

Prince Rupert

Terrace

Smithers

Houston

Burns Lake

Prince George

Kitimat

Quesnel

Williams Lake

Chilanko Forks

## Accessing Care requires families to travel from all across Northern BC

### JOINING CLINIC, CONNECTING FAMILIES

A family should never feel alone in navigating their child's illness. The first step we took to tackle feelings of isolation and build community was to travel to outpatient clinics in Prince George and Terrace alongside the BC Children's team so that we could meet families in person.

Our in-clinic presence transformed the support offered to families both during and after their appointments by connecting them with each other as well as with new life-changing resources such as our virtual education library, school toolkit and community support network.

Our visits also enabled us to have in-depth conversations with families and provide them with a platform to share their stories. This led to the creation of a new and dedicated [Northern BC Centre Hub](#) highlighting local family stories others could resonate with. Our work gained local media coverage in the [Prince George Post](#) and renewed the discussion of access to healthcare in Northern BC.

### IDENTIFYING GAPS IN CARE

Relationships built in-clinic also allowed us to conduct needs assessments with families and learn about their first-hand experiences caring for a child with a chronic condition in a remote part of the province. This critical engagement work has given us a deeper understanding of the wide scope of complex barriers families face when attempting to access care and support in Northern BC.

In addition to the [needs assessment survey](#), we also conducted an environmental scan of existing local services and resources that may be available to Northern BC communities. This information can be imperative to the success of newly diagnosed families getting started with navigating their "new normal" but who may not know where to access support. This information also supports the work of healthcare professionals who know that additional resources exist but, unfortunately, do not have the capacity to source and vet them.

*"The experience of being a parent of a child with juvenile arthritis can be very isolating; it's rarely discussed – especially when you live in a rural community. But once I found Cassie + Friends and met others experiencing the same thing, I really didn't feel so isolated anymore"*

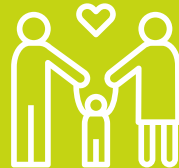
**- Parent, Prince George**

## Through our work, we've been able to...

**Visit Prince George and Terrace clinics four times**



**Engage with over 50 families from 10+ northern cities/towns**



**Mobilize 26 individuals to get involved by joining our annual run/walk & sharing stories**



## We've also been able to learn about and begin collecting data on the key challenges facing Northern BC families including:

**Lengthy delays in reaching diagnosis**



**Heavy financial burden felt from travel + accommodation costs of travelling to appointments including unpaid time off of work**

**Unsafe and unreliable road conditions when driving to and from appointments**



**Systemic barriers experienced by BIPOC communities, especially when Indigenous (see [In Plain Sight](#))**

**Food supply shortages**



**Lack of access to care in between appointments from shortage of Family Doctors, Ophthalmologists and Pediatric Physiotherapists**

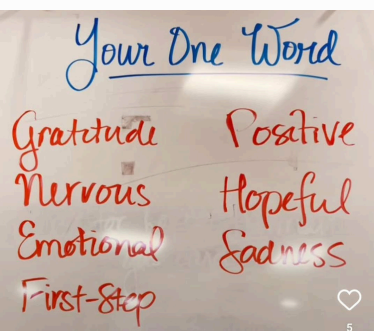
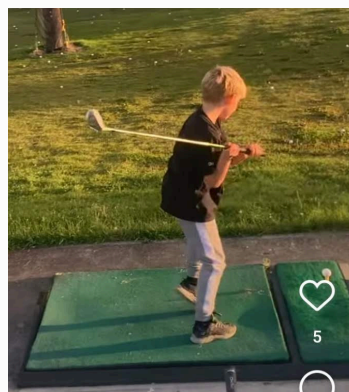
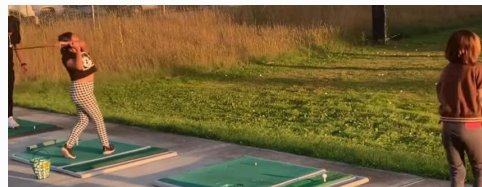


# FAMILY EVENT IN PRINCE GEORGE

## Keeping the momentum going for kids like Scarlett, Oliver, Ryus, Addie, Asia and many more.

On September 21, 2022 we hosted a Family Connection and Education event in Prince George alongside the BC Children’s Hospital team. It was attended by 20+ Northern BC families.

For many kids and families, this was the first time meeting others navigating the same medical journey as them - let alone experiencing the same regional challenges. In addition to offering the event free of charge, we provided dinner, childcare/kids activities and financial support for travel and accommodation to and from the event.



# Supporting Rural & Remote Communities

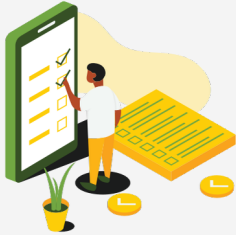


navigating childhood rheumatic disease

## WHAT WE DID

### ENGAGED WITH COMMUNITY MEMBERS

We conducted in-person meetings, online surveys, and Zoom interviews to build connections with families in Northern BC impacted by childhood rheumatic disease. We asked parents and caregivers to share their experiences in seeking and receiving a diagnosis for their child in the rural context.



### LISTENED TO STORIES SHARED

Parents described their experiences of first noticing their child's symptoms, to seeking help, to receiving a diagnosis, then beyond. We learned what supports were found to be helpful, and where things could have been better for their families.



## WHAT WE LEARNED

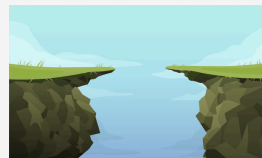
### NAVIGATING THE DISEASE TAKES AN EMOTIONAL TOLL

The journey to diagnosis can be traumatic, confusing, and overwhelming. Families may encounter feelings of isolation, uncertainty, and grief as they confront childhood rheumatic disease.



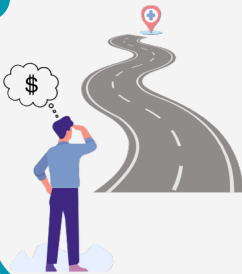
### GAPS IN DISEASE AWARENESS IMPACTS EXPERIENCE

Lack of disease awareness in rural and remote communities mean parents and caregivers spend a significant amount of time seeking answers while disease symptoms persist.



### RURAL FAMILIES BEAR THE COST OF LIMITED ACCESS TO CARE

The low physician-to-population ratio and lack of specialist care in rural and remote regions means families spend a significant amount of time, money, and energy seeking equitable care for childhood rheumatic disease.



### IT HELPS TO CONNECT WITH OTHER FAMILIES

The opportunity to share experiences and hear from families who understand what it is like to navigate life with childhood rheumatic disease is supportive and reassuring.



## WHAT WE RECOMMEND

### SEEK OUT PARENT AND CAREGIVER PERSPECTIVES

Parents and caregivers are the subject matter experts of their own lives. Engage with community members to build connections, generate ideas, and discover what supports they need.



### BUILD A KNOWLEDGE HUB

Create an accessible repository of useful information and supports for the community. Seek input from users to ensure resources are relevant and useful. Ensure it can be easily maintained.



### EXPLORE WAYS TO FACILITATE COMMUNITY CONNECTIONS

Increase opportunities for community connection and raising disease awareness by planning accessible events that bring people together. Consider how to reflect the unique characteristics of the community to promote inclusivity and learning.



### RECRUIT PARENT NAVIGATORS

Explore recruiting navigators to provide families support, information, and access to useful resources. Consider those with lived experience to welcome new families to the community.

