Who:

This is our son, XXXXX. He was diagnosed with Nephrotic Syndrome, in October 2012, at the age of 6, 2 months into kindergarten.

What:

Nephrotic Syndrome is an auto-immune disease that attacks the kidneys and stops them from working. There is no known cause and currently no cure. It prevents the body from responding to immune-system triggers correctly. When the immune system is triggered (by a cold, virus, bug bite), instead attacking the trigger, the body attacks the kidneys. As a result the body swells up because the kidneys can't keep the right balance of protein inside the bloodstream. Treatment involves high doses of steroids, and immuno-suppressant medications.

How he is feeling now:

XXXXX takes medication to maintain in remission, and we hope each day that these medications continue to work to keep him in remission and that we escape the dangerous side effects. The medications are immune-suppressants and are used to calm his immune system so his body does not attack his kidneys. They are serious medications, given to transplant patients and used in cancer treatments.

If XXXXX reaches September 1st without a relapse, we will begin to taper one of the 2 immuno-suppressants. If successful, this process will take almost a year, and is simply trial and error. If we successfully taper the medicine without a relapse, the other medication he will continue to take, best case, for an additional year or two.

What we are working on at home:

Helping XXXXX care and advocate for himself given his situation. Wash his hands, avoid others who appear sick, drink water constantly, minimize sun exposure, make healthy choices.

How can YOU help:

* Help XXXXX look out for himself. Help him navigate the social challenges he will face trying to navigate this as a 2nd grader.
* Support him when he makes good choices.
* Remind him to wash his hands: between activities, after contact with a lot of people, and always before eating or drinking.
* Encourage him to drink water.
* Separate XXXXX from anyone who is sick, exhibiting symptoms, or has sick family members at home.
* Let us know if you or other teachers / students are sick.
* Communicate potential risks to parents so they can decide whether to send their child or keep them home.
* Chicken Pox and Shingles can be life threatening and require immediate hospitalization. Please call at ANY hour if there has been potential exposure.
* Strep / Flu are also extremely dangerous. Please inform us if others have either.

Thank you!

Through all this XXXXX has shown unbelievable strength, yet it has been a lot. Anything you can do to keep our family healthy, greatly improves Wilson’s ability to live a normal life as well as his chances of beating this disease in the long run.

Thank you so much. We are so grateful to those around us who help us each day with these efforts. Please call at any time!

Parents’ Names

Cell phone number