

# Sphere

The Herpes Viruses Association | THE JOURNAL

You can call the office 10am - 8pm:

**020 7607 9661**

or talk to helplineers weekdays 6-9:

**0845 123 2305**

[info@herpes.org.uk](mailto:info@herpes.org.uk)

[www.herpes.org.uk](http://www.herpes.org.uk)

## 'Stigma story' is getting noticed

The HVA was launched in the 1980s as a response to the herpes stigma - which seemed to appear out of nowhere.



[Read the story.](#)

For a long time, we were the only people who explained why/how it was created. There was no stigma before 1980. It came with 'raising awareness' of herpes because there was a new drug. For a while it was explained on our Wikipedia page because it was the reason that this charity exists. The page was removed by Wikipedia...

Now people are starting to explain the reason behind the stigma. The explanation in our former Wikipedia page was copied and pasted to other sites like [Honeycomb](#).

In 2012, it appeared on the website of US based [ProjectAccept.org](#).

### Wikipedia gets it

An article we wrote for Spiked! in 2011 is a source for the Wikipedia [Genital Herpes page](#), while the Wikipedia [Herpes Simplex page](#) (yes, there's one of those as well), references two discoveries made by the HVA in its research that proved

that there was no herpes 'psychological morbidity' (i.e. nobody was bothered about it) before 1980. These are "Selling sickness: the pharmaceutical industry and disease mongering" by Colin Moynihan, published by the BMJ and "Psychological morbidity in a clinic for sexually transmitted disease" by R Mayou (also BMJ); a 1975 study from the London Hospital where herpes simplex was not mentioned at all when clinic patients were interviewed after being diagnosed with an STI.

### Cracked.com gets it

These jigsaw pieces have contributed to what is becoming the accepted picture of how the herpes stigma was created. It is pleasing to see that this truth is being picked up and explained to readers of some of the smarter online magazines. Cracked.com got it as far back as 2013 in an article ["5 basic facts of life"](#) were made up by marketing campaigns

### They're all getting it (apart from the BBC)

This year On March 3<sup>rd</sup> Vice (an influential and growing news organisation) published [a page](#)

**Make new friends in our secret Facebook group, see last page**

### Content

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quoting the HVA and others and this was quickly followed by [Teenvogue](#) less than a week later. The truth is out there now. People are getting it. This will help you if you need to tell a partner what all the fuss is about. There wasn't a stigma. There doesn't need to be a stigma. Informed sources are explaining how society was misled by a marketing campaign. At last the media is getting it - apart from the BBC. See separate story for our battle with Radio 1 Newsbeat.

## Cold sores and Alzheimer's?

All over the papers in March, we were seeing stories saying 'Herpes causes Alzheimer's disease'. The Telegraph led with it, other papers picked it up. None of them explained the facts.

### What's the real story?

**Cold sores (HSV-1 or herpes labialis) along with chlamydia and syphilis may possibly be implicated in the development of Alzheimer's Disease (AD) in people who carry the APOE4 genome. Treating people with early Alzheimer's disease (AD) for these bacterial and viral conditions might help to prevent AD from continuing to develop, but trials would be necessary to find out.**

**None of this is refers to genital infection. The use of 'herpes' in the headline, which everyone assumes refers to genital herpes, is a combination of ignorance and scaremongering from the media.**

### Read more:

Long-term readers of Sphere will recall that Dr Ruth Itzhaki's research has been misrepresented in this way previously. After reports in the media about AD and herpes, for *Sphere* 23/3 (in 2006), she sent us this:

*"In most cases, the causes of AD are unknown but a few years ago an inherited susceptibility factor was found - the type 4 form ('allele') of the gene which codes for a protein known as apoE4. However, apoE4 is neither necessary nor sufficient to cause AD, so it must act in combination with one or more other factors."*

In what is described by Rachael Feltman in the Washington Post as 'an open letter to other scientists' the authors of an editorial, signed by an international group of 33

researchers and clinicians state: "Despite all the supportive evidence, the topic [of linking infections to Alzheimer's disease] is often dismissed as 'controversial'." "The implications could be just as important with regard to Alzheimer's disease," co-author Ruth F. Itzhaki, PhD, of the Faculty of Life Sciences at the University of Manchester, United Kingdom, told *Medscape Medical News*. "Patients could be treated with antiviral agents. These would not cure them, but might slow or even stop the progression of the disease," she said.

The 'letter' continues "In summary, we propose [that means 'theorise' not 'state'!] that infectious agents, including HSV1, *Chlamydia pneumonia*, and spirochetes [cause of syphilis], reach the central nervous system and remain there in latent form. These agents can undergo reactivation in the brain during aging, as the immune system declines, and during different types of stress (which similarly reactivate HSV1 in the periphery). The consequent neuronal damage ... recurs, leading to (or acting as a cofactor for) progressive synaptic dysfunction, neuronal loss, and ultimately AD..."

This 'open letter' points out that since we do not know yet what cause AD and "given the failure of the 413 trials of other types of therapy for AD carried out in the period 2002-2012 ... We propose that further research on the role of infectious agents in AD causation, including prospective trials of antimicrobial therapy, is now justified."

"While these observations are interesting and warrant further research, there is currently insufficient evidence to tell us that microbes are responsible for causing Alzheimer's disease in the vast majority of cases," says Dr James Pickett, head of research at the Alzheimer's Society UK.

### Final word from the Washington Post:

"There's nothing wrong with trying to direct more research at this proposed link. But implicating HSV — a disease that already gets way more stigma than it is due [see cover article] — as the dastardly culprit behind a devastating disease is *not* based on sound science."



Professor **Ruth Itzhaki**. Professor of Molecular Neurobiology, Manchester

# Dr David Pao spoke at our AGM in January. He was informed and informal. Get the lowdown here

Dr Dave Pao is a 'Physician in Sexual Health' at the Exeter sexual health clinic now - but has worked at many hospitals from Brighton to Inverness. He was kind enough to answer many specific questions during his talk. In the report below, we start by reporting these. Then you can read the second half of his talk - on vaccines and shame.

Dr Pao told us all about how the virus works. You will have seen it in the leaflet 'Genital Herpes - the facts', 'Antiviral Tablets'. He explained asymptomatic shedding - see our 'Transmission' leaflet. He agreed with other experts' comments that unless a person is getting 'a lot of outbreaks' - which is usually defined as more than 6 per year - then after 2 years, don't worry about asymptomatic shedding. *[Ask us if you would like another copy of any of these leaflets: 020 7607 9661 or info@hva.org.uk.]*

Here are some of the questions people asked - and further down, we report in detail his description of 'where we are at' with regard to vaccines.

Woman: Why do I get an outbreak on my arm?



Dr Pao: Many people catch herpes simplex on their fingers when they first contract it, or self-infect during the first days (very rare), before the antibodies develop that prevent self-inoculation [spreading it around your own body]. The dermatome [nerve area] that includes your fingers goes right up your arm and across your shoulder to the spine. Therefore, a finger infection could recur anywhere in that region. Also you might notice the nerve sensations that herpes simplex can cause in the surface of your arm.

Man: I have pain down my leg - constantly. Could this be herpes simplex?

Dr Pao: Again, the dermatome for the genitals includes the back of the legs right down to the toes. However, one of the ways that you can differentiate herpes simplex neuropathy from, say, sciatica, is that herpes simplex pains come and go quite fast, with no gradual improvement. Just 'there' or 'not there'. And not linked with any particular positioning of your body. And not following any unusual exercise.

Remember that herpes simplex sensations are almost always on one side of the body only. They may swap sides from time to time, but if something is happening on both sides, seek a different cause.

Woman: "Is it true that they don't do C-sections for herpes simplex anymore?"

Dr Pao: The Royal College of Obstetrics and Gynaecology has got together with the British Association for Sexual Health and HIV to create a single, up to date guideline for herpes simplex in pregnancy and childbirth.

They report that it is safe to take antivirals at any time in pregnancy, with a recommendation that women might like to take them from 36 weeks onwards to ensure no outbreak at term.

Even if there is an outbreak at term, the baby will carry the mother's antibodies, so a normal delivery is expected.

Man: Does this mean that her children will never catch herpes?

Dr Pao: The maternal antibody protection fades away over the first months of life. A woman can keep it going longer, protecting her baby from any of the illnesses that she has antibodies for, by breast feeding. But the protection fades away, otherwise the viruses for measles, chickenpox, whooping cough, and so on, would have been eradicated by now.

Woman: "My doctor won't give me antivirals, and the clinic says that now they cannot keep on giving me pills, I have to ask my doctor. So I am in a Catch-22 situation."

Dr Pao asked which clinic it was, and suggested that the patient try a different one. Aciclovir is now cheap (so the NHS doesn't need to hoard them) and safe. In fact, there is now no need to have blood tests (for liver or kidney function) if you are on long-term antiviral pills.

Marian added that via the link on the HVA's website links page (<https://herpes.org.uk/useful-links>), people can buy three months' supply for £60 if that is easier for them.

Dr Pao was surprised that people had to do that. The NHS really should not force people to buy their own pills.

Women: Will taking antiviral suppression reduce my body's efforts at building antibodies?

Dr Pao: Not at all. I think it is actually a good idea early on - there is no evidence that it helps, but I suspect it does. But since now you might be having only one outbreak a year, it might not be necessary to take the antivirals. So when you are over the roller coaster part of your life, when you are willing to take on the bit of uncertainty, just stop! Expect the bounce-back outbreak in the first two weeks, treat it with 800 mg 3 times a day. Switch from suppressive to episodic treatment. To see what it's happening... You could find that you don't need the pills, but if you do, then you can resume suppressive therapy.

## Vaccines

Dr Pao said: So far all the searches for a vaccine against this have been fruitless. In fact, viral vaccines are difficult to create. There are a handful of candidates in the pipeline, in phase I and phase II.

Phase I is to test for safety - the vaccine is given to 10-20 healthy men who do not have the condition to see that it is not going to harm them in any way.

Phase II is to test safety and efficacy - various different doses of the vaccine are given to people who have the virus to see that it is safe for them, and to check it works. [E.g. raises antibody levels].

Phase III - a standard clinical trial - continues to evaluate efficacy. The vaccine or a placebo are given to hundreds of people.

Most candidate vaccines have not got past phase II: safe but not effective. Gen 003 is in phase II - recent results, unfortunately, have shown it to be just as effective as placebo. [LAUGHTER]

## New vaccine idea

There is a blue sky, futuristic vaccine which is not even in phase I. Herpes simplex virus lives and travels in the nerve - it is a neurotropic virus. The mechanism for this new idea is that you put your antiviral (or something that shuts down herpes simplex) inside another herpes virus such as cytomegalovirus or EBV (Epstein Barr virus) which are common and do not affect nerves. So this is used as a vector to travel back down to the nerve ganglion and deliver an antiviral dose to the nerve body. It has been shown to work in vitro - in cell lines - but not even tried on animals yet.

The other thing is that whilst the original idea of a vaccine is prevention i.e. you give someone the vaccine to stop them getting smallpox, measles or polio, there are a lot of vaccines now which are being used as therapeutic vaccines; to lessen the symptoms in someone who has the condition.

A good example of this is the wart vaccine (against HPV) given to school girls. It protects them from cervical, and also anal cancer, throat cancers - really nasty cancers - and it stops them from getting the actual warts, the harmless lumps in the genital area. What we have also found is that if they already have



warts or cervical cancer, then giving the vaccine helps to reduce the warts themselves, and prevents the transition to cancer.

Pharmaceutical companies are spending plenty of money on trials and since there has been a vaccine against chickenpox (herpes varicella) since 1976, no doubt one day one of these vaccines will work.

However, taking aciclovir 400 mg twice a day is already as good as vaccines can expect to be, in terms of preventing outbreaks and transmission.

Woman: Wouldn't it be better to prevent transmission by giving everyone who has it antiviral tablets so that they could not infect anyone else?

Dr Pao: Yes, you mean like putting the oral contraceptive pill in the water supply? [LAUGHTER] The problem with all these viral infections, including HIV, there is a massive chunk of people who don't know they have it. So the undiagnosed people don't realise that they are passing it on.

NS: With herpes simplex, 80% don't know they have it. The drug company that invented aciclovir had an interesting idea and went to the mayor of Detroit. They offered to provide free herpes simplex type 2 blood tests to undiagnosed adults. They suggested that the people they identified might then wish to take antivirals to prevent transmission to a partner. Nice little earner. The mayor took medical advice and refused their 'kind offer'.

Dr Pao: What mayor wants the publicity of that kind! [LAUGHTER]

## Shame and blame

Working in sexual health, I hear a lot of people who are ashamed - and a lot who are blaming others or themselves. There is a Texan social worker called Brené Brown (below) who is famous for giving TED-talks. She has had 7 million views. I am going to show



you a clip from a talk she gives on vulnerability and shame.



“I’m imperfect & I’m enough”

Shame is defined as being unworthy of belonging to a group or a flock. “There is something wrong with me that makes people in my community not want to connect with me. I am not worthy of connection”. We all feel shame at times. The reason why I like defining shame is because it is distinct from guilt. Guilt is the same idea of people not wanting to connect with us but that is because of something we have done, not just for who we are. Shame is bad news for us, but guilt is a positive thing. If we say “I am really sorry, I didn’t mean to kick your puppy” [LAUGHTER] you are reporting your guilt. It is a growing thing to do: “I will learn from this I won’t do it again.”

The shame thing would be “I kicked your puppy because I am a bad man.” So when you come to STIs, it is so easy for people to have a shame response to an STI “I got herpes because I am a bad person - this now proves to the world that ...” But if you can be aware of this, the feeling of shame, of non-worthiness and turn it through guilt “Yea I shouldn’t have slept with him... I should have used condom... etc.” then you can learn from this feeling of guilt.

I want people to realise this because they can, at the beginning, stay in this area which is dark - and they can stay in a hole. I want to bring them out, so that they can move away from this and live normally again.

The more we talk about shame or how we feel shame, the more we dissipate it. The more we don’t talk about it, the more we build a worse world for ourselves. The more we share it with people we love, that brings us back into the world. We are all about relationships aren’t we?

And by the way, I want to say how glad we are when we see people in the clinic who are not students. It makes us so relieved to know that people of all ages are enjoying a sex life.

Dr Pao plays the Brené Brown video [“I am a blamer”](#) [LOTS OF LAUGHTER]

Dr Pao: Check out her “Empathy v. sympathy”

Woman: The first doctor I saw was really not interested at all, I struggled with lots of outbreaks and she was not sympathetic.

Dr Pao. It is a question of getting doctors to understand the issue: six times a year may be OK for some, but not for others.

Woman: Well, I think it is a matter of attitude. At first it is traumatic, then over time other things happen in life ...

Dr Pao: This is what is happening when you think a doc is cold or flippant, uncaring, saying “It is only herpes, it won’t kill you”. They will be seeing ten people a month over years, they are used to it. It is so easy for the doctor to forget our experience is not the same as people who don’t have medical info. We have the knowledge of how good the drugs are, the dosages, and the [lack of] risk of transmission and safety of childbirth, whereas the woman or young girl with the

misconception that it might give you a malformed baby - that is the end of the world - but totally erroneous. The world is full of skewed medical beliefs and then you have Google to talk to...

Man: 30 years ago I was told, ‘There’s nothing to be done - end of.’ On a positive note, when I found the HVA about 4 or 5 years ago it was like the light coming on. It has changed how I think about it, and there’s treatments, questions and answers, helpline people - it is like a complete transformation from twenty, thirty years ago.

Marian thanked Dr Dave Pao and presented him with an anthurium [APPLAUSE]

## Lomaherpan for facial or genital sores

Have you tried it yet? Do so!!!

Lomaherpan is a cream that helps stop herpes simplex virus causing a sore. (It blocks the virus’s access points.) Rub it in as soon as you feel anything - some people use it daily as a preventative. People on our trial (72% success rate) said it prevented the outbreak from developing.

*“I used the cream this morning and this afternoon the lump has gone down and the pain has gone away.”*

**NOTE: You can use just a tiny bit - and rub it well in. Any left gleaming on the skin surface is not helping.**

Lomaherpan cream, 5g, £6 with £1 p&p to each order. Go to <https://herpes.org.uk/shop/> and order – or phone the office 020 7607 with your card.

**ALSO:** LomaProtect melissa salve (stick) with SPF 30. Better for facial infection, but fine on genitals: £5 plus £1 p&p for any number of creams/ salves.

# Medical Matters

## Vaccines

### Admedus

Dr Ian Frazer has injected phase II volunteers with Glycoprotein-gD - results of phase I expected end 2016

**Phase II, on people**

### Agenus

HerpV has shown only limited results (weak reduction in viral shedding by 14%) but it may be that this vaccine takes time to work.

**Phase II, on people**

### Gen003

A protein subunit T cell-enabled therapeutic vaccine; has been found to reduce number of outbreaks – but so did the placebo version of the vaccine. It does reduce shedding better than placebo

**Phase II, on people**

### HSV-529

Dr Knipe's replication-defective vaccine looks promising, as Sanofi Pasteur (well-known for vaccines) are financing him.

**Phase I, on people**

### RVx:

Dr William Halford's live attenuated vaccine is different from the others. Pre-clinical studies show that it's vastly superior to the sub-unit vaccines that were the mainstay of failed HSV-2 vaccine efforts for the past 30 years. He may be reaching phase I stage very soon.

**Laboratory**

## A new idea for treatment drug

A report on the University of Utah's website stated:

### “Hidden in plain sight: well-known drug could yield new treatment for herpes viruses”

Their text explained the family of herpesviruses - we know of nine which affect humans. One of them is herpesvirus number 4 which is EBV (Epstein Barr virus) the cause of 'mono' or glandular fever. Professor Swaminathan of Utah University School of Medicine has found that a routinely used heart treatment spironolactone, can act to prevent outbreaks of EBV. He deduces that it might work against other herpes viruses.

The drug, spironolactone, could be developed as a new medicine against EBV, a common and dangerous infection among transplant and other immunocompromised patients.



They find that the drug's antiviral properties stem from its ability to block a key step in viral infection that is common to all herpesviruses. Spironolactone's target is distinct from that of existing drugs, revealing that it could be developed into a new class of anti-herpesvirus drug.

Because all herpesviruses depend on SM-like proteins to spread infection, the work also has broader implications. Spironolactone could be a template for a new class of drug directed against all herpesviruses.

“We have found a new therapeutic target for herpesviruses,” says Swaminathan. “We think it can be developed it into a new class of antiviral drugs to help overcome the problem of drug resistant infections.”

## Reminders of other things in development

**DNA helicase-primase inhibitors:** Astellas was working on this. The idea is to create an antiviral drug that works in a different way from the three antivirals we have now: aciclovir, valaciclovir (Valtrex) and famciclovir (Famvir).

**Gels to kill virus, bacteria (and sperm) for women to use:** microbicide gels may be found to work, still being tested. The difficulty has been to find a compound that will destroy the virus and bacteria that are not wanted, but which is not so 'strong' that it damages the delicate skin of the vagina).

## Tales from the helpline - not everything that happens on your bits is caused by herpes simplex

A lady reports:

"I was so sore - I tried non-stop suppression therapy, no effect at all. On the helpline, I was told to use 400 mg three times a day, instead of twice a day as my doctor had said. Still no benefit. Had I got some sort of resistant herpes virus that did not respond to aciclovir?"

The helpliner persuaded me to go back to the gynaecologist (I am not in the UK, so there is no STI clinic) and just tell her my symptoms - instead of saying 'my herpes is killing me...'

The gynaecologist said it was a blocked gland and prescribed antibiotics. Next day, for the first time in two weeks, I was feeling less sore and two days later I was better.

I wish I had not blamed herpes simplex for the soreness and got help sooner!"

**Moral of the story: if your symptoms do not respond antivirals, consider other causes**

## Brisk walks could prevent 10,000 breast and bowel cancers a year, say researchers

This isn't a herpes simplex story - but it is one that Marian wants you to know about... Join her on the London LOOP this year. Email [info@hva.org.uk](mailto:info@hva.org.uk) to let her know you are interested.

The *Times* says researchers at the World Cancer Research Fund have claimed that around 10,000 cases of breast and bowel cancer could be prevented every year in Britain if people quickened their walking pace and became more physically active. They believe that up to 4,600 bowel cancer cases and about 5,500 breast cancer cases could be avoided by such activity, which causes the heart to beat faster and increases breathing.

Physical activity is also known to reduce the risks of endometrial cancer, which affects the womb. Rachel Thompson, deputy head of science for the WCRF, said people can reduce their cancer risk by making 'small changes'. The *Daily Mail* adds that alongside brisk walking, other activities that could count include cycling at a leisurely pace, dancing, swimming, gardening and vacuuming combined with other housework.

Government guidelines recommend that adults take aerobic exercise five times a week for 30 minutes or more for maximum health benefits, but a survey this year found 44% of adults are too busy. The *Daily Express* notes that the WCRF is launching Walking Together, a campaign aiming to get the public to organise walks with friends and family.





# The state of your mind affects the state of your body – what are you doing about it?



Be like Ted - believe in the power of your mind

First, a few facts. Fake drugs (placebos) can work even if you know they are fake. Hypnosis cures IBS (irritable bowel syndrome). Mindfulness slows the progress of multiple sclerosis. Meditation thickens your prefrontal cortex.

Jo Marchant has written a book about these and other facts. It is called *Cure - a journey into the science of mind over body*. Current medical practice often ignores evidence that in some cases we can do without pharmaceuticals. On the other hand, tricksters and charlatans seek to exploit the gullible by pretending to be 'healers', as followers of Sphere should know - we have written about many of them over the years.

## The power of placebos

Jo Marchant advocates the scientific method, which has demonstrated the power of placebos. As recently as 1954, an article in The Lancet said that they only work for "unintelligent or inadequate patients". Things have moved on and it is now accepted that the body can be profoundly affected by the mind. This does not simply mean that placebos lull the patient into feeling less pain - actual physical changes occur. As one doctor explains, "the active ingredient is meaning". If a treatment signifies care and hope, it may work - even when the patient knows the treatment is a placebo.

Jo Marchant even claims to have cured her own headache with a fake drug - an experience that is borne out by our own Marian Nicholson whose

migraine receded although she forgot to take the tablet. She returned to kitchen to discover the unused tablet still sitting on the worktop.

## All in the mind

"All in the mind" is a powerful place. Chronic fatigue syndrome has been relieved by cognitive behavioural therapy, not because the problem is 'all in the mind', but because of the impact the mind can have on the workings of the body. There are powerful arguments for looking at herpes simplex in the same way.

A few more facts. Herpes simplex is one of the most common infections carried by humans. A World Health Organisation report, published in 2015 stated that 75% of all the people in the world under the age of 50, have herpes simplex type 1. (People over 50 are the same, by the way.) What we don't understand is why up to 80% of these people are undiagnosed (and therefore not bothered) - and why half of the people who have been diagnosed get no further symptoms (they are not bothered either). What is going on? Why do the people who get symptoms, get them?

Two things may be going on: (1) some people are genetically less well equipped to suppress the virus (2) some people get more outbreaks because the diagnosis itself has created stress that has lowered their immune response. There may be a combination of the two. Of course the herpes stigma has contributed to this. Read about it elsewhere and learn not to be fooled by it.

## What can you do about it?

You have joined the HVA because you are more bothered than the average person. You may be getting more outbreaks, you may be more anxious, or both.



The average person has 'herpes' just like you do, but most of them are not bothered. Do the usual things - get enough sleep, eat food, relax and unwind when you can - all these will help your body and immune system to work more effectively.



Dr Jo Marchant

Look at your mind as well. Change the way you think. Don't allow yourself to remain a victim of stigma, shame and worry. You are a normal person with a skin condition that most people on the planet share with you. Tell yourself this: "I am normal, the same as everyone else. I can do what everyone else does."

Many of the people who are not getting recurrences are in this fortunate place because they are not expecting to get recurrences - they are not thinking about recurrences - or herpes - at all. This is the way people who have had a facial cold sore behave. As soon as it's gone, they forget all about it. Be like them. Your mind is powerful and you can be in charge of it. Take control and direct your thoughts towards where you want to be - and switch them if you start thinking about herpes again.

## The future is out there

Deal with outbreaks when they happen, but don't spend any time thinking about them when they have gone. Expect good things to happen. Expect a positive future. You deserve this just as much as everyone else.

Jo Marchant makes some self-evident statements in her book, "Believing in an angry or judgmental God seems to make people more stressed", for example.

As she says, "Taking account of the mind in health is actually a more scientific and evidence-based approach than relying ever more heavily on physical interventions and drugs." The future of medicine is out there and part of it is in your mind.

Nigel Scott

## Don't believe the NHS or CDC websites if they differ from us

The NHS and CDC (Centre for Disease Control, USA) should have top class information - but often they haven't. We have written to ask the CDC to change what they say about pregnancy: "I'm pregnant. How could genital herpes affect my baby?" We have said:

"A primary infection in early pregnancy used to be considered a possible risk for miscarriage. Forty

years of observation have now shown that this is not the case. The BASHH (expert sexual health doctors) in the UK have amended their guidelines to show this. And you can also assure readers that it is only catching herpes simplex in the later stages of pregnancy that increases the risk of premature delivery.

Please change your wording so that you do not worry women unnecessarily if they have had herpes simplex from before conception."

We have sent a similar email to NHS Choices website to ask them to remove the 'herpes off towels' warning.

We have had polite emails back from both organisations to say they will pass it on to their authors.

For real information on pregnancy and transmission, read the [herpes.org.uk](http://herpes.org.uk) website.

The CDC and NHS Choices are out of date!

## Information Standard

You can trust HVA information because it goes through a process to qualify for the Information Standard. This means that we know that what we say is correct and we have the evidence to prove it.



# The BBC doesn't get herpes



The BBC is the largest and oldest broadcasting organisation in the world. It has existed as a state corporation since 1926. Its mission is to “inform, educate and entertain”. But the BBC doesn't get herpes.

Herpes simplex (caused by HSV-1 and/or HSV-2) is one of the most common viral infections amongst humans. According to a World Health Organisation in 2015, 75% of the world's population under the age of 50 has HSV-1. (If you are over 50 the prevalence is similar.) Genital herpes (herpes simplex when caught on the genitals) was subjected to an awareness raising campaign that started in the 1980s. This was organised by a pharmaceutical company to assist in the marketing of the first effective antiviral drug. This caused a stigma that has upset patients and confused the medical profession ever since.

The existence of a stigma for a common skin condition only when it affects one part of the body but not if it is caught elsewhere, is a bizarre phenomenon. It has been used to persuade people to buy treatments they do not need for symptoms they probably will not get. It has been used to worry people about transmission to a partner, when most partners will have it already and few will notice.

You might think that this in itself is a news story - and you are right, it is. The UK charity for patients with herpes infections, the Herpes Viruses Association (HVA) has been telling people how the stigma started for many years. But many journalists and editors remain stuck with the stigma theme. It makes herpes easy to write about.

“How herpes ruined my life” was the headline on a London Evening Standard feature some years ago. The article told a completely different story of how a woman had been diagnosed and had gone on to meet her partner, get married, have a family and live happily ever after. The sub editor who wrote the caption probably never read the story. But there is light at the end of the tunnel. Some news organisations have started to catch on to what happened. An article in Vice by Haley Potiker explains the stigma story very well:

[https://broadly.vice.com/en\\_us/article/did-big-pharma-create-the-herpes-stigma-for-profit](https://broadly.vice.com/en_us/article/did-big-pharma-create-the-herpes-stigma-for-profit)

But the BBC doesn't get herpes - and the BBC never apologises

In 2014 the HVA complained to the BBC about an unfunny herpes joke in the TV show ‘Uncle’. This was part of the reply:

“We did raise this with the programme production team and whilst you have a legitimate argument that all STIs are a very serious issue, this is a sitcom, very clearly setting up Andy as a flippant and irresponsible character. We have to have these moments to frame the ultimately redemptive warm character within.”

So that's alright then. However irresponsible Andy is, the scriptwriters would not have put racist insults or jokes about people with disabilities or HIV into his mouth, but herpes jokes are OK. The one group that doesn't complain can be insulted with impunity by the BBC. The BBC doesn't get herpes.

## 2016 - times don't change for the BBC

On to 2016 and BBC Radio 1 Newsbeat. Radio 1 is the BBC's music station for young people. Its news magazine is short and punchy and aimed at teens and twenties. There is also a web presence.



A journalist, Rick Kelsey approached us because he wanted to interview a young person who had been diagnosed with genital herpes for an online feature. He spoke to HVA director, Marian Nicholson, several times.

Marian spoke to one of our members who agreed to be interviewed. However, it became clear that Mr

Kelsey wanted to interview a 'sufferer with mental health issues', not the person we were suggesting, who had got her head around it and was getting on with things. This did not fit Kelsey's agenda. Reluctantly we withdrew from the discussion.



The article appeared, with a different subject: the interviewee that Kelsey had found was having a miserable time, so she fitted his preconditions. There was no useful information, nothing about how the stigma was created and no balance.

## We complained to the BBC

This is part of what we wrote:

"The BBC's mission is to, 'inform, educate and entertain'. The bias in this article means that it fails to inform or educate in any meaningful way. It takes the form of a case study/interview of a young woman with genital herpes who is unhappy. Because the article focuses on one person, there is no context and no attempt is made to explain how common and usually asymptomatic herpes simplex infections are or why the artificially created stigma that surrounds 'herpes' can upset people when they are diagnosed and afterwards.

The BBC should aim to be part of the solution, not part of the problem.

In conclusion, the article is a wasted opportunity and falls well below the standard that the BBC should aspire to, especially on a page aimed at a young and sexually active audience.

The author approached the HVA, was spoken to at length and was offered contact with an informed interviewee who would have provided a positive as well as realistic herpes experience. It is regrettable that despite this offer of support he chose to write the article he had always intended to write; one that perpetuates the misinformation and stigma that surrounds genital herpes."

The BBC has come a long way in ninety years. Its supporters claim that it still follows its mission to inform, educate and entertain. We are not so sure.

## The BBC still doesn't get herpes.

Nigel Scott



easyfundraising.org.uk  
feel good shopping

# All aboard for big donations



✓ Holidays    ✓ Ferries  
✓ Flights    ✓ Accommodation

**This is what you do:**

- Go to <http://www.easyfundraising.org.uk>
- Register your details - it's free
- Choose Shingles Support Society as 'your charity'.
- Click on a company - and get shopping - easy! Choose from over 2,600 'shops' from AA to Zizzi - inc. P&O Ferries, Thomas Cook, Travelodge, etc.



Expedia.co.uk    Thomson    Hotels.com    Thomas Cook    James VILLA HOLIDAYS    cottages.com



# Thank you!

Thank you to all the people who renewed their subscriptions. (For historical reasons, January is a major renewing month.) And a bigger 'thank you' to those of you who added donations on top.

We had some splendid donations last year to help us to cope with the shocking loss of our website and consequent rebuild.

We are on track to have only a small over-spend this year. However, we will need to pay for our new computers as well as a new supply of the Lomaherpan cream from Germany.

## We need more splendid donations to make up the funding gap...

Surveys by 'Remember a Charity' (umbrella charity supporting other charities) show a disconnection between the 35% of people who say they'd be happy to leave a charitable gift (once they've taken care of loved ones) and the 7% who actually do it.

If just a further 4% of the public were to include a charitable gift, it could generate an additional £1 billion for charities.

Remember a Charity is also seeing a rise in competition within the market. More charities from more sectors are talking about legacies to their donors for the first time: arts, cultural and heritage organisations, hospices, hospitals, and universities. They are suddenly

becoming a bit louder about legacies. Successful fundraising charities will be those who give their entire staff the tool, knowledge and confidence to talk about gifts in wills.



## Donations - and legacies to "Shingles Support Society"

A former committee member, sadly succumbed to cancer recently and has left the HVA a small bequest in her will. We recognise the wonderful way she helped the HVA as a volunteer helpline and in the office - and we are very appreciative that she has remembered us in this way.

So, please remember the Shingles Support Society in your will:

We know that many people leave money to charities in their wills. We would really appreciate it if you would consider this kind of donation. If you already have a will, you can leave something to the [Shingles Support Society](#) in a codicil, which is an addition to your existing will. This is easier (and cheaper) than writing a whole new will.

Mr Stone left us money; his son told us: *'My father found the information that you supplied made such a difference to his quality of life in his final years that he wants others to benefit as well.'*

Mrs Scott's church arranged a special collection for us in her memory and donated it to our charity. We were very touched.

Mr G. asked the Rotary Club he was very involved with, when he died to send the money raised 'in lieu of flowers', to us. *'The Shingles Support Society is my favourite charity,'* he told them.

As a registered charity (no. 291657) we are checked annually by the Charity Commission to ensure that we are fulfilling our constitutional 'statement of aims,' so you can be sure that your legacy would go to help spread information about treatments for PHN to everyone who needs it.

### Free money

An easy way to get us 'free money' is shown on the previous page: by signing up to Easyfundraising with 'Shingles Support Society' as your charity and then **remembering to shop via this virtual mall**, you provide money for us at no cost to you! Shingles Support Society is our authorised sub-group run from same office with same staff.

# "Get Over it Day"- decide to move on

**14<sup>th</sup> May - The day that teaches you to feel confident about talking with a new partner... The day you meet other lovely members and share with them as much as you want to. Below, we show you an ordinary response: it is from a lady at the 'day' in Feb 2016. Only one person has ever given us less than 4 out of 5. (Some have given us 6 out of 5!)**

I thought the day was so unbelievably helpful - here is my feedback from it - please feel free to quote me.

Question 1: What did I gain from the day?

Reassurance that there are so many "normal" people like myself who have contracted it. That I appear to be very lucky to have type 1 rather than type 2. That the diagnosis is not a death sentence to my future love life, as well as some really lovely new friends who properly understand my situation

Q2. What were the most valuable elements?

Further education as to the cause, recurrence and how to manage the condition. Evidence sites of statistics and how this will help. Top tips of how to broach the subject with a new partner. Reassurance that everything will be ok. Meeting people in the same boat. [The tea breaks and the lunch break are actually really helpful - this was the first time that some people had ever met another person who knows that they have this virus.]

Q3. What could be improved?

More time at the beginning to hear everybody's stories - how long they've had it for and their experiences. This

networking and story sharing side of the meeting was invaluable and I think more time on this and less time on other elements (e.g. why the stigma came about in the first place) would be good. We know it's a problem, but dealing with it is the most important thing

Q4. Message to a person who is considering it:

DO IT, DO IT, DO IT !!  
It will make you feel so much better.

Q5. Has your perception of this virus changed because of this day?

Yes, as I can see how common it is and how many "normal" people have it.

Q6. Do you feel you fully understand the importance of the hype in creating the stigma about 'herpes' - so that you can change how you think about it.

Yes!

Q7. Overall, how helpful was the day - out of 5?

5! Undoubtedly invaluable. Everyone who is bothered by their diagnosis should be directed to this programme by the doctor/clinic. It is a no-brainer that details of your organisation should be given out at the very start.

P. S. Four of us have met up again to continue the chats... It is great to have supportive friends like this.

Sign up for the next one on 14<sup>th</sup> May - send £39 to secure your place by 'donating' £1x39 on [www.herp.org.uk/shop](http://www.herp.org.uk/shop) - or by phoning the office - or by posting a cheque.

As Hugh Laurie says:



"It's a terrible thing, I think, in life to wait until you're ready. I have this feeling now that actually no one is ever ready to do anything. There's almost no such thing as ready. There's only now.

And you may as well do it now. I mean, I say that confidently as if I'm about to go bungee jumping or something - I'm not. I'm not a crazed risk taker. But I do think that, generally speaking, now is as good a time as any."



# Dates and Mates



If you are thinking of putting at advert in, why not answer a few first?

**Late 40s female, Derbyshire.** WLTm friends for chats. Yes, I'm also up for meeting that one special N/S man. I'm n/s, light drinker, tall, slim, no kids of my own, different, outgoing but love to curl up in front of the fire in winter. Enjoy folk music, learning a musical instrument, WARNING: I'd like to go to dance classes together. Creative soul, outdoorsy to a degree, you'll need to own a pair of wellies. Good at DIY and tidying if you need a hand! Allergic to football but can watch motor-racing. Like to laugh. Looking for friends, email pals, or maybe something more. EMAIL ALA.

**Male, 35, 6ft, medium build.** I'm told I'm funny and good-looking. OHAC. I enjoy holidays, friends, family, keeping fit as much as I can, music festivals, pubs (clubbing days might be over!), good meals out, cosy nights in - just the normal stuff. I'm looking for a female 25-40 with a GSOH who shares similar interests and could maybe show me a few more. If things develop I'd like to settle down. I don't have kids at the moment but it's not a problem if you do. In west London, so London and surrounding areas is fine. Email:

**Glasgow - male, 6ft 5in** (you guessed it, not Glaswegian by birth), 48 feel 28, traveller, city lover and country lover. That's a lot of love. Into people, experiences and knowledge rather than things. (I flirt with Buddhism but am too badly behaved to be one full-time.) I like to get into the hills, commuting/ weekend/month cycle rides, loitering around museums. I have an adventurous side, I like tattoos, demos & thinking about the how not the why (but do overuse parenthesis). Would love to be doing some or all of this with a lovely lady. Email:

**Attractive, young-looking 38 yrs Yorks lass,** amazing blue eyes, 5'8". I am a bubbly lady with a zest for life & wicked sense of humour with a vacancy for an attractive, understanding & caring man to share nights in & fun nights out with good conversation. I am more than willing to consider a relationship of distance to find my perfect match. OHAC & good career. Based on N. Yorks coast. Please get in touch with a photo. A.l.a. SL/6199/N or [EMAIL](#)

**Ask for the full list if you need it - there are people all around the country.** You can contact them until they ask for the ad to be removed. (Email for a new copy: [info@herpes.org.uk](mailto:info@herpes.org.uk)).

## THIS IS HOW IT WORKS:

Each new ad is added right away to the end of the master list which is sent to all new members. Even if your ad went in years ago, each **new** member is reading it...

**You can ask us to run your ad again. Make a change in your ad and it automatically appears in the next SPHERE with the same box number as before.**

Abbreviations:

GSOH = sense of humour

WLTm = would like to meet

n/s = non-smoking or non-smoker

OHAC = own home and car

a.l.a. = all letters answered

app. = appreciated

pref. = preferred

## PEN PALS – MEETINGS – FRIENDS?

**NEW:**

**Jexxx near Liverpool** wants to be in touch with others in their **20s-30s** for sharing and support - email EMAIL

**20 yrs old, female,** Blackpool/Preston. Looking for other young people for moral support, someone to confide in and someone who can try and make me understand, and help me in coming to terms with it, also friendship. EMAIL

**Hi everyone, male, late 30s, in Herts,** 5'10, n/s, in possession of a GSOH and kind heart. I enjoy creative writing, cooking, running, reading autobiographies, nights out or quiet nights in with a DVD and good company. I also enjoy volunteering and social groups. Looking for penfriends, and/or local buddies. Ala. Box RG/92714/A

**Bristol lady, 40s, looking for contacts locally:** I love the outdoors, keep fit, holidays, cinema and snuggling at home. Own my own home and enjoy my challenging job. N/s and light drinker (odd glass wine nice) PHONE NUMBER or write to box GL/6012/P

**Female, 60s, n/s** classical music, books, films, theatre, country walks, historic places, conversation, laughter, simple wining/dining. Would welcome friends and comrades... A.l.a. Phone or text xxxxx. Surrey and anywhere. Or write to ML/4341/P

## THIS IS WHAT YOU DO:

**To answer a letter:** write your reply, put it in an envelope, write the box no. on the **back** of the envelope, put that in another envelope and post it to our office. Please enclose a donation to cover our costs. How much? Consider what ads in other papers cost and be generous!

**Meeting:** When using any contacts listings, please make sensible arrangements. For your first meeting, choose a busy, public place. Do not pass on your home address or phone number until you are comfortable about it. A genuine person will respect that.



## Special events London:

**Social: PM in the lounge/bar and then evening boozing with the crowd:**

**Saturday, 7<sup>th</sup> May:** arrive any time from 3 pm. Join Marian and others in the Atrium, President Hotel, Guilford St, London WC1N 1DD. Chatting with other people who really understand your situation. Comfortable area - tea/coffee/drinks from £1.30 a cup. (Happy hour cocktails: £4.50 from 5 pm!)

**At 6 pm, we leave to join H-type group** (they are an on-line group, all have been diagnosed). We will walk down to xxxxxxxx to meet the crowd from H-type. We will eat somewhere reasonable on the way. (It was Wagamama last time.)

From 7.30 till as late as you like, mingle and chat.

**Social and educational: The 'day' you get confident and move on**

**Saturday, 14<sup>th</sup> May:** From 10 am join us at the office learn all you need so as to gain confidence for when you meet a new soul mate.

£39 for the day includes lunch - see report on previous page. More details on pink invitation enclosed.

## Meetings near you

Regular event in Bury - check with the office for the next date.

In Kent, we have a member organising meetings.

In Glasgow we have a member who is happy to make arrangement to meet with you.

Email or phone office for more information on these: [info@hva.org.uk](mailto:info@hva.org.uk) or 020 7607 9661

Plus, we can help get you started if you would like a meeting near you.

- advert -

**Eladon Ltd.** specialise in high strength standardised herbal extracts



f t elagenextracts

**Eladon**

The immune system is our defence against all kinds of illnesses and infections (viral, bacteria and fungal). Our increasingly hectic lifestyles put increased pressure on our immune defences leaving us vulnerable. Many of us look for additional protective support.

People who carry the herpes simplex virus will know only too well that being run down will very often result in a cold sore or an outbreak.

During and following trials that focused on reducing the severity and frequency of herpes outbreaks, many HVA members said that they found Elagen and Olive Leaf to be very beneficial.

For any information or advice on the herpes simplex virus, please contact the HVA on 0845 123 2305 or visit their website [www.herpes.org.uk](http://www.herpes.org.uk)

### Special discount price for HVA members

**ELAGEN**

Only £18  
60 capsules  
(rrp £21.12)



### Plus FREE P&P for HVA members

**OLIVE LEAF**

Only £13.50  
60 capsules  
(rrp £14.40)



For further information regarding our products please contact us or visit our website, [www.elagen.com](http://www.elagen.com)

To view our full range of products please visit our website where you will find knowledgeable information and testimonials.

**[www.elagen.com](http://www.elagen.com)**

Eladon Ltd  
PO Box 111  
Bangor  
LL57 1ZB

**Tel: 0845 345 1636**



**[www.elagen.com](http://www.elagen.com)**

# MY STORY

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I am trying to work out why there was such a long gap between when I first had herpes simplex symptoms and when I subscribed. The HVA website is fantastic and it has been so encouraging to receive your magazine, I really wish I had done it before.

When I got my first herpes sore it came totally out of the blue: I was 19, and throughout school and college the emphasis had always been focused on HIV. The rest of the STIs were passed over as insignificant. So when genital herpes was diagnosed, I was shocked and upset, and found it hard to take in. I came home with a handful of leaflets - and a small card with the HVA helpline number on it.

First I was told that herpes simplex may not recur after the first episode, so I waited in the hope that I could just forget about the whole thing. When I started getting outbreaks quite frequently, the first thing I wanted to know about were details of how the virus worked - for example I didn't know (and still am not 100% sure) whether you could pass it from genitals to lips. *[Editor: You will not infect yourself on a different area - if you could, every child with a cold sore would be doing so...]*

I lived for about 3 months being really paranoid about oral sex on my mouth anyway! No one at the health clinics was able to answer the questions I wanted to know which made me feel very nervous of HSV and very

alone and very frustrated. Although I received two more HVA cards from health workers, they were handed to me as an afterthought, whereas they should have been saying "Look, I simply don't know the answers to your questions, but these people will."

I wish that they had sounded more enthusiastic, instead of "Oh... you could try phoning these people." They need to say "If you have any more questions which you need answering in detail, if you need someone to talk to, whatever you need, then phone this number and they'll help you."

I realise that people can't make your decisions for you though and I know that I have a tendency to ignore problems for as long as possible.

The other thing was that I had no previous knowledge of "help groups" and I kind of thought they were for neurotics who couldn't cope with their problems - and HSV is such a minor problem I couldn't see what the HVA could offer. The other thing is that sexual health clinics have little time to help and listen: when I knew that I was getting a recurrence but the doctors didn't recognise it, and didn't believe me, it was really discouraging! I got annoyed with myself as much as them. Eventually I could stand it no longer so made up my mind to phone anyway. What did I have to lose?

That phone call changed my life. It was the start of my way back to normality. I had never spoken to anyone that I knew had herpes before. I realise now that I had got my herpes jumbled up with my own lack of self-confidence and self-worth.

That was then. Now I am a lot more assertive and confident than I was at 19. I have faced up to fact that genital herpes was occasionally making me feel (emotionally) very miserable. Not any more! I have decided not to be a passive "victim of circumstances".

I hope I haven't babbled at you mindlessly and that this may be useful to you in some way. You're more than welcome to stick any of it in Sphere or anywhere else. I'm now in contact with two others I found through the HVA and we've met up for a chat which was really great.

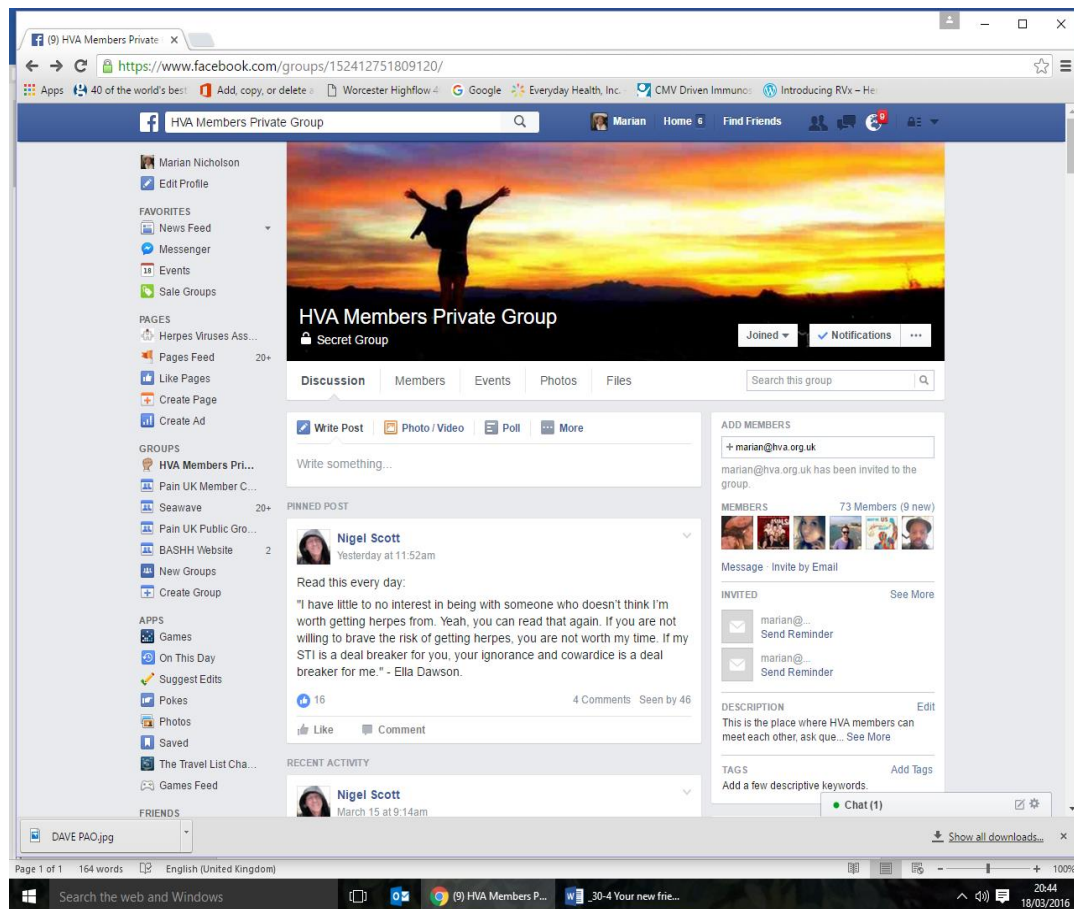
I've booked to come down to London for the next 'Study Day' because I've got a new boyfriend - we are using condoms but I want to tell him before we get to the point of stopping using them. Fingers crossed!

Vikki

Editor: Later she emailed to say that she had 'more or less' told him in the way she had planned to - but it had all 'come out in a back-to-front way' - but that anyway he was fine about it...

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## Your new friends are waiting to hear from you



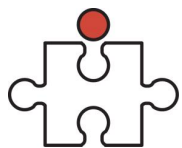
We have launched our secret Facebook group. It has over 80 members. They are getting to know each other and asking us questions (which we answer). They are sharing experiences and finding out what a lovely bunch we all are.

### What are you waiting for?

It is private and secret. Your other Facebook friends will not know you are in it - unless they are in it too. It is only for HVA members - so there are no strangers - only friends we don't yet recognise.

### How do you join?

Let the office know the email address you use for Facebook. We will get the page to invite you to join. It may be email address you have already told us about, or it may be one you just use for Facebook. See you there!



# Sphere

The Herpes Viruses Association | THE JOURNAL

**41 North Road, London N7 9DP**

The HVA does not necessarily agree with or endorse contributors' views expressed in *Sphere*.

Patrons: Professor Michael W Adler, CBE MD FRCP FFCM, Dr David Barlow, MA BM FRCP, Dr B A Evans, FRCP  
Dr Raj Patel FRCP, Dr Elizabeth Claydon MBChB MRCP Dr Colm O'Mahony, MB FRCPed BSc DIPVen  
Dr Miriam Stoppard MD FRCP, Dr David Bull MBBS BSc, Dr Phil Hammond MB BChir MRCGP

**Registered Charity No 291657**



Do something splendid in 2016: help the HVA to continue its vital work... Print off this page – fill in and send it to us. (Your bank needs your real signature.)

Think about it - did we help you? Would you like us to continue to help others? What would have happened if you had not been able to contact us?

Only the people we help know how important we are. We rely on you to keep us going.

Please could you set up this standing order so we can continue to help others like you in the years ahead.

Fill it in and send it back... Many thanks.

**Standing Order:** use this form to set up a standing order

To *(your bank)* .....

At *(address of branch)* .....

.....

Please pay:  
**Santander plc**                      Branch: BOOTLE                      Sort code: 09-01-55

For the credit of:  
**SPHERE**                      A/c no: 7094 6905                      Quoting ref: .....

The sum of *(the minimum amount is £19 for annual payment or £3 for monthly payments)*

£ *(in figures)* ..... £ *(in words)* .....

Commencing *(date)* ..... and thereafter annually  
until further notice or until *(date of last payment)* ..... and debit my  
account accordingly: sort code \_ \_ - \_ \_ - \_ \_ a/c No. \_ \_ \_ \_ \_ \_ \_ \_

Name of account to be debited *(your account)* .....

Name: ..... Signature: .....

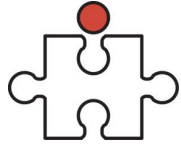
Address: ..... Signature: .....  
For joint a/cs where both signatures are requested

.....

..... Post code: .....

Date: ..... **Now send this form to:**

**HVA, 41 North Road London N7 9DP - *thank you very much.***



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