



FACT SHEET

What is the Alberta Rare Diseases Drug Program?

This new program covers the cost of drugs for Albertans with rare diseases.

Individuals who receive this funding will be required to pay premiums and make co-payments consistent with their government-sponsored drug coverage.

What is a rare disease?

For this program, a rare disease is a genetic disorder that occurs in fewer than one in 50,000 Canadians or fewer than 50 Albertans.

Diseases currently eligible for coverage consideration include: Gaucher's disease, Fabry Disease, MPS-I (Hurler/Hurler Scheie), Hunter disease and Pompe disease.

Who is eligible for this program?

Albertans with rare diseases, who have government-sponsored drug coverage and whose physician has applied for coverage, will be considered.

An individual or family must reside in Alberta for five years to be eligible for the program. The residency requirement will be waived for individuals moving to Alberta from another province in Canada if they were covered by that province's program for these drugs.

Who will decide coverage?

A panel of specialists in genetic disorders is being established to provide advice to the Expert Committee about the drugs covered by this program, treatment guidelines and criteria for coverage.

This panel will also make decisions on individual patient coverage and monitor patient response to therapy.

When does the program start?

The program is expected to begin April 1, 2009.

Why is government paying for these drugs?

These drugs cost between \$250,000 to \$1 million per patient per year, which is beyond the reach of most Albertans. For ethical and compassionate reasons, government is funding this program.

For more information ...

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