



# Special Board of Directors Meeting

15 October 2025

MS Teams Video-Conference

# CLE-Vanishing White Matter: Second Clinical Trial

In June 2024 the Board voted to approve a single-person clinical trial of an experimental drug treatment for Cree Leukoencephalopathy (CLE), as this research directly addresses the well-being of the children of the Cree Nation. The trial was led by Dr. Genevieve Bernard.

In this meeting, **the Board voted to approve a second clinical trial to be led by Dr. Bernard and entitled *Single Patient Investigational Treatment for Cree Leukoencephalopathy (Vanishing White Matter Disease)*, for an experimental drug for CLE that may improve clinical outcomes for children with CLE.** The approval is contingent upon Dr Bernard continuing to provide regular updates to the Research Governance Committee and to collaborate with patient partner groups such as the Eeyou Awash Foundation.



## Designation of Authority for Administrative Processes Specialist – General Management

**The Board authorized the Administrative Processes Specialist, providing support to the Executive Director, to approve requisitions up to a limit of \$25,000 within the financial management system.**

This authorization aligns with the current Policy Concerning the Purchase or Lease of Good and Certain Services and with the approval process within the financial management system. The \$25,000 authorization increases the Administration Processes Specialist's availability to approve purchases and requisitions within this system, supporting the Executive Director.



# Copyright Transfer of IRS Recovery Stories to CNG

**The Board voted to transfer to the Cree Nation Government the copyright of several books (three published, one forthcoming) of recovery stories addressing the impact and legacy of residential schools in Eeyou Istchee.**

Story-telling is important to support miyupimaatisiun and preserve the history of residential schools. The CBHSSJB has published three books addressing this history and its associated mental and physical health impacts (notably the high prevalence of diabetes). These books include:

Dyckfehderau, R., & James Bay Cree Storytellers. (2019) *The sweet bloods of Eeyou Istchee: Stories of Diabetes and the James Bay Cree* (1<sup>st</sup> ed.) CBHSSJB; Wilfrid Laurier University Press.



- Dyckfehderau, R., & James Bay Cree Storytellers. (2021) *The sweet bloods of Eeyou Istchee: Stories of Diabetes and the James Bay Cree* (2<sup>nd</sup> ed.) CBHSSJB; Wilfrid Laurier University Press.
- Dyckfehderau, R., & James Bay Cree Storytellers. (2023) *E nâtamukw miyeyimuwin: Residential School Recovery Stories of the James Bay Cree, Volume 1*. CBHSSJB.

In addition to the copyright to these published volumes, the Board is transferring the copyright to the forthcoming second volume of *E nâtamukw miyeyimuwin: Residential School Recovery Stories of the James Bay Cree*.



# NEXT REGULAR BOARD MEETING

December 2025





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