Annual Report
2020

Herpes
Viruses
Association

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

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

Herpes Viruses Association
Annual Report
April 2019 to March 2020

Letter from the Chair

Welcome to the Annual Report for 2019-20 which showcases our work and our achievements.

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

The herpes enigma

We help people who have been diagnosed with genital herpes, 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. They 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.

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

Our mission and activities

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

People approach us for support and are helped in a number of ways. HVA’s website has become the first point of contact for many patients, especially

> *Thank you so much for the incredible work you do. I have followed your website for years and listened to your piece on Woman’s Hour. The information has been of great comfort and helped to normalise everything for me. Woman*, February 2020*

* We promise anonymity to everyone who contacts us.

the newly diagnosed. Clinics and doctors recommend it. Free Google AdWords help people find it.

Our helpline continues to offer callers the chance to talk to a sympathetic, well-informed friendly voice. Our office staff also take helpline calls – to keep themselves informed of service users’ concerns – and they also train the new volunteers.

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

The quarterly online journal, Sphere, is sent to HVA members and we run the very popular ‘Study Days’, enabling members to gain a deeper understanding of how the virus works and how to talk to partners about it.

These days can be life-changing for the participants and have empowered many people to overcome the loneliness caused by herpes stigma, resume dating and find a life partner.

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

Lobbying and campaigning continues to be a priority. Our involvement with the All Party Parliamentary Group on Sexual & Reproductive Health gives us a voice at Westminster, where we can raise the concerns of patients and argue for effective and responsive healthcare.

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

This year was the last full year of Nigel Scott’s employment as our second full time worker. He is due to retire in June 2020 after over 22 years of continuous service. His contribution to our literature and lobbying power has been considerable and his reassuring advice to thousands of callers and visitors will not be forgotten. We are grateful that he will remain in contact if we need to call on him.

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

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

G M S Davies

G Davies

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 and now provides information on all the human herpes viruses with emphasis on herpes simplex (genital herpes and cold sores). The Shingles Support Society, our sub-group, established in 1996, gives information and advice on shingles (herpes zoster) and on treating the pain of post-herpetic neuralgia. This mostly affects people over 60 and tends to be worse the older the patient is – see page 13.

Why we exist

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

Genital herpes (like the other herpes viruses such as chicken-pox 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 diagnoses made in sexual health clinics for 2019 - these are the most recent figures available:

There has been a slight rise in the diagnoses of genital herpes (34,570 in 2019, 33,867 in 2018). However, in comparison with the 4.7% rise in all diagnoses from 2018 to 2019, this is only a 2% rise.

Diagnosis depends on access to a sexual health clinic when symptoms are present. Unlike other sexually transmitted conditions, herpes simplex can only be diagnosed when symptoms are visible. A change in access can translate into a change in diagnosis, without reflecting the true number of cases.

We help patients to understand the psychology of herpes

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

The stigma regarding 'cold sores on the genitals' was a result of a US advertising campaign to persuade patients to ask their doctors for a prescription when the new drug was marketed in 1970s [Cuatrecasas 2006]. Treatment is usually optional as genital herpes heals on its own. This US-based campaign spread to other English-speaking countries.

What they find when they 'Google'

Once the stigma had been created, it became self-perpetuating. New patients routinely turn to the web for information. Most of what they find is either wrong or overblown. Websites selling potions and lotions exaggerate the symptoms and highlight the most severe cases in order to promote sales.

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

The internet allows misinformation to be repeated on every blog and forum. Comments from the US, where the stigma is huge, are repeated elsewhere. Anyone doing a search for 'herpes' will stumble across this kind of cyber-bullying.

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

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

To try to mitigate the stigma, our aims include:

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

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

People find these comments when they google 'herpes':

18-03-2020 Mediaite
Greg Gutfeld Rips College Kids Still Flocking to Beaches Despite Coronavirus: Tell Them It's 'Worse Than Herpes, They Might Go Home'

12-03-2020 Celebrity Insider (blog)
Former The Apprentice Employee Noel Casler Accuses Trump Of Being A Herpes-Ridden 'Addict ...

28-02-2020 Daily Mail
Qantas uses HERPES disinfectant during a 36-hour long deep clean of its planes in an attempt to ...
(actually a hospital-grade disinfectant)

14-02-2020 Fudzilla
Android catches herpes
(actually a malware infection)

13-02-2020 Yahoo Finance UK
Regret is herpes. ... ," Orji told the crowd. "Regret, it stays with you forever

21-12-2019 The Guardian
Impeachment is like herpes – you either have it or you don't.

7-11-19 TheWrap
Jimmy Kimmel Poll: Even Matt Damon and 'Genital Herpes' Could Beat Trump in 2020

15-8-19 Anti Aging News (and others)
Most Astronauts Experience "Space Herpes"
(actually about cold sore virus in saliva)

13-08-19 The New York Times
No diagnosis, apart from cancer, can as reliably bring a woman to tears as an STI. Especially when it's herpes.

24-06-19 The Jerusalem Post
"I compare antisemitism to the herpes virus," Lipstadt said. "It never goes away.

Medical facts - for the public

We aim to normalise the way that herpes simplex is described to the public – on websites and in other media. In particular, we try to dispel alarming myths associated with genital herpes. Some common errors are: "it can be spread around the body", "you can pass it on via towels/toilet seats/etc." "it will necessitate a Caesarean-section for childbirth", "it turns into HIV". These are all false.

Adding to and correcting websites:

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

If we learn of incorrect or misleading information on any UK-based website purporting to be authoritative, we ask for this to be changed. This requires emailing the 'webmaster' and asking for misinformation to be corrected, or for badly written posts to be reworded. In some cases, our emails are ignored. Websites are constantly being revised so misinformation can reappear after we have previously obtained a correction.

See websites that 'get it wrong' in the box right >>

A new threat:

Online clinics offer private antibody tests. These purport to show if a person is 'clean' or carries herpes simplex virus antibodies. Despite the authoritative CDC (in the USA) and NHS stating that this test should not be done the clinics' advertising is persuasive - so people pay for it. However one in ten positive results is wrong and up to three in ten negative results is wrong [De Vries 2016].

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

TV, radio, newspapers, magazines, books

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

Magazine and newspaper editors usually require personal stories to secure coverage. The herpes stigma means that very few people with herpes simplex will talk to the press. Nonetheless, we are referenced by:

- The Sun: Dear Deirdre, 30 August 2019
- The Sun: Dear Deidre, 4 May 2019
  Circulatin of The Sun: 1,206,595 - February 2020

Factually incorrect 'information' provided on the internet:

NHS Choices - neonatal herpes https://www.nhs.uk/conditions/neonatal-herpes/ states:
"Cover up any cold sores to avoid accidentally touching your mouth and then breast – this is enough to transfer the virus"
The British Association of Sexual health and HIV guidelines for doctors, states that this does not happen.

Centers for Disease Control and Prevention https://www.cdc.gov/std/herpes/stdfact-herpes.htm states:
"Some people who get genital herpes have concerns about how it will impact their overall health, sex life, and relationships."
In fact, there is no impact on overall health.

Useful stories countering the stigma

"Unlearning the stigma"
13-12-19
https://www.yahoo.com/lifestyle/

How the "**Herpes** Panic" Created a Stigma That Still Exists Today
3-12-19 InsideHook

The Angle: Sex Panic Edition
State Magazine

The Horror of Herpes? It's way overblown. How physicians can bust myths about herpes
Medical Economics 22-11-19

3-6-19 How the stigma behind herpes is often more damaging than the virus itself
Dailyuw
Herpes often bears the brunt of STI jokes

- Marian Nicholson is quoted in the anti-stigma piece on “Ending the stigma” https://www.theupcoming.co.uk/2019/08/27/are-we-close-to-ending-the-std-stigma-in-the-uk/
- We are mentioned as a useful resource in many of the postive comments, following the Guardian’s “The woman with the STI” 23 August 2019

We supplied a case history for Malcolm Duffy, an author of stories around ‘issues’ for teenage boys. His new book will focus on the embarrassing area of sexual health.

Our information was used in an article about cold sores in:
- Daily Mail, 6 June 2019

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

NHS Choices website uses videos to improve understanding: a patient talks about their condition or a doctor explains it. In the case of genital herpes, it is difficult if not impossible to find a patient willing to ‘go public’ about the condition. Marian Nicholson, the HVA’s director has voiced her own personal journey for the NHS Choices website. This 5-minute video clip is also on YouTube. This, and other shorter clips giving personal comments on aspects of living with this condition, have been placed in our website itself - where the text is appropriate. People have commented positively on these - see ‘call out’.

> *It was amazing to see you talk about your experiences on the video on the website. I don’t know anyone with it, and certainly I wouldn’t let anyone know I have it, so seeing someone like you be open about it was marvellous. Thank you so much … Woman, May 2019*

The medical angle for health professionals

Patients may be given inaccurate statements by medical staff. For instance, callers regularly report being told by medical staff that they are obliged to disclose their diagnosis to future partners. Whilst we encourage this for many reasons, there is, in fact, no legal requirement to disclose any sexually transmitted infection or HIV.

We were invited to write articles for pharmacists which were published in:
- Healthcare Review, 17 January 2020
- Scottish Pharmacy magazine, 17 January 2020
- Welsh Pharmacy magazine, 17 January 2020

Research - finding candidates for medical research

Since suffering from recurrences is a fact of life for some patients, anything that is more effective than the current antiviral medication will be welcome. Dr F LeGoaster in France, reported her trial showing the chickenpox vaccine, Varivax, could reduce the number of recurrnces. It was a small trial and should be repeated. We worked with Dr Bret Palmer, Reading Hosptial, to recruit patients for his follow-up research, via our Facebook pages as well as directly advertising to our members.

Training the frontline staff - 12 venues over the year:

The HVA helps medical professionals in their dealings with patients. For medical professionals in Departments of Sexually Transmitted Infections or Dermatology, herpes simplex is considered to be an occasional nuisance but seldom a danger. Staff know it is extremely common and that most people who catch it never have symptoms. Because staff know it is medically unimportant, sometimes they are taken aback by the emotional reaction from a newly diagnosed patient.

The HVA offers training talks for the staff at NHS sexual health clinics on "*Counselling Patients with Herpes Simplex"*. This offer is popular and this year we addressed more than 200 staff at their clinics, with a satisfaction score of 92%: in Hayes, St Helier (S London), Chester, Birmingham, Oxford, Aylesbury, Hatfield, Wickford, St George's (London), Colchester, Croydon and Mortimer Market Centre (London) Several clinics invite us to repeat the talk when staff turnover necessitates it.

Understanding our work, means that more and more clinics refer patients to our website or helpline.

> Thank you again for your amazing work and the awesome resources that are so easily accessible when they are most needed. I finally got a call back from an NHS practitioner today. I told her that, because I couldn't find out anything useful on their website I had been using yours. She said "good - don't go anywhere else as there is a lot of misinformation out there". Woman February 2020

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

Our Information Officer, Nigel Scott, was consulted by a genitourinary registrar doctor in November 2019, regarding the use of aciclovir while breastfeeding, because there are no medical guidelines. We were able to provide a reasoned reply that this is acceptable.

GPs and other non-specialists may have little knowledge of appropriate treatment or even of the basic facts – e.g. that herpes simplex can appear, and be diagnosed, many years after infection:

> I am driving myself mad with constant worry. I had a sore come up at Christmas out of the blue. I went to the GP's out of hours doctor and they said: Yes, it's herpes. I was mortified the way they made me feel. ... My boyfriend doesn't have anything, so he suspects me of going with someone else. It is on my mind every minute if every day and I am not sleeping and it's making me ill constantly waiting for the next one to show up ... Looking at pictures on the Internet has made it worse I wish I had come across your site first. Thank you, Marian, you have been helpful. I wished I had come across your site and emailed you 4 months ago rather than getting myself in to a state like I have Woman, March 2019

Consulting on other organisations' websites and leaflets:

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

A representative from the HVA is an active member of the panel set up by the British Association for Sexual Health and HIV to pilot ensure patient engagement in their actiives and services and has attended all three of their meetings this year. This panel provided comments on their new range of leaflets for patients on various aspects of sexual health. We provided input into the three new 'vlogs' (short video interviews) aimed at edcuating young people.

A major work of the panel, during this year, was to advise on the wording of the new BASHH service guidlines.

What we do for the public – our services

Website – https://herpes.org.uk - 425,000 unique visitors this year

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

In a web search for 'herpes', https://herpes.org.uk is the first site listed on Google UK. Our ranking is assisted by use of 'Google AdWords', an advertising service that is provided free to charities. This means that the HVA is often the first or second promoted site that appears in search results, in addition to its non-promoted placing.

In a Google search for 'cold sores' the HVA website comes second. Visitors to the site find it very different from other websites. They send in unsolicited testimonials:

> I can't thank you enough for your response, I am so thankful for your website and all the information you have given me. I hope I can find it in me one day to feel normal again, it's definitely a long process but with people like you and your website it makes it much easier. Woman, March 2020

> While I am messaging, I also wanted to thank you for all you do and the stigma you fight against! Thank you! Woman, Feb 2020

Emails – info@herpes.org.uk

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

> I can't thank you enough for your response, I am so thankful for your website and all the information you have given me.
>
> I hope I can find it in me one day to feel normal again, it's definitely a long process but with people like you and your website it makes it much easier.
>
> Thanks again. Woman March 2020

> Thanks for the detailed email. ...
> Once again : you were formidable help. Woman February 2020

> Thank you so much for email and for the level of information, encouragement and support that you have given me over the past week or so without even realising it. … my recent diagnosis came as a bolt out of the blue. Since then, I have read your information so many times that I could probably give a very informed 10-minute talk on the subject.
> I was a teenager in the 80s and was very aware of the hype about genital herpes - although I was unaware that it was marketing led at the time. That history certainly didn't help when I found out I had a Type2 virus.
>
> After reading Flo's recent article … If there is an opportunity to do so, please let her know that her article made a difference. As did the link to Marian's video on the NHS website.
>
> I've given myself a good talking to along the lines of me being the same person to the same special people that I was before my diagnosis. That has helped a lot.
>
> At present it feels a bit like having a bald tyre - before you know about it, it isn't an issue but once you know, it is something that worries you and you don't want to get caught / have an accident!
>
> I have no idea what the future holds but I feel confident knowing that you are there should I have a wobble or need more information. Woman, February 2020

Facebook

There are many herpes-specific Facebook pages. We run a secret one for our members - totally invisible to their friends and contacts.

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

Helpline (0845 123 2305) - 2,882 callers this year - 10.4 callers every day.

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

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

The helpline service is available for over 60 hours a week, with core times of 10.00am to 8.00pm on weekdays, sometimes at weekends and on bank holidays too. When there are multiple volunteers, the number of person-hours available can reach 80. Anyone can call to get help and support. Commonly callers are:
- people newly diagnosed with herpes simplex;
- people whose new partner has told them that they carry the virus;
- people with too many outbreaks;
- worried people who want advice on how to inform a new partner;
- pregnant women, who tend to phone our helpline in the last weeks of pregnancy to ask about childbirth.

Calling our helpline from a landline costs the same as a local call; it does not generate income for the charity.

- Callers are between 17 and 75 (these ages are volunteered, we do not ask) with the average being 37.2 years.
- Callers can talk for as long as they wish.
- Calls average 10.25 minutes – which includes some calls lasting over an hour.
- Callers may be crying or mention suicide so our volunteers need to be strong emotionally as well as being trained with 'all the answers'.

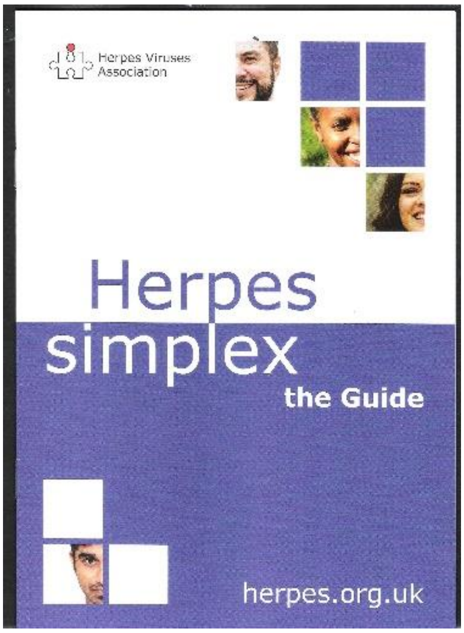
Thanks a ton! You are the best.
Man, February 2020

Transaction Description:	Ms X: Your helpline service is invaluable thank you
Transaction Amount:	£50.00

I just wanted to write to say a very big THANK YOU to the man I spoke to on the phone on Thursday about protecting and telling my partner that I have HSV-2. I have been unable to discuss this with friends and family on account of the stigma I have been feeling. I would usually discuss things with them so the inability to do so felt alien and isolating. You made me feel lots better about everything and your calmness, practicality and reassurance were very deeply appreciated. I felt slightly emotional towards the end of our conversation so felt that I hadn't thanked you properly. Suffice to say, I did tell my partner and it went well and he didn't run away screaming. A huge thanks once again. Woman, June 2019

'Herpes Simplex - The Guide'

6,582 copies of *Herpes Simplex – the Guide* were distributed through sexual health clinics in the financial year ending March 2018. *The Guide* is a 16 page, 6,000 word, A5 sized illustrated booklet. It has been written and updated by people with herpes simplex for their peers and is revised for each new edition. The information in this 13th edition is endorsed by doctors working in sexual health and carries the Information Standard logo.



Thank you so much for this booklet. My daughter was diagnosed on Monday & it arrived yesterday - It is so well written & with such common sense, a huge thank you from us both. Woman, May 2019

"Their [the HVA's] booklet is just fantastic. We've had hundreds of them" said Dr Colm O'Mahony, former consultant at the Countess of Chester Hospital and previous media spokesperson for the British Association for Sexual Health and HIV (BASHH).

Meetings for the public

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

> I couldn't shake, the now slightly reduced, sinking feeling when I reminded myself that I had genital herpes. I decided to go to one of the London meetings to chat with Marian. Nervous and inexplicably somewhat embarrassed, I entered the Atrium Lounge at the President Hotel and soon saw Marian and went to introduce myself.
> I chatted to her about the type I had contracted, my outbreak, future outbreaks, how to speak to a partner about it, what treatments were recommended and soon realised that this is not the end of the world. This skin condition is incredibly common and not actually something that is going to stop me living my life the way I want to.
> I felt such a huge sense of relief that I had gone to see Marian because I really did leave that meeting fearing absolutely nothing about herpes. My whole view of the virus had changed. I had been reassured.
> Woman, May 2019

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

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

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

> It was good to meet you yesterday evening and thank you, I feel normal again after many weeks of very much not.
> Woman, June 2019

Additional services are provided for members

> Once again: you were formidable help. Woman. February 2020

Leaflets

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

We have acquired certification to use The Information Standard (TIS) logo. TIS is the NHS's quality mark for medical information for patients. Any organisation achieving it has undergone a rigorous assessment of the information production process to ensure that the information produced is high quality, evidence-based, balanced, user-led, clear and accurate. Leaflets, as well as other materials such as booklets and web pages are all subjected to the process – a referenced version is available on request. All 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.

> The information I have received so far since subscribing has very much helped me start to understand better and accept my situation 12 years on. Woman Feb 2020

> Thank you for sending me the information and everything you are doing to support us!
> I must confess that I have found a lot of emotional and psychological comfort in the leaflets & documents.
> It is so valuable to be well-informed, and I have been able to talk about it freely with my friends and some ex boyfriends. Woman Feb 2020

Journal - Sphere

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

> I've been waiting for it to come as I love reading it and it's always very positive. Thanks again for this site and all that you do. The past few months have been a particularly difficult and dark time, but you guys have always answered the phone and responded to my emails. I appreciate it more than you'll ever know. It's very easy to get caught up in the stigma and feel very alone, but you guys offer a bit of light at the end of the tunnel and a kind, listening ear when it feels there's no-one else to turn to. It's helping me to move on and I'm sure it's helped many others.
> Woman, April 2019

Meetings just for members

As well as open meetings mentioned on page 10, the London-based office staff organise various types of meetings around the country just for members. These may be hosted and organised by local volunteers - but the London office does the inviting to ensure member confidentialty. These meetings help this self-selected group of patients to recognise the 'normality' of other people with genital herpes which is something that quite often comes as a surprise to them.

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

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

Continued on page 16

Shingles Support Society

Sub-group recognised by the Charity Commission

Our sub-group, the Shingles Support Society (SSS), was formed to allow people suffering from herpes zoster (shingles) to find support for the treatment of post-herpetic neuralgia (PHN), a pain that sometimes accompanies this condition. In older patients, this pain frequently continues long after shingles blisters have healed.

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

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

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

Private individuals are helped directly and personally:

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

> Thank you very much not only for sending me the comprehensive collection of literature about shingles but also for your patients and kindness of the telephone last week! It was amazing to me that a complete stranger should take the time to talk to me as if my case of shingles was the most deserving of care and attention ever!
> I am sending £20 but now that I have discovered this amazing source of comfort, solace and advice. I shall Certainly give this charity a lot of thought in the future. Man, June 2019

We were interviewed on radio and also provided quotes for the press about shingles, how it can cause PHN, how PHN can be treated and how the new vaccine can prevent cases. Marian Nicolson is often asked by pharmaceutical companies to talk at staff training sessions about how shingles and post-herpetic neualgia can change a person's life...

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

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

- ◦ Pain UK - there are 32 pain charity members and over 1,400 individual members who receive alerts and newsletters.
- ◦ Pain Alliance Europe – she attended eight meetings in Brussels and one in Valencia, Spain, where she was the representative from Pain UK. These meetings include the EU's MEPS' special interest group on Brain, Mind and Pain. PAE has 42 charity members from all over Europe. She is also involved in the steering group for the Societal Impact of Pain.

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What did you think of the Study Day?

Your voice of reason on the phone when I first called, upset and scared, and particularly the **workshop on 'How to Tell Your Partner'** where I met other wonderful and empowering women in a similar situation, and the magazines and guidance you've offered, tirelessly, since.
All priceless! I can't thank you enough.
Woman May 2019

What would you say to others thinking of coming?

Definitely go, particularly if they are struggling with coming to terms with it, suffering lots of outbreaks, or telling a partner.
I feel apart from a better understanding of the condition, a great bunch of people with whom I can discuss any issues I may face moving forward.

Other events:

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

I just wanted to say a massive thank you for holding the meeting on Saturday. I hadn't realised quite how useful I would find it.

It really helped seeing how normal the other people were who are in the same position as me and hearing about their experiences. I'm glad I came to the meeting after only a couple of months after catching Herpes as I believe it's helped give me a better perspective early-on about living with the condition. Woman, April 2019

Working with other associations

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

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

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

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

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

As well as the organisations listed above, we are members of:
- British Association of Dermatologists' Patient Support Groups – this enables us to work with many other professional bodies, e.g. British Dermatology Nursing Group, the British Skin Foundation, pharmacists, as well as the pharmaceutical industry.
- 'HealthUnlocked' and other appropriate websites and umbrella groups.

Who does what: staff and volunteers - monitoring and training

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

Marian Nicholson, director, works from noon to 8pm. Nigel Scott, administrator and information officer, works 10am to 6pm. This schedule allows for a more comprehensive service. The advantage to the public is that when volunteers are not available Marian and Nigel are available to answer helpline calls over an extended period. They also volunteer by answering calls and responding to Facebook Messenger enquiries in their own time. This also helps to keep them aware of the current patient concerns.

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

Executive Management Committee

The association was registered with the Charity Commission in 1985. The Executive Management Committee is elected from the membership at the Annual General Meeting. Committee meetings are normally held monthly to oversee the work of the association, direct its future, and approve exceptional expenses. There are currently eleven members, three of whom are male.

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

Funding for 2019-2020

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

Membership fees raised £21,627, up a little on the previous year. The first year's fee is £30, and £25 for renewals. Membership numbers were higher before the internet age. The lower total today reflects the increased availability of useful advice and information on our website which is provided free of charge. This counters a torrent of badly written web pages and outright misinformation about genital herpes that is found online.

Donations totalled £28,942. We continue to encourage members and service users (on phones, emails, website) to be generous with donations. Over fifty of our members have set up regular monthly donations by standing order of varying amounts between £2-£30.

Profits from selling booklets, and the creams and supplements (therapeutic materials which we have trialled and found useful in preventing herpes simplex outbreaks) generated around £15,000 gross profit – that is without making allowance for cost of writing and designing and sales administration.

Corporate donations/payments in the year 2019-2020**:**

- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £1,210 this year.
- A link on our website goes to MedExpress, approved by the Care Quality Commission to sell antiviral drugs. This sponsored link raised £10,800.

Fundraising

Challenges because of the stigma associated with genital herpes:
Consultations with fund-raising specialists have indicated that the HVA is hard to place as a charitable cause with a large company: there is no PR gain as the herpes stigma will not create a favourable impression with customers. Similarly, organisations such as the Round Table, Rotary and Freemasons have to date been unwilling to encourage their volunteers to fundraise for a 'herpes' charity because of the associated stigma.

Charities routinely encourage members and beneficiaries to assist with fundraising. Our members are not able to do so because it would require them to 'go public'. Therefore, community fundraising activities like running marathons or undertaking sponsored challenges are off our agenda. Nevertheless we acknowledge the generosity of many of our members who make extra individual donations and set up monthly standing orders.

Fundraising activities
The public is invited to donate to the HVA via several links on the HVA's website. These include MyDonate, a free service which is popular as donations made via this website can be anoymous. We ask all contacts to use www.EasyFundraising.co.uk when they are using 'online shops'. This web portal includes over 3,700 online shops including many well-known companies (including Amaxon, Asda, ASOS, InterFlora, M&S, Travelodge, Zizzi). A percentage is donated to the charity chosen by the shopper. We ask people to nominate the Shingles Support Society as their designated charity. This year we have received £322.

Trusts
We received an unresticted donation of £1,000 from Druces LLP. We will continue to ask for grants from charitable trusts and we are optimistic that this avenue may prove productive in 2020-21.

About accounts for 2019-2020

The accounts for 2019-2020 were signed by an Independent Examiner: Josh Botham of Josh Botham Tax & Accounting Services Ltd.

Gross income: £ 150,836
Expenditure: £ 135,870

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

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

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

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

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

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

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

Our reserves figure is updated annually in line with inflation and changing redundancy costs. For the year 2019-2020, the target of target of £68,900 has been met.