in I will definitely be sending a healthy donation! Lady, May 2022

I wanted to say what a great person Cameron is. Not only is he professional, he made me feel normal again after speaking with him. Cameron is a credit to your charity. He is very knowledgeable, he made me at ease and took away all the stigma I have been feeling about my self about GH. Lady Sep. 2022

Just sending you a quick message to say 'thank you!' I called you yesterday worried about telling my girlfriend, and you reassured me that it is normal and that most partners take it well.

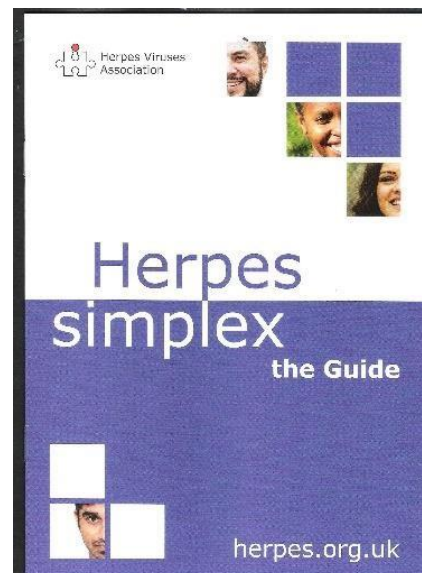
She did! So I wanted to say thank you for all you do supporting people in navigating the stigma around herpes! 😊 Lady, Sept 22

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.



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".

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 for the amazing support you provide. Lady, Dec. 2022

I've worked for 3 different national health charities and in the last of those was a Head of Department with the Health Info Team under my remit, so I really understand the work that goes into producing content to Information Standard level. It's been a change to experience, now that I am a "person affected," the massive positive impact that well researched, non-sensational, myth-challenging info has on a person's experience. Huge thank you to all in your small team. Lady, March 2023

I really appreciate all your resources. They've already helped me massively. I panicked and felt so depressed when I first found out. Your resources have made me feel so much better and helped me so much in navigating these conversations with partners/potential partners. I feel so much calmer about it now.

Thanks for all you do. Lady, Jan 2023

Journal - Sphere and mini-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.

Since June 2021, we have added 'mini-SPHERE' that is sent to members on the 1st of the months when we do not publish the journal. It includes articles that may not be specifically about herpes simplex such as on 'dating' or 'talking about STIs with your children.'

Jan: Really good edition once again. Especially the final story about the nurse, also the medical updates about how it's being used to treat disease such as Parkinson's, and the Keto diet findings
Sian

Hi Marian, April 2022
I just wanted to say 'My Story' from Ros was such an inspiring story and was wonderful to read. I felt it was like reading about myself except Ros has been lucky to have found a loving partner and I am still on my own. It gave me hope that it is possible to have a normal relationship with herpes and be happy. I shall keep that article as a reminder that there is a light at the end of the tunnel!
Thank you! Alison Johnson

Meetings just for members

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

Expert's talk

This yearly event was even more popular this year as 31 people signed up to attend via Zoom. 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 recorded Dr Viv Wholey'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.

One commented that:

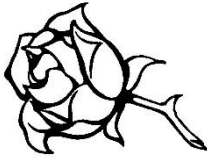
"You must tell her what a really great talk it was, and how grateful we are for your Saturday pm plus all the work that went into creating the PDF."

Another attendee said that of the three annual talks he's attended, this one was the best as it was the most in depth. "I loved it because it went beyond the facts that 'everyone knows' (or ought to know if they've read your leaflets) and explained things that I didn't know."

Study Days

"The First Day of the Rest of Your Life" is a full-day's seminar and is provided virtually. Over the year, we offered four of these. They are limited to 16 attendees so that people can have the individual attention they need.

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



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. *Zostavax*, a vaccine to help prevent shingles, is now available to people from age 70 to 80. We promote vaccination so as to lessen the burden of ill-health the virus causes.

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 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.

Private individuals are helped directly and personally:

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

Thank you so very much for your prompt, informative reply. I will discuss this with my GP. However, GPs are not over-zealous at being proactive and sorting issues out before they become a crisis. I was a social worker working with people with physical disabilities and saw it all the time, as has happened with myself and thankfully I had the knowledge of how to minimise the poor outcome. So, I thank you once again for your prompt email.
Woman, November 2022

This year we wrote an article about shingles that was published in Pharmacy Business. Pharmacists are often asked to diagnose shingles as it rarely makes a person feel 'ill.' We helped with the content – so that the article had correct information – and we were quoted in shingles articles in

Newsweek website - September 2022
Irish News website - January 2023

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 700 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, is also an active trustee on the boards of two umbrella groups for pain charities:

- Pain UK - with 41 pain charity members and over 1,400 individual members. Marian co-ordinates the news alerts and newsletters.
- Pain Alliance Europe is active with the EU's MEPS' special interest group on Brain, Mind and Pain and many other medical and patient-facing charities/organisations. PAE has 46 charity members from all over Europe. Marian masterminds PAE's yearly pan-Europe surveys and writes the reports when data has been analysed.

In May 2022, she attended a Pain Conference in Dublin to present the results of one of these pan-Europe surveys. The presentation, to a plenary session, was on how Covid has affected people living with long-term pain across Europe, including the UK.

anticipated difficulty is one of the most frequently repeated fears, as is shown on the helpline topic chart on page 15. These events are assessed by the attendees and averaged >4.7 out of a possible 5 points across several measures.

What did you think of the Day?

Again, I would like to thank you all for taking the time on Sunday. It's been a really great help and all the information I have gained is amazing.

I'll hopefully be able to make one of the live events over the next few months.
Kind regards, Man, May 2022

*Thank you so much for your advice, I feel empowered by my new knowledge.
Keep up the great work! Lady, July 2022*

Who does what: staff and volunteers - monitoring and training

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

Marian Nicholson, director, works from noon to 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.



Dressed for the BASHH 100th Birthday Dinner at Sadler's Hall

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'.

- Our helpline volunteers are trained and then join the roster which covers weekdays 9 am-8pm
- Helpline volunteers are supported by telephone with their original trainer.
- Email updates containing facts and helpful suggestions are regularly sent to our helpline, keeping them abreast of news.
- Monitoring of helpline services continues at all levels.
- Helpline 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 have organised group meetings before the pandemic. They are not formally trained but, when possible, office staff attend to support them. We hope to encourage people to start these up again.

Three volunteers have assisted with various admin tasks in the office at different times over this year.

Executive Management Committee

The association was registered with the Charity Commission (CC) 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, one trustee resigned so that there are currently ten members between the ages of 24 and 72, two of whom are male.

The CC has given us a dispensation so that we do not show the names of the HVA's committee members on the CC's website. Neither are they shown on the HVA's website 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 2022-2023

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 £19,397.50 - a decrease on the previous year's £23,941 - for the second year running. This is disappointing as we have been encouraging people who call the helpline to subscribe, and we have been sending more emails to encourage member-retention. 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. It 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 down for a second year: £17,923.46 (from £19,768). We continue to encourage service users (on phones, emails, website) to be generous with donations.

This is a thank you for the helpline call. It was so good to have someone knowledgeable to answer my questions. (£20 donation) Man, May 2022

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 £18,000 gross profit - that is without making allowance for cost of writing, designing the booklet and sales administration.

A few weeks ago, my mum emailed you to get some tablets and cream dropped off with very short notice. Just wanted to say a big Thank You for how out of your way you went to get them to me in time for my holiday! I really appreciate the effort put in and everything you guys are doing!
Thank you! Woman, June 2022

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 £1,150 this year.
- A link on our website goes to MedExpress, approved by the Care

Fundraising

Challenges because of the stigma associated with genital herpes:

Fund-raising specialists 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 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 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.

Therefore, we are very glad of the generosity of many of our members who make extra individual donations and set up monthly standing orders.

Quality Commission to sell antiviral drugs. This sponsored link raised £10,800.

A one-off donation of £860 was made by a law company for the assistance we provided when they were defending a client from a vexatious litigant who was suing for having now got a cold sore on his face.

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 2023-24.

Legacies

We received an unrestricted legacy of £76,518

Fundraising activities

The public is invited to donate to the HVA via several links on the HVA's website. These include:

- Nochex, a free service which is popular as donations made via this website can be anonymous.
- Donr text-giving: people can donate on their phone. These donations amounted to around £200.
- Amazon Smile account, using the name Shingles Support Society. This raised £95 in the year.
- We ask all the people we help to nominate the Shingles Support Society as their designated charity on www.EasyFundraising.co.uk: an on-line portal that will take them to over 3,700 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 a This year we have received £129.

About the accounts for 2022-2023

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

Gross income: £ ???
Expenditure: £ ???

This year we had a legacy of £76,518.

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.

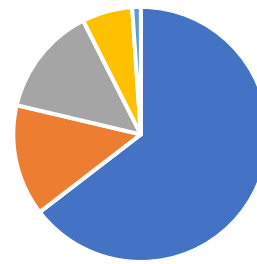
Taxation

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

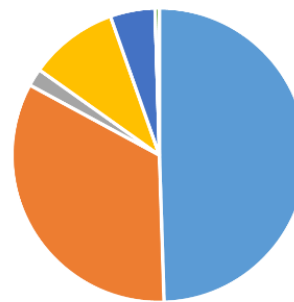
In line with the recommendations of the Charity Commission, the Management Committee has formulated a Reserves Policy to enhance our medium-term security,

Sustainable funding comes from:



■ Sales ■ Donations ■ Subscriptions ■ GAD ■ Trust

Spending goes to:



■ Salaries, PAYE, pensions ■ Buying therapeutic items for resale
 ■ Educational materials/events ■ Rent & utilities
 ■ Postage & couriers ■ Accnt/insurance

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 2022-2023, the target of £86,320 has been met.