

Mapping one family's experience with pain

The Future

What does it look like?

Taking the extra Grade 13 year

Transition to Adult Care



Co-authored a scientific paper

Focusing on living with pain vs. pain improvement.

Pain (migraines) worsen after dental surgery

17 yrs old

Increase in pain year over year

no referrals
no resources
no care options

Check back in a month, if things are not better.

Our family felt abandoned by the system



Children's Wish Foundation (Shark Tagging)

Sailing Certificate

14 yrs old

New symptoms cropped up

Grade 7 would be his last year at school.

Joint pain started

We felt like there was a bigger issue going on



Required travel to access care

There's no where close to home to get the care we needed.

Took 16 years for a diagnosis

Ehlers Danlos Syndrome

16 yrs old

school board worked with us to help him keep up with his education

An education program that allows flexibility is everything.

14 yrs old

Completed Marine Biology course, Vancouver Aquarium

I don't have an answer.

neuro-ophthalmologist

Took a long time to see a neurologist

Check back in a month, if things are not better.

I don't have an answer. neurosurgeon

We're going in circles

I don't have an answer.

4 different pediatricians

Check back in a month, if things are not better.

How it Began

Procedural Pain was not addressed

6 yrs old



Pain (migraines) after surgery

Pain episodes not looked at as connected

We felt that they could have been treated together.

10 yrs old

Began to see a pain psychologist

Only able to access because we had the financial means for it.

10 yrs old

Pain (migraines) worsened

Perception of his pain not acknowledged or addressed

A factor that still effects him today.

That really hurts, and the nurse said, No it doesn't.

13 yrs old



Partnering for Pain

Shaping pain research & care for kids, together.

partneringforpain.com

This project is grateful for the incredible contribution of shared experience from patient partner Zach, and his mom Isabel.

