Leading MS/PML experts recommend genetic testing to prevent fatal brain infection stemming from medication

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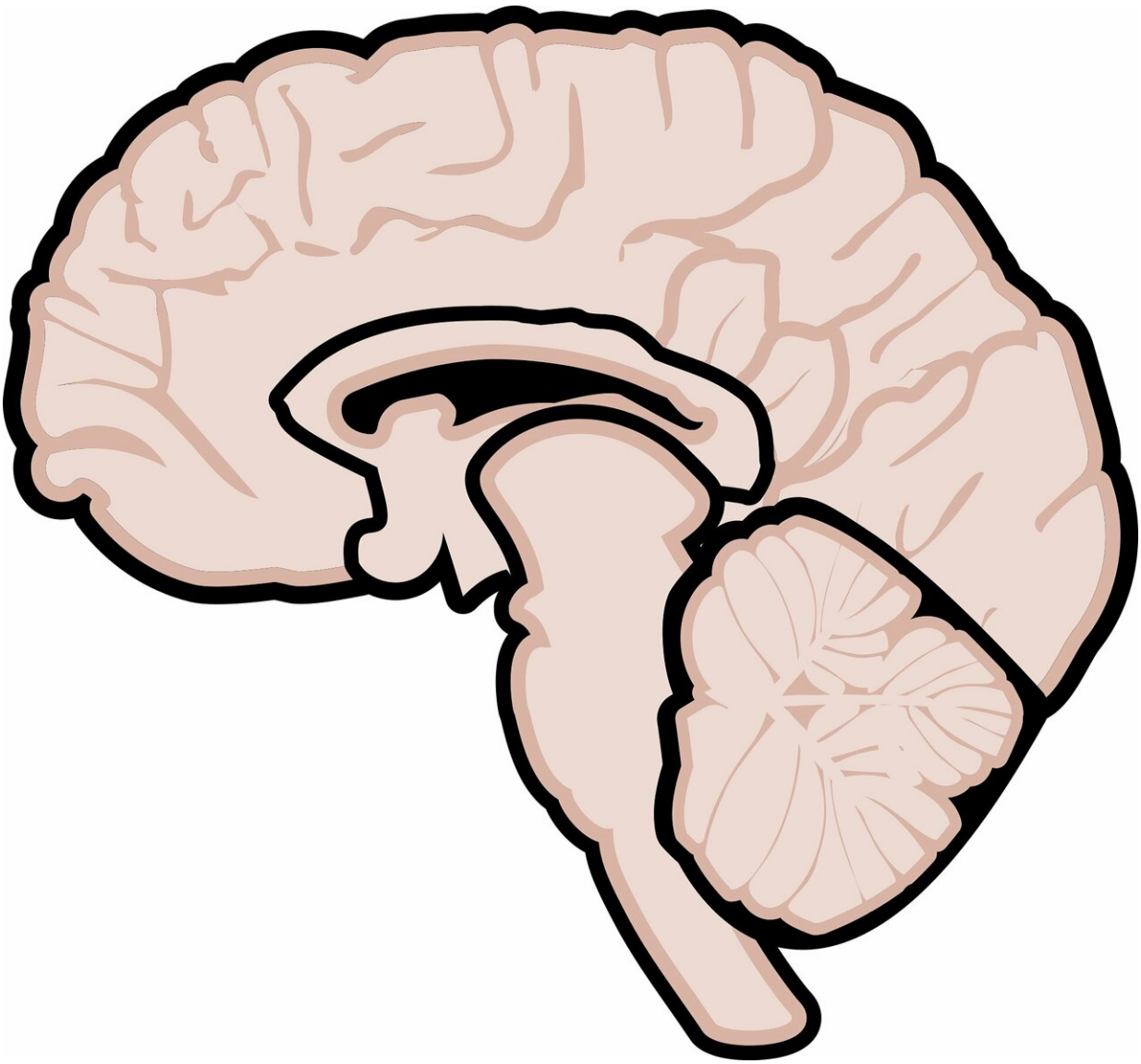

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In an editorial in the journal *Frontiers in Neurology*, two leading multiple sclerosis (MS) experts are advocating for genetic testing to identify MS patients who are at higher risk of developing a devastating side effect from their medications.

People with MS are faced with the excruciating decision of whether they should take medications that are effective in slowing the progression of the disease, but may also trigger this potentially fatal complication, a rare brain infection called progressive multifocal leukoencephalopathy (PML).

The two authorities, Joseph Berger, MD, and Hans-Peter Hartung, MD, write, "The availability of a simple, relatively inexpensive test that can identify the genes that put one at risk for PML would be enormously helpful in the management of patients. The widespread use of such testing could potentially allow the physician to use alternative therapies that do not carry the same risk of PML."

Dr. Berger is MS Division Chief at the University of Pennsylvania Perelman School of Medicine and Dr. Hartung is Neurology Chair of Heinrich Heine University in Düsseldorf, Germany and a Specialty Chief Editor for *Frontiers in Neurology.*

The editorial was written in support of a recently published study that confirmed a strong link between four genetic mutations and PML. The original study, also published in *Frontiers in Neurology*, found that these four variants were far more common among patients who took PML-linked drugs and developed PML than patients who took those drugs and did not develop PML. Neither of the editorial authors were affiliated

with the original study.

PML patient and Tysabri inventor support genetic testing

"Preventative screening for these variants should become part of the standard of care," said Dr. Lawrence Steinman, whose lab developed Tysabri, a breakthrough MS treatment that carries a Black Box Warning for PML. When Franklin Jordan, 58, a PML survivor who developed the side-effect after taking Tysabri, learned about the availability of the genetic test, he said, "I would have taken the test in a minute. If I knew I was positive, I wouldn't have taken Tysabri."

It is expected that preventative screening will become a routine part of patient care, as recommended by Drs. Berger, Hartung, and Steinman. But to fill the immediate need, the PML Foundation is currently offering a free test online. Simpler than a COVID swab, the at-home saliva test is processed in a CLIA-certified lab by PreventionGenetics, a leader in the field for almost 20 years. The free test is available at pmlrisktest.org.

PML is caused by the JC virus, which is very common but remains dormant in the vast majority of carriers. However, certain immune-modifying drugs, including those used to treat MS, have been found to induce PML in rare cases.

Many MS medications currently carry a PML warning, including Tysabri, Ocrevus, and Rituxan, as well as Gilenya, Kesimpta, Mavenclad, Mayzent, Ponvory, and Tecfidera. But it's not just MS drugs that can lead to PML; medications widely prescribed for blood cancers and organ transplants, as well as autoimmune diseases like inflammatory bowel disease, lupus, and rheumatoid arthritis also include PML warnings on their drug labels.

Drug-induced PML is on the rise as more powerful immunosuppressant therapies are developed. Since 2011, drug-induced PML cases reported to the FDA have more than doubled. In 2022 alone, there were nearly 600 cases in the FDA's adverse event reporting system. In that database, over 70 drugs have been linked to PML.

More information: Joseph R. Berger et al, Commentary: Progressive multifocal leukoencephalopathy genetic risk variants for pharmacovigilance of immunosuppressant therapies, *Frontiers in Neurology* (2023). DOI: 10.3389/fneur.2023.1146027

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