PROGRESSIVE MULTIFOCAL LEUCOENCEPHALOPATHY (PML)

WHAT IS PML?

Progressive multifocal leucoencephalopathy is a serious viral infection of the brain.

"Encephalo" means brain. "Pathy" means disease. Encephalopathy is a disease of the brain. "Leuco-" means white. Leucoencephalopathy is a disease of the white matter of the brain.

"Progressive" means that this disease gets worse in a short time. "Multifocal" means that it shows up in several places at the same time.

Researchers estimate that about 6% of people with AIDS develop PML. Most cases of PML show up in people with CD4 cell counts below 100. The exact rate is hard to know because PML is difficult to diagnose.

Most cases of PML used to be fatal. People diagnosed with PML lived an average of 6 months, and most died within 2 years. However, if people with PML start taking strong antiretroviral medications (ARVs) to control their HIV, they can survive much longer. Now only about half of people with HIV and PML die from PML.

The "JC" virus causes PML. Between 80–85% of all adults are exposed to this virus worldwide. In people with weakened immune systems, JC virus can become active.

HOW CAN PML BE DETECTED?

The first symptoms of PML are weakness or coordination problems in an arm or leg. There may be difficulty thinking or speaking. Vision and memory problems, seizures, and headaches can occur.

These symptoms can also occur with other opportunistic infections, including toxoplasmosis, lymphoma, inner ear infections, or cryptococcal meningitis. It is important to rule out these other diseases.

PML can be diagnosed using a scan of the brain by magnetic resonance imaging (MRI). Another way to test for PML is by checking spinal fluid. The sample is taken by inserting a needle into the spinal canal. This procedure is called a spinal tap.

HOW IS PML TREATED?

A major problem with treating any brain infection is the "blood-brain barrier." The blood vessels around the brain are different from the rest of the body. They are "tightly woven" to protect the brain from toxic substances. Chemicals that dissolve in fat can get through. Those that dissolve in water can't. Unfortunately, this includes most antibiotics and many other medications.

There is currently no proven treatment for PML. Research studies have had conflicting results. Some possible treatments have not been carefully studied. However, PML has slowed down or stopped in some patients taking strong ARVs to fight HIV.

Ara-C (Cytosine arabinoside or cytarabine) has been tried against PML. It was given intravenously, or pumped directly into the brain. It seemed to work in one small study, but not in later ones. Ara-C is very toxic, and damages bone marrow.

High-dose AZT has been tried against PML, because it crosses the blood-brain barrier. Other substances that have been tried with different degrees of success include acyclovir, heparin, peptide-T, beta interferon, dexamethasone, n-acetylcysteine, topotecan and cidofovir. Some studies show that IV (intravenous) cidofovir can make the brain work better in people with PML.
Because PML can progress rapidly, it is important to begin treatments quickly.

WHERE CAN I GET MORE INFORMATION?

An excellent source of information is the book *Progressive Multifocal Leucoencephalopathy (PML): Case Studies and Potential Treatments.* Peter and Lisa Brosnan wrote the book in 1993. They are not medical specialists. Lisa's brother was diagnosed with PML and the Brosnans began searching for possible treatments. Lisa's brother died, but they continued and published their work.

You can get a copy of their book by writing to Peter Brosnan, 1709 N. Fuller Avenue #25, Los Angeles, CA 90046. To cover his costs, he asks physicians and institutions to send $30, people with AIDS $20, and in cases of hardship he will send it free.

THE BOTTOM LINE

PML is a viral infection of the brain. It is fatal in about 50% of cases. It can be confused with other medical conditions.

There is no approved treatment for PML, although several treatments may be helpful. Any treatment must be started as early as possible. Combination antiretroviral therapy (ART) may slow the progress of PML.