

# HELPING THE STUDENT LIVING WITH FABRY DISEASE

## Questions and Answers for Educators, Counselors, and School Health-care Professionals

Information to guide school professionals as they support the student living with Fabry disease and help other students understand this hidden, chronic condition.



Amicus Therapeutics has developed this educational resource in collaboration with the rare disease community and thought leaders.



## What is Fabry disease?

Fabry disease is a rare disease that runs in families.<sup>1-3</sup> When people have Fabry disease, their bodies lack some of the things that help break down certain substances. Because of this, these substances may build up to unhealthy levels.<sup>2-5</sup> This can cause problems in many parts of the body, including the kidneys, heart, nerves, stomach, eyes and skin.<sup>5-7</sup> Everyone living with Fabry disease has a different set of problems that is unique to each person.<sup>5-7</sup>

It's important to be aware that everyone experiences Fabry disease differently.<sup>3</sup> Some people may have many significant changes, while for others, changes are few and mild.

Often, Fabry disease is hidden.<sup>8</sup> A student living with Fabry disease may appear healthy, while feeling pain and experiencing other physical or psychosocial changes. That's why it is essential for the school nurse to see the student for any health complaint, no matter how minor it seems. Some schools may not have a school nurse, but it is essential that the student's health complaints are appropriately escalated, no matter how minor they seem to the teachers or administrators.

### Can Fabry disease be managed during the school day?

Yes. Students may receive treatment that helps manage the effects of Fabry disease.<sup>5</sup> Students, parents or guardians and health-care professionals can provide treatment information on medical forms approved by the school. An up-to-date student medical record should be kept on file with the school, to chart the student's health and monitor any changes that may affect the student's well-being. The student's health-care professional should have a template that will help keep track of the expected symptoms.

### How does Fabry disease affect life at school?

Fabry disease may cause changes, like pain, fatigue or reduced sweating, that affect a student's ability to participate fully in physical activity.<sup>1,3,9</sup> A student may need special considerations for physical education, sports or breaktime.

Some students with Fabry disease experience nausea, diarrhea or other changes that require frequent trips to the toilet.<sup>5</sup> Educators can give a student open toilet permission, to avoid the waiting and potential embarrassment of asking for a break each time. A student can also benefit from open permission to visit the school nurse or office as needed for doses of medication or for health support.

A student with Fabry disease may need extra support from counselors, teachers and speech therapists, to facilitate fitting in with their peer group and to sustain psychosocial health.<sup>1,9</sup> These interventions may also improve communication and peer relationships in a student experiencing hearing loss due to Fabry disease.<sup>5</sup> Hold meetings and discussions for support privately, away from peers, and reinforce that school personnel are there for the student.

School administration can identify a “point person” at the beginning of the school year to be the student’s advocate. A “point person” can answer questions, help handle problems, and offer guidance. Counselors, nurses or teachers are all good options for this role.

Everyone benefits when school personnel listen to the student living with Fabry disease and foster open communication.<sup>10</sup> Empathy and a non-judgmental attitude can validate a student’s feelings and diminish a sense of being different from peers.<sup>10</sup>

### **How can a school deal with absences related to Fabry disease?**

Fabry disease is a serious, chronic condition that may force the student to miss school. Major reasons for unavoidable absences are medical appointments and feeling unwell.<sup>11</sup>

Here are some tips to address absences:<sup>10,11</sup>

- Work with the student’s parents or caregivers in advance, to learn about any expected absences, especially long-term absences. Make a plan for missed school days with the student and family. A lenient approach to absences is best, so as not to place further stress on the student
- Use technology and digital resources in the classroom to help the student keep up academically during necessary absences
- Encourage teacher note-taking and sharing, to help the student complete homework assignments and avoid falling behind
- Ensure that the student, parents and teachers are all on same page as to what classmates will be told about Fabry disease and why the student might miss class or leave the room more frequently than other students
- Respect student’s personal choices about what to tell, who to tell and how to tell about Fabry disease

### **Where can schools get more information?**

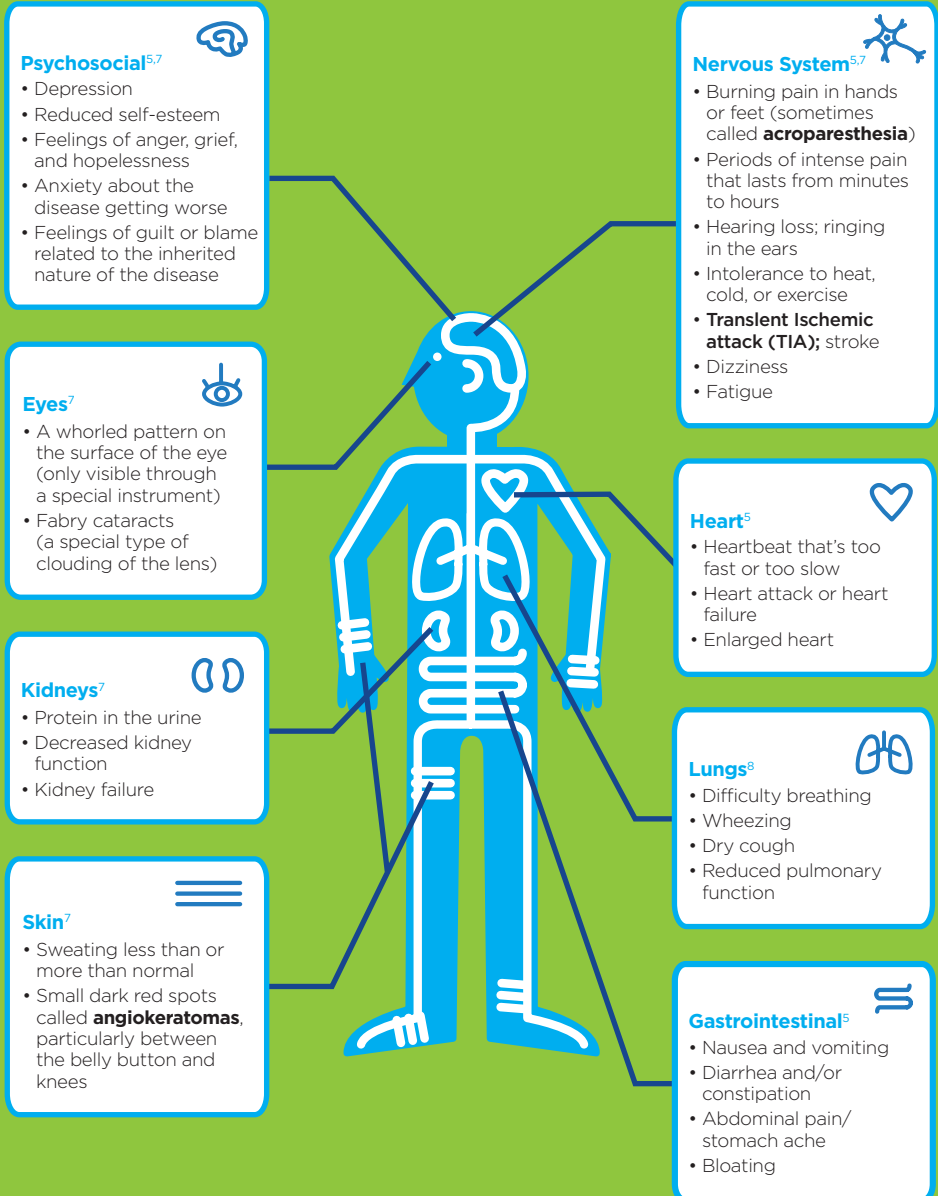
- Fabry International Network
- Fabry Support & Information Group
- The National Fabry Disease Foundation
- The MPS Society (UK)
- Global Genes
- Canadian Fabry Association
- Fabry Australia
- National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS) Fabry Disease Information
- National Organization for Rare Disorders
- Rare Diseases Europe



For more information about Fabry disease, scan the code with a mobile phone or go to [A Visual Guide to Understanding Fabry Disease.](#)

## What might a student with Fabry disease feel or experience?

Since Fabry disease affects many parts of the body, a student may experience many symptoms and these will vary dramatically between individuals.<sup>5-7</sup> Some of these are included in the diagram below. The diagram shows most of the symptoms of Fabry disease, but people can also have other symptoms in addition to those shown.<sup>5-7</sup>



# How can a school make a positive difference for a student living with Fabry disease?

Schools can help students with Fabry disease by implementing the 6-part plan below.<sup>9-11</sup>



## What do these words mean?

**Angiokeratoma:** small dark red spots that appear when a tiny blood vessel widens

**Acroparesthesia:** burning or tingling pain in the hands or feet

**Gastrointestinal:** the body system that includes the stomach and intestines

**Gene variant:** the gene's function, sometimes resulting in diseases or conditions

**Psychosocial:** the interrelationship between a person's mental health and social conditions

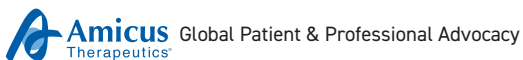
**Transient Ischemic attack (TIA):** temporary period of changes similar to those of a stroke. TIA lasts only a few minutes and doesn't cause permanent damage

## References:

1. Bugescu N, et al. *J Pediatr Genet.* 2016;5(3):141-149. doi: 10.1055/s-0036-1584357. 2. Schäfer E, et al. *Hum Mutat.* 2005;25(4):412. doi: 10.1002/humu.9327. 3. Germain DP. *Orphanet J Rare Dis.* 2010;5:30. doi: 10.1186/1750-1172-5-30. 4. Cairns T, et al. *Postgrad Med J.* 2018;94(1118):709-713. doi: 10.1136/postgradmedj-2018-136056. 5. Ortiz A, et al. *Mol Genet Metab.* 2018;123(4):416-427. doi: 10.1016/j.ymgme.2018.02.014. 6. Laney DA, et al. *J Genet Couns.* 2013;22(5):555-564. doi: 10.1007/s10897-013-9613-3. 7. Mehta A, Hughes DA. In: Adam MP, et al, eds. *GeneReviews®* [Internet]. Seattle, WA: University of Washington, Seattle; 1993-2019. 8. Svensson CK, et al. *Eur Clin Respir J.* 2015;2. doi: 10.3402/ecrj.v2.26721. 9. Hopkin RJ, et al. *Mol Genet Metab.* 2016;117(2):104-113. doi: 10.1016/j.ymgme.2015.10.007. 10. Paz-Lourido B, et al. *Health Qual Life Outcomes.* 2020;18(1):109. doi: 10.1186/s12955-020-01351-x. 11. Emerson ND, et al. *J Sch Nurs.* 2016;32(4):258-266. doi:10.1177/1059840515615401.

Please discuss any medical questions with a health-care professional (HCP).

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November 2021 NP-NN-ALL-00061121