

For Immediate Release
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PROVINCIAL MINISTERS OF HEALTH REAFFIRM COMMITMENT TO SUPPORT THREE-YEAR POST-MARKET STUDY OF FABRY DISEASE

TORONTO - Provincial and Territorial Ministers of Health today reaffirmed their commitment to partner with the two drug developers on a three-year post-market study on Fabry disease treatments.

Ministers are pleased that the Federal Government has publicly committed to this study. Once the Federal Government approves its funding contribution, expected by the end of June, legal agreements can be finalized so that the study can begin in July.

While the study focuses on Fabry disease treatments, it will also help address the challenges of assessing the effectiveness of all rare disease drugs, and making evidence-based decisions on public reimbursement for these drugs. Due to the extremely small patient population, drug therapies for rare diseases present challenges to collecting enough information from clinical trials.

As part of this study approximately 100 Canadian patients with Fabry disease, a rare genetic disorder caused by a deficiency of the enzyme alpha-galactosidase A, will gain access to enzyme replacement therapy. All Canadians with Fabry disease will also be registered on a national database. The disease is most prevalent in Nova Scotia, which has more cases than any other province.

Patients who qualify for the independent post-market study will receive treatment with either Fabrazyme, developed by Genzyme Corporation, or Replagal, developed by Shire Human Genetic Therapies. Both drug developers will participate in the project.

The governments and two drug companies will invest a combined total of \$100 million over three years.

Longer-term, the issue of rare disease treatments is being considered as part of the National Pharmaceuticals Strategy, which federal and participating provincial and territorial governments are developing to improve access to safe and effective drug therapies for all Canadians.

Canadian medical experts, under the auspices of the Fonds de la recherche en santé du Québec (FRSQ), the Government of Québec's agency for health research and the Canadian Institutes of Health Research (CIHR), the Government of Canada's agency for health research, developed the

post-market study including the eligibility criteria. FRSQ and CIHR are partnering with provincial governments and Health Canada to ensure that the project meets internationally accepted standards of scientific excellence.

The study responds to a commitment made by Health Ministers in October 2005. Work continues with Health Canada, the drug developer and the provinces and territories to reach a similar agreement on MPS1-Hurlers Schie.

- 30 -

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