Novartis celebrates Canada-wide implementation of newborn screening for spinal muscular atrophy

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- *Prioritization of screening programs for spinal muscular atrophy (SMA) will ensure early diagnosis across Canada and bring lasting impact to babies and caregivers*

Montreal, August 20, 2024 — Novartis Pharmaceuticals Canada Inc. (Novartis) applauds the work done by Muscular Dystrophy Canada and the provinces to ensure that every newborn in Canada will be screened to detect spinal muscular atrophy (SMA).

As of today, all provinces and territories have implemented newborn screening programs for SMA. With these programs in place, a blood test routinely done shortly after birth will be able to detect SMA before symptoms appear. This is a significant advancement for this rare, often debilitating genetic disease, which for some babies can be life-threatening. Novartis is pleased to have contributed to this shift in policy across the country through a multi-year multi-phase collaboration with Muscular Dystrophy Canada.

“Effective implementation of policy change on this scale is only possible when key stakeholders collaborate openly towards a common vision. We are thankful for the partnership which led to the vital shift that will identify babies with SMA at birth,” said Stacey Lintern, CEO, Muscular Dystrophy Canada. “We are most proud that the opportunity for early detection of SMA is now equitably offered to all newborns across the country.”

Early diagnosis to treat SMA quickly is crucial to stopping progression of the disease and gives these babies the opportunity to reach more advanced motor milestones like walking.

“We couldn’t be prouder to support the implementation of newborn screening for SMA for all Canadian babies. This positive progress is in large part thanks to the commitment and leadership of Muscular Dystrophy Canada whose determination has fundamentally changed the course of an SMA diagnosis in this country,” said Mark Vineis, Country President for Novartis Canada. “Being able to identify and treat SMA in a timely manner brings hope and the possibility for patients to have better outcomes. For many families this will be life altering.”

In Canada each year one in 6,000 to 10,000 babies are born with SMA[1], a rare, genetic neuromuscular disease caused by a defective or missing *SMN1* gene[2]. The most severe form of the disease (Type 1) constitutes approximately 60% of all SMA at birth or 21 cases per year in Canada[1]. Without a functional *SMN1* gene, infants with SMA gradually lose motor neurons responsible for muscle functions such as breathing, swallowing, speaking and walking.

About Novartis

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In Canada, Novartis Pharmaceuticals Canada Inc. employs approximately 600 people to serve the evolving

needs of patients and the healthcare system and invests over $30 million in R&D yearly in the country. For more information visit www.novartis.ca.

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