Kaposi sarcoma, or KS, is a cancer of blood vessels mainly affecting the skin, mouth and lymph glands. The disease can also affect the body internally. Before the start of the AIDS epidemic KS was quite rare in the US, but its distinct physical signs of illness quickly became a visible reminder that a new epidemic was emerging. Before the use of HIV drugs, about 1 in 5 people with HIV had some form of KS.

What is Kaposi sarcoma?
KS is associated with the virus called human herpes virus 8, or HHV8. This family of viruses also causes oral and genital herpes, such as cold sores. Scientists do not know the exact way HHV8 causes KS disease, but everyone who develops KS tumors has HHV8 present in their bodies. A person can carry HHV8 for a long time before developing KS.

How is KS spread?
HHV8 is found in saliva and genital secretions, so it’s most often passed through wet kissing and unprotected sex. Although it’s most often found in men who have sex with men, heterosexual men and women can also get HHV8. More recent data show HHV8 may be passed in other ways, though this is not clearly defined yet.

Symptoms
Most people who get HHV8 do not have symptoms during this acute infection. If they are present, then symptoms can include fever, rash and swollen lymph glands. However, when HHV8 infection develops into KS disease, then the most obvious signs are lesions found on the skin, usually on the legs and feet or in the mouth (about 1 in 3 people). Skin lesions can grow slowly or quickly. You may not feel any symptoms from internal lesions.

The skin lesions are typically flat and painless. On white skin, they usually appear as red or purplish spots while on darker skin they’re normally bluish, brownish, or black spots. They can change by growing together or becoming raised above the skin. KS can become more life-threatening when it spreads in the body. Advanced internal lesions can cause difficult swallowing, coughing, fever, bleeding or shortness of breath.
Kaposi sarcoma and HIV disease

How is KS diagnosed?
Doctors do not routinely screen for HHV8 in the blood. Normally a doctor will look at the lesions for typical signs of KS. A skin biopsy of a lesion can diagnose KS of the skin. Your doctor may need to use a thin tube called a bronchoscopy to look at your windpipe and lungs, or even use an endoscopy if KS is suspected in your upper or lower abdomen.

Who is at risk for KS?
In the US, men who have sex with men are 10 times more likely to contract HHV8 than others. Also, people who engage in unprotected sex and wet kissing are at increased risk for the virus. However, not everyone who gets HHV8 will go on to develop KS disease.

How to prevent KS?
HHV8 may be difficult to avoid since most people do not know they have the virus. Not engaging in deep kissing or using spit as a lubricant during sex may help prevent getting or passing the virus, as well as using water-based lubes during sex.

There’s some evidence that using certain anti-HHV8 drugs can prevent KS disease. However, their side effects of these drugs outweigh their possible benefits, and so using drugs to prevent KS disease are not routinely used.

How to treat KS?
In most cases, the best way to treat mild-to-moderate KS is through potent HIV therapy. This helps keep your immune system strong and better able to control other infections, such as KS. The lesions may stop appearing, get smaller or even disappear altogether. Skin lesions that are not painful or not causing cosmetic problems are generally not treated.

For mild-to-moderate skin lesions, several therapies are available although lesions often reappear after treatment.
- Freezing with liquid nitrogen
- Localized surgery
- Radiation treatment
- Injection with an anti-cancer drug
- Applying a topical gel like Panretin

For more severe skin lesions and disease found or suspected in internal organs, anti-cancer drugs may be used to treat the whole body, called systemic treatment. These include Blenoxane (bleomycin), DaunoXome (daunorubicin), Doxil (doxorubicin), Oncovin (vincristine), Taxol (paclitaxel), Velp (vinblastine), and VePesid (etoposide). Doxil and DaunoXome come in a liposomal form, which means they’re contained in small fat bubbles. This potentially helps the drugs last longer, move to needed areas, and possibly reduce side effects.

The drug interferon-alpha can inhibit some of the growth of KS but it’s more useful when CD4 counts are above 200. A few other drugs appear to be active against HHV8, notably some that are used to treat CMV disease such as ganciclovir and foscarinet. However, given their serious side effects, they’re not routinely used to treat HHV8 or KS. Drugs are also not used as maintenance therapy for KS, as is done in other diseases such as PCP or MAC. In this case, the best way to keep KS at bay is by using an effective HIV regimen.

Special considerations for women
Far fewer women get KS compared to men: a ratio of about 1 to 9. Treating women with KS is the same as for men. However, treating active KS disease in pregnant women may pose special problems given the side effects of many of the anti-cancer drugs. In this case, treatment should be done in consultation with a specialist.
What can help to ask my doctor?

- What symptoms should I tell you about, and when should I tell you?
- Do you see cases of KS in your practice? And when do they usually happen?
- Should I change my regimen since I have a few skin lesions?
- What kinds of drug interactions are possible between my HIV meds and treating the KS?
- How do we evaluate whether I have internal lesions?

Where to get treatment?

The medicines used to treat KS are available by prescription through your doctor. Some states may cover KS meds through their AIDS Drug Assistance Programs (ADAPs). To see if you’re eligible and what meds are covered, contact your state ADAP, department of health, or Office of AIDS. Information can also be found through the AIDS Treatment Data Network at 1-800-734-7104, or visit www.atdn.org and click on “Access Project.” People who lack coverage for meds can sometimes gain access to them through the manufacturers’ Patient Assistance Programs. A good resource for this is www.rxassist.org, though you must sign in for the service. Another online resource is www.pparx.org.

What does recent research say?

In the last several years, more cases of KS are appearing in relatively healthy people with higher CD4 counts and lower or undetectable viral loads. Most of these individuals are men with an average age of 50 and having lived with HIV on average for 17 years. The great majority have been on effective HIV therapy and reported generally mild symptoms.

This type of KS appears to be benign in these men, as those who did not undergo treating this new KS have remained fairly stable in their symptoms. Although they persist, the symptoms don’t appear to be aggressive, invasive or lethal. Researchers are cautioning to not be too aggressive with treating this form of KS, instead taking a wait-and-watch tactic to continually assess each case until treatment is needed.