

Batten Disease Advocates Applaud B.C. Government's Reversal on Brineura Funding

July 18, 2025—Batten Disease Support, Research, and Advocacy (BDSRA) Canada, the BDSRA Foundation, and its Batten Disease Clinical Centers of Excellence (CoEs) applaud the British Columbia Government's decision to reinstate funding for Charleigh Pollock's life-sustaining enzyme replacement therapy, Brineura, to treat CLN2 Batten disease.

"We applaud the B.C. government for reversing this decision for Charleigh and her family," said Jennifer Vermilion, MD, Chair of the Centers of Excellence and Director of the University of Rochester Batten Center of Excellence. "Going forward, we urge a thorough review of the current discontinuation criteria to ensure that they reflect the benefits of treatment beyond a narrowly defined numeric score."

On Wednesday, July 16, the Batten Disease CoEs and Research Consortium sent a letter to B.C. Minister of Health Josie Osborne opposing the decision to withdraw funding for life-sustaining enzyme replacement therapy from Charleigh and called for a review of the current discontinuation criteria. Drawing on their collective and unparalleled expertise in CLN2 disease, the Clinical Directors expressed their concern for the clinical and scientific justification employed by the B.C. Ministry in their decision to withdraw treatment coverage.

B.C. Premier David Eby [acknowledged the letter](#) in a press conference on Thursday, July 17. You can read the full letter [here](#).

"This decision reversal is incredible news, not only for Charleigh and her family, but also for the global CLN2 Batten disease community," said Ineka Whiteman, PhD, Head of Research & Medical Affairs at the BDSRA Foundation and Program Lead of the Batten Disease Clinical Centers of Excellence program. "We are grateful that the B.C. government valued the strong input from our Batten disease researchers and clinicians from the Centers of Excellence and Batten Disease Research Consortium to help make the right decision by Charleigh and her family."

The letter was prompted by the B.C. government upholding its initial decision to discontinue funding Charleigh's Brineura infusions on July 11. Before that, BDSRA Canada President Lori Brown, Charleigh's mother, Jori Fales, Bioethicist and Executive Director of the Isaac Foundation, Andrew McFadyen, and Whiteman met with Minister Osborne on July 4 to discuss Charleigh's case.

"On behalf of BDSRA Canada and the BDSRA Foundation, we are grateful for the response from our U.S clinicians, who united rapidly and resoundingly in support of Charleigh and the broader CLN2 Batten community," BDSRA Canada President Lori Brown and BDSRA Foundation President

& CEO Amy Fenton Parker said in a joint statement. “Each CLN2-affected individual deserves funded access to Brineura. This decision reversal upholds that sentiment as we continue our fight for treatments and cures for all 13 forms of Batten disease.”

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What is Batten disease?

Batten disease or Neuronal Ceroid Lipofuscinosis (NCL) is a family of inherited neurodegenerative disorders that primarily affect the central nervous system. It is characterized by the buildup of waste materials in cells, leading to a range of symptoms including vision loss, seizures, cognitive decline, and motor skill deterioration, ultimately resulting in early death. There are 13 known forms of Batten disease, named according to the affected NCL gene (CLN1 disease to CLN14 disease – there is no CLN9). It is estimated that 2-4 births per 100,000 in the U.S. are affected by Batten disease. Currently, there is no cure for Batten disease.

About the Batten Disease Center of Excellence Program

The Clinical Centers of Excellence Program is a national network of Centers that aims to provide the highest level of comprehensive Batten-specific care for patients and their families. Together, the Centers aim to optimize patient outcomes, accelerate clinical research, and improve the quality of life for individuals affected by Batten disease and their families.

Visit bdsrafoundation.org/batten-disease-centers-of-excellence to learn more.

About the BDSRA Foundation and BDSRA Canada

The BDSRA Foundation and BDSRA Canada are patient advocacy organizations that fund research, provide support, and advocate for Batten families of all 13 CLN types in the United States and Canada, respectively.