Kaposi Sarcoma (KS) is a type of cancer. It was one of the first life-threatening diseases seen in people with AIDS. It is also an AIDS-defining condition, and remains one of the most common cancers in people living with HIV.

The virus called KSHV (Kaposi sarcoma-associated herpesvirus) causes KS. In the family of herpes viruses, it is known as HHV-8. Up to 5% of Americans are infected with KSHV, but it is more prevalent in people living with HIV. However, having the virus is not enough to cause KS. Disease becomes more of a risk as a person’s immune system weakens, as a person gets much older, or if a person has an organ transplant or needs transfusions.

In contrast, about 1 in 5 gay and bisexual men have KSHV compared to 1 in 3 gay men living with HIV. Only 2–3% of transfusion recipients or hemophiliacs with HIV have the virus. As for heterosexual women with HIV, about 3–4% have KSHV.

When KS occurs, the virus infects some of the cells that line blood and lymph vessels. This causes those cells to divide over and over and to live longer than they should. New vessels may also form and inflammation may increase. Altogether, these conditions can lead to cancer in the form of a tumor in the skin or other body tissue.

Several forms of KS are found worldwide, occurring more often in men than in women. A slower, somewhat benign form is found in men of Mediterranean and Jewish descent while a more aggressive form is common in younger men in Africa. Transplant and transfusion patients are also at risk due to the steroidal drugs they take. In some cases KS affects mostly the skin while in other forms it can be seen throughout the body.

The risk for developing KS disease generally increases the lower the CD4 count goes, especially below 200. Therefore, being on a potent HIV regimen over time often prevents KS from occurring in the first place. However, KS does occur in some people with HIV at higher CD4 cell counts, such as above 500. What causes this is still unknown although research continues to better understand it.

What are the symptoms?

KS tumors or lesions can range in color from pinkish-red to brownish-blue or purplish and can look different in various skin tones. At first, the spots are usually flat, painless, and do not turn white when pressure is applied to them (unlike bruises). Later, as the disease progresses, they can
become painful and bleed.

KS disease can progress differently from person to person. In some, it develops very slowly with a new lesion appearing every few months or so. For others, lesions can appear more rapidly causing disease over a few weeks.

KS lesions on the skin are not usually life-threatening. However, they can be emotionally troubling, particularly when they occur in places where others can easily see them. Over time, lesions can develop in other body parts like the mouth, throat, lungs, gut or lymph glands. Other symptoms may suggest KS in these places, such as difficulty chewing or swallowing food, difficulty breathing, or diarrhea, cramping and bleeding.

How is KS diagnosed?

Although the KS virus can be found in blood, it doesn’t mean a person has KS disease. Therefore, a clinician will examine lesions visually as well as do a biopsy to diagnose it.

For skin lesions, a small piece of tissue is removed and examined in a laboratory. For lesions in the mouth, biopsy is also used. For the throat, stomach, small intestine and lungs, a thin tube microscope is used to look for lesions, and a biopsy will be done if there are any present. An X-ray may also be done to examine the lungs. A stool sample may be done to see if blood is present. A colonoscopy may also be done to find lesions in the colon and rectum, also with biopsy.

How is KS treated?

First, KS is not curable but it can be treated and controlled, and the type of treatment is based on the severity and location(s) of the lesions. However, if a person has detectable HIV, then starting or switching medications is the first way to get KS disease under control. No specific HIV medication is preferred over another in this case.

Next, no treatment is 100% effective, and more than one treatment may be needed to reverse or stop KS progression. Less than half of people actually see their KS lesions fully disappear. Further, some may not see their lesions fade away, but they may see a dramatic improvement in their size, shape and color, or, new lesions may stop forming.

When making treatment decisions (especially for treating KS of the skin), a person’s desire to be treated—along with their ability to deal with side effects—may play a role, especially if the KS is not posing a seriously harmful situation. This can be true for visible lesions on the face or other body parts that aren’t serious but can be stigmatizing to the patient.

Because skin lesions are not usually life-threatening, they may not need to be treated and just monitored over time. Several drugs can be applied directly to the lesions, but that doesn’t mean that new ones won’t form.

Chemotherapy and systemic treatments are usually used for internal and more advanced KS, although they can be used for skin lesions as well, both to treat existing lesions and prevent new
ones from occurring. These medicines can cause serious side effects though. If internal lesions are not treated, the KS can become life-threatening.

Using corticosteroids while having active KS should be avoided or used under close observation, as in people who have had transplants. In this case, corticosteroids can actually cause KS to occur or cause a life-threatening situation.

Topical treatments:

- **Minor surgery**: When lesions are small and few in number, surgery may be used with a topical pain killer.

- **Gels**: The vitamin A-related drug alitretinoin (Panretin) is FDA approved and is applied to lesions three or four times a day. Side effects include irritation and lightening of the skin.

- **Cream**: Imiquimod is applied three times a week for 24 weeks. Side effects include redness and itching.

- **Cryotherapy**: Applying liquid nitrogen to lesions can help freeze and kill KS cells and is used for treating smaller lesions. Side effects include swelling and blistering, and may take several weeks to heal.

- **Low-dose radiation**: Usually used for larger and deeper skin lesions and on more sensitive skin areas like sex organs or feet.

- **Injections**: Vinblastine (Velban) and other drugs can be given by needle into the lesion to reduce its size and appearance. Side effects include swelling, blistering and pain.

Systemic treatments (oral, IV):

- **Liposomal doxorubicin (Doxil, Lipodox, Lipodox 50) and paclitaxel (Taxol)**: Both of these drugs show about the same response rates for treating KS and preventing new disease. However, doxorubicin is preferred due to more favorable side effects, while paclitaxel is often used if disease returns after using doxorubicin.

- **Standard chemotherapy**: Other anti-cancer drugs may be used to treat systemic disease similar to the two above, including vincristine, bleomycin and etoposide. Combination treatment is also possible, and side effects increase when using more than one drug.

Can KS be prevented?
No, not at this time. However, using drugs to prevent KS may be possible in the near future. Researchers are also looking at various drugs to see if they are effective against this virus. People living with HIV who have KSHV and low CD4 counts may benefit greatly from these types of drugs, as they may prevent KS from occurring in the first place.

Are there any experimental treatments?

Yes, several. Over the past few years, researchers have learned a lot about KS, including the way in which lesions form. Several promising new drugs are now in clinical studies.

One possible new class of drugs is called monoclonal antibodies and show promise in controlling KS disease. In a recent study this year, nine men with HIV were treated with one of the anti-cancer drugs nivolumab (Opdivo) or pembrolizumab (Keytruda). All were on HIV treatment, and four had skin KS while the rest had systemic disease. After treatment, five had partial remission, one had full remission and three had ongoing stable disease. Both drugs were well tolerated.

If you would like to find out if you are eligible for studies of new therapies for treating or preventing KS, visit ClinicalTrials.gov. The site has information about all HIV-related clinical studies in the United States. Or, call toll-free at 1-800-HIV-0440 (1-800-448-0440) or email contactus@aidsinfo.nih.gov.

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