

PROGRESS/BENEFITS TO PUBLIC HEALTH: RESEARCHERS

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Recommendations for Future Progress

- Public education sites (data registry): provide current, accurate information to investigators, clinicians, and patients
 - e.g. NINDS Office of Communications and Public Liaison
 - NINDS Information Page (Neurological Disorders A-Z, PML included)
- Public liaison offices: enhance communication strategies to promote research and utilization of new ways to stratify risk
- Patient advocacy group: leverage the effectiveness of at-risk patient population groups as means of garnering support for and advancing knowledge & research

Further Considerations

- Increase the focus on PML research at national/international professional societies/organizations
- Designation as a reportable disease
 - ▣ Better understand what makes a disease rare and the point at which it becomes a public health issue