

Glanzmann's Research Foundation Classroom Plan

504 Plan

Section 504 of the U.S. Rehabilitation Act of 1973 is designed to help parents of students with physical or mental impairments in public schools, or publicly funded private schools, work with educators to design customized educational **plans**. These **504 plans** legally ensure that students will be treated fairly at school.

We recommend calling a meeting at the beginning of the school year with your child's teacher, the school nurse, P.E. teachers, bus drivers, school principal, and any other personnel with whom the parent or school feels should have basic information about GT. This will give you the chance to educate those with your child during the day and reassure them that their main responsibility is to call the parent regarding medical issues, rather than trying to fix anything.

Bus

If the child is a bus rider, he or she should sit in the front seat in order to allow for communication between the driver and the child without delay, especially for younger riders. The front seat provides a smoother ride and eliminates horseplay between riders.

Physical Education

GT students can participate in many activities. Depending on the age of the student, these activities can vary and be evaluated based on situational circumstances. GT students should avoid contact sports and "roughhousing" activities as a safety precaution. This means no dodgeball, soccer, baseball, basketball, football, etc. P.E. activities should be limited to non-contact activities. Strenuous activities such as running for too long could cause bleeding in the joints muscles. Younger children will require limitations, while older students should have the opportunity to self-limit their activities as much as able. Activities such as tennis, golf, and swimming are great alternatives for GT students, and they should be encouraged to participate in these types of sports. Again, the age and maturity of the GT student should be taken into consideration. An older GT student can make physical activity decisions for himself/herself. They also need to make sure to keep themselves hydrated.

At the first sign of any pain or discomfort, the GT student should elevate and ice the limb/joint that is hurting. Remember the acronym RICE which stands for Rest, Ice, Compression (ace or aqua wrap), and Elevation of the affected limb or joint.

Recess

An assessment of the playground equipment should be made by the GT child's parents, regarding what is safe and suitable for a GT child to play on. This should be completed prior to, or as close as possible to, the first day of school each year. For example, no tetherball or merry-go-rounds, limitations on climbing equipment if no supervision, etc. Also, young children may need to wear a helmet every day as a precaution against head trauma, particularly if the playground has high slides or other potentially risky equipment.

School Lunches

No chips, popcorn, hard shell tacos, and any other hard or crunchy items should be included in their diet to decrease the occurrence of mouth and gum bleeds. Alternative snacks should be kept in the classroom so the student has options when restricted foods are being provided. If possible, have the child brush his or her teeth after lunch or rinse out the mouth after lunch to help reduce oral bleeding and good oral hygiene.

Tests and Classroom Work

Students with GT may miss extended periods of school due to appointments or hospitalizations. The student should not be penalized for a missed class due to issues related to the diagnosis, and a plan should be developed at the beginning of the school year to ensure a student is able to succeed in school even when unable to attend in person (handouts, lesson plans, notes, etc.)

Field Trips

If possible, GT parents should volunteer to chaperone all field trips, especially overnight field trips. If no parent is available, every effort should be made to have a staff member capable of administering first aid (nurse, health clerk) to accompany the child. GT children may not be able to walk long distances and based on the age of the child, a stroller, a wagon, or even a wheelchair may be required for trips to the zoo, amusement parks, or other venues that require a lot of standing and walking. The GT student should inform his/her teacher at the first sign of pain. At that time a stroller, wagon, or wheelchair should be made available for the student. If the parent is unable to chaperone the field trip, make sure that the parent is notified of the location and the

activities of the field trip.

If possible, provide a first-aid backpack for your child containing the most important medicine and a “nosebleed kit” for these field trips, in case the school does not provide it.

Snow sledding, skiing, ice-skating, and horseback riding are risky activities that GT children should avoid. Make sure the GT student wears his or her medic alert bracelet or necklace that day. The best practice is to wear the medical alert bracelet at all times.

Field Day

Like P.E., GT students can participate in many field day activities! Depending on the age of the student, these activities can vary and be evaluated based on situational circumstances. Sack races, tug of war (unless at the front of the line & wearing gloves), and 3-legged races are not suitable activities for a child with a bleeding disorder. Again, the age and maturity of the GT student should be taken into consideration. An older GT student can make physical activity decisions for himself/herself.

Treatments

Supplies should be kept in the office/health office as well as in afterschool programs if necessary. Students should be allowed to keep Novo7RT at the school and properly stored if necessary and available in case of an emergency. This enables the medication to be given by a parent or sent with a student to the hospital, as well as managing a lockdown of the school for any reason.

Nosebleeds

Keep a nose clamp in the child’s backpack and an extra one in the nurse’s office or school office. Nose clamps may not work for smaller children, and direct pressure will need to be applied. This will allow the nose to be pinched while the parent is being notified and on the way to school.

If possible, create a “nosebleeding” bag and keep it in your child’s backpack or at the nurse’s office. I would include in it (gauze or tissues removed from two tissue boxes, a plastic bag for disposal of the dirty tissues, gloves, and a nose clip). This bag can be handy when a child is away from school on a field trip or on the bus and has a nosebleed. Depending on the kid’s age, allow the nurse or any staff member to help

with holding pressure to the student's nose, in order to help it to stop quickly. A person's hand can get pretty tired after holding pressure for too long. If the nosebleed last longer 15 minutes notify the parents. (I don't want to change everything here but I would never ask them to wait 15 minutes. I'd rather know immediately during a fast bleed so it can be evaluated and responded to as needed). They should always notify you either way.

Bruises & Joint Injuries

RICE (Rest, Ice Compression, and Elevation of the affected limb or joint)

Parents should be notified of bleeds and injuries that require a trip to the school nurse or office. All head injuries, as well as blunt force injuries to the body, should warrant a trip to the Health Office for evaluation and notification be made to the parent.

Generally, teachers and school personnel are not trained to deal with bleeding or to recognize the degree of severity a GT bleed is. GT children should have a 'code' for the severity of their bleed so that the urgency can be relayed to the teachers, nurse, and parent.

1. **SEVERE:** Rush me to the nearest doctor or hospital
2. **BAD:** Pick me up from school, but we can probably take care of the bleed at home or in our doctor's office
3. **MODERATE:** I can take care of this myself until the end of the school day (scraped knees, slightly oozing nosebleed, gum bleed, painful bruise, etc.)

GT children should be taught to visually inspect their stool and report any bleeding to the teacher, who should call the parent immediately if there are concerning signs reported by the student such as red or black stool.

911

In the event, a 911 call needs to be made, make sure it is clear which hospital is to be used and that the EMTs or paramedics are told that the student has a Qualitative Platelet Disorder. The student's physician's phone number should be on file at the school and that physician is to be called immediately if the school is unable to contact the student's parents. Have a single paper that is kept in the student's file that includes the diagnosis, medications, doctor's phone numbers, allergies, etc. Office staff should be taught to hand this sheet over to the medical transport to be taken to the hospital with the student.

Example of a letter sent to the PE teachers for a teenager student with GT:

To: Physical Education Instructors and Other School Personnel

_____ has Glanzmann's Thrombasthenia (GT), a platelet function disorder. Small superficial cuts are generally not a problem and will stop easily with pressure. If this technique is unsuccessful in stopping the bleeding, call the phone number listed on the student's emergency information card. The primary symptoms of bleeding in patients with GT include bruising, mucosal bleeding (mouth, nose, stomach), and petechiae.

Physical fitness is important for _____. She/he should participate in physical activities that promote muscle strength, joint mobility, and aerobic fitness; physical fitness can even help prevent bleeding into muscles and joints. In addition to the physical benefits, participating in group sports fosters normal social development. We encourage children and adolescents with bleeding disorders to be involved in sports and physical activities that can continue into adulthood.

Any activity that increases the risk of head trauma or significant trauma to the body should be avoided. The risk of serious bleeding in persons with GT generally requires a careful review of physical activities. The following are general information about the recommendations for activity limits for this particular child or adolescent.

Discouraged Activities: Football, wrestling, boxing, lacrosse, competitive diving, as well as aggressive types of volleyball/dodgeball

Encouraged Activities: Swimming, bicycling (with a helmet), tennis, golf, basketball (carefully), ping pong, bowling, and softball. Weight training is also encouraged. However, performing maximal lifts or Olympic style weightlifting is not recommended. Stretching exercises to maintain or increase joint mobility is recommended. Some dance classes and yoga could also be beneficial.

The staff at the Hemophilia Center at _____ is available to meet with staff involved with _____, to provide education, answer questions and address concerns regarding his hemophilia and ability to participate in activities.

If you have questions regarding physical activities not mentioned above, please feel free to call one of us listed on the letterhead.

Important Traveling Information for GT Patient

A GT patient can perfectly travel anywhere in the world with some previous prep and plan.

Traveling in your country:

1. Notify your hematologist, if needed, you are going out of town. If you know you will be gone for a long period of time, try to get the name of the local area hematologists and hospitals.
2. Check all your prescriptions to make sure you have enough of it for the duration of the trip.
3. Make sure you have a designated bag, for easy access, to the medicine at the security area at the airport. Always arrive at least 2 hours before, in case they need to check all your medicine.
4. Carry a letter of Plan of Action from the hematologist doctor, stating you have GT, what it is, all the medicine you must carry with you at all times, and what are the procedures in case you need to be seen by another doctor or taken to the hospital.
5. Carry with you a "nosebleed kit", including tissues removed from at least two boxes, extra bags to dispose of the dirty tissues, a few pairs of gloves, some pieces of gauze, and a nose clip.
6. Also, always carry extra clothes for you and your child in case yours get dirty with blood
7. Ziploc bags to put ice in case you need to place it on a bruise, bump, or nose.
8. Bring appropriate and enough snacks in case you need to take medicine with food and can't purchase any or do not have access to any due to late hours.

Traveling abroad:

1. Notify your hematologist, if needed, you are going out of town. Try to find out which good hospitals are in the country and a doctor referral if possible.
2. Check all your prescriptions to make sure you have enough of it for the duration of the trip
3. Make sure you have a designated bag, for easy access, to the medicine at the security area at the airport. Always arrive at least 3 hours before departure, for international flights, in case they need to check all your medicine.
4. Carry a letter of "Plan of Action or Standard of care" from the hematologist doctor, stating you have GT, what it is, all the medicine you must carry with

you at all times, and what are the procedures in case you need to be seen by another doctor or taken to the hospital. If possible, have it translated to the native language of your country (Spanish, Portuguese, Arabic, Italian, etc), in case it is not English, or if their English is limited.

5. Carry with you a "nosebleed kit", including tissues removed from at least two boxes, extra bags to dispose of the dirty tissues, a few pairs of gloves, some pieces of gauze, and a nose clip.
6. Also, always carry extra clothes for you and your child in case yours get dirty with blood
7. Ziploc bags to put ice in case you need to place it on a bruise, bump, or nose.
8. Bring appropriate snacks in case you need to take medicine with food and can't purchase any, or do not have access to any due to late hours.

Example of Letter for Traveling with a GT child/patient:

To whom it may concern:

_____ (name of the patient) is under my care for treatment of Glanzmann Thrombasthenia (GT). GT is a qualitative platelet defect in which _____ (name of patient) platelets do not aggregate normally. As such, _____ (name of the patient)'s skin may have extensive petechiae and bruises, and she is at risk for bleeding, primarily mucosal bleeding, such as oral, nasal (or menstrual – women's case).

Standard of care, should _____ (name of the patient) have a bleeding episode, would be a transfusion of leuko-reduced and irradiated platelets. _____ (name of the patient) should receive 15-20 cc/kg (or what your doctor prescribed) of platelets if the therapeutic course is taken. Her most weight in our clinic was _____ (kg – lbs). However, because the development of antibodies against transfused platelets occurs frequently in patients with GT, thus limiting their effectiveness, I have recommended that Luisa avoid platelet transfusion if possible. Alternative therapies to control bleeding include treatment with recombinant activated factor VII (NovoSeven RT) at the dose of 20-30 mcg/kg every 2-4 hours until bleeding is controlled, and for nose bleeding, packing the nose with Afrin soaked Gelfoam. There is extensive case-report literature describing the effectiveness of NovoSeven in this situation and we have successfully controlled nose bleeds in _____ (name of the patient) with pressure only and Afrin soaked Gelfoam. However, in the event of a life-or-limb threatening hemorrhage, I would transfuse platelets.

_____ (name of patient) currently takes _____ of (your iron pill supplement) ___x day to correct iron deficiency. She can also use Amicar 250mg/ml _____ (dosage) orally every 6 hours as needed for mucosal bleeding. Lysteda 650 mg tablets _____ (dosage/times per day) can also be used for mucosal bleeding. She also takes Allegra (or allergy medicine) for allergy as needed. She should only use Tylenol for pain, as ibuprofen is contraindicated.

_____ must travel with all of these medications at all times. This includes both the medication and the diluent bottles. She must have these medications with her on all plane/boat/train trips. This medication cannot be stored with her luggage. Please feel free to contact me with any questions.