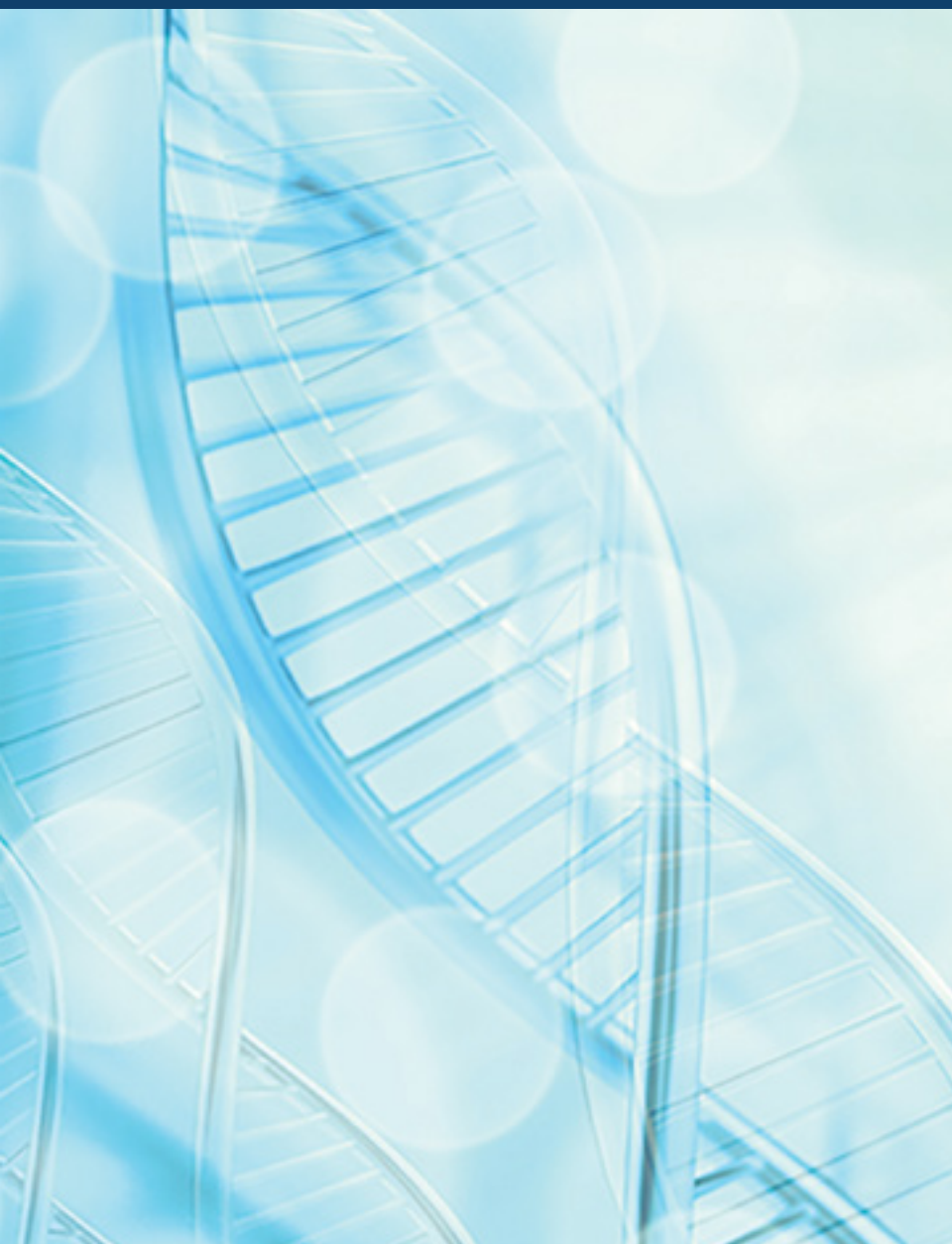


WHAT YOU NEED  
TO KNOW ABOUT  
**FABRY  
DISEASE**



A TEACHER'S GUIDE



# WHAT IS FABRY DISEASE?

Fabry disease is a rare genetic lysosomal storage disorder caused by a deficiency of an enzyme called alpha-galactosidase A.

This enzyme is responsible for breaking down fatty deposits in the body. But as Fabry patients are deficient in this enzyme, the fatty deposits build and accumulate in the cells of the body. Without this enzyme functioning, these waste products build up and cause progressive damage.

As Fabry is an invisible disease, it can be exceptionally challenging; as individuals appear to be healthy, they may be experiencing pain on the inside.

# SYMPTOMS

## OF FABRY

A wide variety of signs and symptoms are associated with Fabry disease. A person with Fabry disease may not experience them all and the severity of symptoms can vary from person to person. Here are some of the symptoms your student may experience:

- Low tolerance to exercise
- Pain and burning in the hands and feet
- Fatigue
- Impaired sweating
- Intolerance to hot and cold
- Frequent bowel movements, stomach cramping and pain
- Skin rash (angiokeratoma)
- Psychosocial impact
- Heart involvement (later onset)
- Kidney involvement (later onset)





As school is a safe space for all children, it is paramount to be aware of certain “triggers” that can bring on your Fabry students’ symptoms. Knowing what these are can aid in your planning and inclusive teaching strategy.

FABRY

# TRIGGERS

Pain and discomfort can be brought on by several factors; listed below are common everyday triggers:

- Flu, cold, or other viral illness
- Emotional stress
- Exercise
- Certain foods
- Fatigue
- Temperature changes



HOW TO BE

# MINDFUL

WITH YOUR FABRY STUDENT

Children with Fabry disease may need a little extra acknowledgment and support in order for them to be successful in their school setting. Listed below are some accommodations you can put into place to best support your students' individualized needs.

## SYMPTOM: Exercise Intolerance

Your student may not be able to tolerate physical exertion, may tire easily, or become overheated (due to impaired sweating). This may also bring on episodes of pain.

### ACCOMMODATION:

Flexible and inclusive programming for this student during physical education class or during outdoor play. Encourage them to drink plenty of fluids, and check in to see how they are feeling during high levels of physical exertion. If the student is unable to keep up to their peers, feelings of frustration may be associated. Be mindful of their limitations and find alternative forms of play for them to be included.

## SYMPTOM: Behaviour

A behavioural issue may occur as an outlet to express pain, frustration, lack of understanding with peers, or due to embarrassment about disease.

### ACCOMMODATION:

Keep an open dialogue with the student and ask the student how they are feeling, and if there is something they need at that time. Encourage student to self-advocate and educate peers on their condition when they are comfortable to do so. Co-creating strategies with them to utilize in moments of anger or frustration will be beneficial.



## **SYMPTOM: Fatigue**

Student may experience bouts of fatigue throughout the day.

## **ACCOMMODATION:**

May need to manage their activity level and encourage them to take frequent breaks.

## **SYMPTOM: Gastrointestinal Issues**

Your student may suffer from gastrointestinal issues leading to frequent trips to the washroom. They may also experience stomach pain and discomfort.

## **ACCOMMODATION:**

Understanding and accepting their request to leave the classroom when they need to. Talk to your student, and formulate a game plan that both of you are comfortable with so they don't need to continuously ask permission to leave.

## **SYMPTOM: Psychosocial Issues**

As Fabry disease is a genetic disorder, it has been passed from a parent who also has Fabry. Growing up they may have watched their parent suffer with daily symptoms, and/or serious lasting effects from the disease. Their parent may not be able to partake in outdoor sporting activities in the same way as their friends' parents. Mixed emotional responses, anxiety, worry, and nervousness may be present in your student.

## **ACCOMMODATION:**

Like any psychosocial concerns in the classroom, it is imperative to help the child understand their emotions and give them a sense of empowerment. Exploring therapeutic approaches with them, for example, different forms of art, can offer both insight and an outlet to their emotions, thus bringing a sense of calmness, and a communicative expression.





## The Canadian Fabry Association

is an organization that aims to inspire hope  
and improve the quality of life for all those  
affected by Fabry disease  
through the support of research,  
public education, patient empowerment,  
and awareness.

Our vision is to inspire all those affected  
to live well with Fabry and be champions  
of their own quality of life.



CdnFabry



Canadian Fabry Association Page



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[www.fabrycanada.com](http://www.fabrycanada.com)



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