

Hello –

Welcome back from summer break! I want to introduce myself and more importantly, [NAME] to you. He is in one of your Xth grade classes. He is on an IEP for his medical condition. He has a complex lymphatic anomaly (CLA) specifically Kaposiform Lymphangiomatosis that primarily affects his right leg and pelvis. More on that at the bottom for those that are interested!

What I'd like you to know

He has bone lesions in his femur and pelvis. He should not be involved in contact/impact sports and activities. He knows his limits very well and does not take advantage of it. He has a significant limp & scoliosis due to leg length discrepancy and has a modified shoe to help with this. His right leg is significantly larger than his left and has discoloration that looks like bruising. He usually wears a compression garment and doesn't seem to be self-conscious about it. Ibuprofen is given for both pain control and fevers (possibly an effect of the disease or medication; not due to infection) but he shouldn't require taking anything at school except for if he forgot it in the morning (it happens).

If there are any contagious diseases that have been identified in his classes/grade, I would appreciate a call since he is on the immunosuppressant. He really has been very healthy, so we aren't anticipating issues. Hitting adolescence is a little challenging as it is (!) but we may need to make changes to his meds as we navigate through this experience. If there are anticipated effects, I will clue you in. Currently the main side effect from his meds may be occasional mouth sores.

What are complex lymphatic anomalies?

CLAs are a set of rare diseases characterized by abnormal growth of lymphatic vessels that may involve multiple organ systems, including lung, spleen, soft tissue, and bones. Less than 500 people worldwide are diagnosed with this condition.

He is taking an immunosuppressant, Rapamune.

Very few doctors, none regionally, know much about this condition. He was diagnosed in X. We travel to Children's Hospital in Cincinnati for follow-up. Generally, he has an annual MRI and continues with the immunosuppressant. He also receives an intravenous drug treatment at Children's Hospital in Omaha to increase his bone strength.

We are fortunate to have found the Lymphangiomatosis & Gorham's Disease Alliance (LGDA) website – www.lgdalliance.org. If you are interested in knowing more about the disease, I recommend this site – www.lgdalliance.org/about-the-disease/.

I am very involved with this patient community. I am an advocate for LGDA and know that it takes more than just me to successfully raise this kiddo. If you are still reading this far, then you know that you are part of that group!

If you ever have any questions or notice something worth mentioning, you can call or email at any time – [XXX-XXX-XXXX]; email [TEST@email.com].

Best,

[XXX]