Annual Report 2018

Herpes
Viruses
Association

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

Herpes Viruses Association
Annual Report
April 2017 to March 2018

Letter from the Chair

Welcome to the Annual Report for 2017-18 which showcases our work and our achievements.

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

The herpes conundrum

We help people who have been diagnosed with genital herpes, which has been called the second most stigmatised of all diseases (after HIV - source: Harris Interactive USA poll, 2007). Yet the viruses that can cause it - herpes simplex, types 1 and 2 - are common. The infection is rarely serious and most of us have caught at least one of them. 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% has the other type (HSV-2). These two viruses cause genital herpes and facial cold sores. So why are they feared?

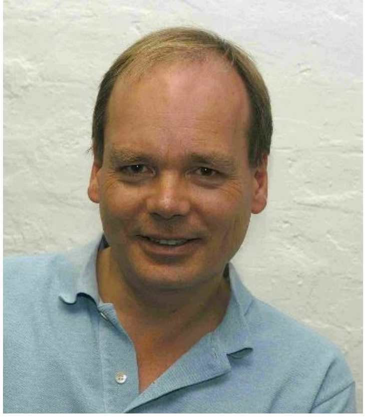
A partial explanation is ignorance. Only one person in three of those who are infected is aware of it – the others get minimal symptoms and are usually not diagnosed. Most people catch it on the face, where it is called a cold sore, not on the genitals, where it is stigmatised – and because there are different names for the same infection, depending on location, 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.

The Herpes Viruses Association works to educate patients, medical professionals, journalists and the wider public about this reality – see pages 6 and 7.

People approach us for support and we help them in a number of ways. In recent years, the HVA's website has become the first point of contact for many patients, particularly the newly diagnosed. It is recommended by many clinics and doctors. We have free Google AdWords placing.

Our helpline continues to offer callers the chance to talk to a sympathetic – and well-informed - peer. As well as taking helpline calls themselves, our staff train volunteer helpliners. We are very grateful to these volunteers and would welcome more!



We continue to produce the quarterly online journal, Sphere, for HVA members and we run the very popular 'Study Days', when members gain a deeper understanding of how the virus works and how to talk to partners about it.

We offer a private Facebook group where our members can interact and where staff can deal with queries. This complements the public-facing Facebook page that has been running for several years:

> *I love the group honestly it has taught me so much, ... not only about the condition and other health issues but also it has taught me so much about myself, others views, ... It's helped me grow as a person.*

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. Our director Marian Nicholson is a trustee of two umbrella charities: Pain UK and Pain Alliance Europe. This enables her to work with other charities both domestically and across Europe to raise awareness of the problem of chronic pain – see page 13.

Our work and survival is only made possible with the financial contributions 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.

The HVA is well managed and efficiently run and is well able to meet the challenges that face it.

LMS 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, created to accompany 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 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.

In the case of herpes simplex, this fact is used by pharmaceutical companies and complementary therapy manufacturers to exaggerate its importance, by calling it 'incurable'. This can mean that patients take on a psychological burden as they believe themselves to be disease carriers with a high risk of infecting future partners. However, the majority of carriers (around 66%) are not diagnosed at all as their symptoms are so mild - and they escape the 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:
- Sexual health clinic staff
- National Sexual Health Line (Public Health England)
- the 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 advancing public education about herpes viruses and the means by which these conditions may be most effectively prevented and treated.
2. To promote, or assist in promoting research into the prevention and treatment of herpes simplex and its effects on the persons who contract it, and to disseminate the useful results of such research for the benefit of the public.
3. To relieve persons with symptoms of herpes simplex.

Annual statistics for 2017 – diagnoses made in sexual health clinics:

- There has been a slight fall in the diagnoses of genital herpes (32,737 in 2017, compared to 33,040 in 2016). This might only reflect that it is becoming more difficult to access the services. Herpes simplex can only be diagnosed when symptoms are visible, so if access is delayed, diagnosis cannot take place.
- Only in two groups has the level of diagnosis risen: females in the 25-34 age group up 2%; and men and women over 65 up 15% to a total of 359.

Information from a psychological angle

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

As mentioned on the previous page, a stigma regarding 'cold sores on the genitals' was created when medication was first brought to market.

The reason for this is that treatment is usually an option, not a requirement, as sores heal without intervention. Advertising was required to persuade patients of the need to ask their doctors for prescriptions. The 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. Newly diagnosed patients routinely turn to the internet for information. Most of what they will find is either wrong or wildly exaggerated. Websites are created to sell potions and lotions: these 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.

'Good news' is not newsworthy. The internet allows misinformation to be repeated on every blog and forum. Comments from the US where the stigma is serious are repeated elsewhere. Anyone doing a search for 'herpes' can 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.

To try to mitigate the stigma, our aims include:

- educating the people who are diagnosed with genital herpes with the real 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 hidden, 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':

17-9-17 Aspen Times

Glenn K. Beaton: Like herpes, Hillary Clinton just won't go away

Certain dread diseases are not curable. They might go away for a while, but eventually they come back with ugly pus-filled sores that itch, fester and ooze. They're painful and embarrassing.

Hillary Clinton is like that.

6-10-17 Death and Taxes

Arnold: Herpes 'more popular than Congress,' but they're still re-elected

Or, as Arnold Schwarzenegger put it outside the Supreme Court Tuesday, "**Herpes** and colonoscopies are more popular than Congress, but for some ...

3-11-17 San Francisco Chronicle

The ISIS virus is spread like **herpes** — through close contact

ISIS is like **herpes**. That's why public health protocols likely can teach us more about fighting the Islamic State (also known as ISIS) than our current ...

9-11-17 CBC.ca

Accused killer and girlfriend compare Laura Babcock to '**herpes**'

In a text message to his girlfriend, Dellen Millard compared Laura Babcock, the Toronto woman he is accused of killing in 2012, to "**herpes**" that he ...

8-12-17 Metro US

Fake news or nah: Amy Adams might be pregnant

"Fake news is as pervasive in today's hellscape as genital **herpes…**"

26 Feb 2018 HuffPost

Laura Ingraham Says 'Liberals Are Kind Of Like **Herpes**' At CPAC

Information from a medical angle - 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 C-section for child-birth", "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 the examples of websites that 'get it wrong' in the box opposite:

TV, radio, newspapers, magazines:

We seek publicity both for the condition – to improve knowledge - and for the Association so that people are aware of where to come for information.

Magazine and newspaper editors usually require case histories to secure coverage. The herpes stigma means that very few people with herpes simplex will talk to the press. We provided information/interviewees for several articles, a TV programme and a radio programme which then did not appear.

Our information/interviewees were used in:

- Channel 4
- Radio Scotland
- Metro-on-line (by Violet Fenn)
- Patient Magazine on line (by Sally Turner)

We succeeded in getting one very misleading article taken down from Mare-Claire website.

NHS Choices video:

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 their 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. It has been praised by viewers:

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"

But the British Association of Sexual health and HIV guide-lines for doctors, state this does not happen.

British Association of Dermatologists – patient 'information leaflet' http://www.bad.org.uk/for-the-public/patient-information-leaflets/herpes-simplex states:

- Use tissues when washing to dry the area, and dispose of them by bagging or burning, to prevent others from becoming infected.
- Do not use a communal towel.

In fact, these are unnecessary actions.

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.

I just wanted to write to you to say that a few months ago I discovered I had caught HSV-2. I have had moments of being absolutely distraught with this and other times when it seems to bother me less. I have had a lot of outbreaks, and as a 20-year old girl at university I am really, really struggling with coming to terms with it fully.

So tonight, again I had a bit of a meltdown about it, I was googling and reading too many scary articles and I got in to an absolute state. I decided to come on to your page (as I have done before since being informed of it by my GP) and have a read.

I had not seen the video on the website before, and the consolation it gave me in a time when I was very distressed was amazing. I wanted to say that you have helped me so much in all the times that I have seen absolutely no light in this situation. The work that you all do I am so grateful for. You are wonderful people!! You are an amazing and special help for people like me, that just need to be reminded it's not as bad as it seems, and you do exactly that so, so well.

So thank you, for all the work that you do and for once again, stopping me from becoming completely and utterly hopeless. **- Woman December 2017**

The medical angle
- for health professionals

Patients may be given inaccurate statements by medical staff. These are wrong advice:

> *I was told I would have to use a condom forever, how can I get pregnant?* **Woman – by phone**
> [we explained transmission risks and remedies]
> *The doctor asked how many sexual partners I had had. She implied that only promiscuous people get this.* **Woman - by phone**

Training the frontline staff:

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 they know it is unimportant, sometimes they are taken aback by the emotional reaction from a newly diagnosed patient.

The HVA offers talks on "*Counselling Patients with Herpes Simplex*". This offer is taken up by Sexual Health Clinics for their training days: 4 this year. Several clinics invite Marian Nicholson to repeat her talk when staff turnover necessitates it.

Clinics can receive free supplies of the leaflet 'True or False' or 'patient cards' - see previous page

> *"The clinic handed me your card only whenI went back a thrid time with more questions about this. I had seen conflicitng information on the intenet. They should've given it to me right away? It would have saved me a lot of misery."* Woman, June 2017

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:

> *The GP told us that one of us must have been unfaithful, but we know that we haven't.* **Woman - on the phone.** [We were able to explain possible infection from a cold sore – or unrecognised infection from before they met.]

Consulting on other organisations' leaflets:

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

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 the new range of leaflets for patients and has attended all three of their meetings this year.

Reviewing reports and responding to consultations:

We submitted our evidence/opinion to the government's consultation on 'Changes to the teaching of Sex & Relationship Education and PSHE'.

Cochrane requires 'consumer referees' for protocols and final review/meta-analyses. This year, we volunteered to review a protocol for a rare medical complication of herpes simplex infection: 'Systemic interventions for treatment of Stevens-Johnson Syndrome (SJS), Toxic Epidermal Necrolysis (TEN) and SJS/TEN overlap syndrome'

What we do for the public – our services

Website – https://herpes.org.uk - 450,000 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:

> *First off I want to thank you guys for comforting and making me feel accepted more than any other website.… you helped me more than you can imagine.* Man, March 2017
>
> *Hello there, I actually don't have a question but I do have a big thank you for you all. (I can't donate yet I'm afraid so I hope my thanks is enough.) I recently met a girl, a great girl at that and she told me that she has herpes. I freaked out! That was until I read every single word on your frequently asked questions page. So thank you so much for putting my mind at ease! Keep up the good work and you'll be seeing a donation as soon as money hits my account.* Man, March 2017
>
> *I cannot tell you what a help your site has been and I just wanted to say thank you so much.* Woman, January 2017

> *The advice and support the HVA gave me was amazing. It gave me the tools and confidence to be honest and upfront with my partner at a time when I was myself in such turmoil.* Woman, October 2016

Emails – info@herpes.org.uk

Despite the comprehensive information provided on the HVA's website, we also individually answered 740 emails, many of which had detailed questions about transmission and required a great deal of reassurance. These personalised replies frequently elicit 'thank yous'.

> *Hi thank you for all your work, and I hope you never give up on us or move on. I got genital herpes 3 years ago had one outbreak then a minor outbreak a month later, and after that I never had an outbreak or symptom again.* **Man, December 2017**

> *I seem to get more sense from you than any other doctor over the last 2 years...Thank you for being so brave and standing up for people with HSV-2 and helping them out.* **Man, December 2017**

Helpline (0845 123 2305) - 2,585 callers this year - 10.8 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 are well informed about treatments. The value of this peer support is especially relevant 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 more than one volunteer answering at a time, 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.

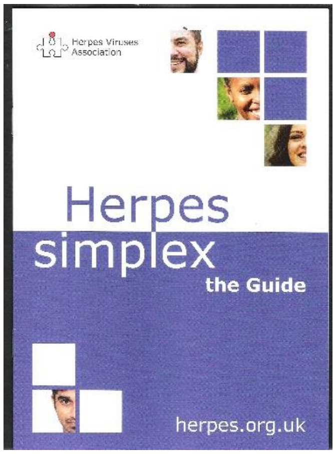
- Callers can talk for as long as they wish.
- Each helpliner takes an average of 12 calls per session
- Calls average 10 minutes – which includes some calls lasting over an hour.
- Callers may be crying or mention suicide so our volunteers need to be strong emotionally as well as being trained with 'all the answers'.

> *Speaking to Marian made my day! This is the first step to a better quality of life for me and know it is a journey which hopefully I will be able to tap in to advice to guide me through the twists and turns ahead. Thank you very much.* **Anon, March 2 2018**

> *The good news is, I rang you for advice back in September just as I was starting to see a really nice man… I was very worried about to tell or not to tell, etc. and I found your*

> *advice very reassuring. I did tell him and he has been very kind and accepting and we have a very good relationship… I would like to thank you and your team for helping me find the right words.* **Woman, Jan 2018**
>
> *I've had 3 very reassuring and informative calls with you over the last 4 years since I was first diagnosed. I have always phoned you in a bad state, got straight through to someone and come off the phone feeling massively better. So thank you. It really is an amazing service you run. With warmest regards,* **Woman, Jan 2018**

'Herpes Simplex - The Guide'



7,865 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.

> ***"Their booklet is just fantastic. We've had hundreds of them"*** said Dr Colm O'Mahony, 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.

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 events – open to the public - in London last year attended by approximately 100 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.

Additional services provided for members

> *I just wanted to say a massive THANK YOU for making HVA so good. I was so ashamed when I was diagnosed, and have felt this weight on my shoulders since, avoiding relationships in order to avoid having to have 'the chat' or face this head on.*
> *This week I sat down to tell my boyfriend I had herpes, after reading all the leaflets and armed with all the facts. Despite trying to make it not appear a big deal I was terrified of his reaction and worried that it would end things between us. … he said this made no difference to how he felt about me at all. …*

> *Anyway the weight is well and truly lifted from my shoulders, and I could weep at the relief. I feel excited to look to the future with him and have started planning our first holiday.*
>
> *Thank you for keeping HVA going and being so 'real' with it, it has been such a support to me.* **Woman, January 2018**

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 are an Information Standard certified organisation. The Information Standard 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.

Health & care information you can trust

The Information Standard ✓ Certified Member

> *By the way, I've had a recent diagnosis and your leaflets have been absolutely wonderful in helping me to think things through and also talking to other people about it. Thank you so much for writing them.* **Woman, Feb 2018**

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.

> *There were times before finding HVA, that mentally I would never live a normal life. Whilst the condition itself if / when I think about it too long or indeed get an outbreak, still makes me feel some of the things I use to feel, things are most definitely better and I'm way more comfortable in myself than I have ever been and in main, a lot more relaxed about the condition than I ever was. So thank you.* **Man, January 2018**

Meetings just for members

As well as open meetings mentioned on page 10, members and the London-based office staff organise various types of meetings around the country just for members. This enables 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.

Thirty four people attended a "Study Days" offered. Four were 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 >4.3 out of a possible 5 points across several measures.

> *What did you think of the Study Day?*
> *It's changed my though process. Really very helpful.* **Woman, October 2017**
> *It has make it seem less horrendous. I had built up an idea in my mind but hearing the stats has changed my perception.* **Woman, October 2017**

Other events:
- 24 sharing/talking events in London (with approx. 110 people attending) – as mentioned above in the section on public events
- 2 purely social events such as clubbing, in London
- 10 social events hosted by members in other cities nationwide: Kent to Glasgow

Working with other associations

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

The International Union against Sexually Transmitted Infections (IUSTI) gave our director a free delegate place at the three-day annual educational meeting in Helsinki.

The British Association for Sexual Health and HIV (BASHH) gave our information officer a free delgate place at the three-day annual conference in Belfast.

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

This year was the 100th Anniversary of the founding of the 'free, open access, anonymous service to treat VD'. Our director was one of the 100 special guests a dinner in the Guildhall of the Royal College of Apothecaries. The guests were chosen by BASHH for having really helped in their work.

Also, a repesentative of the charity sang at the BASHH Centenary Concert Party: *"When You are Old and Grey" by Tom Lehrer.*

We attend meetings of the following APGs where we can make comments from the patients' persepctive:
- All Party Parliamentary Group on Sexual and Reproductive Health
- All Party Parliamentary Group on Skin

This year we were consulted by the FPA (formerly the Family Planning Association) on the script and presentation of a new three-minute video 'cartoon' blasting a 'myth'

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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 to find support for the treatment of post-herpetic neuralgia (PHN), a pain created by the chickenpox virus when it reactivates. In older patients, this pain frequently continues long after shingles blisters have healed.

We send out a 17-page information pack for sufferers to share with their GPs explaining medical treatment. The first line treatments for PHN are generic tricyclic antidepressants and anti-epileptic drugs, and some GPs remain unaware of how useful they can be. Sometimes patients who have been prescribed these drugs do not take them as it has not been explained to them how 'the wrong drug' could actually be very 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 others for mutual support.

The vaccine, Zostavax, helps to prevent shingles. It is provided by NHS to certain age groups. Although the Joint Committee for Vaccination and Immunisation approved its use for all 70-79 year olds in England, it is being introduced slowly. The complicated allocation of this new vaccine causes confusion, even amongst GPs.

- Many people get in touch to find out if they qualify for it – and to get an explanation as to why it is only available to certain ages. This year the Department of Health offered the vaccine to people who were 70-74 or 78-79 on the 1st September 2016.
- We provided a patient for a Zostavax training video for professionals, by Merck.

Private individuals are helped directly and personally:

- 678 phone conversations. Topics included transmission, treatment of PHN and the new vaccine to prevent shingles.
- 88 people received the 17-page information pack as well as personalised information
- 41 people had their problems dealt with only via email communications

We gave interviews on radio and quotes for press to explain shingles, how it can cause PHN, how PHN can be treated and how the new vaccine can prevent cases.

- Daily Mail health section
- BBC Radio 4 Northants

Our logo and contact details are used in other organisations' materials as useful resource. This year we gave permission for this to:

- The Immunisation, Hepatitis and Blood Safety Department, Public Health England requested the use of our logo for the leaflet on shingles immunisation
- The Brain and Spine charity

Our shingles and post herpetic neuralgia work led to the charity's involvement with other organisations that campaign for improved treatment 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
- Pain Alliance Europe – she attended five meetings in Brussels where she was the representative from Pain UK - including the launch of the EU's special interest group on Brain, Mind and Pain. PAE has 38 charity members from all over Europe. She attended the Societal Impact of Pain event in Malta as a patient representative.
- She worked with the Chronic Pain Policy Coalition on the treatment of chronic pain.

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about genital herpes. They had funding for six of these videos. They chose to correct the idea that "You'd know if you had herpes". We were able to ensure the wording was totally clear and unambiguous.

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

Two full-time staff 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 on days when volunteers are not available Marian and Nigel are available to answer helpline calls during an extended period, giving callers a wider choice of times when they can call. They also volunteer and answer calls in their own time. An advantage for the staff is that by taking helpline calls they are kept aware of the public's topical concerns.

Volunteers are essential to our service. Over the year, we have had help from ten helpline and other volunteers.

- Our helpline volunteers are given training and joined the roster: weekdays 9 am-8pm
- Helpline volunteers are given support by telephone from their original trainer.
- Emails are sent out regularly to keep them up-to-date with factual information and suggestions for counselling.
- Monitoring of helpline services continues at all levels.
- The volunteers fill in a report sheet (helpline log) to enable supervision of the information provided and to target appropriate training or information.
- Around the country there are 'local contacts' and organisers of group meetings who are supported by the office staff but do not receive formal training.
- Four volunteers have provided useful office help from time to time.

Executive Management Committee

The association was registered with the Charity Commission in 1985, under a constitution. The Executive Management Committee is elected at the Annual General Meeting from the membership. Committee meetings are normally held monthly to oversee the work of the association, direct its future and approve exceptional expenses. There are currently nine members, one of whom is not a service user. Two are male.

The Charity Commission has agreed to keep the HVA's committee members' names confidential. They are not named on our website or on any published document either.

Funding for 2016-2017

The charity's continued existence is dependent on the financial support it receives from patients and families who have been helped by our activities: proof of the vital role that the HVA continues to play, in meeting a genuine need for countless people and proof that this need is not met by other bodies.

Regular sources:

A survey found that, each year, about one third the 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 brought in £18,741, a slight increase on last year. The subscription fee for the first year is £30 - renewal remains £25. The number of subscribers is low, which we consider is a reflection of the increased availability of useful advice and information on our website which is provided free of charge as a public service in order to counter the torrent of badly written web pages and outright misinformation about genital herpes that is online.

Donations totalled £20,456. We continue to encourage on our members and 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) amounted to over £15,000 gross profit – that is without making allowance for cost of writing and designing and sales administration.
- Responding to our appeals, over fifty of our members have set up regular monthly donations by standing order of varying amounts between £2-£30.

Corporate donations/payments in the year 2017-2018**:**
- Eladon Ltd, a manufacturer of herbal treatments and vitamins, some of which we have trialled to show benefit to herpes simplex patients, donated £2400 this year.
- A link on our website goes to MedExpress, approved by the Care Quality Commission to sell antiviral drugs. This sponsored link raised £9,900.
- For doing an interview for a video for their staff, we received £250 from Merck Ltd.

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.

Whilst many charities encourage their members or 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. This includes MyDonate, a free service which is population as donations can be anoymous.

We ask all contacts use www.EasyFundraising.co.uk when they are using 'online shops'. This web portal includes 2,700 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 have an expert fundraising volunteer giving us advice and will continued to apply to secure funding from appropriate grantmaking trusts and charitable foundations.

We are optimistic that this avenue may prove productive in 2017-18.

About accounts for 2017-2018

The accounts for 2016-2017 were signed by an Independent Examiner: Josh Botham of Josh Botham Tax & Accounting Services Ltd.

Income: £ 128,687

Expenditure: £ 129,783

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 for tax which is returned to us 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 Association'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 2017-2018, the target of target of £68,730 has been met.

REGISTERED CHARITY NUMBER: 291657

Report of the Trustees and Unaudited Financial Statements for the Year Ended 31 March 2018
for
Herpes Viruses Association

Josh Botham Tax & Accounting Services Ltd
Archer House
Britland Estate
Northbourne Road
Eastbourne
East Sussex
BN22 8PW

Herpes Viruses Association

Contents of the Financial Statements for the Year Ended 31 March 2018

Herpes Viruses Association
Report of the Trustees
for the Year Ended 31 March 2018

The trustees present their report with the financial statements of the charity for the year ended 31 March 2018. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number: 291657

Principal address

41 North Road
London N7 9DP

Trustees

Trustees are elected from the membership at the Annual General Meeting or on an ad hoc basis at any time in the year. The Charity Commission has given permission for their names not to be shown.

Independent examiner

Josh Botham Tax & Accounting Services Ltd
Archer House
Britland Estate
Northbourne Road
Eastbourne, East Sussex
BN22 8PW

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes an unincorporated charity.

Organisational structure

Trustees sit on an executive/management committee which meets monthly. There are currently nine trustees, only one of whom is not a service user, three are male.

Risk management

The Trustees ensure that available resources are used appropriately to fund work priorities and when necessary curtail activities if funds are not available. The trustees consider ways of ensuring income levels for all aspects of the work of the Herpes Viruses Association. The trustees identify and review the risks to which the charity is exposed and ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

OBJECTIVES AND ACTIVITIES

Charitable objectives

The principal objective of the Association is to promote good health by advancing public education about all aspects of herpes viruses and the means by which the symptoms they cause can be effectively treated. The Herpes Viruses Association is a non-profit-making organisation and a registered charity.

OBJECTIVES AND ACTIVITIES

Charitable activities

This is a charity run by patients for patients. Last year, there were approximately 31,000 new cases of genital herpes diagnosed in sexual health clinics. Many more diagnoses are made by GPs which are not recorded.

The charity hosts a website which received 871,000 visitors this year, it provides an information line which is primarily used by people with genital herpes and their partners/family. This is answered by staff members and by trained volunteers. Individual answers are provided by email/post. Meetings which are open to non-members are held in London and other towns around the country. For people with shingles and the pain that can ensue [post herpetic neuralgia] there is a stand alone website, and they can also get information by email, post and on the helpline.

People can subscribe to become members. There are seminars/talks in London and informal self-help meetings in towns around the country. Members are sent quarterly journals and specialised leaflets on particular aspects of herpes simplex - these aim to help them physically and psychologically with this condition. A private FaceBook page is popular, it allows the HVA me

The purchase and sale of therapeutic items, guides and leaflets, although profitable in themselves, are primarily undertaken to assist patients and members treating and managing their medical conditions.

Volunteers

Volunteers log on from their home numbers to answer helpline calls which are switched through to them. Around the country, volunteers host a variety of meetings: some are self-help, others are social in nature.

ACHIEVEMENT AND PERFORMANCE

Financial status

There was one corporate donation of £250. The charity secured a grant to buy a new photocopy machine. There was little change in the charity's regular income streams: subscriptions, donations and sales of therapeutic materials.

FINANCIAL REVIEW

Reserves policy

In line with the recommendations of the Charity Commission, the Management Committee has formulated a Reserves Policy to ensure medium term security, taking into account the different level of certainty of the various income streams. 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. Therefore, the target for this fund is assessed each year in line with running and redundancy costs. For the year 2016/17 the target of £68,730 has been met.

Approved by order of the board of trustees on 16 July 2018 and signed on its behalf by:

....
George M Davies

Independent Examiner's Report to the Trustees of Herpes Viruses Association

I report on the accounts for the year ended 31 March 2018, which are set out on pages four to nine.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I have examined your charity's accounts as required under section 145 of the Charities Act 2011 ('the Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

My role is to state whether any material matters have come to my attention giving me cause to believe:

1. that accounting records were not kept as required by section 130 of the Act; or
2. that the accounts do not accord with those records; or
3. that the accounts do not comply with the accounting requirements of the Act; or
4. that there is further information needed for a proper understanding of the accounts.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission I have found no matters that require drawing to your attention.

Josh Botham

Josh Botham Tax & Accounting Services Ltd
Archer House
Britland Estate
Northbourne Road
Eastbourne
East Sussex
BN22 8PW

Date: 17 July 2018

Herpes Viruses Association
Statement of Financial Activities
for the Year Ended 31 March 2018

	Notes	31.3.18 Unrestricted funds £	31.3.17 Total funds £
INCOMING RESOURCES			
Incoming resources from generated funds			
Voluntary income	2	62,505	60,850
Activities for generating funds	3	66,082	51,840
Investment income	4	100	270
Total incoming resources		128,687	112,960
RESOURCES EXPENDED			
Costs of generating funds			
Fundraising trading: cost of goods sold and other costs		35,354	28,449
Charitable activities			
Associated costs of ordering/despatching therapeutic materials		26,423	25,223
Charitable Activities		65,058	64,971
Governance Costs		2,948	3,047
Total resources expended		129,783	121,690
NET INCOMING/(OUTGOING) RESOURCES		(1,096)	(8,730)
RECONCILIATION OF FUNDS			
Total funds brought forward		73,126	81,856
TOTAL FUNDS CARRIED FORWARD		72,030	73,126

The notes form part of these financial statements

Herpes Viruses Association
Balance Sheet
At 31 March 2018

	Notes	31.3.18 Unrestricted funds £	31.3.17 Total funds £
FIXED ASSETS			
Tangible assets	8	1,599	511
CURRENT ASSETS			
Stocks	9	11,841	9,848
Cash at bank and in hand		62,318	67,467
		74,159	77,315
CREDITORS			
Amounts falling due within one year	10	(3,728)	(4,700)
NET CURRENT ASSETS		70,431	72,615
TOTAL ASSETS LESS CURRENT LIABILITIES		72,030	73,126
NET ASSETS		72,030	73,126
FUNDS	11		
Unrestricted funds		72,030	73,126
TOTAL FUNDS		72,030	73,126

The financial statements were approved by the Board of Trustees on 16th July 2018 and were signed on its behalf by:

R A Slayden

....
R. A. Slayden

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Accounting convention

The financial statements have been prepared under the historical cost convention, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008), the Charities Act 2011 and the requirements of the Statement of Recommended Practice, Accounting and Reporting by Charities.

Incoming resources

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Resources expended

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings	- 25% on reducing balance
Computer equipment	- 25% on reducing balance

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. VOLUNTARY INCOME

	31.3.18	31.3.17
	£	£
Gifts	-	(2)
Gift aid	8,175	6,588
Subscriptions	18,741	18,717
Member & service user donation	20,456	23,243
Shingles Donations	445	2,987
Corporate Donations	14,688	9,317
	62,505	60,850

3. ACTIVITIES FOR GENERATING FUNDS

	31.3.18	31.3.17
	£	£
Elagen, cold sore cream etc	59,371	46,189
Sales of 'Herpes Simplex the Guide'	6,711	5,651
	66,082	51,840

4. INVESTMENT INCOME

	31.3.18	31.3.17
	£	£
Deposit account interest	100	270

5. SUPPORT COSTS

	Management	Finance	Human resources	Totals
	£	£	£	£
Associated costs of ordering/despatching therapeutic materials	21,454	1,715	3,254	26,423
Charitable Activities	55,257	429	9,372	65,058
Governance Costs	2,557	-	391	2,948
	79,268	2,144	13,017	94,429

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2018 nor for the year ended 31 March 2017.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 March 2018 nor for the year ended 31 March 2017.

7. STAFF COSTS

	31.3.18 £	31.3.17 £
Wages and salaries	66,388	66,388
Social security costs	3,909	2,349
	70,297	68,737

The average monthly number of employees during the year was as follows:

	31.3.18	31.3.17
Management	2	2

No employees received emoluments in excess of £60,000.

8. TANGIBLE FIXED ASSETS

	Fixtures and fittings £	Computer equipment £	Totals £
COST			
At 1 April 2017	18,076	909	18,985
Additions	-	1,754	1,754
At 31 March 2018	18,076	2,663	20,739
DEPRECIATION			
At 1 April 2017	18,076	398	18,474
Charge for year	-	666	666
At 31 March 2018	18,076	1,064	19,140
NET BOOK VALUE			
At 31 March 2018	-	1,599	1,599
At 31 March 2017	-	511	511

9. STOCKS

	31.3.18 £	31.3.17 £
Stocks	11,841	9,848

10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.18 £	31.3.17 £
Trade creditors	1,000	1,002
Taxation and social security	1,424	1,667
Other creditors	1,304	2,031
	3,728	4,700

11. MOVEMENT IN FUNDS

	At 1.4.17 £	Net movement in funds £	At 31.3.18 £
Unrestricted funds			
General fund	73,126	(1,096)	72,030
TOTAL FUNDS	73,126	(1,096)	72,030

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	128,687	(129,783)	(1,096)
TOTAL FUNDS	128,687	(129,783)	(1,096)

Herpes Viruses Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2018

	31.3.18	31.3.17
	£	£
INCOMING RESOURCES		
Voluntary income		
Gifts	-	(2)
Gift aid	8,175	6,588
Subscriptions	18,741	18,717
Member & service user donation	20,456	23,243
Shingles Donations	445	2,987
Corporate Donations	14,688	9,317
	62,505	60,850
Activities for generating funds		
Elagen, cold sore cream etc	59,371	46,189
Sales of 'Herpes Simplex the Guide'	6,711	5,651
	66,082	51,840
Investment income		
Deposit account interest	100	270
Total incoming resources	128,687	112,960
RESOURCES EXPENDED		
Fundraising trading: cost of goods sold and other costs		
Opening stock	9,848	22,313
Purchases	37,347	15,984
Closing stock	(11,841)	(9,848)
	35,354	28,449
Support costs		
Management		
Wages	66,388	66,388
Social security	3,909	2,349
Insurance	254	253
Telephone	1,546	1,551
Postage and stationery	6,102	5,111
Accountancy	300	300
Volunteer's expenses	18	252
Experts' talks and AGM	-	279
Sundries	-	5
IT Costs	-	91
Carried forward	78,517	76,579

Herpes Viruses Association

Detailed Statement of Financial Activities for the Year Ended 31 March 2018

	31.3.18	31.3.17
	£	£
Management		
Brought forward	78,517	76,579
Educational event	85	1,498
Computer equipment	666	170
	79,268	78,247
Finance		
Bank, Card and Paypal charges	2,144	2,029
Human resources		
Rent and Rates	13,017	12,965
Total resources expended	129,783	121,690
Net expenditure	(1,096)	(8,730)