Horizon Therapeutics Canada is proud to be one of the few companies actively working to make rare disease medicines available in Canada. Our goal is to deliver medicine to Canadians living with some of the most challenging and devastating rare diseases in the world. As Horizon Therapeutics Canada continues to grow, so will our efforts in the cystinosis and rare disease community. We have developed this resource to be transparent about our past, current and future activities and to detail on support that is available from Horizon Therapeutics Canada and other organizations.

You have our commitment to do our best to better the lives of Canadians living with cystinosis. We are honoured to work with such a strong community, and will continue to invest in the care of Canadians living with cystinosis today and into the future.

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- National Organization for Rare Disorders (rarediseases.org)
- Rare Disease Information and Resource Centre (français.org, rnc.org)
- Peer 2 Peer Network at Rare Disease Foundation (rarewebsitesfoundations.org)

Reference:

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Support and Assistance
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### Financial support
- Reimbursement assistance
- Co-pay assistance
- Compassionate use programs

### Healthcare services
- Pharmacy counseling and free home deliveries
- Medication re-orders
- Over-the-counter support
- In-home nurse training when necessary
- Gastrostomy tube use
- Medication administration

### Patient education and management
- Reminder calls about order to ensure patients are taking medication as prescribed
- To answer any questions they may have

### Price Does Not Impact Our Patients
The cost of our medicines is either covered by private insurance, government programs, Horizon patient support and compassionate use programs, or through our co-pay assistance program.

**$1 billion** in global patient support provided by Horizon every year since 2016

**5.8%**

Expected percentage of total Canadian pharmaceutical drug expenditures for rare disease drugs in 2018*

Community Engagement

50+

patient advocacy group partnerships globally, including leading cystinosis and kidney advocacy organizations

### Research and Development

**$180 million+**

Invested from 2005–2017 toward the research, development, and approval of our cystinosis treatment*

Additional investments were used for manufacturing and supplying our cystinosis treatment, and providing support and resources for a patient population of fewer than 100 in Canada.

10 cystinosis studies

8 studies exploring our cystinosis treatment in other rare disease types

9 clinical trials involving:

- **132** Patients living with cystinosis
- **142** Other study volunteers

70% of patients were Canadian

9 clinical trials

18 research projects

18 research projects led by academic institutions and other organizations have been funded by Horizon*, including:

- 18 research projects
- 10 clinical trials in cystinosis studies
- 8 clinical trials exploring our cystinosis treatment in other rare disease types

ADVANCING NEW RARE DISEASE OPTIONS

**$225 million** in research and development expenses incurred by Horizon in 2017 for rare and rheumatic diseases

- **3** clinical research programs exploring new compounds
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- Rare Disease Information and Resource Centre (frenchcan.org)
- Peer 2 Peer Network at Rare Disease Foundation (rarediseasefoundation.org)

If you would like to speak with Horizon about our work—or have ideas you would like to share—please send an e-mail to connect@HorizonPharma.com.

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Support and Assistance

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Support and Assistance

Financial support

- Remuneration assistance
- Co-pay assistance
- Compassionate use programs

Healthcare services

- Pharmacy counseling and free home deliveries
- Medication re-orders
- Over-the-counter support
- Home nurse training when necessary
- Gastrostomy tube use
- Medication administration

Patient education and management

- Reminder calls about orders to ensure patients are taking medication as prescribed
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In partnerships with academic institutions and other organizations, Horizon has invested $225 million in research and development expenses incurred by Horizon in 2017 for rare and rheumatic diseases.

- 3 clinical research programs exploring new compounds
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