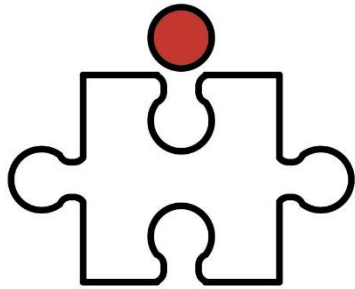


# Genital 'cold sores': helping you to help your clients



Herpes Viruses Association  
41 North Road  
London N7 9DP

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

# Your speaker...

HVA charity registered in 1985

Marian Nicholson MBE:

- volunteer since 1985
- director of HVA from 1995
- member of the British Association of Sexual Health and HIV (BASHH) “HSV special interest group” since 2004

# What we do – for public/professionals

***Herpes simplex – the guide***: distributed via GUM clinics

**Website**: over 350,000 visits yearly – rising...

**6 posters**: accepted for BASHH, ASTDA and BASHH/BHIVA conferences

**Talk**: IUSTI conference, by Zoom, 2020

**Talks**: BASHH, IUSTI & BAD conferences

**Trials**: 9 herbs trials found 3 useful herbal products

**For the public:**

- **Two Zoom sessions** per month
- **One drop-in session** in London per month
- **Answer emails/helpline** calls (for as long as they wish)

# Today's programme

- About the virus – 8 slides (including the latest from the BASHH guideline, 2024 – and the joint guidelines on childbirth by RCOG and BASHH)
- **What you can say to help the patient – and what they say to others...**
- Please put questions in the chat as we go...

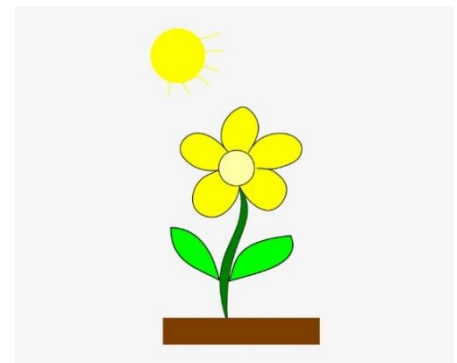
# Herpes simplex virus: very common

**At age 25, in UK about 70% carry at least one type** - mostly without symptoms.

Data from **Australia**: women aged 35-44 type 1 is 85%, and 22% type 2. Men are lower: 77% and 19%.\*

**Two virus types**: either type can be caught anywhere, but -

- Oral sex + cold sores = genital infection
- Type 2 recurs more frequently on the genitals. Type 1 more often on the face, much less genitally.
- Most people only catch one type.
- Each type gives partial protection against the other.



\* Cunningham AL, Taylor R, Taylor J, Marks C, Shaw J, Mindel A. Prevalence of infection with herpes simplex virus types 1 and 2 in Australia: a nationwide population based survey. *Sex Transm Infect* 2006;**82**:164-168  
doi:10.1136/sti.2005.016899

# What does the virus do?

**Often, nothing:** Only 1 in 3 who catch it has obvious symptoms that get diagnosed.

**Not dangerous.** “You get better *with or without* treatment, like flu.”

**It's normal.** Dr George Kinghorn, GU consultant in Sheffield stated: “... *to be infected with a herpes simplex virus is a state of normality...*”

**Some get symptoms only once.** Average is meaningless where range is 0-18! (Type 2 is 4.6, type 1 is 0.8 yearly.) Genetics play significant role.#

# Kriesel JD, Jones BB, Mastunami N, Patel MK, StPierre CA, Kurt-Jones EA, Finberg RW, Leppert M, Hobbs MR. C21orf91 Genotypes Correlate With Herpes Simplex Labialis (Cold Sore) Frequency: Description of a Cold Sore Susceptibility Gene. *J Infect Dis.* (2011) 204 (11): 1654-1662.

# Diagnosis

Diagnosis is only by swab test from the affected area – when there is something to swab!

Online, **patients can buy private blood tests**. These tests for HSV antibodies are unreliable.

1 in 10 positive results is wrong.  
Up to 30% false negatives.\*

Online: ‘urine test’ for HSV are bought by ‘worried well’  
HSV-1 result does not tell them if it is a genital or a facial infection.

A recurrence is on one side only. Can swap sides.

\* van Rooijen MS, Roest W, Hansen G, et al. Sex Transm Infect doi:10.1136/sextrans-2015-052213

# Transmission

**“Skin to skin contact, with the affected area, when the virus is active, with friction.”**

Skin to skin: not via towels, sheets, baths, swimming pools, toilets, or by touching one’s genitals and later touching someone else.

When it is a facial infection not via cutlery, food, make up, toothbrushes, etc.

The one exception is sex toys/hands: immediate person to person with warm wet pus...

Affected part: when it is facial, arms never have virus on them. When it is genital, face is never infectious.

When the virus is active: think cold sores! But see next slide.

With friction as the virus cannot dig, swim, move...

# Asymptomatic shedding

**Asymptomatic shedding:** the people taking part are not 'normal' – no controls. Studies are done with type 2. Type 1 is very much less active in the genital region.

The tests (NAATs) pick up low levels of virus – even viral particles – these are not infectious.

It happens mostly just before/after outbreak.

BASHH states:

It is most likely in first 6 months. It becomes less frequent: after 2 years it can be ignored as it has nearly stopped, unless the patient is having more than 6 outbreaks per year.

Since it 7 out of 10 sexually active people by age 25 are carriers, these others will shed too.

PCR tests show 1.3% adults shed type 1\* orally but we don't kiss through cling-film.

Reichart PA. Oral mucosal lesions in a representative cross-sectional study of aging Germans. Community Dent Oral Epidemiol 2000; 28: 390–398.

# More on transmission

**Some people notice first symptoms years after original infection so:**

- **It isn't necessarily caught from the most recent partner.**  
(‘Cheaters’ charter’?)



Partners with same type are highly unlikely to reinfect each other.

It's not spread around the body once the primary infection is over – though it can appear nearby, within the dermatome. (See slide 15)

# BASHH statement on condoms

Condoms are worth using, especially if carrier is male – don't say "Condoms won't help."

When the woman has the virus, then condoms do help – but not as much.

BASHH: "Condom use reduced per-act risk of transmission from men to women by 96% ( $P < .001$ ) and marginally from women to men by 65% ( $P = .060$ )."

(However, women are only one sixth as likely to infect men as the other way round.)

Using a condom as little as once in every three sexual acts has a measurable impact on reducing transmission.

# BASHH with the RCOG: Childbirth

BASHH and the Royal College of Obstetrics and Gynaecology: joint guideline on herpes simplex and childbirth, updated edition 2024.

If asked, you can reassure people:

- **Vaginal delivery even if recurrent lesions are present at term, this is safer than C-section.**
- Mums with cold sores kiss their new babies and there are no problems.
- Babies acquire 'maternal antibody' from month 7 onwards.
- Suppressive therapy (optional) from 32 weeks if patient is worried about lesions at term.
- Even if lesions were present during the birth, there is no need to keep a baby in hospital longer than any other baby ('normal post-natal care').

# What you/they say! Choose words carefully\* – it matters!

**Call it ‘cold sores.’** Helps to distance from the stigma of ‘herpes’.

**Don’t use the initials: HSV.** It is confused with HPV, HCV – or HIV.

**Avoid these medical terms:**

- **‘*attack*’** - that’s for heart attack or terrorist attack. Say episode, recurrence, symptoms, or flare-up.
- **‘*chronic*’** – that’s a synonym for serious
- **‘*disease*’** - that’s for “serious illness” only
- **‘*incurable*’** – is a synonym for fatal. In fact, this is cured by the immune system.
- **‘*meningitis*’** – that’s a (bacterial) infection that kills people
- **‘*sufferer*’** and **‘*victim*’** ...

\* O’Keeffe M, Michaleff ZA, Harris IA, Buchbinder R, Ferreira GE, Zadro JR, Traeger AC, Thomas R, Belton J, Darlow B, Maher CG. Public and patient perceptions of diagnostic labels for non-specific low back pain: a content analysis. Eur Spine J. 2022 Dec;31(12):3627-3639. doi: 10.1007/s00586-022-07365-x. Epub 2022 Oct 5. PMID: 36198841.

# Compare to other herpes viruses

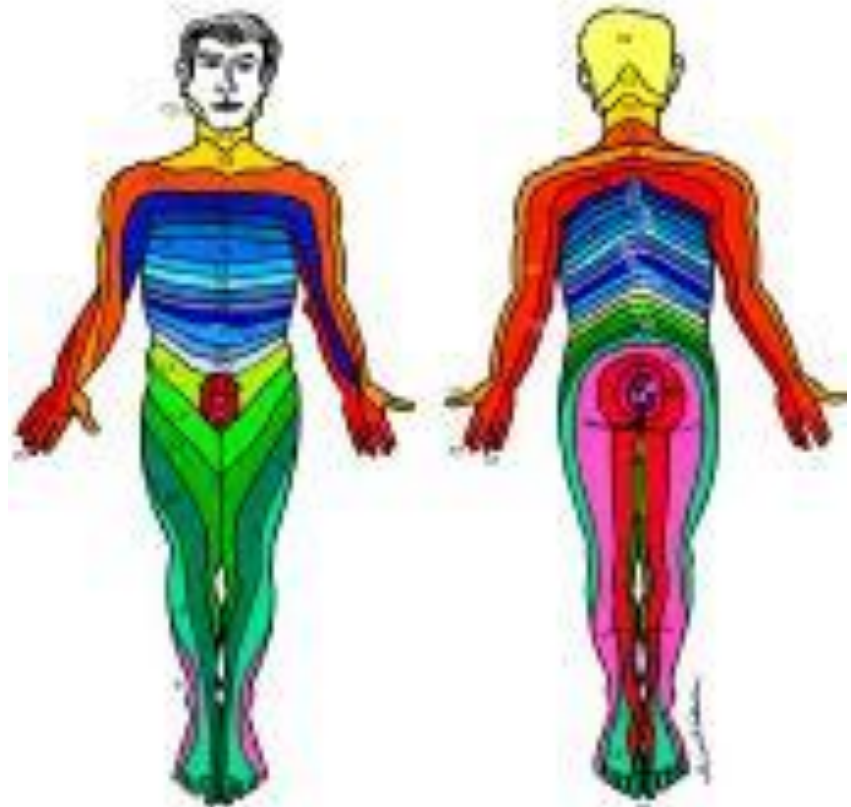
Compare to chickenpox (herpes varicella) and glandular fever (HHV5)

All 9 herpes viruses remain in the body, but we don't worry about that. See slide 26.

In fact: *“We have more virus, bacteria and fungal cells in our bodies than we have cells with our own DNA.”* (This combats any ‘sense of pollution/dirtiness’.)

# Dermatomes

Dermatomes: like  
“walking a dog through  
a bacon slicer” ...



46% of women and 19% of men  
report anal recurrences.

# Stigma

**What is stigma?** Briefly it is described as “slang or language used to separate people into us and others.” And I would add “to put them down/denigrate them.”

- *“I still feel ‘less than’, even though I’ve had it ages.”*

People who call our helpline recognise that it is not medically important but:

- *“I don’t mind having it, I would just die if I passed it on.”*
- *“It doesn’t matter while I’m with Sue, but if I caught it and we broke up, I just don’t want to have to deal with it in a future relationship.”*
- *“I can’t talk to my friends about it because it’s so stigmatised in the media and other places.”*



# Stigma causes suicide

Herpes simplex is 2<sup>nd</sup> most stigmatized STI, after HIV: US survey.<sup>[1]</sup>

Seth Stephens-Davidowitz, with a Google research tool, found that **before searching "suicide," the most common search was "depression" and next most common was "herpes."** <sup>[2]</sup>

There will have been suicides. We know of two in UK - but we cannot know how many. Mostly people so shamed by "herpes" do not put it on the suicide note.

[1] Neal TMS, Lichtenstein B, Brodsky SL. Clinical implications of stigma in HIV/AIDS and other sexually transmitted infections. Int J STD AIDS. 2010;21:158–160.]

[2] Seth Stephens-Davidowitz is the author of "Everybody Lies: Big Data, New Data, And What the Internet Can Tell Us About Who We Really Are."  
<https://podcast.clearerthinking.org/episode/034/seth-stephens-davidowitz-search-data-and-self-improvement>

# The 'herpes stigma' is new

Between 1974 and 1982, Abigail Van Buren, known as “Dear Abby” changed her advice. In 1974:

*“My medical experts inform me that herpes type 2 should to (repeat not) be classified as a venereal disease ... No need for you to be embarrassed.”*

In 1982: *“Sanitize linens/cutlery used by people with herpes.”* and contradicted a reader who said it was *“just like having a cold or the flu.”*

2002, US: between 1970 and 1985 it is estimated the prevalence of HSV-2 rose from 13.6% to 15.7% . Around this time, doctor visits for genital herpes increased tenfold - which was taken as evidence of an epidemic. With hindsight, in 2022, the increase in doctor visits seems like evidence of something else, including a rise in awareness due to drug ads in US media.

As a commentator for the New Republic wrote in 1982, *“If herpes did not exist, the Moral Majority would have had to invent it.”* Herpes was the perfect plot device for a society ambivalent about the sexual revolution.

# From Dr Des Maitland's presentation

## Herpes simplex – the 70s

Common and non-serious medical condition.

Symptom relief only.

No mention in medical textbooks.<sup>1</sup>

There was little to no shame or stigma associated with having genital herpes.<sup>2, 3</sup>

1. Obstetric and Gynaecological Nursing, Rosemary Bailey 1975 - word 'herpes' is not the index.
2. *Sexual Pollution: The Fall and Rise of Venereal Diseases*, Ivor Felstein, 1974 - word 'herpes' is not the index.
3. Mayou, R Psychological morbidity in a clinic for sexually transmitted disease. *British Journal of Venereal Disease*. (1975) **51**: 57

# From Dr Des Maitland's presentation/2

## Acyclovir discovered: hype is created

- 1974 Acyclovir first created from Caribbean sea sponges
- 1977 First report of its activity against herpes family of viruses
- There is no market for this drug!
- **1979 US patent** (1985 capsules; 1991 tablets)
- **Don't believe the hype.** It was part of a marketing strategy to get the new antivirals to the public.
- Disease-mongering is a recognised ploy.<sup>1</sup>



1. Moynihan R, Heath I, Henry D (2002) Selling sickness: The pharmaceutical industry and disease mongering. *BMJ* **324**: 886–891

# Hype (early days)

TIME magazine featured it twice.

**1980, and again Aug 02, 1982 >**

## **SCIENCE**

Environment: The OPEC of the Midwest  
(Environment)

Science: Singing the Blues at J.P.L

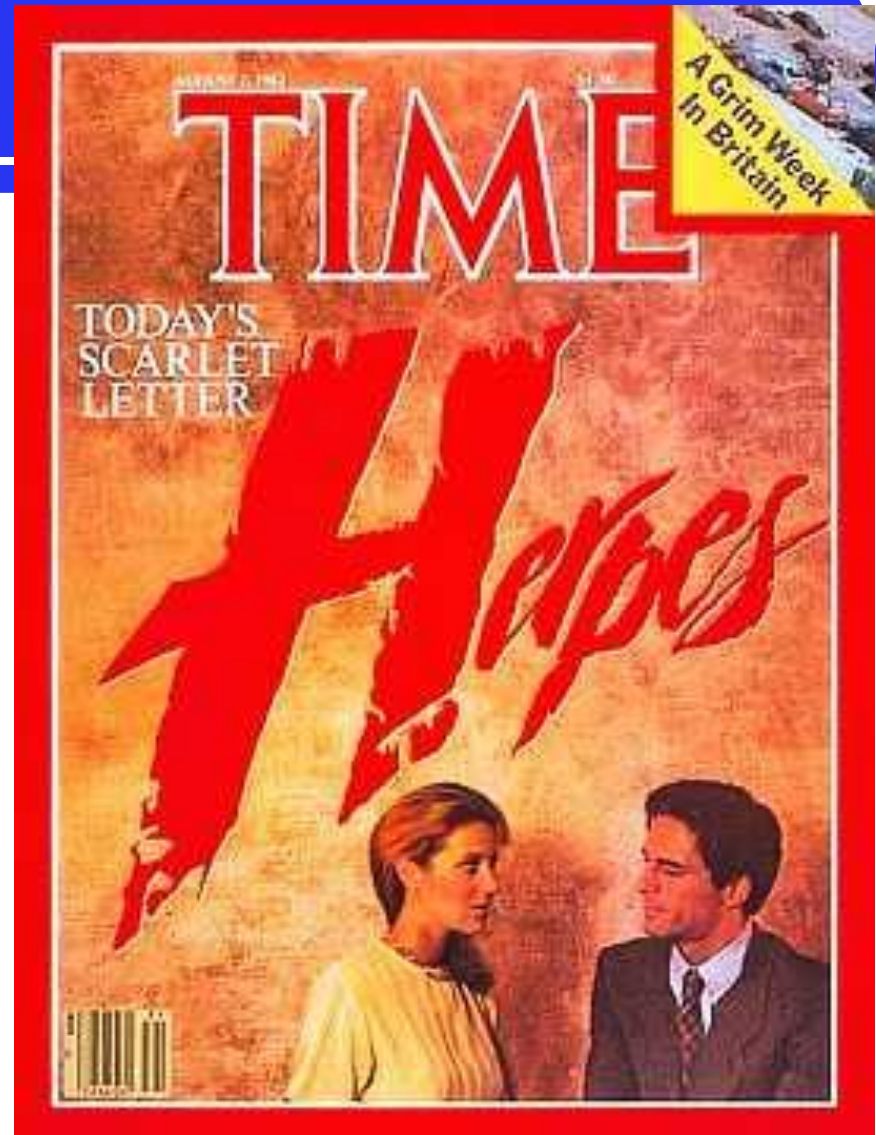
## **SOCIETY**

In New York State: Culture's Front Porch  
(American Scene)

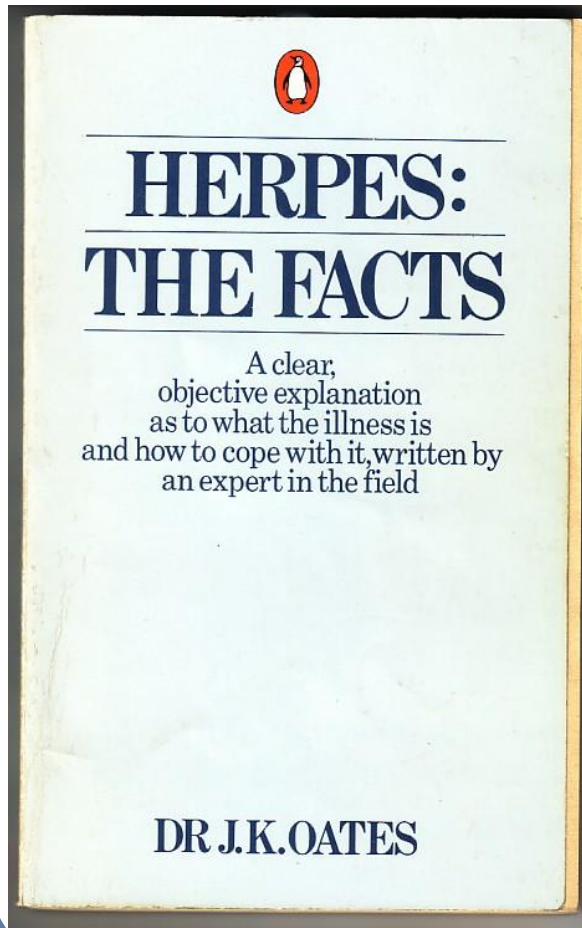
Behavior: Snake Venom and Earwax  
(Behavior)

The New Scarlet Letter (Behavior / Cover Story)

Herpes, an incurable virus, threatens to undo the sexual revolution



# The view from '83: 'Introduction'



**Twenty years ago [1963]**, I wrote a number of leaflets concerning common sexually transmitted diseases. My reason for doing this was that patients were often so worried about what they feared was wrong with them that they did not understand, or even listen very closely, when they were told what was wrong. Also I had to admit that sometimes they did not get all the explanation that they might have done.

All the usual illnesses were covered, but **when my colleagues and I got to herpes we could only write about eight lines, and a debate ensued as to whether it was worth printing such a short account.** We did print it, but it was rather a pathetic and little used leaflet...

**In 1980, so many people were asking about herpes that I wrote a twelve-page booklet on the subject,** designed especially for those who were worried about the disease. It wasn't enough - the booklet answered many questions and relieved many anxieties, but it also posed additional and more complex questions. It also made it clear that very many people were worried about genital herpes.

That is the reason for this book, which is an attempt to explain to patients what I know ... and, above all, to try to put the disorder into some sort of perspective. It has caused, and still causes, many of my patients more anxiety and unhappiness than any other disease that I treat, and **in my opinion much of this load of worry is, in the majority of cases, quite unnecessary.**

# Stigma - How to Get Rid of It?

Educate others; pass on facts; challenge myths and stereotypes. Focus on the positive.

## **Campaign level:**

**Spend** - it is suggested that the Spastics Association spent £3 million in 1996 – worth about 7 million now - on changing their name to Scope. (Scope, a nice neutral abstract word, cannot be turned into a term of abuse.)

Get **public** behind you – if it is something like race or disability it is a public issue. Herpes is not since herpes is hidden and people with herpes will not be outing themselves.

**Or it can vanish** – e.g. a change in treatment. Defective eyesight was highly stigmatised. [see: *Gentlemen Prefer Blondes*] All changed with the advent of contact lenses. Now glasses are a fashion statement.

**Meanwhile, while waiting for a £7 million windfall,  
what can be done on a daily basis?**

# Normalise with facts

At individual level. Clients can tell people:

- By age 25, seven out of ten have it. Higher levels if you are older.
- Most people don't have it as badly as you – in fact only 1 in 3 notices catching it.
- Treatment is optional.
- No requirement that new partners are told about it<sup>[1]</sup> - but it's a good idea. It is shown to reduce transmission.

And if **you (healthcare professional) have it**, tell the person.  
People hugely appreciate being told of this.

1. Crown Prosecution Service "Intentional or reckless sexual transmission of infection " Draft, page 10.  
"With regard to consent, there is no legal requirement that a person must inform their partner that they have an STI."

# “Debunk and prebunk”

The ‘inoculation process’ consists of two components: (1) a forewarning (i.e., that they may be manipulated by false information) and (2) the prebunk or preemptive refutation [Sander van der Linden]

**Debunk in advance: Slides 21-25 on the creation of the stigma.**

## **and Prebunk**

- (A) Provide the four points already mentioned: how common (7 out of ten – because type 1 causes g.h. via oral sex); two in three don’t notice; treatment is optional; telling partners is a good idea but not compulsory.
- (B) Refer them to the HVA. We can explain, advice, support them...

Be ready to deal with “myths”

- **Any story about it that is scary, or merely worrying, is likely to be wrong...** Tell them to get the facts - from you or HVA helpline or website.
- Not spread by hands or on towels, etc. [BASHH]
- Does not turn into HIV (common misconception)
- Not a cause of cervical cancer – but other herpes viruses are > > >

| Medical name   | Everyday name  | Symptoms  | How common?  | How is it caught?   |
|--|--|---|--|---|
| <b>Alpha humanherpes viruses – affect the skin, hide in the sensory nerve ganglia</b>                                  |  |   |  |   |
| <b>Herpes simplex type 1 and 2</b><br><br>HHV-1 and HHV-2<br>or HSV-1 and HSV-2  | Cold sores,<br>genital herpes,<br>whitlows                 | Blisters/sores anywhere on the body, especially face (we call them 'cold sores' or fever sores') and genitals         | by age 14 about 25%<br>by adulthood about 65% (or more) of which about 12.5% is type 2                             | direct contact with the affected area, "skin to skin with friction"<br><br>Incubation: 2 days or longer, but most often 4 or 5 days after contact |
| <b>Herpes varicella (HHV3)</b>   | Chickenpox   | Blisters/sores anywhere on the body   | by 12, almost 100%   | In the breath<br>Incubation: 2 weeks  |
| <b>Herpes Zoster</b>   | Shingles   | Recurrences are called shingles – and it can be followed by PHN (post herpetic neuralgia)                             | Lifetime risk 13.5%, but at 70 yrs shingles reaches 15%.<br>10-18% then develop PHN. But at 70yrs this can be 75%. | develops when a person who has had chickenpox in the past is run down   |
| <b>Beta humanherpes viruses – affect the whole body, hide in the lymphatic system</b>                                  |  |   |  |   |
| <b>Cytomegalovirus HHV-5</b>   | Glandular fever-like illness                               | Fever, aches, sore throat, swollen glands   | about 50-60%   | Saliva, other fluids<br>About 4-7 weeks   |
| <b>Humanherpes viruses 6, 6a and 7</b>   | Roseola  | fever and rash in babies  | Over 90% by age 5  | Saliva<br>About 5-15 days   |
| <b>Gamma humanherpes viruses - hide in the lymphatic system between outbreaks and are implicated in causing cancer</b> |  |   |  |   |
| <b>Epstein Barr virus HHV-4</b>  | Mononucleosis, called "kissing disease, or glandular fever | Fever, aches, sore throat, swollen glands   | over 90% of adult population   | contagious, usually saliva<br>4-6 weeks   |
| <b>Kaposi's sarcoma virus (HHV8)</b>   | Kaposi's sarcoma   | Mostly no symptoms. Rarely, cancerous lesions on the skin that are purple, red or brown and can appear flat or raised | 1% in USA<br>Up to 20% in some Mediterranean countries<br>As high as 80% in some African countries.                | Probably in saliva<br>It takes many years for the lesions to develop, if at all.  |

# On the issue of 'disclosure'

Is it necessary to reveal facial cold sore infection before kissing?

“There is no legal requirement to disclose any STI or HIV.” [Crown Prosecution Service] But do not be reckless or malicious, and don't lie if asked.

BASHH guideline has added the advice “Disclosure is advised in all relationships” **to protect the health care professional.**

However, it is known that talking with a partner halves the rate of infection.

When talking to a new partner – here's how to **Stop the Stigma:**

- Use 'cold sore' so the partner doesn't overreact
- Explain how common it is – see slide 6. Most people over 25 have herpes already. So, they have total or partial protection
- Only one in three will notice when s/he is infected
- HVA members' survey reported 83% success of disclosure
- “Persons who are undiagnosed are more apt to transmit infection than those with known infections.” Corey, L. Clinical Tools for Preventing Sexual Trans. of Genital Herpes. Medscape 03/29/04

# Resources

- Our patient information leaflet (patient information leaflet)
- This is available in many languages.
- If you have it yourself – share this with patients as we do on our helpline. This is hugely reassuring.
- Get “Herpes simplex in a Nutshell” – a crib card for staff when talking to patients. Bullet points of what to say... <https://herpes.org.uk/nutshell>
- **SUMMARY: Any story about genital herpes that is scary, or merely worrying, is likely to be wrong...**

# Thank you ...

Provide the HVA's website: [www.herpes.org.uk](http://www.herpes.org.uk)  
and helpline number: 0845 123 2305  
which are on the Guide:

- 'The Guide' (£90 for 100)
- HVA posters (free)
- HVA 'True or false?' leaflets (free)

**"The Herpes Viruses Association booklet - to take away and read - gives the patient clear, unbiased information that can be discussed at the following consultation."**

Dr Colm O'Mahony MD FRCP BSc DIPVen.

**THANK YOU! Questions?**

