As an educator, what can I do?

Education is intertwined and linked to health outcomes. While every child and family's experience of chronic rheumatic disease is different, for the most part, our patients want to be treated like any other kid (a couple of them sat down with us for an interview, which you can watch at cassicandfriends.ca/schooltoolkit). They'll tell you it's important to simply be aware of the impact their disease can have on their education journey. They ask that you grant kids like them the autonomy and permission to do what they can, when they are able to. That way, they have every opportunity to keep pace with their peers.

Everybody's journey is different. You can help by:

- Learning more about chronic rheumatic diseases, and the specific symptoms that arise from each disease (links below);
- Understanding that symptoms can vary for each individual and may change over time—sometimes within a single day;
- Talking with students and families to find creative ways to best accommodate learners living with a chronic rheumatic disease.

Disease information resources

aboutkidshealth.ca (general, lupus, JIA, morphea) arthritis.ca/about-arthritis/life-stages/kids-and-teens arthritis.org/diseases/juvenile-dermatomyositis (jdm) cassieandfriends.ca/classrheum scleroderma.org

Education-specific resources

aboutkidshealth.ca/learning cassieandfriends.ca/schooltoolkit simpletasks.org/tips-to-help-your-child-with-a-rheumatic-disease









Chronic **Rheumatic Diseases**

Negatively Affect School Attendance & Performance

What are childhood-onset chronic rheumatic diseases?

The most common of these diseases is juvenile idiopathic arthritis (JIA), which affects 1 in 1,000 to 3,000 Canadian children. Other systemic autoimmune diseases include systemic lupus erythematosus (SLE or lupus), Sjogren's syndrome, dermatomyositis, and systemic scleroderma. These diseases can affect many organs, including (but not limited to) the skin, muscle, digestive tract, kidneys and brain.

How do these diseases affect children's lives?

Kids living with these diseases will often spend a good portion of their pre-adulthood lives feeling physically or psychologically unwell. The presentation and severity of symptoms (e.g. bodily pain, fatigue) can vary over time or even within the same day. These symptoms may force kids to miss class and social events. They may also need to miss class for medical appointments, infusions, or hospital stays. Children and youth with childhood-onset chronic rheumatic diseases are also at higher risk of depression and anxiety than their peers. It's easy to imagine how all of these factors could impact their school performance.

What effect do these diseases have on education outcomes and enrolment?

Our study of Manitoban youths revealed those living with childhood-onset chronic rheumatic diseases significantly underperformed their peers on their Grade 12 language arts and maths standards tests. Additionally, they had lower rates of age-appropriate Grade 12 enrolment.

We also found that among all the kids with these diseases, those whose diseases were more severe and more difficult to treat performed worse on their standards tests.

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J Rheumatol 2023 Sep;50(9):1165-1172

When children were compared to a control group of their peers, we found that

Having a chronic rheumatic disease is linked to:

Small effect on Language Arts test scores (Grade 12) Lower school enrolment Lower school enrolment Lower ageappropriate Grade 12 enrolment rate

^ Greater disease severity is linked to even worse performance, but does not significantly affect enrolment.

Our study also reinforced that social factors¹ and psychiatric conditions² negatively affect education outcomes—with effects equivalent to, and up to three times more than, what we found amongst children living with childhood-onset chronic rheumatic diseases. These factors include:

- Low family socioeconomic status
- Maternal age at first childbirth younger than 25 years
- Out-of-home care

As physicians and teachers, we need to be especially aware of the social environment in which a child grows up, as this can worsen the effects of having a chronic illness on education performance.

"This is a very fluid condition. A kid that might not be able to walk in the morning might look completely fine by 10 am. Sometimes that can be misconstrued as faking it, being moody or not wanting to participate in school."

¹ Social factors studied include maternal age at the first child birth, child in out-of-home care, children in families requiring income assistance, and socio-economic status

² Psychiatric conditions studied, included ADHD, conduct disorders, substance use disorders, mood & anxiety disorders and psychotic disorders.