**To**: Teachers, Administrators, Health Professionals

**Re**: Student

**Date**: September 7, 2017

**From**: Parents

We were very happy, blessed and grateful that our son, [STUDENT], did so well in pre-kindergarten last year. He was well taken care of in the classroom and by all the staff that worked with him on a daily basis. All necessary precautions were always adhered to. As you already are aware, [STUDENT] has a rare health concern that we would like to remind you of. For those of you working with [STUDENT] for the first time, we would like to make you aware of his illness and precautions that must be taken to ensure his safety and medical well-being in school.

[STUDENT] has Shwachman-Diamond Syndrome (SDS). One major component of this rare,

life-threatening illness is **Neutropenia**. **Neutropenia** is a medical term for an abnormally low number of one type of white blood cell, the neutrophil. The neutrophil is a very important component in the body’s defense against many bacterial infections. A normal **Absolute Neutrophil Count** (ANC) for a healthy person is 1,000 or greater. Anything below an ANC of 1,000 is considered neutropenia and means the body is at a greater risk for an infection/illness to occur. [STUDENT]’s “normal” ANC is 700-800 so we are usually cautious with him. \***Last month, his counts fell way below into the 500s so we have had to be even more cautious with him**. An individual’s ANC is determined by running a **Complete Blood Count** (CBC). It is usually done by a finger stick. [STUDENT] gets regular CBC’s every 1-2 months at his hematologist/oncologist, or sooner, if he is ill or has fever. [STUDENT] has this compromised immune system and it is typical for him to have a hard time battling infections, or even a simple cold. We do our best to keep [STUDENT] as healthy as possible by taking a few extra precautions (see outlined list below). If you could all help, while he is at school, we would greatly appreciate it. We want him to be able to have the same educational experiences as a normal, healthy child.

As we all know, young children are pros at passing around germs. He has had colds (viral infections) in the past and has sometimes been fine and able to combat them pretty rapidly, but other times, they did get more serious and he required hospital treatment. Sometimes at home, he receives daily injections to help his bone marrow and neutrophils work harder (they boost his ANC, we currently have had to stop these injections due to the concerns on past bone marrow biopsies. These injections could increase his chance of a malignancy so we now have to be even more cautious). Every Sunday, he also receives subcutaneous immunoglobins (IGG) for 2 hours, in which other people’s antibodies and put in to him. This continues to be a blessing for our family and helped him and us lead a more normal life “outside of a bubble.” We are hoping that this treatment plan already in place, with the precautions we are asking of all of you, that he will continue to do okay.

There really aren’t any special things that you need to do for [STUDENT]. He does not require any drugs or treatment. We just ask that you be aware of the issue and help us out with the following, which we assume you would probably do anyway:

1. If there is a major infection at the school – strep, staph, or some other bacterial thing, please let us know immediately. (Colds are viral and seem to pose no special threat to him, but we would still like to know, so if he gets ill, we have a source). Please have his classroom teachers, his 1:1 nurse or the school nurse alert us asap.
2. If [STUDENT] runs a high fever at any point (over 100), we also need to know right away. We would also need to know if along with the fever if he physically appears lethargic or fatigue. That could indicate his sugar level is <60. His sugar should be tested immediately. He may need to be stress-dosed with hydrocortisone by his 1:1 nurse (only after contact is made with mom or dad via their cell phones or at work). The nurse should also provide him with juice, a snack, or a packet of glucose gel right away and then retest till his sugar level increases. Follow the plan set forth by [STUDENT]’s endocrinologist on his Medical Forms.

\*In an **EMERGENCY**, if he totally appears unresponsive (adrenal crisis/adrenal insufficiency) or extremely fatigue/lethargic, the nurse or any member of the school staff MUST:

* Administer Solu-Cortef- IM (in his medical supply box) right away.
* Then call 911 and us (parents). If there’s an option, have EMS bring him to [HOSPITAL NAME] (where all his doctors are affiliated with and know his/his conditions).

\*It is imperative that you do the above in the sequence listed above.

3) If he gets injured during physical education, outdoor recess, or anytime during the school day, the wound should be cleaned immediately, an antiseptic ointment should be applied and it MUST be covered. If his platelet level is low (we will notify you if this is ever the case), it may take some time for the blood to clot.

Again, I assume that you would do these things anyway, for any child, but wanted to let you know why we might have these special concerns for [STUDENT].

The only other thing you could do for him, is to be sure that he – and the other children – learn all about hand-washing and other personal hygiene. I’m sure this is already part of your school routine, especially for Kindergarten. [STUDENT] should be especially encouraged not to pick at his skin (he has a tendency to do this)– hang nails, fingers in his mouth, scabs, bug bites, etc. – as these are sites where opportunistic infection enters the body (he forgets, so a gentle reminder is useful). I have sent in a few containers of Lysol wipes and antibacterial (alcohol-free) hand wipes to use for him and for the classroom. If you start to run low on anything, just drop me a note and I will replenish the supply. If the nurse can wipe down his chair, desk and work space (it should be an adjustable desk/chair) with Lysol wipes, that would be a great help. I have also sent in a yoga mat and “sit upon” (whichever he prefers). If the nurse could wipe this down after the children are done for the day on the meeting area/carpet and keep it in his cubby, we would appreciate it! [STUDENT] should have his own school supplies separate from his classmates: scissors, crayons, markers, glue, paintbrushes, pencils, mouse, keyboard, instrument (if any) etc. **[STUDENT] may NOT drink from a water fountain**. When using manipulatives or materials, [STUDENT] should have his own or they should be wiped down or sprayed prior to use. He should wash his hands immediately when any of these subject areas conclude. The nurse should dispense the hand soap for him or we will provide his own as well as seat liners for the toilet seat that can be discarded after each use. He will have a stepstool to assist him in the bathroom due to his short stature. As far as the bathroom, he may need assistance wiping if it’s a bowel movement (due to the consistency which is a cause of having pancreatic insufficiency). He does tend to take a little while to go to the bathroom as well. Please be patient. We also ask that he leaves 5 minutes early before his class to go to the cafeteria with his 1:1 nurse so if he eats hot lunch (at times he may want to), he can get on line and avoid the traffic jam and/or get injured due to his height. We have provided notebooks for his 1:1 nurse, OT, and speech therapist to communicate back and forth any issues/concerns, as well as for him to use in his sessions. Due to his short stature (another feature of Shwachman-Diamond Syndrome), he may need a box/bolster under his feet (which should have been ordered back in June 2017) and assistance coming down the stairs. His hands should be wiped after touching any handrails. On a daily basis, [STUDENT] consumes 24 pills (pancreatic enzymes) a day. He has pancreatic insufficiency (his pancreas does not absorb fat in foods which causes him not to gain weight as the average child his age). He will take pancreatic enzymes administered by his 1:1 nurse with all meals and snacks to help absorb the fat in foods. Without his enzymes administered correctly, he could experience an upset stomach, stomach pain, and/or have very loose, greasy bowel movements. His 1:1 nurse will have full control of the enzymes and the administration of them with snacks/meals. As a side note, [STUDENT] is a very difficult eater, but MUST eat. We are trying to avoid a feeding tube at all costs, so he will definitely need “prompting” during snack time and meals. If another child is sick within the classroom, we have included on the IEP for [STUDENT] to be not in a close proximity to that child.

Lastly, as stated on his IEP, [STUDENT] requires a climate-controlled classroom (air conditioning) on hot or humid days. If the classroom temperature is 78 degrees or higher, he requires air-conditioning. His air purifier should be turned on for the beginning of the school day till the end of the school day. Filter maintenance for the air purifier should be monitored by school custodial staff and replaced when necessary.

Please know that despite all he goes through (he spends lots of times at doctors and in hospitals), [STUDENT] is a happy and lovable boy. He absolutely adores his older brother and will talk about him often. [STUDENT]’s socialization with his peers has greatly improved. We have enclosed/attached a packet on the components and symptoms of bone-marrow failure, in his case, SDS, and how school staff can support a child/family. Please feel free to share the literature with any staff member that will be directly working with him this school year, as well as his IEP.

Thanks so much for taking care of our little guy! You have no idea how appreciative we are to all of you. Please do not hesitate to ask us if you have any questions or concerns.

Sincerely,

PARENTS