

# Sphere

The Herpes Viruses Association | THE JOURNAL

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## News from the north: Norway - no stigma! Finland - updated European herpes guidelines



Marian Nicholson was at the Marina Congress Centre, Helsinki (above). She reports back - see highlights, [page 4](#). These include updates on the European genital herpes guidelines, the news from Norway that the stigma has faded away in the last 20 years ([page 7](#)), ideas about testing and treating other conditions – as well as some ‘tourist comments’ from Marian’s trip (on [page 14](#)).

The conference ended with a debate on what doctors should be telling their patients. Our patron Professor Colm O’Mahony won the debate – see [page 11](#).

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# Medical Matters

## Vaccine moves towards the patient:

### **We could be active in a Theravax trial - can you help?**

The HVA could apply for a grant from National Institute of Health Research to start a phase 3 trial here in the UK.

This would require time and some scientific knowledge... We know which doctors we can ask to 'approve' this application - but are you able to work on the application with us? Email [info@hva.org.uk](mailto:info@hva.org.uk) to find out where we have got with this application.

**Theravax vaccine** is a live-attenuated virus vaccine. 'Live-attenuated virus' is the same technique that was used to create chickenpox, polio and smallpox vaccines.

**Theravax vaccine** has already been injected into 20 (rich) patients from the US who flew into St Kitts in the Caribbean, to find out how effective it is at preventing recurrences. These are people who are having too many

### **What is "Named Patient Basis"?**

All medications in the UK are regulated by the Medicines and Healthcare Products Regulatory Agency (MHRA), the Government agency responsible for ensuring that medicines and medical devices work, and are acceptably safe.

Manufacturers must obtain marketing authorisation for any medication that they want to sell. Once licensed they will be listed in the Monthly Index of Medical Specialities (MIMS). Generally, if the medication your doctor wants to prescribe is not in MIMS, then he or she will not prescribe it.

However, there is an exception to this rule! Some medications can be prescribed on a "named-patient" basis. This means that, in certain circumstances, a doctor can prescribe medication because the patient has a special need for it.

Reasons why drugs may be supplied on a named-patient basis are:

- A licence has not been granted yet due to ongoing clinical trials
- Discontinuations
- Drug shortages
- Temporary supply problems
- Clinical trials
- Special needs of an individual patient

Theravax will not be licensed (yet), so the only way it might be obtained now would be with a prescription on a "named-patient" basis.

**We hope to find some private clinics which could stock this vaccine and will be collecting details. We will be letting our readers know - from January 2018, email [info@hva.org.uk](mailto:info@hva.org.uk) for the latest information.**

outbreaks, which they have found difficult to control with antiviral tablets.

A few of these people have been in touch with us to tell us how the course of 4 injections, at US \$1,500 each, has transformed their lives. However, one lady told us that she finds that she needs a repeat every 6 months or so, in order to maintain her freedom from outbreaks.



### **Future developments?**

This vaccine has been in the news lately. The reason that the injections have been administered in the Caribbean, and not in the US, is that the US Food and Drug Administration (FDA) forbids any trials with live-attenuated vaccine for fear that the patient could develop the illness that it is meant to prevent. Of course in this particular case, all the patients already have the condition. (And if this FDA rule, which was brought in in the 1970s, had applied a few decades earlier the world would not have got the vaccines that have rid us of smallpox and have got control of polio.)

Agustín Fernandez III, the CEO of the company developing Theravax, has been in touch with us. He explained that first he verified that in St Kitts, as in Europe, a doctor can give any patient any treatment on a named-patient basis. (See box on previous page.) The doctor has to consider the treatment appropriate - and has to be prepared to defend this in any possible disciplinary hearing. Under this system, he hopes to involve more patients in testing the new vaccine by bringing it to Europe.

Meanwhile the US news is full of stories about this potential vaccine because they are highly critical of the impudent small company flying in the face of the establishment in the form of the FDA and running 'illegal research' outside the USA. As Oscar Wilde said: 'there's no such thing as bad publicity'?

Watch next issue of Sphere or the <https://herpes.org.uk/news> page for more on this Theravax vaccine.

# Report from the Helsinki conference

**'2017 European guidelines for the management of genital herpes'** is an update published by the International Union against STIs (IUSTI). Doctors all over Europe can refer to this.

Marian Nicholson was given a bursary to attend the IUSTI conference in the Marina Congress Centre on the Helsinki harbourside - she reports back:

Dr Raj Patel presented the main changes that the authorial team had made to the previous guideline. He added that they had received more comments on the draft which had been sent out for comment to doctors all over Europe - than on any other IUSTI guideline!

## In the herpes simplex guideline:

### **Treatment**

**Episodic treatment** (this is in order to prevent an outbreak that the patient can feel is starting up):

- Aciclovir 800 mg three times a day for 1 to 3 days, or
- Valaciclovir (Valtrex) 500 mg twice daily for 3 days

### **For suppression, then:**

- Aciclovir 400 mg twelve hours apart
- Valtrex 500 mg once a day for people having fewer than 10 outbreaks a year
- Valtrex 1000 mg for people having more than 10 outbreaks a year.

## How to take Valtrex:

**Raj told the audience (that even for Valtrex): "It is always better to take half that dose twice a day. So you might tell patients they might need to break/bite the tablet in half."**

**If the patient is still getting outbreaks on those doses, then move to:**

- Aciclovir 400 mg three times a day
- Valtrex 250 mg twice a day
- Valtrex 500 mg twice a day.

## Pregnancy

IUSTI is now saying that if a woman is getting a lot of outbreaks in pregnancy then she **should** (not 'might') be offered aciclovir suppression from 36 weeks until the birth.

Raj explained that this was because there had been litigation where aciclovir was not offered in pregnancy (he did not mention where). But he added "Don't use antivirals in the first and second trimester for recurrences unless you have to."

A woman can deliver vaginally even when she has a repeat outbreak. This is standard in UK and Netherlands.

## Serology (antibody tests)

Don't rely on them as antibodies can be lost over time for both types 1 and 2. A negative result is wrong between 12-30% of the time. The risk of a false-positive type 2 result is higher for who already have type 1. These type specific IgG tests might be helpful if a couple want to see if their antibodies match.



## Disclosure

Raj said "IUSTI is less severe on disclosure than the BASHH guidelines." The guideline does **not** tell doctors to tell their patients they should tell partners. This reflects the lack of stigma about cold sores on the genitals in non-English speaking countries. It states:

**"Advice on disclosure should be practical and tailored to the patient's personal situation. The low physical morbidity and high population prevalence should be stressed."**

'Low physical morbidity' means herpes is mostly unnoticed and undiagnosed, and even most of those who do notice are unlikely to get severe or frequent recurrences.

Marian comments "I very much liked that last point. Raj was emphasising that most people don't realise they have caught it, and by middle age the prevalence (infection rate) is over three quarters of the population."



**Proctitis** i.e. herpes simplex can infect the first inches of the rectum - often asymptomatic in male and female. It is often not from anal sex but follows reactivation in a nearby site - see diagram [page 20](#).

**Tenofovir gel** to prevent HIV also reduced HSV acquisition by 51%. A study on PreP (this means drugs taken to prevent catching HIV) in Seattle checked HSV shedding in women using Tenofovir orally or as a gel. Swabbing twice a day found that oral Tenofovir gave mild improvement, whilst the gel gives 60% improvement. However, daily aciclovir reduces shedding by 80%.

## **New drug - pretelivir**

Current antiviral drugs for herpes simplex use thymidine kinase which inhibits the virus from multiplying. However, helicase primase inhibitors (HPI) are looking very good.

Helicase primase is what allows HSV DNA to unwind (which is needed before it can replicate). Current drugs don't work immediately, so if started at day 4 of an infection then the symptoms will peak at day 8 instead of at day 11, whereas HPIs work immediately. This can totally prevent further symptoms. Eleven different HPIs have been trialled and Pretelivir is furthest along. However, toxicity is a major concern as helicase primase is also in other cells - which you do not want to prevent from working! So Pretelivir will not be widely used - it can be useful in HIV patients with resistance to current antivirals.

## **Serology**

Antibody testing in Africa doesn't work well. This is because the current tests use proteins from the out-of-Africa strain, because the test was created for the developed world. [There are two strains of herpes simplex type 2, one found in Africa; one found everywhere else.]

In this same research, it has been proven that type 1 developed with humans. Type 2 was only caught from chimps by early humans about 1 million years ago.

# No stigma in Norway - Marian finds

Our patron Dr Raj Patel, kindly gave me a spare ticket to the elegant dinner outing to the Helsinki Yacht club (photo).

"We don't have the herpes stigma in Norway now" said Kirstin, a Norwegian lady doctor, as we awaited our turn at the buffet table that evening. I found this surprising, so I took the opportunity to find out more.



"Maybe 20 years ago it did, but since then it has faded away." I asked her why she thinks that might have happened. "Doctors don't talk about it - we talk about malignant melanoma more, since Norway is one of the worst countries for this [skin cancer]."

I asked her if patients expressed emotion when diagnosed. "No, I don't think so. If a patient asks us [more about the virus], then we tell them it is common, and unimportant."

I checked this with another Norwegian lady doctor sitting at the same table, after all, this was pretty amazing stuff. "That's right," she said. "You need to talk to them and tell them about it if they have questions. If you just closed down the conversation, then they will go and look at Google. But it is not a serious infection, so why should they worry about it?"

And lastly, I spoke to an Irish doctor who now works in Norway. What did she think about the difference in attitudes? "I never get anyone in hysterics about it here. I think that they have a calmer attitude about all these [sexual] things."

Kirstin added "I was surprised by the idea that anyone would go to the police. [A UK doctor mentioned the single UK case during his presentation]. "I was pleased to hear you stand up and explain how it was a mistake. You spoke very emphatically about it."

A Swiss lady doctor sought me out to ask about this case too. And another lady had congratulated me for standing up to the presenter who tried to argue that this was going to be normal in the UK!

So double luck: I had a boat tour of the harbour followed by dinner - and I also discovered a riveting, inspiring piece of information!

# Syphilis - has it lost its stigma?

The word 'syphilis' was once considered so obscene that you could not say it to a woman. Dr Alexandre Wenger explained how information about syphilis was slipped into the public domain through art!

He started with Italian art. In Botticelli's famous picture of Venus, from 1486, she is pure and innocent - see picture. At that time, syphilis was not a problem in Europe.



It was to become an epidemic when a new strain arrived from the New World, probably brought by the sailors on Columbus' returning ships. A later painting of Venus shows a distraught man in the background, supposedly because 'love' gave him the infection.

A recent piece of historical detective work has calculated that in 1774, in Chester, 8% of under 35-year olds were infected with syphilis, so by then it was endemic.

Syphilis caused serious damage, not least because it could be passed on to the sufferer's children. It has been suggested that Henry VIII gave syphilis to his first wife Catherine, causing at least six failed pregnancies. She only bore one live baby – Mary.

So to educate young people, sexual education took the form of poetry! A French poet created a long poem which subtly informed the reader of the sad consequences of trusting a roué (someone who has too many sexual partners).

Another idea was to display anatomical models of bodies with syphilis symptoms - this "musée anatomique" toured Europe.

Dr Wenger continued "Infection with syphilis was always a personal calamity but in World War I, VD's such as gonorrhoea and syphilis were presented as a social scourge." This was because treatment with mercury compounds was painful and took over a month, putting 5% of soldiers out of action at any time.

As soon as films were invented, they were used to give a sexual health message. At the end of the 19<sup>th</sup> century, a film called "End of the Road" told the story of May, who was a good girl. Her friend Vera came with her to New York, but she just wanted 'fun' - and caught



syphilis. (However this was before 'talkies' and the word 'syphilis' was not used on the white on black 'dialogue cards'.)

In order to persuade Vera that she must have the nasty mercury treatment, May, a trainee nurse, arranged a tour of a (no doubt genuine) women's syphilis hospital. We see skin hanging off legs, noses vanishing, inability to walk. At which point Vera faints!

## What does this have to do with herpes?

In his summary, Dr Wenger pointed out that "nowadays we don't associate STIs with morality or blame. We don't show consequences. We don't appeal to patriotism." He added that "We use the same sort of visual pedagogy, but we use the right tone."

The HVA thinks that is because when effective antibiotic treatments for syphilis and gonorrhoea appeared, they became less terrifying.

### Are clinics no longer judgmental?

Dr Wenger's comments surprised Marian very much. The HVA frequently gets callers on the phone who are very upset by what they perceive to be the judgmental behaviour of some staff at clinics. And doesn't all sex education in schools use slides that 'show the consequences' of unsafe sex?

Marian checked with some English doctors and they said that not all medics would agree with Dr Wenger. (Ha ha! They would say that wouldn't they!). They added that society as a whole would definitely not side with him.

Marian's view is that his comment shows that sex and STIs are viewed differently in France (where Dr Wenger practices).

## Men in pain - you are not alone!

A survey, presented in Helsinki by Dr Josef Beatrice, found that between 2.7% and 6.3% of males reported pain in the pelvis/genital region that lasts for three months or longer (usually not herpes simplex related).

Serious causes may



An 8-metre high statue 'pissing' into the harbour. Is he saying 'ouch'?

include trauma, infection, auto-immune inflammation, muscle spasm, and more.

Once treatable causes (infections) have been ruled out, he suggested that treatments could include: tricyclic antidepressants, anti-epileptic drugs such as gabapentin. Strong pain killers (opioids) can occasionally be used. Surgery should be avoided unless there is a clear reason for it.

## Might you have shingles, not herpes?

Barry Vipond, clinical scientist at Public Health England in Bristol had 10 minutes to talk about a new lab procedure that tests for four viruses at once.

This has been developed by the Australian company SpeedX. They have opened a London office and have received the CE mark (European approval) for an earlier test.



Traditionally laboratory tests check for herpes simplex types 1 and 2. The new SpeedX 4-way test looks for both herpes simplex types, as well as human herpes virus 3 (shingles to you!) and also syphilis.

Mr Vipond reasoned that it is helpful to find the people with VZV to “eliminate the psychosocial burden of the stigma of herpes.”

Using the new test, it was found that up to 3% of the swabs were positive for varicella zoster virus. Sores and sensations of shingles are just like herpes simplex - so 3% of the people who are self-diagnosing with the help of Dr Google and ‘decide’ they have genital herpes, actually have shingles.

This finding will also account for some of those who are ‘clinically diagnosed’ with genital herpes by doctors (by looking) but this is never confirmed by a swab test.

If your genital herpes diagnosis has never been confirmed by a swab - maybe you have shingles.

# Debate: To tell, or not to tell?

The debate was on the last day, in the afternoon. Medical opinion is divided:

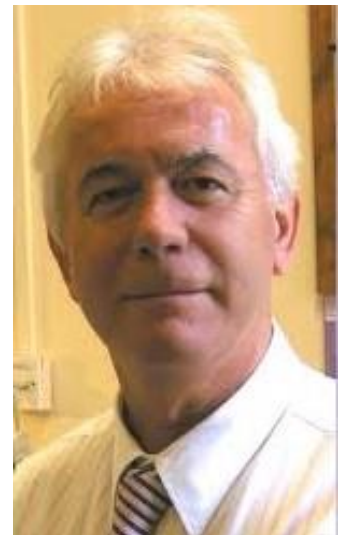
**"This house thinks that every doctor should strongly encourage their patients to disclose their HSV status to future partners."**

The doctors who debated 'for' and 'against' this statement are well-known to Sphere readers because they have given talks at our AGMs – reported in detail in past Spheres – and the same subject was debated in front of a British audience in the recent past.

**Professor Colm O'Mahony, MB FRCPed BSc DIPVen., started with the argument 'against' the proposition:**

"What are we talking about here? This is a cold sore!

"Drugs companies created the hype, the stigma about herpes. In fact, we should be careful what we pick up from drug companies. They created an epidemic of psychologically damaging herpes.



The HVA helps defuse patients' anxieties. The first line of their excellent 'talking to partners' leaflet says '**Do you have to?** No, not necessarily. People with facial cold sores don't usually think it is necessary, so why should you?' It is a cold sore in a different place.

It is usually mild - in this slide of a young woman who wanted me to see her recurrence, I could not, until she pointed to this tiny ulcer. Does she have to tell? Another woman gets a type 2 outbreak on her back - where her bra strap has rubbed - should she tell?

The case of David Golding caused ripples. But in my view it was ridiculous. Are we going to send children to prison for passing on chickenpox?

I was on TV with the young lady and Eamonn Holmes was good. He gets cold sores and he asked her why she thought it was appropriate to go to jail for passing on a cold sore. By the way, the young lady now has a baby with another man.

Raj then wrote an article in the BMJ saying that you do need to tell patients to tell their partners. But this is to protect doctors in case a patient comes back and sues them for not providing the information.

In Canada, a woman sued a man and the judge was so unimpressed by the case that he ordered the man to pay her just \$218 compensation. Currently Usher is being sued - but if his lawyers do their job, the woman will not get compensation.

Tell, or don't tell. If you are on suppression, is there be any need to tell?

The BASHH guideline is harsh. ["Doctors should tell patients to tell partners."] The IUSTI guideline is better. ["Go by the custom and usage in your country."]

If you have a newly diagnosed patient who is really upset, do you want to go into this issue? The patient won't be able to take in the details and you are just compounding the impact of the diagnosis by talking about this.

In Romance, is total honesty required? Don't partners fake orgasms? (Please continue to do so!) Don't we like and indeed expect a bit of mystery in our lives? This is a detail - I prefer not to know."



**Peter Greenhouse, FRCOG FFSRH, (all those initials after his name show that he is a doctor, also a surgeon) supported the point. He started by examining the terms:**

"It says you 'should' [tell your patients to tell partners]. This is a conditional - it is not stating that you must [tell your patients to tell partners]. You are being 'strongly' advised to do this as there is evidence for it and it is opinion based. Colm said it is too hard to do on the first visit, so tell your patients this at their second visit or at least put it in the leaflet that you hand out.

Is it ethical, is it honest not to encourage them to talk about it? I think that not to tell your patients is the easy way out ('cos I agree it is difficult to do). But it is the doctor's duty of care - to inform patients carefully.



Will telling partners stop the spread of the virus? No, but it will slow it down. We owe it to the patients to give accurate advice. So that their partners can give informed consent. In fact, talking about this with a partner is a proof of honesty, courtesy and concern. The response will be a test of character and the suitability of the partner.

### **Five out of six partners already have at least one type**

In fact, most partners are already infected. So in this case, we need to look at the 'Numbers Needed to Tell' NNT. **The number of partners who have neither type is 15%.** (Data from a Swiss antenatal clinic.) This means that the NNT before you would be likely to find a partner who can catch it off you is 6. (Of course, most of these potential partner who have it, are unaware that they have it.)

Obvious recurrences are more likely when the patient is stressed - so by getting this off their chest they reduce stress, and possibly reduce outbreaks.

### **Low transmission rate for the diagnosed**

**Early in a relationship, it is transmitted in 8.5 out of 10,000 sex acts. Later in a relationship it is transmitted in 0.7 out of 10,000 sex acts. Men are 7 times more likely to transmit to females than the other way round.**

### **With type 1 do I have to tell?**

No, over 80% of young people have type 1, so there is no need for doctors to tell them to tell.

To sum up - OK, there can be embarrassment and stigma. Doctors will avoid broaching the subject of disclosure. It adds to the stress of diagnosis. But this is not caring for your patient. It should be explained to them that telling

- reduces the risk of transmission - it has been shown that when the partner knows transmission rates go down
- facilitates the patient use of suppression (no need to hide the pills)
- makes condom use more likely

and if the partner does catch it, if you have told your partner, you can give him/her some of your aciclovir early in the infection.

**At the end, Raj announced that the swing is against the motion. Colm has won, so doctors 'don't need to encourage your patients to tell their partners.'**

# Tourist comments from Helsinki

Marian Nicholson, director of the HVA, was given a complementary place at the three-day IUSTI conference at the Marina Congress Centre. She did not stay at the Grand Marina Hotel, with rich the doctors, but at the nearby Eurohostel (free morning sauna included in the price). Marian reports:

## Doctors endorse the HVA

It was a fantastic networking opportunity and I was thrilled to hear several speakers who were talking about genital herpes mentioned the excellence of the work of the HVA!

The work of patient support charities is not well known in Europe, so curious doctors came and asked me during the breaks what we actually do. Between mouthfuls of reindeer sandwich or shrimp salad, I explained the concept of self-help groups and open-access helplines staffed by trained volunteers. They found it fascinating.

As well as attending talks all day, there was an opportunity for sight-seeing. And here is my 'tourist view' of Helsinki.

## Charming and interesting

Gazing out of the plane window as we came in, I spotted the runway surrounded by towering fir and silver birch trees. Riding the bus into town, I noticed the granite of the land poking through the earth like whale backs in the sea. Where is the soil to support such tall trees I wondered?

Helsinki is charming and empty of cars and crowds. It is small enough for you to walk from one side to the other in under an hour. But you don't have to! The buses and trams (and even the train to the airport) all operate on the same easy-ticketing system: buy the ticket and you can ride anything in town within the specified time.



The pool in Helsinki harbour

And there is plenty to do. People popped out of the conference to visit art galleries, the Sibelius monument, museums of all sorts - such as the Design Museum - Finnish design shares the Scandi-cool look.

One doctor told me he went to a rock concert with his partner on the one night we had 'off'. On that evening, I took a ferry to the island of Suomenlinna and spent hours wandering the leafy lanes, and exploring the forts and battlements that rim the island. I checked with the ferryman when the last ferry back would be. (Like every person in touch with visitors, even the bus drivers on town buses, he spoke good English.) "Two in the morning", he replied.

## **Fresh water and open air swimming**

The Baltic Sea is almost fresh water – fed by rivers, and is far from the Atlantic Ocean. It has no tides to speak of. This means that the edges of the island are

lake-like, scenic vegetation right down to the water, unlike our shore which has to allow for a major tide each day. The lack of 'salt smell' from the water was rather disconcerting! Right in the middle of the main harbour (see picture on previous page) there are the three



floating swimming pools at the 'Allas Pool' (with saunas in the changing rooms, of course!). Two are heated to 28C, all year round - one is at 'natural' temperature – I watched two hardy souls plunge in, but they didn't stay long in the 16C water!

"I only had that one evening off, as on the first evening we were all invited to a welcome reception in the City Hall, (pictured below) completed in 1833 – to be welcomed by the sexual health councillor of Helsinki's city administration – and to eat gorgeous seafood and salads... and drink wine if you like that kind of thing.

"On the final evening I was given a spare ticket for the 'gala dinner' - although as they are not allowed to have 'galas' they call it a 'networking dinner'. That's where I learnt the interesting fact about Norway and the herpes stigma - see [page 7](#).

# What is with the stigma? A plea for understanding and sanity

**Sarah tells us how she got her head around it:**

*HSV2 or genital herpes as it's otherwise lovingly called affects more people than you'd probably ever think but why is it not more openly discussed and why do most people not know it is so common?*

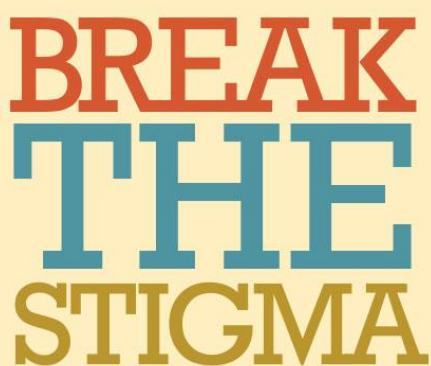
**...And what is with the stigma??**

Well, I think it boils down to the fact that people get all funny when they think about things that affect their nether regions!

Anything that goes on down there suddenly is taboo... think of these words and see what reaction you have! Piles! Thrush! Sanitary towel! Pubic hair! Jock strap! Funny choices I know but do all of them invoke a kind of nose wrinkling from you???

Yes - add herpes to that list... I bet it initially does the same thing. However, let's take the terms out and see... Thrush! OK, nothing really makes thrush better, it's thrush but it's not serious! Brazilian! Cup! Let's add... cold sore!!!!

See what I did there! Straight away changing the reference for something that basically means the exact same thing but suddenly it sounds less offensive, less shocking, less gross! So what's my point! My point is we are a culture fed on shock, fitting in, pointing fingers at people's life choices, judgements and misunderstandings.



**BREAK  
THE  
STIGMA**

## **Herpes sells newspapers**

The media will use whatever they can to shame people. We hide away things that we see as embarrassing because the terms used to describe them make us believe there's something wrong with us. "Usher gives woman herpes".... It doesn't have the same impact as if they said "Usher gives woman cold sore"!!!

Herpes is a virus, it's not ideal to have, I won't lie, but neither is eczema. My virus isn't there all the time and I take medication to control it, limit the risk of passing it to my partner and I make other choices to reduce its effects.



On the whole it doesn't affect my life, my friends, my sex life or pretty much anything else about me. It doesn't affect the way I love, behave or think. So I'm kind of sick of stigma making people think that it should. I'm sick of stigma making me feel like no one would love me or find me attractive when I got diagnosed. I'm sick of stigma making out that people who have this virus are slutty or dirty or deserve to be judged.

### **Having sex is nothing to be ashamed of**

Why should it? We didn't do anything wrong... we had sex, or maybe we didn't even have full sex?! Just like every other sexually active person out there all we did was take our clothes off with someone at some point and rub our bodies about a bit. Some of us might have been drunk. Some of us might have been having an affair. Some of us might have been getting to know a new person. Some of us might have been virgins. Some of us might have been in love with the love of our lives.

The point is, it doesn't really matter what you did or who you caught your virus from. At that time and in that moment you were doing a perfectly normal human grown-up act!! And at that time you were doing the very same thing millions of other people were doing round the world! Yet after it at some point you discovered you were left with a little (annoying) reminder of the fact it happened.

You may not ever know who you picked up your virus from, or you may know exactly (I know mine was in my first relationship after the breakdown of a twelve-year marriage.)

### **Don't sweat the petty stuff**

For some people the stigma sends them a bit crazy and they try to work out who, when and where it happened. They drive themselves nuts thinking that if they had done something differently, they wouldn't have it.

The truth is some people will never know, and it shouldn't matter. Many people catch a [mouth] cold sore as a child from a parent's kiss. Does that mean you love your parents any less? Does that mean they gross you out and you don't want to be around them or have them touch you? Of course not! So why are we made to believe this should be any different? I've gone through an awful lot of soul searching since I found out I have HSV-2, mostly, I think, just because of the stigma.

Weirdly now, I believe as hard as rejection is for me (and I know no one likes it) my virus is actually looking after me. It made me identify that the relationship I was in with the person I caught it from was a

bad stressful and negative place, as while I was with him I was so run down I would get frequent outbreaks - my body was telling me it wasn't happy. After we broke up I was very nervous about the prospect of telling people I was getting involved with, so first I told all my friends to gauge their reactions.

### **Friends can be supportive**

All but one either didn't understand what it was or were very much, "So, as long as you're OK, that's the main thing." We laugh and joke about it now. With one friend I had a lot of explaining to do; she was very judgemental in the beginning, still is a little and is totally grossed out about the thought of it happening to her.

However, she still has unprotected sex with new partners so it's not scared her completely. All my male friends said that if they were with me as a partner they wouldn't find it off-putting and any man I meet who is put off by it clearly isn't good enough for me anyway. (Very sweet of them I know, but I also know that until they meet a woman who has this and they want to date her, they can't say for sure that it wouldn't matter). I know it's because they know and love me and are all a bit baffled why I haven't yet met a nice man.

So far I've only told two partners, one was totally freaked out (even though he blamed it on other factors) and we broke up the week I told him. The other wasn't put off in the slightest (sadly I didn't really feel a strong connection to him) but it was nice to feel the reassurance that I thought I knew, that not everyone would freak out and run a mile.

Also I have found out that 3 of my direct friends also have it, and I know of at least 2 friends of friends, so now we talk about it openly. And these are just the ones who have been frank with others about it; there may well be more who just haven't been open yet because of the stigma.

### **Better understanding is the key**

If everyone was open, I wonder if perceptions would change? I wonder if those who are embarrassed or ashamed would feel better? I wonder if we could finally understand it's not something we should be judged by, or think we should be judged by? I wonder how many people are dealing with it on their own for no real reason other than ill-informed and uneducated misconceptions? It makes me sad to think that.

**I'm lucky, I haven't told the world yet, maybe one day I will. But the point is I shouldn't really have to. The world shouldn't care.**

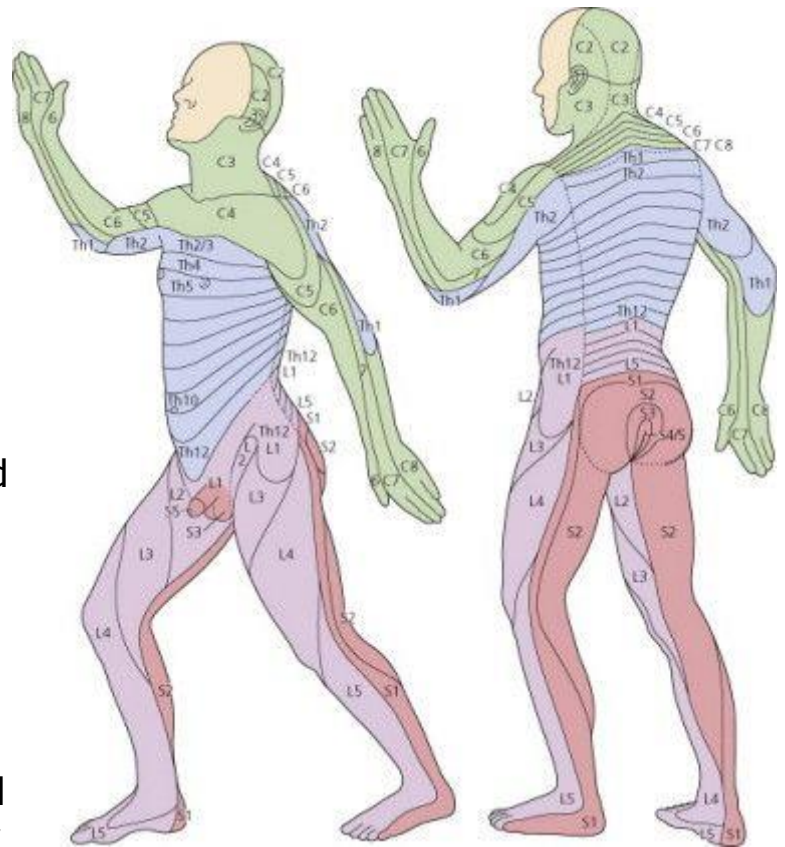
Sarah

# Stories from the helpline

**Our helpline volunteers get asked this kind of question a lot:**

"I have been diagnosed with genital herpes, now the virus is causing xxx [insert random symptom here]. Is this something the virus cause?"

The xxx in that question could be "itching all over my body" "aches in my ankles" "spots on my buttocks" "non-stop irritation around my genitals (or bum)" and many other symptoms. Today, a person with cold sores was convinced his sore throat was caused by the virus. No! He had a cold! (Because cold sores return on the lip, not the throat, and his nose was also running...)



**Re above: you can expect every genital herpes recurrence to be only in the sacral dermatome (labelled S2, dark red), only on one side, to last a maximum of, say, two weeks.**

Having genital herpes does not stop you from having haemorrhoids, boils, warts, eczema, lichen sclerosis, or thrush.

**Helpliners are not trained relationship counsellors, but we often find ourselves making comments about the relationships that callers are describing and the behaviour of their partners.**

One caller told me that her boyfriend of two years had now 'dumped her because of herpes'. I asked for details.

She said that "I told him really early on and he was fine about it for two years. But now he has said that he cannot handle it."

I explained that it was not because of genital herpes that he had left. If it was OK for two years, then he was just using the word 'herpes' to ensure that she did not make a fuss when he wanted to leave her.

Another caller was describing her relationship with a bully. When I said that was what he sounded like from her description, she agreed

that he was but that "he really loves me even though I have this." Wow! What a hideous thing, to stay with a bully because you think you have to...

Facts that helplineers can use to help people in this situation are:

- By age 35 over 85% of women have HSV-1 and/or HSV-2 somewhere – most don't know. (This is an Australian statistic but we think people in the UK and Australia have similar sex lives. It matches research in a Swiss antenatal clinic.)
- You are a safer partner than two thirds of these 85%, because you have been diagnosed, so you will avoid contact at the most important times.
- 83% of potential partners are cool when you tell them – according to a survey of our members in 2015

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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)

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# MY STORY

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**Both the above points are illustrated in the personal story below.**

## **A member writes about treatment and relationships**

I just wanted to say thank you so much for all this (information for new members). Your matter-of-fact style was incredibly helpful when I was getting my head around the diagnosis two years ago - the clinic gave me one of your leaflets and I used it when I told my then new boyfriend about the situation - about which he initially seemed to be quite accepting.

### **Too many outbreaks**

Unfortunately, I had not long been diagnosed and was still having monthly outbreaks and there seemed to just be a few days' window between my (heavy) period and the prodromal symptoms starting again. I started taking aciclovir but it didn't seem to work at first and so I switched to valaciclovir instead. I tried to keep things positive, saying 'They will start to get less frequent, and everything will be fine' and I was investigating how to deal with the heavy periods too. (On that point, the Mirena coil was like a miracle, incidentally!)

Then, about five months into the relationship I started being in pain pretty much permanently and a while after that I was diagnosed with a chronic nerve condition: post-herpetic neuralgia/vulval pain syndrome. I was given amitriptyline, which took some of the edge off the pain but mostly just made me feel tired and sleepy.

### **Other complications**

But a month or so after that my skin went crazy. Initially I thought it was a huge herpes outbreak, but it turned out to be dermatitis, which put me off the scent completely. I came off the amitriptyline and, although I was very sore, at least I felt better in myself and not such a zombie.

It took about 18 months all in all (including an 8 month wait to get an appointment with the dermatologist at the local hospital) to establish that my skin had reacted to an ingredient in the Instillagel

2% numbing gel I'd been given at the sexual health clinic, and that the corticosteroid I had been given to treat that reaction actually ALSO contained the ingredient I was allergic to and made it even worse.

The dermatologist finally found me a corticosteroid ointment I wasn't allergic to and healed the skin - only to find that the pain was still there and the original diagnosis of post-herpetic neuralgia had in fact been correct.

By this point, my partner had left - about two weeks before that appointment. His frustration and anger about the situation, often directed at me, had led to another blow-up and him storming out again saying he was leaving, and this time I didn't follow to smooth it out and bring him back.

### **Why did he leave?**

I'm not sure whether I'm most upset about the whole mess ruining my relationship or perhaps the increasingly strong suspicion that my own feelings of guilt, shame and gratefulness that he was sticking around at all were blinding me to the actually very unhappy, stressful and dysfunctional nature of the relationship itself.

In reality, quite quickly he had found my frequent outbreaks very frustrating and would get very pissed off when I had to say we couldn't have sex again. My heart sank and the anxiety rose every time this happened.

I was so upset. I so wanted things to work out with him and I couldn't believe my condition was ruining what I had thought was finally my relationship with 'the one' and I felt guilty for bringing him into something when I couldn't fulfil what was needed a lot of the time.

### **Control freakery**

He had quite a few anxieties, though, and these had started to show more strongly after just a few months, when he moved in. He had always been suspicious about who I was talking to, checking up on me on Facebook and Twitter and I had to keep my phone face up and not on silent to show I wasn't hiding who was texting or who was calling.

He hated me being away overnight or having an extra shift at work or even getting home late, and while initially it seemed kind of sweet, if over-anxious, the anxiety quickly turned to anger and resentment and big blow-ups where he would say lots of mean stuff, threaten to leave or drive off and smash things. But then afterwards, once he

had calmed down, he would say how much he loved me and would blame all the irrational behaviour on being worried about me and frustrated by the herpes and neuralgia, etc. and I felt guilty for putting him through it and grateful that he loved me enough to stay despite what was wrong with me.

And when we made up he was lovely and I believed it was because he cared so much that it was making him crazy. But as time went on and the cycle continued, I would find myself feeling increasingly anxious about what mood he would be in and walking on eggshells (the stress of which no doubt contributed massively to the physical issues).

Eventually I understood that the herpes was a hook to hang his own insecurities and anger on: an excuse. And I realised actually how unhappy I was.

Looking back, jealousy played a big part in his issue about the herpes. He was jealous of previous boyfriends who he imagined had had this amazing sex life with me that he could not - at least, not unrestricted for now - and he couldn't stop thinking about it. And in particular he was focused on the man who had given me herpes and had 'ruined his life'. ('His' life?!)



The fact that his anger and black moods were ruining my mood too and destroying the relationship he said he wanted above all else, he couldn't seem to grasp. Even when we knew the herpes wasn't the problem, he kept going back to it as the trigger for everything that was wrong.

Eventually, my faith in him started to fade and finally I lost the desire for intimacy, and just felt lonely and sad and hopeless. And when the inevitable next blow-up happened and he stormed out again saying he was leaving, I let him go.

### **Finally, a new direction**

So it has been a pretty hellish time, as I'm sure you have heard many times before, and I am still pretty low. So it was amazingly helpful and surprising when I finally got round to reading the email, with Sphere 31/4, that you had sent when I had just renewed my

membership. It included the link to [the podcast](#) from the Vulval Pain Society which really rang true with my experience and made me feel a bit less alone with it all.

So all that is to say that the work you and the Vulval Pain Society do is so important and so good, not least because of the damage and hurt that can affect us because of the way the stigma and isolation of these conditions can knock our self-esteem and cause us to quietly slide down to rock bottom without even noticing.

What you guys do in normalising what seems so traumatic at the time and helping people gain perspective and feel stable and confident again is so important. Holding onto that has actually kept me sane in the end, I think.

Time to re-build and move forward.

Robyn



## Sphere

The Herpes Viruses Association | THE JOURNAL

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

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Marian and Nigel at the HVA office hope you enjoyed this issue of Sphere.

Would you consider setting up a standing order so that we can depend on an income to enable us to continue our work? This will be very much appreciated. Especially by all the new people who find us when they need us...

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