

Dear Principal,

As you know my daughter has Turner Syndrome. February is Turner Syndrome Awareness Month.

**What is Turner Syndrome?**

It is a chromosomal condition that exclusively affects girls and occurs when one of the two X chromosomes normally found in females is missing or incomplete. It affects 1 in 2000 girls! Under-diagnosis and delayed diagnosis of TS is a real problem, with the average age of diagnosis at 15 years, arriving too late for life-altering treatments, early interventions, and most importantly health screenings for a potentially fatal heart defect.

***My main goal of awareness is to reduce the age of a girl being diagnosed with TS from middle school age to early elementary school age.***

I would greatly appreciate if you could include the attached info in your February E-Newsletter as well as share this info on the school's Facebook page.

I attached the Proclamation signed by Gov. Nixon declaring February as Turner Syndrome Awareness Month and a flyer briefing parents on the symptoms.

I request that you please pass this info on to the school nurse so he/she will be on top of looking for symptoms in girls as well. The school nurses are a key role in catching these un-diagnosed girls! Here is a link for the nurses to receive a complimentary CME for watching a video on TS and some posters to display. <http://www.turnersyndrome.foundation.org/physicians.html>

One new addition is the fantastic news that Cardinal Glennon opened a NEW Turner Syndrome Clinic! There are now 26 TS Clinics across the nation!! St. Louis is very privileged to be hosting one of them! This is great news in medical advancement for girls with TS. The clinic provides multidisciplinary care for children with Turner Syndrome. Patients have the benefit of seeing multiple dedicated professionals in one visit. In addition, families have the chance to meet other people with Turner Syndrome in order to gain social and emotional support. <http://www.tss-stl.org/clinic>

Thank you very much for your consideration in my quest to raise awareness!

Sincerely,

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Help me crush ignorance of Turner Syndrome!  
It affects 1 in 2000 girls!

***Take a closer look at short girls...screen early and offer treatment options for the best outcomes!***