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Sphere
The Herpes Viruses Association | QUARTERLY JOURNAL

You can call the office
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6 pm - 9 pm:
0845 123 2305

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No prescription charge for STI treatment

Since January 2020, you can get prescriptions for STI treatments such as aciclovir written by a GP free of charge.

Make sure any antiviral prescription from a GP is endorsed with 'FS.' There is no need for the GP to write anything else on it.

From the prescribing team in the Dept. of Health and Social Care:

"We have enabled prescribers to endorse the FP10 prescription form to show the pharmacist that the item(s) prescribed are for free-of-charge treatment for a sexually transmitted infection (STI) … because we understand

Continued below:

Rational Vaccine is on the blocks waiting for the starting gun

RV01 vaccine trial's phase 1/2 needs 200 people with genital herpes, between 18 and 64. You will be inter-viewed either by phone/video call or at the research sites (London's Chelsea and Westminster Hospital and

Continued next page…

Contents

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that treatment for STIs is increasingly being provided prescriptions from GPs and we want to make sure that people aren't charged a prescription charge for this treatment which the law says must be given for free.

A new prescriber endorsement 'FS' has been introduced for 'free supply of sexual health treatment' to enable prescribers to endorse prescriptions for STIs to indicate to dispensers that the patient should not be charged."

https://www.nhsbsa.nhs.uk/changes-fp10-nhs-prescription-form

Continued from cover…

Southampton's Royal South Hants Hospital): thirty medical questions, your number of recurrences, and how treatment works/does not work for you, etc.

From these results, for the next stage, people will be selected to go and have the vaccine injected.

It does not matter where you are in the country. And it is fine if you are using antiviral suppression.

You will need to have swabs done and these can be done by you at home or one of the two sites.

What's the delay on the starting gun?

The Ethics Committee has to approve the protocol, the informed consent form that you will have to sign, etc. The business people need to sign the contracts with the various hospitals and research companies involved.

Get a head start

To go on our list of volunteers, send an email to info@hva.org.uk with your age, and your phone number.

And if you wish, you can say which of the two venues you'd go to IF you are selected to have the injection.

As soon as we get the 'go' I will send the list of names/contact details to the researchers, and you will be ahead of the crowd.

Interesting research reported under "false colours"

Kiss of death for cold sores as scientists discover 'on/off switch - The Telegraph – on line

Cold sore sufferers could one day be free from outbreaks, after scientists discovered the causes of repeated flare-ups.

The blister-like sores are caused by infection from a highly common herpes virus… The root cause behind resurgences in cold sores has been a mystery, but scientists from the University of Wurzberg, in Germany, unearthed how the viruses are triggered.

The boxed story above shows how this was reported on the web, for instance, in the Telegraph… However, the headline is wrong. The research is not about cold sores but about a different herpes virus. It's just that the journalist reporting the medical results doesn't know that there are 9 humanherpes viruses so he imagines that anything with 'herpes' in it must be about cold sores!

When you read on, you find that Prof. Lars Dolken was actually working on human herpesvirus 6 (HHV-6), which causes roseola, a very common virus in toddlers causing a high fever followed by a rash on the torso then arms, legs, back, and face. Like other HHVs it can reactivate later when the body is under stress.

In the course of evolution, most herpesviruses have learned to use small RNA molecules, so-called microRNAs, to reprogram their host cells to make new viruses. Prof. Dolken's research team has now been able to show for the first time that a viral microRNA acts as a master regulator to induce the reactivation of the virus. In the journal *Nature*, the researchers present the previously unknown cellular mechanism by which HHV-6 triggers its own awakening.

A small piece of genetic material made by the virus, called miR-aU14, acts like a switch to turn the virus on and off. This triggers a sequence where the body's immune system is no longer able to suppress the viruses, allowing them to replicate. How the cascade is set in motion still remains an open question, however.

Discovery could open up new treatments

Prof. Lars Dolken, author of the study, told The Telegraph: "Once the initial stress factor has triggered transcription of viral miR-aU14, it may promote virus reactivation by two different means. It either allows the reactivating virus to survive intrinsic host immune responses or it may further promote the activation of viral gene expression itself.”

In the research, published in the journal Nature, the researchers added that by targeting MiR-U14, they may be able to “provide new therapeutic options for preventing [other] herpes virus reactivation”.

They say that the virus “hijacked” the body’s normal processes and that now the key mechanism has been identified, it “should be readily druggable”.

"How herpes viruses reactivate from a dormant state is the central question in herpes virus research," Prof. Lars Dölken added. "If we understand this, we know how to intervene therapeutically."

Monkeypox – or cold sores?

A new health scare? No, say sexual health doctors.

Sexual health clinics are diagnosing monkey-pox: 550 cases in the UK as of 16th June. The people with these symptoms could have assumed it was a herpes simplex infection.

The UK Health Security Agency (UKHSA) states: "Anyone can get monkeypox, particularly if you have had close contact, including sexual contact, with an individual with symptoms. Currently most cases have been in men who are gay, bisexual, or have sex with men."

When such sexually active people get blisters, they are likely to assume it is herpes simplex and head to an STI clinic. You can see from the pictures that the blisters could easily be misdiagnosed, particularly if they are in the genital region.

What is monkeypox?

Monkeypox is a viral zoonotic disease, meaning that it can spread from animals to humans through contact with an affected animal. It started moving from animals to people in central and west Africa, and it is now being spread between people and appearing all over the world - sometimes following travel from these regions, but sometimes without any obvious route.

People with monkeypox are infectious while they have symptoms (normally for between two and four weeks). It is caught through physical contact with someone who has symptoms. The rash, bodily fluids (such as fluid, pus or blood from skin lesions) and scabs are particularly infectious. Clothing, bedding, towels or utensils/dishes that have been contaminated with the virus can also infect others. It is not clear whether people who do not have symptoms can spread it.

Ulcers, lesions or sores in the mouth can also be infectious, meaning the virus can spread through saliva. People who closely interact with someone who is infectious, such as health workers, household members and sexual partners are therefore at greater risk.

Symptoms

After the ‘usual flu-like symptoms’ lesions will appear, ranging from a few to several thousand. The rash tends to be concentrated on the face, palms of the hands and soles of the feet. They can also be found on the mouth, genitals and eyes.

Treatment and prevention

No specific medication is used – just treating the symptoms and alleviating discomfort. If a person is severely ill, they may be given treatments originally developed to treat smallpox, such as tecovirimat (TPOXX).

The smallpox vaccine that people over 40 will have had as children is somewhat protective against monkeypox. This vaccination programme ended in 1980.

The original smallpox vaccines are no longer available to the public. WHO is working with the manufacturer to improve access to a newer vaccine that was developed for smallpox (MVA-BN, also known as Imvamune, Imvanex or Jynneos) which was approved in 2019 for use in preventing monkeypox, but it is not yet widely available. Some laboratory personnel or health workers may have been vaccinated with these more recent smallpox vaccines.

Bottomline: It is not yet something that is an epidemic, and as it needs ‘close contact’ (sex?) to be transmitted, it will not reach COVID levels. However, people who are having a lot of sexual partners should be aware of this virus and act accordingly.

EBDT – an improved formula?

You may remember members were invited to take part in a trial for a new formula from Vimuneco, a Swiss manufacturer of natural products.

The powder trial we ran in 2020 found that the product was difficult to take, and that overall there was not a great difference between those who took the real thing and those who were assigned to the placebo arm of the trial.

New formula

The new product is a liquid, containing vitamin C, vitamin E and also various important peptides. Peptides are strings of amino acids, which are the "building blocks" of proteins. Your body makes peptides – which are the used to build the proteins you need for the constant rebuilding of bone, muscle etc. which goes on all the time.

Lab-made peptides can mimic some of those found in your body. They may be used in medications for conditions ranging from diabetes to multiple sclerosis, so the idea of using them against herpes viruses is logical.

The participants

86 people were recruited via SPHERE and also on various Facebook pages, as well as in
Switzerland and the Netherlands where Dr Moudon works.

Volunteers were given ampoules to take on a weekly basis: 68 had the EBDT liquid and 18 were given a placebo version (that does not contain any of the ‘useful’ ingredients).
The participants varied from 24 to 72 years, with 70 females and only 12 males.

Dr Moudon asked a series of questions:

Where do your symptoms appear? (Answers can add up to more than the number of people since they can select several answers as separate items.)

68 on genitals/buttocks, 28 on face, 4 mentioned eyes, 2 other.

What triggers recurrences?

Stress 44, fatigue/tiredness 37, ill health 12, weather 3.

Are you using antivirals? About one in five say that the antivirals are 'not effective' for them.

Placebo: 28% were taking antivirals (i.e. 5) and 4 said they are effective, 1 not.
EBDT product: 40% were taking antivirals (27) and 23 said they are effective, 4 not.

Regarding overall health statistics of the participants: nearly one third were overweight or obese; mostly they reported a medium or high level of stress and fatigue. However, sleep quality and bowel health were reported as quite good. Very few said they were doing much 'sport' activity.

Not many people reported any overall 'immunity problems' and there were few with 'co-morbidities' (other serious illnesses).

First results

Participants have finished the course of treatment and have completed weekly reports.

The researchers were expecting/hoping that the volunteers would have recurrences during the treatment because this is a good sign that the body is reacting to the ampoules. And it was found that they did.

Some people who have had breakouts since the end of the trial have taken an extra ampoule that they were all given to have in reserve. At three months and six months after the trial, they will be asked how they are doing. We are waiting till then for the full analysis.

So far, there is no dramatic difference between the two groups, but:

People who were in better health before the trial began, responded better to the EBDT. This is very interesting as no previous complementary trial we have been involved with has asked people about their general health. So, take on board the information that you will react better to EBDT (and perhaps other treatments) if you are, in general, healthier!

People who had symptoms, and in particular bad symptoms, in the first weeks of the trial were more pleased with it at the end. This is explained by the idea that your body is reacting to the introduction of these peptides and therefore creating the result desired.

Herpesvirus and neurological symptoms in patients with severe coronavirus disease

Another study that mentions 'herpes' - and again it is ***not 'our herpes'****:*

A study in Brazil looked at the prevalence of humanherpes virus in patients with COVID-19 to determine if co-infection is associated with poorer outcomes and neurological symptoms.

53 hospitalised patients with COVID-19 were checked for humanherpes viruses. Eight in ten of the patients had at least one of the possible 8 viruses they tested for, with some people having 4 of them active at once.

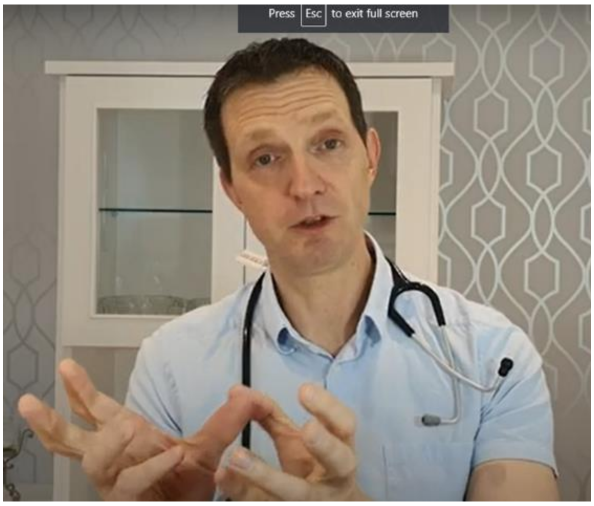
The research established that there was no direct link between the type of herpes virus (cold sore, chickenpox, glandular fever, etc.) the patient had and the severity of their COVID-19 illness. However, a quarter of them (26.4%) had central nervous system-associated neurological symptoms as well as active symptoms of one of the HHV.

It shows that all humanherpes viruses share the same characteristic: when you are unwell, they appear and bother you more...

Check out our new YouTube video:

Herpes Facts – What doctors should tell patients

Chickenpox vaccination stopped herpes simplex episodes for a Reading woman



Dr Bret Palmer, at Reading Hospital’s Florey Unit, has been looking at the use of chickenpox vaccines as a potential treatment for herpes simplex ever since reading about the trial by Dr Jacqueline LeGoaster in France. She reported success with this for her patients. (See *Sphere* 27/2, Oct. 2012).

Dr Palmer has just had a report published in the BMJ (British Medical Journal) about a patient of his who bought two doses of the Varivax injection at a local private health clinic (two months apart). She went from having an average of two recurrences a month to being free of outbreaks for 7 months – which is when the report was written.

Dr Palmer was taking blood samples from her during this time. The level of her antibodies to chickenpox went up dramatically after the first dose, and was still more than double the original level at the end of the project.

He suggests that the vaccine increases overall cytokines which boost the immune response to all viruses.

Dr Palmer has a range of You Tube videos, including a new one all about this case: https://youtube.com/watch?v=v-vRCq6GVJg

Justin Bieber makes Ramsay Hunt famous - *by Cameron Poole*

It is safe to say that more people have heard of Justin Bieber than they have Ramsay Hunt.

The Canadian pop idol made news recently when he developed Ramsay Hunt Syndrome, which is an acute form of shingles reactivation on one side of the face causing palsy (the old medical term for paralysis) in that area. He pulls faces and the right side of his face remains still… (See below)

In appearance it is similar to the effects of a stroke but it is not damage in the brain. It is damage to the facial nerve and is caused by the varicella-zoster virus (Herpes type 3) – *herpes varicella* and *herpes zoster* being the medical names for chickenpox and shingles, respectively.

Bell's palsy causes similar symptoms and is difficult to distinguish from Ramsay Hunt syndrome. The cause of Bell's palsy is not yet clear, however there is *some* evidence to suggest a link to herpes simplex. It affects about 20 in 100,000 around the world.

Untreated, the prognosis for Ramsay Hunt syndrome is much worse than for Bell's palsy with well over 50% suffering from permanent residual weakness and some having a permanently complete paralysis on one side of the face. Early treatment with plenty of antivirals lowers the risk of a bad outcome.

However, Ramsay Hunt syndrome is rare, especially for someone in their twenties (Justin Bieber is 28) and has an incidence of only 5 in 100,000 people per year.

So, who was Ramsay Hunt?

James Ramsay Hunt (1872-1937) was a famous neurologist who first documented the condition.

Shingles as a result of COVID-19 too

Medical reports are full of case histories of bad cases of shingles following COVID. Again, this is not something the population needs to be worried by. Nearly everyone has had chickenpox at some time. Therefore, we can all develop shingles at some time. (Shingles is the name given to a recurrence of chickenpox.)

Like herpes simplex, herpes zoster (the scientific name for shingles) tends to appear when a person is run down, unwell, exhausted, etc. So, it is natural that a bout of COVID-19 is a likely trigger.

The fact that these cases are rare enough to be published in the medical press shows that this is not of concern to the public.

Older people need their Zostavax or Shingrix jabs

Just because you've had your COVID vaccines, don't think you are done!

People 70-79 should get the anti-shingles vaccine – free from their GP. People under that age should encourage their elders to be vaccinated with Zostavax!

As we reported in the last magazine: Zostavax is the standard vaccine, but for people with a compromised immunity there's the double-dose Shingrix. So there's no excuse to duck it. And if/when you meet someone who is suffering from shingles, you will be so glad you are vaccinated.

STIs Can Be Fine. There's Even One That's Good.

Science writer Rachel Feltman on the misunderstood viruses and bacteria:

Sexually transmitted infections aren't some special class of hell-viruses, contends Rachel Feltman, the executive editor of Popular Science, and the author of *Been There, Done That: A Rousing History of Sex*. Her book covers everything from why bats have oral sex to Cleopatra's (rumoured!) masturbation habits.

We have a weird line in the sand between things that are sexually transmitted, and then stuff you don't have to feel bad about catching. We really think of STIs as being ickier than other infections. But sex is just one very efficient means of disease transmission.

Having sex is a great way to get COVID! Anything that you can get from saliva or rubbing your skin on each other, you do those things during sex.

No one should ever feel ashamed about anything they catch. But we have all of this unnecessary weight around STIs. The pictures that are used to show what a herpes outbreak looks like are taken from herpes outbreaks in people who had full blown AIDS. Like any infection when you’re immunocompromised, of course you could have the worst possible symptoms.

The way we talk about STIs is really based on these nightmare scenarios in terms of what symptoms might be – which makes having one seem like a really terrible club you didn’t want to join.

In fact, we are full of viruses. We have tons of them inside us all the time. A lot of them are benign, and some of them are important the same way some bacteria are important.

For instance, bacteriophage is a type of virus that infects bacteria. In fact, the word "bacteriophage" literally means "bacteria eater," because bacteriophages destroy their host cells. Thus clearing the bacteria from our bodies. One study suggests that people absorb up to 30 billion phages every day through their intestines.

We know of at least one helpful virus in humans which is passed on during sex. It’s a relative of hepatitis called GBV-C. It’s really common, especially in certain parts of the world. And in most people, it seems to just float around like many other aspects of our microbiome. But research has shown that if people who carry this virus are exposed to HIV, they may have better outcomes. It seems to have some kind of protective effect.

This isn’t a reason to go have a bunch of unprotected sex and try to collect a bunch of STIs like they’re Pokemon. But I think it does really serve as a reminder that STIs are just microbes. The reason we switched from calling them “sexually transmitted diseases” to “sexually transmitted infections” is that there are lots of things you pass around sexually that don’t cause symptoms, i.e. don’t cause disease. For example, we know a lot of people have herpes and it’s usually asymptomatic.

STIs of course can be dangerous, can be deadly. Like any other virus or bacterial infection, something new could show up at any time. That’s why safe sex is so important, because it’s not just about the STIs we know about, but the ones we don’t know about yet.

On the other hand, I think we should stop thinking about them as some other category of infection that is different from everything else humans pass around.

A live BASHH conference

Marian was invited to the attend the annual conference of BASHH (British Association of Sexual Health and HIV) in Sheffield. At last, after several years of this conference being online, about 380 delegates gathered in Cutler's Hall to attend lectures from 8 am till 5.30, to read the scientific posters - and, of course, chat and catch up during the breaks. More were booked to attend, but train strikes and COVID meant that a proportion didn't come.

A talk to 300+ sexual health professionals

The conference is a three-day event and on day two (the best day as some people leave before day 3) there was a 'patient session.' Five 10-minute sessions were given by representatives of charities or organisations on such things as 'teaching sexual pleasure as part of RSHE' and 'taking account of the needs of LBGTQ+ people' and 'have you considered whether people with various disabilities can access your sexual health clinic?'

Marian's 10-minute section was 'an interview with a HVA helpliner,' (Ruth Mayo). Because of the train strike, Ruth had to join the talk virtually and they conversed (with an annoying time lapse) over the ether. You can see the slides and the script that they wrote out in preparation. Of course, they didn't actually read that out, they wrote it while preparing: https://herpes.org.uk/37-1-supplement-bashh-conference-text/

In outline the talk covered:

- You have to de-Google the callers/ patients.
- Ask what *in particular* is worrying them
- Use normal language like you would for cold sores on the face.
- Explain why *incurable* is irrelevant with other examples: chickenpox or thrush.
- Be non-judgmental, don't dramatize it, like "You don't want *that*" "I'm sorry I've got terrible news" "It's one of the worst."

- Help overcome shame by explaining how common it is – with data.
- Childbirth is fine even with a recurrence.
- Treatment is not essential (this helps normalise herpes simplex) and mention lidocaine 5% pain relief.
- Transmission – condoms are very helpful when men have it/ women are half as likely to infect men/ Prof L. Corey has said "Persons who are not diagnosed are more apt to transmit that those with known diagnosis."
- And that's all there is time for, so invite me to give the one hour 'Helping you to help your patients' session at your clinic.

Lots of people told Marian afterwards how good the talk had been and/or how much they'd enjoyed it.

Our new project

Marian talked to clinicians, particularly the younger ones who might be keen to get a project going, about running a study. It would be to find out how many people who are newly diagnosed continue to have pain on a daily basis; how long this pain lasts; whether antiviral treatment improves the problem. She has not found any previous research about this (but see Poster 2 below)

A project is advanced

Keen readers will remember that we have started a project to change the status of aciclovir from being a prescription treatment to being one that you can buy at a pharmacy. Marian handed out 50 leaflets with a QR code for an online survey where, so far, the only doctor who has said 'No' explained: 'Because we give out as much aciclovir as the patient needs - so there is no need for them to buy it.' (For those of you in North London, this is at Homerton Hospital.) Marian also got the President of BASHH on our side too - important because getting the backing of this organisation would be very helpful.

Guides and talk

Marian was also promoting our Guide, hoping more clinics would buy supplies to hand out to their patients. She was also advertising the talk 'Helping you to Help your Patients with Herpes' for the clinic staff.

Approaching doctors, health advisers and nurses at the event raises their awareness of the charity and how we can help people... Many already know about us and say they give all their new patients our contact details, so the HVA is part of the NHS's 'patient pathway' but we don't get any government funding!

Posters

A prominent part of all conferences are the "posters". These are single page reports of research conducted around the country. There were just a few on herpes simplex:

1) Mystery shopper around the country: over 200 clinics were phoned up to three times asking for a 'herpes appointment.' It was found that only 72% were able to offer an appointment within two days, which is what BASHH guidelines ask for. A shocking 15% could not offer an appointment at all, others offered appointments at three, four or five days… And as you know, to get a diagnosis, it is important to be seen before the sores heal, so this is unacceptable. – *Report from Royal Hants Hospital.*

2) The description of two cases of patients with serious pain problems due to inflammation in the affected nerve. It is called Elsberg Syndrome. It is not the same as the prodromes that we all feel but involves inflammation in the spine. One of the cases came back to the clinic two weeks after being diagnosed with difficulty walking, serious constipation and even inability to urinate. She was given high doses of antivirals for 14 days. On follow-up two months later, she had almost completely recovered. Only some residual numbness in buttock and lower back. – *Report from University Hospital Plymouth.*

3) A study of patients diagnosed on a Monday or Tuesday. They have probably 'suffered' for longer than average, because of the weekend, before getting seen, so they need to be offered more treatment. – *Report from Royal Hants Hospital*

The Gala Dinner – 1920s

For an extra £30 payment, delegates could go to the Gala Dinner, with dancing to a live band. Marian paid up.

As you can see from the photo of Marian with Dr Kez Spelman from Essex Sexual Health, it had a 1920s theme (since the original Medical Society for the Study of Venereal Diseases was formed in 1922). Lots of people had been very inventive. Three of our charity's patrons were there in dinner jackets and bow ties: Colm, Raj and Simon – see box on back cover for their full titles.

Marian sat between Dr Naomi Sutton (https://www.savinglivesuk.com/drnaomi-thesexclinic/) – in full 1920 flapper outfit - who said she thinks what the HVA does is marvellous, and Dr Michael Rayment. He's the doctor in charge of the London site being used for the vaccine study, see cover article. The chat was more about dogs and houses, and favourite karaoke songs, rather than medicine!

The HVA's meeting

Marian stayed on after the end of the conference to host a meeting in Sheffield. See page 20. Despite the train strikes on 21st and 23rd - she was lucky enough on June 22nd to get the 21.43 train back to London.

What exactly do 'Support Groups' support?

It isn't just stigma obstructing the path to rational thinking

- by Cameron Poole

1: Old fashioned stigma and present-day media

The stigma for herpes simplex is alive and well and, despite all our work, shows no sign of abating any time soon. For every individual our little charity psychologically 'cures', there are many more newly diagnosed patients who subsequently wander down the Google rabbit hole into a minefield of negativity and doom on the subject of herpes – and not all of it herpes simplex (the types 1 & 2 which became so infamous when marketed as a modern day leprosy over four decades ago) - but often one of the seven other lesser known kinds – see previous articles in this *SPHERE.*

For example, type 4 (glandular fever) is linked to a form of cancer. Type 8 (Karposi's Sarcoma) is linked to AIDS but headlines won't be concerned with such details as 'type'. To the average person, be they a journalist or a reader, herpes is herpes and even if the article clarifies a distinct disassociation with cold sores, many won't read past the headline. This isn't necessarily a deliberate ploy to perpetuate the stigma, the journalist just wants a scary story – which is warranted by public demand.

As a result, herpes remains a taboo subject while other forms of stigma are being tackled or are eroding over time. Tattoos, for example, are now more accepted than they ever were. Racism, quite rightly, is now frowned upon - reversing the ridiculous stigma of skin colour - a rare step in the right direction for Western society.

But ALL stigma is ridiculous and although it is now reprehensible to discriminate someone for the colour of their skin or for having decorated their skin, to have this very common skin condition is still considered fair game because (insert British gasp) it can involve 'the genitals'. A stand-up comic can get away with a herpes joke because nobody will stand up and tell them they can't, yet they will unknowingly be alienating approximately a third of their audience when making a herpes joke.

2: Language

How we speak about it is another issue. 'Having' herpes (type 1 or 2, facially or genitally) is perfectly normal but we rarely mention it. The lucky majority of people who can get run down or stressed without the virus reactivating do not consider themselves to 'have' herpes - and why would they? Out of sight out of mind. We don't consider ourselves as 'having chickenpox' or 'having thrush' once the condition has passed, even though there is no cure for either and it could recur at any time.

The language around herpes is wrong and confusing. To have herpes *should* sound no more permanent than having a cold sore (exactly the same thing) but the word 'cold sore' hasn't been demonised. It is associated with the mouth, not the genital area which is still considered taboo despite our best efforts to be as sexually mature and as liberated as our fellow Europeans, we're not. We're behind them, which has provided the stigma with the leg up it needed to still be effective today when most countries in the world consider herpes simplex a mere annoyance and don't focus on words like contagious or incurable any more than they would for other harmless come-and-go conditions, for which there are yet no cures to rid them from the body altogether.

3: Medical brilliance without people skills

Fortunately, most doctors and nurses are well informed, kind and understanding. Although not experts on herpes, they will know enough to provide ample reassurance with their aciclovir prescription. However, many don’t. Doctors and nurses are only human and therefore not perfect. Some are medically brilliant but have lamentable people skills.

Shockingly, there have been instances where a doctor or nurse will tell a patient to use condoms for the rest of their lives rather than admit they don’t know the answer to a particular question on the subject of transmission. It is ‘safer’ for the medical professional to avoid potential repercussions by giving a patient a worst-case scenario, rather than give them reassuring facts that would help the patient to feel normal. Naturally, most nurses are compassionate by default but once in a while you’ll get one who is having a bad week or who may have a very outdated and dim personal view on premarital sex and is unable to leave it at home.

4: Blogging from hell

Next up, we have blogs or forums on the internet written by those who believe their life is over following a diagnosis and feel the need to share their misery with the world on a blog or forum. Six months later when they meet the man or the woman of their dreams, they don’t think to locate and delete that blog post they wrote when they were suicidal following their diagnosis - so it stays online for people to stumble across when they too are newly diagnosed. This cements the ridiculous idea that getting herpes is life-changing in the worst possible way.

5: And finally, the herpes support groups

So called ’support groups’ are often started with the noblest of intentions, but rather than normalise herpes simplex as an almost inevitable skin condition which some notice and some don't, it provides reassurance by embracing a leper mentality – like a secret society penned in by mutual misery, sharing tales of rejection and woe - rather than ‘fixing’ people, helping them to reject the stigma and move on with their lives with a well-informed and positive outlook.

Despite this negative energy pool, many find comfort and community with such support groups – but then many find this sort of feeling by joining an underground religion or cult, it doesn’t make it a necessity.

Some will find reassurance from stories of hope and consolation or reassuring facts and statistics but there will always be some who find comfort in communal misery, which is their choice, but it will only further the feelings of isolation for many who discover these groups.

Below is a quote from a former support group member who saw these sites for what they are.

> ***‘There is very little light. I'm all about the light.’***
>
> *‘To read over and over that I will make someone else sick if they touch me, was crushing. I didn't find anything positive scrolling hour after hour on the internet. When I initially joined, it was validation that everything I was feeling was the same as everyone. Post after post of how depressed people were. Post after post of changing transmission rates. Post after post of newly diagnosed people who believed life was over and more people in comments purely supporting the fears.*
>
> *I had started to feel good about dating again. Then I realised that these people are single because the dating world sucks, not because of their herpes!! But is it easier to play victim and blame herpes because of the support pages and combined depressive bullshit others feed each other.*
>
> *Stay away from some online support groups. Get what you need and then leave. Your [the HVA’s] advice and info on your page is clear, concise and without the bullshit. I am not sure the support groups will change. It does give people a safe space to vent be sad and angry but it’s all being projected in a whirlpool of doom and gloom. There is very little light. I'm all about the light. I'm all about mind blowing sex and intimacy and moving forward.’*

Meet-ups? Why not have one in your area? - by Marian Nicholson

Now that the lockdown is over, why not have a meet-up of some sort in your area? As you may know, we have monthly chats in the Atrium of the President Hotel, near Russell Square tube station on the first Saturday of the month form 3-6 pm. See details on http://herpes.org.uk/events/

For the events below, we have only invited members of HVA. You can ask us to put the details of your event onto Facebook pages for you if you want to have a larger group.

Join me in Glasgow on Monday 4th July, 6.30 pm – already 4 people have said they are coming.

I have chosen this place right by the Central Station. From 6.30 to 8.30 or longer if we are having a good time! I will put the usual *SPHERE* sign on the table, and if anyone asks, I say "a philosophy group." Here's the address:

Aria Café/Bar
37 Hope Street
Glasgow G2 6AE

Recent events outside London

Dublin: I invited 10 Irish members to meet me and two came. One more would have joined us, but the day didn't suit her. The two ladies who chatted with me, and each other, were hugely appreciative.

In **Sheffield**, I invited 28 members and although several said they would come, just one lady did show up and we had a great chinwag over halves of cider. She had told a new partner just three days before, he'd been fine about it – and during our couple of hours together, she received a message arranging a date for the coming weekend!

Why not have an event in your area? Choose the kind of event you would like: café, pub (on a quiet night), bowling alley, etc. Or even a picnic/barbeque while the weather is good? Send the details to info@hva.org,uk and we will send out the invitation for you. We'll try and ensure someone comes who has 'all the answers.' We have lots of experience in running these things, so email or phone 020 7607 9661 to discuss your ideas.

The cure is *correct* information!

NEXT EVENT
July 23rd 2022
via Zoom
from
10:30 - 17:00

Attendance £15 via donation.

Email info@hva.org.uk for details or call 020 7607 9661

We recommend calling us first if you haven't already.

Hosted by Marian Nicholson
with Cameron Poole, Nigel Scott and a guest speaker.

PREPARE TO TELL A PARTNER | RESTORE YOUR CONFIDENCE | VANQUISH THE STIGMA

The Assurance Day: next one 23rd July

People sometimes say *"I don't need to come to the Assurance Day as I don't have any potential partner in view."* But perhaps you can recognise that until such time as you feel the inner assurance that you will be confident (well better than now) when you meet someone, you may be subconsciously avoiding the chance of meeting someone.

Come along to the next one on 23rd July? Email us at info@hva.org.uk, phone with a card, or make a £15 'donation' for your place at the event: https://herpes.org.uk/shop/

This will probably be 5 sessions on **Zoom**, but if all the people attending would like to come to the office, we can do it in 'real life' (much more fun).

Overall, the scores for these events average 4¾ (on a 1-5 scale). These are comments following our Assurance Day:

What have you gained from today?

- *So much!*
- *Facts about genital herpes - I learnt what matters and what doesn't!*
- *I learnt how I should not feel like I hold a responsibility for the health of every person I date. It is their responsibility too. They could catch this virus without me! (Or may already have it!)*

What was most valuable?

*The end session on **why, where and how** to tell a partner was particularly useful. It delved deeper into the different parts of 'telling' someone and also highlighted how different circumstances call for different ways of telling and may also mean that you don't have to tell someone.*

What message would you give to someone thinking of attending?

This event really will change the way you perceive this common cold sore virus. It will challenge any feelings of self-disgust, low self-worth or hopelessness you may feel as a result of being diagnosed. It will belittle that annoying demon on your shoulder, that tries to tell you that your dating life is over and that you have to forever live ashamed and alone.'

This workshop will provide you with exactly what YOU need. Whether you were diagnosed a month ago and now just need to get the facts straight, or whether you have had it many years and need to stop suffering in silence - this workshop will help you!

You will meet amazing people of all ages and all backgrounds and with so many different, and yet highly relatable stories. You will never forget these individuals because in just a few hours, you'll become a team who share your 'secret'.

Has your perception of herpes simplex changed because of today?

It definitely has. This [day] has dismantled the stigma and forced me to see the truth - that actually nothing in my life has changed! It has only changed because I thought it had to! A full 3 and a half years of being disgusted with myself has all been a complete misunderstanding... I will not live in regret as I cannot get those years back, but I will now live my life the way I have always wanted to live it. With confidence!

Do you feel you fully understand how the hype created the "herpes stigma" – so that you can change how you think about it?

Yes, Nigel's session on stigma was very interesting as we learnt how and why the herpes stigma exists. It has made me feel very passionate about trying to de-stigmatise all sexual health matters by simply talking about them! If we were able to speak about sexual health in the way we are now able to speak about mental health then perhaps this charity and this workshop and all this suffering would not even exist?!

See details at the end of this journal for more information on the next Assurance Day on 23rd July.

You couldn't make it up! Says Marian – see more comments at the end:

Insurer Told to Pay $5.2 Million to Woman Who Caught STD In A Car (but again, this is not about herpes) by Jay Croft

June 8, 2022 - A Missouri lawsuit adds a new twist to the kind of "bodily harm" in a car that's covered by insurance.

This week, a three-judge panel of the state's Court of Appeals affirmed a $5.2 million settlement by a woman who caught a sexually transmitted disease from her former boyfriend in his car. (But see footnote)

The woman, identified in court documents as MO, said she contracted HPV, human papillomavirus, warts, from her boyfriend.

An arbitrator had found in May 2021 that the in-car sex had "directly caused, or directly contributed to cause" the STD transmission. The man was found liable. The woman was awarded $5.2 million to be paid by GEICO, which insured the man's vehicle.

GEICO has filed for the award to be overturned, alleging it had been denied due process and that the arbitration deal was unenforceable.

Court documents show that GEICO claimed the man's policy covered only injuries that came "out of the ownership, maintenance or use of the … auto" and that the woman's "injuries arose from an intervening cause – namely, her failure to prevent transmission of STDs by having unprotected sex."

The state appellate panel ruled July 7 that the lower court made no mistake in the case and upheld the decision.

The Kansas City Star reported that one of the judges concurred but said GEICO was offered "no meaningful opportunity to participate" in the lawsuit and existing law "relegate[es] the insurer to the status of a bystander."

"This case presents novel and potentially important issues about whether an insurance carrier can be held liable under such policies for the consequences of two adults voluntarily having unprotected sex in the insured's automobile," noted U.S. Magistrate Judge Angel D. Mitchell in court documents. "Interpretation of these policies could have far-reaching implications for other policies with similar terms."

Our comments: **If you look at the Court papers, it becomes stupider.** https://www.govinfo.gov/content/pkg/USCOURTS-mowd-4_22-cv-00082/pdf/USCOURTS-mowd-4_22-cv-00082-1.pdf They had sex in places other than the car. She had sex with other people during this time. His defence was so feeble, that the insurance company is trying to get the issue reopened, suggesting that they are in it together to defraud the company!

MY STORY

From him or…?

"I think I have herpes simplex…"

The clinic doctor looked at me steadily. *"What makes you think that?"* I had been googling my symptoms in the last few days and nothing else seemed to fit.

It had been a pretty traumatic year for me, my Dad had died in January after a short illness. In July, the relationship with my partner of 18 years finally fell apart after a long decline and various attempts at 'starting again' (him) or 'learning a new way of being together' (me).

I moved out of my lovely cottage set in rolling Welsh countryside as I could not afford it and rented a small flat in town. My heart being in the country, I found town life almost unbearable. I felt squashed and enclosed and totally stressed…

Salvation came along in the form of a kind and gentle man I shall call Mike (not his real name). I had known Mike as a friend for a few years. We began a relationship. It was wonderful to feel a real passion for someone, something I had never really felt before.

A few months later, I felt like I was getting flu: a bad headache that lasted a couple of days was followed by dreadful pains down my legs and feet. These lasted almost a week. I could hardly walk. Then came very painful small sores around my genitals. Mike mentioned that he had had little spots on his penis years ago… So I decided to make an appointment at the local clinic. Obviously, the health service being what it is now, I was told I could have an appointment in two weeks. I called the HVA helpline, and it was suggested that I talk to a health adviser (not the receptionist) and explain. She got me in to be seen next day. *"It looks like herpes. Here are some pills. We'll know for sure when the test results are in,"* said the doctor.

Herpes? Is that what Mike's spots were?

I asked the health advisor who said the most common situation is that a person catches it from the person they are having sex with, but that it could have been in me for years before I met Mike… My thought was that I must have just caught it recently, because I'd been way more stressed before than I was now.

After the tests, I had to wait a couple of weeks for the results. They were all negative, including the herpes simplex one. Two weeks later I went back to the clinic to discuss my contraception and they told me the herpes simplex test had just shown positive with type 1. What??? Who had been keeping my results on their desk…? Anyway, I came away with a leaflet and I phoned the HVA helpline for advice. They confirmed that it was likely to be caught from Mike and that it was most likely that he was unaware he had it – because most people have almost no symptoms! No one takes 'a little spot' to the doctor for diagnosis. They also suggested it could have been from Mike's face, via oral sex, but I discounted that as we'd not done that – yet.

Well, my experience of having the virus was pretty bad. I was having constant recurrences, about 3 weeks apart, sometimes only a couple of days between the sores healing and the next episode beginning. I started taking lysine and Elagen, then Olive Leaf Extract as well. By the summer things were still just as bad so my doctor prescribed aciclovir 2 x 400 mg daily. This helped a lot but I'm really not keen on taking suppressive medicine so in the autumn I decided to stop. My symptoms returned as before.

I also tried Duragel (a herbal lotion), vitamin E, icepacks... Nothing really helped although bergamot essential oil diluted in a carrier oil e.g. sweet almond oil (not baby oil) had some success in stopping sores from appearing.

Confirmation at last

Just before Christmas, Mike went to the STI clinic as a sore like the one he'd had way back had appeared again. As I write this, we are waiting for the results of his herpes simplex test (everything else being negative). If it does prove to be herpes simplex, then great! No more worries about transmission – we'll both have the same thing.

Despite my recurrences, there's always aciclovir as a last resort but in the meantime, I've found Mike who's a wonderful man, the love of my life, oh and by the way, I've moved back to a nice cottage in the country. Life just doesn't get better than that!

Pam

Next issue October 1st

Meetings: check out https://herpes.org.uk/events

First Saturday of the month at the Atrium London from 3-6 pm
First Sunday of the month on Zoom from 10 to noon…

One meeting, mid-month, mid-week from 6.30 till 8.30 on Zoom.

Join MARIAN in GLASGOW – 4th July, from 6.30 to 8.30 (or later?) at the Aria Café/Bar
37 Hope Street
Glasgow
G2 6AE

ASSURANCE DAY – 23 July - AGENDA: This is what we do…

5 sessions during Sunday… This is the on-line version of day - **unless everyone who signs up for it agrees they'd like to come to London**. It has been attended (and appreciated) by hundreds of our members.

You get 3 experts, 4 hours of specifically crafted content, plenty of time for questions, 4 opportunities to virtually mingle with other members. This "day" will give you the confidence you need. We hope to see you there.

Send email to info@hva.org.uk or phone us on 020 7607 9661. It will cost £15 online (normally £39, in London, in person).

This is the provisional timetable for the day - but I have been warned by experienced Zoomers that on the day, **timings might change.**

10.30-11.30	**Marian explains** how the virus works, how common it is and how treatment works.
11.30-11.45	Open session -chat with others - go and get your tea/walk the dog - or one-to-one/small group (in a breakout room?) or ask Marian about your symptoms, treatment, etc.
11.45-12.45	**Nigel explains**: "Why we think it matters, anyway" Knowledge is power!
12.45 -1.30	Lunch break – open session – chat etc as above.

1.30 – 2.30 **Cameron:** how I talked about this with my partners (personal story), with discussion/ questions about this

2.30-3.00 Open session, chat with others - and all the options above

3.00-4.00 **When to? Where to? How to?** We discuss disclosure in more detail.

4.00-4.30 Open session, chat with others - and all the options above

4.30-5.30 **Practice explaining to a 'partner'.** You will be assigned a role and (depending on numbers) put into a Breakout Room of three people so each can take a turn. (Well, that's the idea, it often turns into a chat.) This is a full day's event which we know will give you the facts, the ideas and most importantly, the confidence about 'how to tell someone I have herpes'.

See page 22 for comments from people who've attended.

Sphere
The Herpes Viruses Association | QUARTERLY JOURNAL

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