

Progressive Multifocal Leukoencephalopathy Consortium (PML Consortium)

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Research Areas

 **Data-Sharing Enabler**

 **Product Development**

At a Glance

- Status: **Active Consortium**
- Year Launched: **2009**
- Initiating Organization: **PML**
- Initiator Type: **Industry**
- **Rare** disease
- Location: **International**

Abstract

The Progressive Multifocal Leukoencephalopathy (PML) Consortium is a joint multi-institution effort between Pfizer, MedImmune, Roche, and Bristol-Myers Squibb that aims to find methods to enable prediction and prevention of PML associated with immunomodulatory and immunosuppressive treatments. The consortium was formed in 2009 in recognition of the importance of addressing PML and of the benefits of a collaborative approach to obtain sufficient data and samples to conduct research to comprehensively evaluate the disease and identify new potential risk factors. By pooling resources and sharing data, the consortium hopes to make significant progress in understanding how to better minimize the risk of PML for patients, and to achieve the best care and protection for patients. To this end, the consortium is undertaking a variety of research, clinical, regulatory, and communications activities, and is seeking collaborations with the scientific, medical, patient, and regulatory communities.

Mission

The vision of the PML Consortium is to find methods to enable prediction and prevention of PML

associated with immunomodulatory and immunosuppressive treatments.

The mission of the PML consortium is to perform research to understand the pathogenesis and to reduce occurrence, morbidity, and mortality of PML through a multi-company, not-for-profit, collaborative approach with shared strategy, investment, data acquisition and analysis, and communication within a predefined scope and duration.

Structure & Governance

To provide a forum for members of the scientific and medical communities to offer input on the consortium, the consortium has assembled a Scientific Advisory Board composed of invited experts who can speak to the scientific and medical aspects of PML.

The Scientific Advisory Board provides feedback and advice on all consortium research activities, insights into advancements in the scientific and medical communities, and assists the consortium in disseminating information about PML to these communities. In particular, Board members are encouraged to suggest activities that the consortium should take into account and helps the consortium to remain aware of developing issues related to PML.

The consortium is also working with patient advisors, including individuals from patient associations, to keep patient communities informed of its progress and to obtain their input on its initiatives.

Data Sharing

The consortium has built a clinical database and virtual sample bank to enable members to pool demographic information, clinical information, and brain images in a way that allows researchers to carry out more innovative and thorough research into PML and its causes.

Impact/Accomplishment

The consortium intends to develop shared resources such as databases and specimen collections to gain insights into PML that might be difficult to accomplish for each individual partner separately.

These resources will be available to all members, and the consortium is developing plans for making certain resources accessible for third-party scientific exploration. Furthermore, the consortium is developing a research agenda geared to facilitate prevention and to investigate potential treatment of PML, and it is committed to publishing results through publications and presentations in a timely manner, as appropriate.

Sponsors & Partners

Homepage <http://pmlconsortium.org/>
Bristol-Myers Squibb
MedImmune
Pfizer
Roche

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