



Healthy Albertans.  
Healthy Communities.  
Together.

## Introduction



Evidence indicates young children undergoing life-saving procedures early in life are at high risk for developmental delays.<sup>1</sup>

The **CPTFP** addresses the developmental service and information gap in the care of young children in Alberta (and outside Alberta referred to the Stollery Children's Hospital or Alberta Children's Hospital) for new and invasive life-saving therapies.<sup>2</sup>

The CPTFP assures early developmental diagnoses of these survivors and facilitates their developmental and rehabilitation treatment.

## Background

**CPTFP** provides a *systematic* approach to:

1. Determine outcomes, and ongoing health-related needs of these children
2. Link potentially modifiable predictive practice variables to concerns
3. Document trends in interventions, acute care variables, and outcomes
4. Communicate results to others

## Methods

Informed consent is obtained to participate in the Registry and CPTFP, a prospective observational research study.

The CPTFP established in 1996 continues to serve these vulnerable children and families through the dedication of strong leadership and passionate interdisciplinary teams.

Through established interprovincial partnerships for follow-up in the families' local area, longitudinal assessment by multi-disciplinary teams using standardized tools is done.



Children are assessed at:

- 6-8 months post-procedure
- 18-24 months (21 months) of age
- 4-5 years of age

These targeted assessments provide early opportunities for multi-disciplinary teams to assess for concerns, refer for interventions, and connect the family with community supports.

## Results

Children's developmental abilities are supported and enhanced through these assessments.

Clinical care is improved by identifying potentially modifiable predictors of outcomes.

As one example, **delayed-onset progressive Sensorineural Hearing Loss was eliminated** from survivors of hypoplastic left heart syndrome **AFTER** a change in clinical practice following the identification of rapid intravenous bolus furosemide as a modifiable variable.<sup>3</sup>



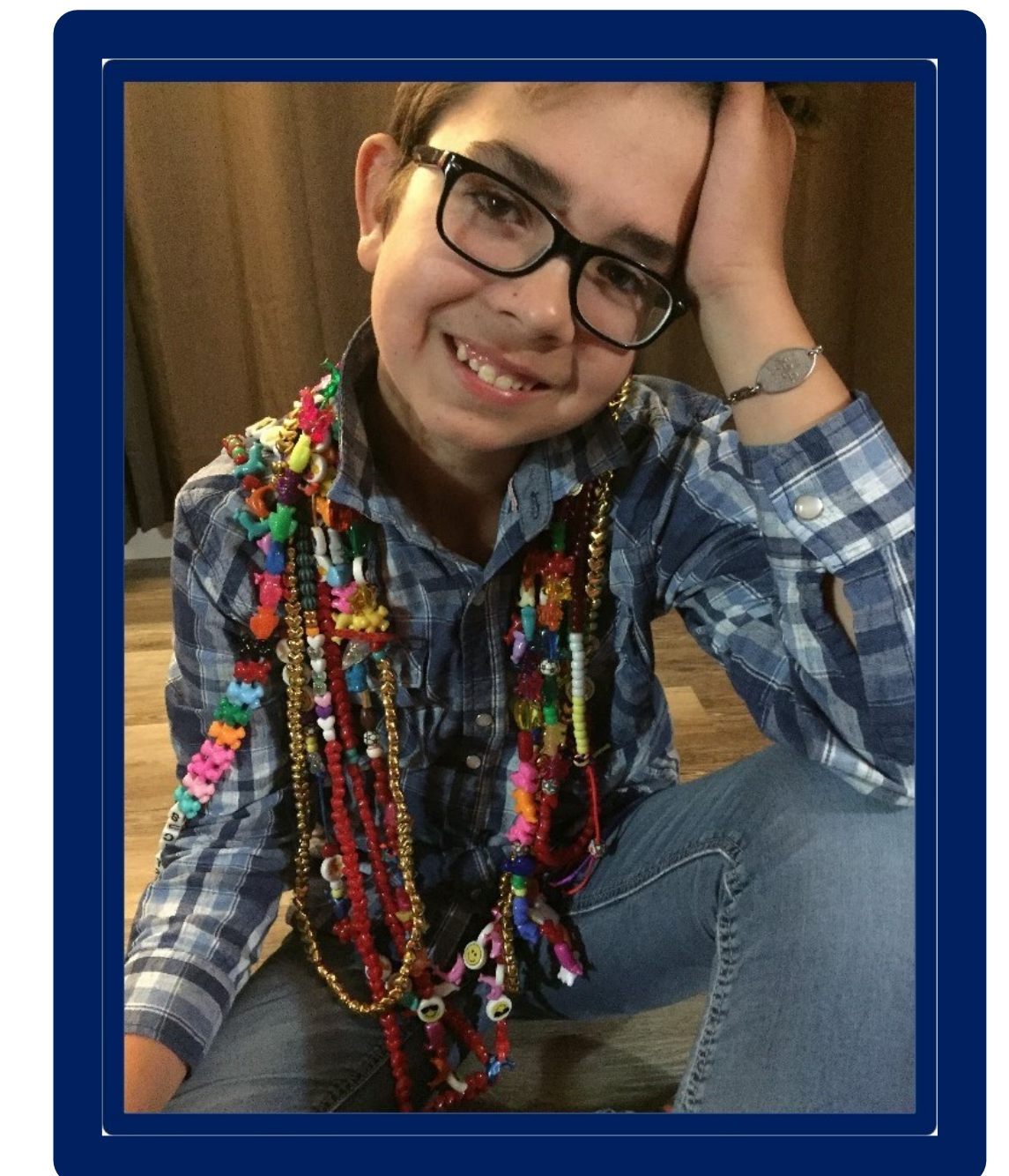
### Family Story

The support by all the specialists we saw at the Glenrose has been incredible!! We greatly appreciated the **constant support** and guidance we received.

This program was extremely valuable and reassuring to know our child had a **WHOLE TEAM** of professionals **Actively listening** and **Advocating** for **him**.

So grateful to have agreed to this program when it was offered to us during his surgical stay at the Stollery ~

## Conclusions



Developmental outcomes research is imperative to ensure all children reach their full potential and to support advances in clinical care for these children.



## References

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