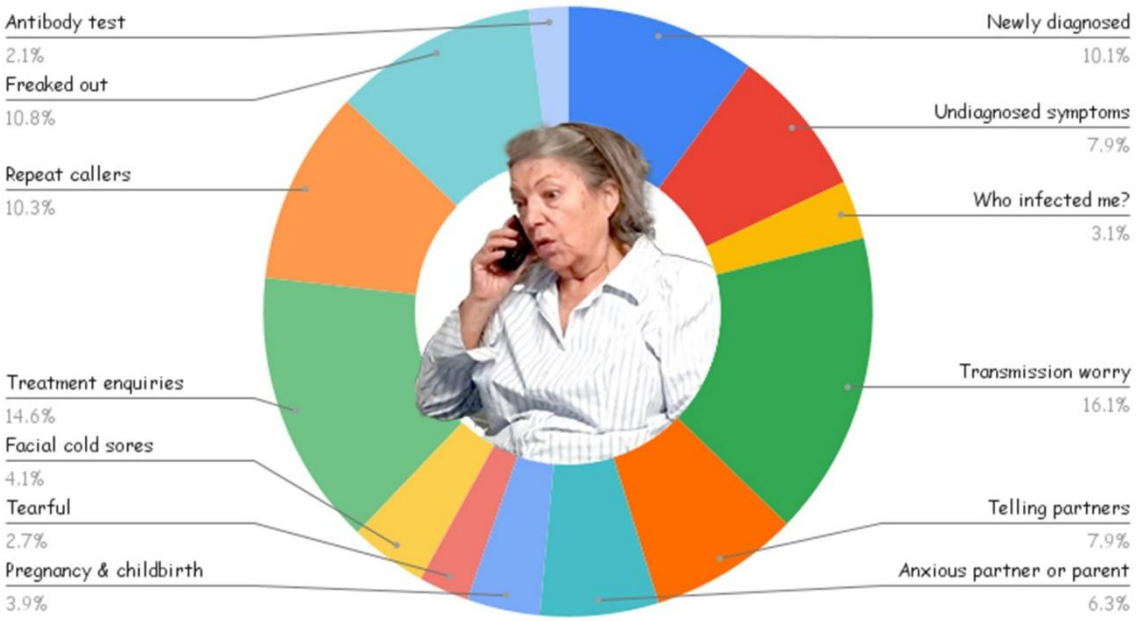
Annual Review
for the
Herpes Viruses Association



2026

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Herpes Viruses Association
Annual Review
April 2025 to March 2026

Letter from the Chair

Welcome to the Annual Report for 2025-2026 which showcases our work and our achievements.

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

The herpes paradox
We help people who have been diagnosed with genital herpes, a condition hugely stigmatised in popular culture. See page 6.

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

So why does the word 'herpes' frequently provoke dread?

Partly, it is ignorance. As well as not knowing how common it is, people do not realise that only one person in three who catches it will notice. The others get no, or minimal, symptoms so are not diagnosed. In most cases it is caught on the face, where it is called a cold sore. But when it is caught on the genitals it is called 'herpes' and stigmatised.

Herpes lives in most of us, unnoticed as it is so mild, yet the misconception that it is an unsavoury problem affecting a reckless minority, continues largely unchallenged. The stigma of the word herpes means that a person who has caught it and educated themself about this virus does not speak out if a joke or a hurtful remark is made.

The medical view
Sexual health clinic staff know that this virus is rarely of any medical importance. But they tell us that they spend a dispro-portionate amount of time counselling people who become distraught, or even mention suicide, on hearing the diagnosis.

Clinics are adding this charity's contact details to the text they send out to patients

with their herpes diagnosis. This means that this charity has become very important to the British National Health Service (NHS), but the charity is not funded by the government or NHS.

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.

Research has found that four out of five patients are not supplied with written information about their condition by the healthcare professional that diagnoses them. This means that increasingly patients ask AI for help. These algorithms are programmed to just repeat the prevailing idea that 'having herpes' is something bad.

The same research found that seven out of ten will look at the NHS pages. We continuously monitor these and have to ask for changes. It seems the doctors who write the herpes pages do not have to be experts.

People approach the HVA for support and are helped in many ways. Our services are based on the constant contact we have with patients. All our information products are co-produced with patients. We continuously tailor the services that we

offer. These include:

- emotional support as well as the facts that underpin the emotional support.
- peer support and connection with others who have this diagnosis.
- well-being support – i.e. practical ideas that complement the prescribed medical treatment.

Combatting stigma

The stigma prevents our members 'going public' about their diagnosis and helping to normalise it as the common skin condition that it is. We routinely encourage medical professionals to work against the stigma with limited results. However, TikTok now hosts many brave young people, mostly women, who talk about their own 'herpes journey' and share sensible messages.

Virtual and in-person support

At least twice a month we offer Zoom chats, available to everyone. These are very popular and are continuing. The monthly in-person meetings in London are also well attended:

"Thanks for everything you do, all the help and hope you give me and people like me, and your tireless work." Paul, 1/1/2026.

* We promise anonymity to everyone who contacts us.

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

Emails are answered promptly, so that people have less time to Google herpes and find worrying and misleading information online.

Services for members

Our monthly print or e-magazine include research and motivational messages.

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

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

Some of our 2025 outputs:
15 training sessions (for medical staff)
12 inputs to medical guideline revisions
2 medical conferences/shows
6 training sessions (for patients)
352,000 website visitors
2390 phone call sessions
1130 email 'conversations' with patients
30 Zoom support sessions (for patients)
14 in-person support groups for patients
4 helpline volunteers: one weekly shift
5 office admin volunteers: once weekly

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

Evaluation of our work

Many charities are able to give accurate results about the value of their services from users' feedback. Our helpline service continues to offer callers the chance to talk to a sympathetic, knowledgeable, friendly voice. It is totally confidential. We do not ask for any identifying details from the people who use it. A link to a survey about the helpline is shown on the 'contact us' webpage. Graphs from these surveys are shown below.

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

Help for shingles patients

Our other main activity is advising patients on the treatment of post shingles pain (PHN) caused by herpes zoster, another herpes virus, via our subsidiary charity, the Shingles Support Society. We are also encouraging the uptake of the shingles vaccines to prevent cases. See page 16.

Our work and survival are only made possible with financial assistance from our members and supporters. Thank you to you all, for contributions large and small.

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

Nigel Scott
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. Nine of our ten trustees have personal experience of the virus, and we have obtained a dispensation from the Charity Commission not to publish a list of their names.

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

Why we exist

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

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

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

People with genital herpes are referred to our services by:

- The staff of NHS sexual health clinics – this is increasing, as cuts are made to these services around the country
- National Sexual Health Line (Public Health England)
- Terence Higgins Trust helpline
- Brook Advisory Services
- GPs
- Sexual partners, family or friends
- And, of course, Google and other search engines…

Our charitable objectives

1. To promote good health by improving public education about herpes virus infections, their prevention and treatment

2. To promote or assist in promoting research into the prevention and treatment of herpes simplex and its effects on patients, and to publicise the useful results of this research for the benefit of the public.

3. To relieve persons with symptoms of herpes simplex.

Annual statistics for the genital herpes diagnoses made in sexual health clinics for 2025.

The number of new diagnoses in 2025 has risen to 28,779, up from 27,867 in 2024. Herpes simplex represents 8.6% of all sexually transmitted infections (STIs) diagnosed that year.

28,779 is 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 access to 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 STIs, a diagnosis of genital herpes requires a swab being taken at a sexual health clinic while symptoms are visible. A reduction in access to clinics will translate into a reduction in cases diagnosed, which does not reflect the true picture.

We help patients to understand the psychology of herpes

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

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

What they find when they Google

Stigma is self-perpetuating. New patients routinely turn to the web for information. Most of what they find is either wrong or overblown. Websites selling 'treatments' exaggerate symptoms and highlight the most severe cases so as to promote sales. Dating websites, just for people with genital herpes, exploit the concerns that newly diagnosed individuals may have about future relationships.

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

The stigma is firmly embedded and highly dangerous:

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

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

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

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

'Herpes' is often used in the media as a synonym for 'something really bad'. Or as '*click bait*' even though there is *no word* 'herpes' in the story.
Google 'herpes': here is a sample of what you will find.

6/12/25
I've been invited to a country-house party! But warning the hostess that I'm vegan was like saying **'I have virulent herpes'**...
By Liz Jones For You Magazine

24/11/25
Urgent warning to 5.5million people who vape in UK over deadly **herpes**
The Mirror
Note: vaping will not even transmit a cold sore, and they offer no justification for their statement.

1/11/25
Like herpes, celebrity scare artist Erin Brockovich is back to plague Bossier City…
The Hayride

30/10/25
'Aggressive monkeys riddled with **herpes**' on the loose after lorry overturns on motorway
The Mirror
Note: monkey virus is not our herpes.

13/10/25
Who Are the Winners and Losers of the Party Conference Season? - YouTube
"Tories Are the **HERPES** of Politics"
YouTube

10.10.25
Drunk driver expresses desire for officers to contract **herpes** and die.
https://www.msn.com/

24/9/25
"We are like the **herpes** of vacation," she quipped. "We just keep returning. They can't get rid of us. Right?"
Decider,com

5/9/25
Epstein Files Are **Herpes** for Trump
https://washingtonmonthly.com/

29/4/25
Woman says she caught **herpes** by holding karaoke mic too close…
NOTE: It is not possible to transmit the virus off an object. Experts are clear on this. The virus does not float or fly. https://MSM.com

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 that get linked to genital herpes. Some common errors are: "It can be spread around the body," "You can pass it on via towels/toilet seats/etc.," "You will need a C-section for childbirth," "It turns into HIV." These are all false.

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

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

The NHS Choices video, our video clips on YouTube and embedded in HVA and others' websites:

The NHS Choices website uses videos to improve understanding: a patient talks about their condition, or a doctor explains it. This is a valuable resource as, according to research by the Patient Information Forum, 7 out of 10 people checking health issues online look at NHS pages.

In the case of genital herpes, it is difficult if not impossible to find a patient willing to be filmed, and 'go public' about their condition. Marian Nicholson, the HVA's director has voiced her own personal journey for the NHS Choices website.

> I wanted to say what great work you do, and I have found all the material and videos very helpful. Marian's interviews in particular .. your helpline was great too. Roger, 30/10/25

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

In August 2024, a 20-minute video interview with Marian Nicholson was uploaded by MyHealthFocus.com In less than a year, 4.8k people have watched it.

Anti-stigma campaigners

On Instagram and TikTok, a search on 'herpes' finds many young, attractive people who have decided to be 'out' and tell the digital world why 'having herpes' should not be so stigmatised.

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

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

Sensible information

Does everyone have Herpes? The answer might surprise you
Yahoo.com/news 7/9/25

Terrific publicity for this virus

'Best place to have **herpes**': New Zealand ad wins top prize - BBC News
BBC.com
"To fix our national pride, the solution is obvious: **herpes**." The charity New Zealand Herpes Foundation's video campaign won creative advertising prizes around the world. Accidentally passing on really good advice.

Stories on 'herpes' curing cancer appear regularly.

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

Adding to and correcting websites:

Explaining and rebutting inaccurate coverage about herpes is a regular part of our work. When we find incorrect or misleading information on any UK-based website purporting to be authoritative, we ask for this to be changed. Our requests always include detailed instructions for the correct wording to be used. The response is usually that the comment has been passed to the relevant team. We are informed that it could be a year or more before a change is implemented.

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 in 2020 a law was passed to allow GPs to endorse prescriptions with FS (for Free Supply). This means the patient will not need to pay a prescription fee at the pharmacy. This new law is not widely known. Our website has a link to the government page that explains this. Patients can direct their GPs to the webpage.

Trials

We help find candidates for medical and psychological researchers

Researchers approach charities for specific medical conditions for help in reaching people who would be appropriate for their research. We show researchers' requests for volunteers 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 the researcher telling us that we can remove the announcement.

We have run trials and surveys

Treatments and 'cures' are advertised on the internet. Occasionally a manufacturer is confident enough in their product to ask us to run trials on their products. Over the years, we have identified some useful herbal treatments:
1995 Elagen (eleutherococcus senticosus) – systemic, double-blind placebo controlled
2000 Olive leaf extract – systemic, open label, comparison between three different products
1997 Lomaherpan (formerly Nature's Vyrbit) – melissa officinalis cream, open label
2007 Liquorice cream – double-blind placebo controlled

Other products have been found to be not effective at all, or not enough to endorse:
2001 'herbal product' from Queen's Medical Centre, Notts
2002 BHA BHT - cream
2004 2LHERP homeopathy treatment from Labo'Life
2004 Herplex – systemic herbal mixture
2017 Erpegen - cold sore cream from Smile, Australia
2021 Target - topical herbal lotion with melissa officinalis

We are currently trialling 'Active Serum cold sore rescue' from BioSource – topical, for genitals.

Information for health professionals

No legal requirement to disclose (but it makes sense)

In order to cover every eventuality, sexual health staff may mention to patients that there have been two prosecutions for transmission of genital herpes. They may add that all partners must be told. However, we reassure doctors that the Crown Prosecution Service states:

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

However, we do 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. We do, of course, explain that they must behave responsibly.

Conferences & training for health professionals

Medical conferences

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

Training the frontline staff - now usually 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 12 training talks this year for the staff of NHS sexual health clinics. Our talk on '*Counselling Patients with Herpes Simplex'* reached hundreds of individual healthcare professionals. The feedback scores from clinic staff always average around 95%.

A virtual presentation for members of the British Society of Clinical and Academic Hypnotherapists was accompanied by an educational article in the Society's magazine.

A talk on helping patients was given to other employees and volunteers of Brook sexual services for young people, and the university student-led organisation Sexpression.

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

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

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

There is still work to be done. Patients tell us that the clinic staff were unable to answer specific questions or gave wrong answers: e.g. that laundry must be done separately, that you cannot go swimming, that it is a legal obligation to 'disclose' the diagnosis to a new partner.

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

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

Providing information sessions for patients of other organisations

Twice a year, we provide the second of the six sessions in a programme organised for women who have psychological issues arising from their diagnosis of genital herpes. Run by the

Psychology Dept, University College London, this event at the Holloway Sexual Health clinic includes lively discussion.

We provided a podcast for Liverpool University's Hope Student Union. We have provided tailored talks for herpes in the trans community for 'Trans People'; and for the 'Societe Noir'

Working with other associations

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

The most relevant of these is British Association for Sexual Health and HIV (BASHH). As in previous years, we were provided with a free place at their annual conference.

Marian Nicholson, our director, is on two clinical guideline writing groups. Last year, BASHH published revisions of two guidelines aimed at general medical personnel. Thee were: *'Management of anogenital herpes'* and, together with the Royal College of Obstetrics and Gynaecology *'Management of genital herpes in pregnancy.'*

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 the patient experience is considered in their activities and services; we 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

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.

Facebook

We regularly post useful messages on our two public facing, non-interactive Facebook pages. 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.

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.

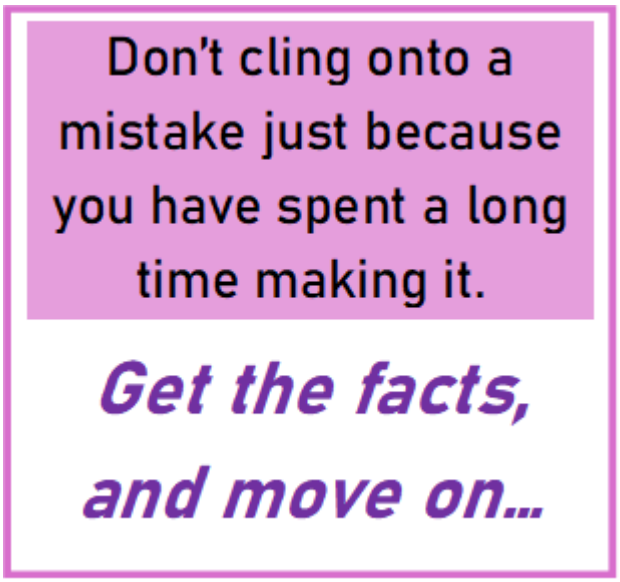
Twitter (now X)

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

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

Instagram

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



Meetings for anyone

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

> Thanks for your time earlier. Again - you really are a life saver. Your approach is just fantastic and so inspiring. Thank you. Georgie, 14/10/25

We also held meetings in Bath, Edinburgh and Liverpool. These are widely advertised via several Facebook groups for people with herpes.

Since 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.

From September 2025, we have added a monthly virtual meeting *on 'Emotional strength in the Face of Herpes'* which is run by a psychologist who has personal experience of the psycho-social impact of the virus.

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.'

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

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

I just wanted to say a massive 'thank you' for everything yesterday. I found the whole event so helpful, and I really appreciated the opportunity to speak so freely with you and gain such clear, clear and kind assurance! Woman, 18/5/25

I know I said it on the call, but can I please just reiterate how thankful I am of the call this evening. It has honestly been so valuable to me. I entered the call a total mess and I now feel slightly calmer about the whole situation. Sian 12/3/26

Website – https://herpes.org.uk – 352,000 visitors

The number of unique visitors has risen 21% on last year – and with the assistance of Google AdWords (free to charities), our website generated over 2 million impressions. As well as 'herpes' Google Analytics shows that 'cold sores' is the third most common term that visitors have used in their search. In a web search for 'herpes support', https://herpes.org.uk is the first site listed on Google UK.

In 2024, we had a free session with the website experts of a major corporation, who assured us that our website was well configured to achieve visitors: it has a good SEO rating.

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

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

Thank you, Marian, for getting back to me appreciate it. I found your website very useful and it has put my mind at ease thank you. Kayla, 3/3/26

I just wanted to say thank you for having such helpful and reliable information available, the website has really helped me mentally. Amy, 5/2/26

I've found all I need on your brilliant website. Kate, 3/11/25

Thank you for the online information and guidance. I have had herpes from the early 2000s and have always felt supressed by it ... unable to be who I had been. I'm nearly 60 now, in a non-sexual relationship. Yours is the first positive website I have read, and it makes me realise that with care and thought I can have loving sexual relations again. Simon, 2/11/25

This article is super helpful and reassuring! It's great that it debunks those misleading antibody tests. Thanks for the clear info! Haka, 13/9/2025

50 people filled in the SurveyMonkey questionnaire asking about their website experience:	Yes	No	I didn't use this option
Did you find this website useful?	50	0	
Did the question you put into the 'search' get you to the answer you wanted on our website?	42	6	3
NOTES: We learn from these answers, and this helps us to continuously improve the website.			

Emails – info@herpes.org.uk – **1130 email 'conversations' with patients (up 5%)**

Despite the comprehensive information provided on the HVA's website, we also individually answered 1130 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 so much for your incredibly quick reply and info and reassurance. I was at work on a very long shift so couldn't phone and it was so helpful to have your reply, so I was able to stop panicking. Marit, 12/2/26

Thank you so much for your reply, I really appreciate your time. The organisation has been a huge help to me during this difficult time, and I would like to thank you for the great work and support you give. Jo, 28/1/26

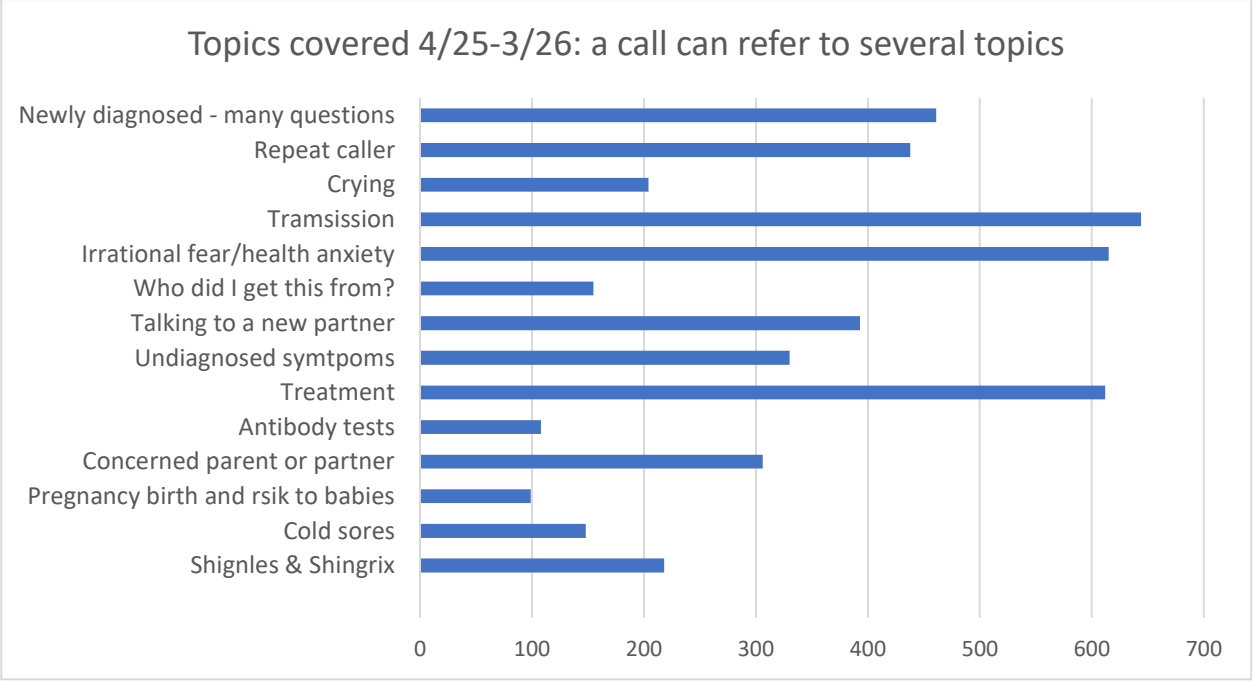
I can't thank you enough for your response, it is SO reassuring and has been incredibly helpful at putting both mine and my husband's mind at rest!! Thank you so much! Laura, 2/9/25

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

Although the helpline was changed to 0345 during the last months of the previous year, this only took effect mid-June. There was a noticeably sharp increase in the numbers of callers (up 32%) and the number of minutes that people talk (up 60%)

More than 2390 phone calls* (up 8% on last year) were taken: an average of 8.8 callers each weekday. The majority are female. The calls can last as long as the caller wishes, with an average of 15.9 minutes. So far, the longest is 112 mins. 8.5% of callers are crying (up 3% on last year) during the call. Although we do not ask, around 18.3% of callers self-identify as a 'repeat caller.'

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



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

- Callers don't feel judged.
- Callers can talk for as long as they wish.
- Callers are anonymous. They are not asked any identifying questions.
- Callers feel able to talk frankly, as volunteers are not 'an authority figure.'

- Callers hear that we are answering calls because the helpline volunteers care.
- Callers can be inspired by our experiences: "You can transcend the diagnosis!" said one caller towards the end of the call.

I called this morning and spoke to Cameron. Such good advice and facts which made me feel a lot better. Sam, 22/1/26

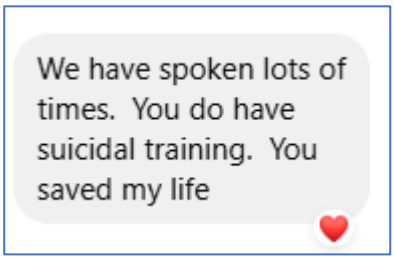
The lovely lady that spoke to me this morning and really helped ease my worries and give me insightful factual information in my time of need. The work you guys do is so, so important. I would be in a bad place without you. So thank you x Eve, 16/9/25

i had the pleasure of speaking with you yesterday 21st July concerning GH, HSV types 1 and 2 and my new partner. After everything else I've seen and read on line, I'm glad i called you. The HVA is by far the best and most informative – and honest - site. Just wanted to say thank you, my partner was very happy yesterday. John 22/7/25

Thank you so, so much for your response! Your service has been very informative and reassuring. I also spoke to one of your amazing people today and he was very reassuring so kind. I was in the middle of an anxiety attack, and he managed to bring me down (not an easy thing to do!) I will have a look into your shop and products, thank you for the recommendation. June, 3/6/25

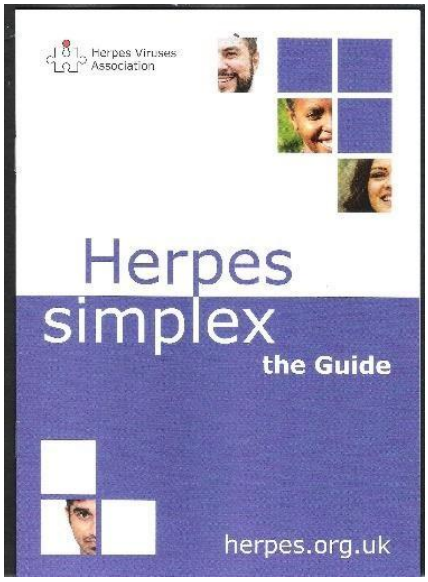
26 people filled in the SurveyMonkey questionnaire:	Strongly agree	Agree somewhat	Neutral	Disagree somewhat	Strongly disagree
This is a very helpful service	20	3			3
The helpline volunteer was knowledgeable	19	4		1	2
This call has changed my view of life with herpes – for the better	16 one abstained	5	2	2	
Notes: Majority of respondents were female. Ages 25-34 was most frequent, but ages from 19 to 66+ were selected. Only one person (out of 26) reported that they 'had a question that could not be answered' but that person did not expand in the provided 'comment box', On one day, the same helpline volunteer had a very dissatisfied caller who gave him a 5 and a very pleased "Call was very beneficial. Great advice."					

- Calling our helpline from a landline costs the same as a local call; it does not generate income for the charity.
- Callers are between 17 and 80 (these ages are volunteered: we do not ask) with the average being 38.8 years.
- Callers may be crying or mention suicide, so our volunteers need to be strong emotionally as well as being trained with 'all the answers.'



Lady 26/3/26

Herpes Simplex - the Guide



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

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

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

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

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. Our leaflets, as well as other materials such as booklets and web pages continue to be produced to this standard. A referenced version of any item is available on request. All materials we produce are tested on people with genital herpes to ensure that they are unambiguous and readily understood. They are then validated by a relevant medical expert.

Journal - Sphere and mini-SPHERE

Sphere is a quarterly journal, 16 A4 pages for print version, and separately formatted for email recipients. It provides updates on research, trials and changes to drug regimens. Articles tackle psychological trauma and anxiety which can be caused by the diagnosis, suggest ways of controlling thoughts, relieving stress, etc. It always includes personal stories and tips from readers.

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

"Thank you for the magazine, I really look forward to reading the back page 'My Story' first as it always brings me hope that I too can find a relationship in the future, and the articles about the scientific work give me hope for a cure, so that no one else has to live like I was until I found your association and got hope for my future." Woman 26/9/25

Private Facebook page just for paying members

Members can join a secret members-only Facebook page which enables them to communicate with others without any possibility of their usual Facebook friends finding out. This is explained more fully on page 10.

Meetings just for paying members

Annual seminar: a talk from sexual health doctor

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

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

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

Study Days

'The Assurance Day' is a full-day – 5 sessions on Zoom. Over the year, we offer four of these. They are limited to 16 attendees so that people can have the individual attention they need.

It was so lovely meeting you, Cameron and the others in the group. I found the course to be hugely impactful personally and I left feeling quite empowered. There's so much I learned that I didn't know before and many a myth were busted. Especially on transmission rates, preventing transmission and shedding. I'm so glad I attended in person and had the opportunity to meet, learn and share with others in the group. My only regret is that I didn't attend sooner (even if it was online) and not have stigma and worry consume me all these years. Better late than never as they say! Elaine, 9/9/25

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

Dates and Mates

For people who have not acquired the confidence to talk about this condition, which they perceive to be so stigmatising, we provide our members with a contact service. Many members have met up and formed relationships as a result of this service.

I would like to remove my advert on Dates and Mates please. A lady responded to the ad earlier this year which led to us both enjoying a full and physical relationship together.

Shingles Support Society

Sub-group recognised by the Charity Commission

Our sub-group, the Shingles Support Society (SSS) allows people suffering from herpes zoster (shingles) to learn more about the treatment of post-herpetic neuralgia (PHN), a pain that sometimes follows. In older patients, this pain can continue long after shingles blisters have healed. We promote vaccination to lessen the burden of ill-health the virus causes.

Shingrix, a vaccine to help prevent shingles, is provided by GPs to people from age 70 to 80. Additionally, people who reach 65 after 1 September 2023 are eligible. This new age qualification has caused much confusion and has to be explained repeatedly.

The makers of Shingrix, GSK, provided an honorarium for our direction Marian Nicolson to talk to the GPs of a very large NW London surgery on the importance to patients of this vaccine.

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

The above information is available on our www.shinglessupport.org.uk website.

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

> I am so very grateful for your prompt and informative reply, your organisation has never failed to provide clear and knowledgeable advice. Once again, many thanks Regards, Trudie 23/6/25 I am so

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

- 707 phone conversations, mostly re-treatment of PHN, and vaccine eligibility.
- 124 print and 61 email versions of the information pack were sent out.

59 people had their problems dealt with only via emails, often a long series of messages.

- West Hampstead Women's Group were given a talk on 'Shingles and the Vaccines.'

> Thank for your prompt and sensible responses to my questions. It is such a relief to find someone who knows all the details of the vaccine [programme] Julie 5/7/25

Wording with other organisations:

Research

The ATHENA trial was created to ascertain if postherpetic neuralgia (PHN, chronic pain) is less likely when newly diagnosed people are immediately given amitriptyline, a common treatment for PHN, before onset of pain. The SSS is on the steering committee for this UK study.

We are also on the trial steering committee for the ZosterFluCOV trial, to see if giving more than one vaccine at the same time is acceptable.

For the 'Global Patients Collaboration' we sent a mailout to 186 shingles contacts to invite them to take part.

Researchers contact us regularly to advertise for people with pain to take part in their surveys. We post these on Facebook pages, and they reach over 2.5K people.

Pain UK

Our director, Marian Nicholson, is also an active trustee on the board of Pain UK - an umbrella group with 46 pain charity members and over 1,200 individual members. Marian co-ordinates the news alerts and newsletters.

continued from page 16

Who does what: staff and volunteers, monitoring and training

< Marian Nicholson and Cameron Poole with Professor Matt Phillips, President of BASHH at the Annual Dinner

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

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

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

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

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

- Our four helpline volunteers are trained and then join the roster which covers weekdays 9 am-8pm. They provide one 4-hour session each week.
- Helpline volunteers are supported by telephone with their original trainer.
- Email updates containing facts and helpful suggestions are regularly sent to our helpliners, keeping them abreast of news, and giving them ideas for how to explain the condition and minimise its impact on life.
- Monitoring of helpline services continues at all levels.
- Helpliners complete a log to feedback the topic covered (see page 13) and to enable supervision of the service as well as providing pointers to further training.

Admin volunteers come into the office to do a half day's work. Five people have assisted with various admin tasks at different times over this year.

Executive Management Committee

The association was registered with the Charity Commission in 1985. The Executive Management Committee (trustee board) is elected from the membership at the Annual General Meeting. Trustees meet monthly to oversee the work of the association, direct its future, and approve exceptional expenses. During the year, two trustees resigned and one was co-opted. There are currently eight members, only one of whom is a man. All but one of the trustees have lived experience.

A Charity Commission dispensation permits us to not show all the names of the HVA's committee members on their website. Neither are they shown on the HVA's website, this Annual Review, nor in the Annual Reports and Accounts. The chair and one other trustee have given permission for their names to be shown.

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 2025-2026

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 £15,691, a decrease of £1,373 on the previous year. 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 because it is needed to neutralise a torrent of badly written web pages and outright misinformation about genital herpes that is found online.

To counter declining membership, we are focussing on recruitment as this is a sustainable source of income. People subscribe for an average of two and a half years. This may be improved as we have been sending monthly email updates (as well as the previous quarterly journal) to encourage member-retention. Over fifty of our members have set up regular monthly donations by standing order of varying amounts between £2 and £30.

Donations were down overall from last year by over £6000. We continue to encourage service users (on phones, emails, website) to be generous with donations.

Profits from selling booklets and the creams and supplements (therapeutic materials which we have trialled and found useful in preventing herpes simplex outbreaks) generated around £18,000 gross profit – that is without making allowance for cost of writing, designing the booklet and sales administration.

Thank you for all the amazing work you do! I am a regular user of LomaHerpan cream [to prevent outbreaks] and it has been a god send for several years. Man, 19/2/26

Excellent product at keeping herpes sores at bay. If you do get a breakout applying this helps to significantly reduce the healing time. Woman 22/3/26

Corporate donations/payments:
We continue to have two regular sources:

- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £700 this year.
- Clearly identified advertisements on our website show links to MedExpress and DrFox, both approved by the Care Quality Commission to sell antiviral drugs. These sponsored links raise £11,475.

Trusts

We received no donations from trusts or corporations.

Fundraising challenges because of the stigma associated with genital herpes.

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

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

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

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

Fundraising activities

The public is invited to donate to the HVA via several links on the HVA's website. This year, these donations were down by about 30%. This is attributed to the general austerity.

As well as straightforward donations, we receive money from the public via:

- 'DONR text-giving' raised £77. DONR allows people to donate on their phone.
- Donations also include funds raised via www.EasyFundraising.co.uk. This is an online portal that will take users to over 7,000 online shops including many well-known companies (including Asda, InterFlora, M&S, Travelodge, Zizzi). A percentage is donated to the charity chosen by the shopper. We ask all the people we help to nominate the Shingles Support Society as their designated charity when shopping. This year we have received £120.

About the accounts for 2025-2026

The accounts for 2025-2026 were signed by an Independent Examiner:
Josh Botham of Josh Botham Tax & Accounting Services Ltd.

Gross income: £145,635
Expenditure: £149,994

Income is £17,000 less than last year; expenditure is £16,000 less.

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

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

Exceptional receipts
The claim made under the Gift Aid Donation scheme includes some claims for previous years, as we incorporate donations made up to four years ago.

Continuing operations
None of the HVA's activities were acquired or discontinued during this financial year.

Donated items
Volunteers have donated their time and expertise to the charity.

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

Taxation
The HVA is exempt from income tax by reason of its charitable status.

Our deposit account interest is paid tax-free as it is in an account created for charities.

Reserves policy

In line with the recommendations of the Charity Commission, the Management Committee has formulated a Reserves Policy to enhance our medium-term security, taking into account the different levels of predictability of the various income streams. We aim to hold a contingency reserve as a buffer to cushion us against an uncertain future. Strategic reserves are to enable the charity to continue with no further support for a period of up to four months and to cover redundancy payments to staff.

Our reserves figure is updated annually in line with inflation and changing redundancy costs.