SAMPLE TOURETTE LETTER

To Whom It May Concern:

[Patient name] has been diagnosed with Tourette Syndrome.

A diagnosis of Tourette Syndrome (TS) is complex. Every student with TS is unique and tics may change, as well as wax and wane, making this a difficult disorder to understand and manage. In addition to the motor/vocal tics, many common related disorders may impact a student's access to a well-rounded education.

In most cases, a student will require education evaluations to determine which of the related disorders may be impacting (his/her***) education. Common difficulties that may occur in a child with TS include dysgraphia (written language deficits); Attention Deficit/Hyperactivity Disorder (ADHD), Anxiety, Sensory Integration, Social Communication Disorder, Processing Delays, Memory Deficits, Executive Function Deficits, and Obsessive-Compulsive Disorders.

It is important that all teachers and support staff (with the permission from the parents) understand the complexities of this disorder so that [Patient name] is **not** inappropriately punished for symptoms, and so that the student can be proactively supported. In other words, please refrain from pointing out, laughing at, asking [patient name] to stop the tics, or asking [patient name] to leave the room when (he/she***) is tic-ing.

It is imperative that [patient name] experiences school as an accepting and supportive environment. This may involve specific special education supports and accommodations. I would strongly suggest that you visit the Tourette Association of America (TAA) website (tourette.org) for detailed lists of accommodations and services.

I recommend that the school identify a designated individual to become knowledgeable about TS and make (him/herself***) known to the student as a trusted support person. The Tourette Association is an excellent resource for parents and professionals. It is often helpful to have a team conference call with a member of the Tourette Association of America Education Advisory Board. The TAA can be reached at 888-4TOURET or at support@tourette.org.

Sincerely,

Your Provider
Pediatric Neurology

Sample Response Plan for Non-Epileptic Spells (NES)

Overview: The clinicians working with [patient name] have determined that he/she has non-epileptic spells that may look similar to seizures, but are not actually caused by abnormal electrical brain activity. These episodes are psychological in nature and therefore do not warrant medical attention. These episodes are not purposeful or intentional. They are typically caused by difficulties coping with chronic stress or anxiety. The body responds physically to these negative emotions, similar to people who have stomachaches or headaches when nervous or stressed.

Other names for Non-epileptic Spells: Psychogenic Non-epileptic Seizures/Spells, "Pseudoseizures," Functional Neurologic Disorder/Symptom, Conversion Disorder

The approach to epileptic seizures and non-epileptic seizures/spells is different. Non-epileptic spells do not require medical intervention. Thus, it is important that those working with [Patient name] feel confident that he/she can recognize the non-epileptic spells. [Patient name]'s non-epileptic spells are described in more detail below.

It is helpful for family members and school staff to respond consistently to the non-epileptic spells in order to minimize their impact on daily functioning. It will be important for [patient] to have designated times in which he/she can use relaxation techniques, learned in therapy, in order to reduce the number of spells, and eventually to prevent them altogether. This may require [patient] to leave class for short (ten to fifteen minute) periods of time. While this may result in [patient] missing some parts of a class, in the long-term this will allow him/her to experience fewer spells and will actually increase the ability to attend as many classes as possible.

Description of non-epileptic spells:

Triggers: [Patient]'s non-epileptic spells are precipitated by increased stress. However, they can occur at any time, and are often not linked to any specific trigger. [Patient] does not appear to know when the spells are going to come on, but there may be some warning that this may occur if *** (***insert any warning sign that has been witnessed or discussed, such as breathing changes, looks different, feels hot etc***).

Description: [patient]'s non-epileptic spells often start with *** . **(***FOR CLINICIAN - delete this statement once you have completed this step. It is important at this point to describe physically what those interacting with patient will see when the patient has episodes so that they are able to recognize signs that it might be coming on and what the course of the episode will involve, be sure to include information about body movement, what the person's eyes look like, if they are making noise, if they are aware or unaware of surroundings. If there are multiple manifestations of spells, they should all be described in detail here***).**

Duration and response to spells: [Patient]'s episodes often last ***. After the episode is over, he/she may be tired, have a headache or not be able to remember what occurred.

It is important to remember that these spells will resolve on their own without intervention. Therefore, it is appropriate to simply monitor [Patient] for safety and allow the spell to run its course.

Response Plan for NES:

1. If you see that [Patient] is having a spell, or states concern that a spell may occur, talk to him/her briefly. Note if [Patient] is able to speak or respond to questions. This information can be helpful for him/her and their therapist in order to adjust treatment.

2. It is all right to give brief reassurance and to state what you are going to do in response to the NES, such as:
   a. "You are having one of your spells. It's ok. You will be fine. Right now you need to have some time to calm down. I am going to stay close by but step away so that you can have some time to relax." OR
   b. "You're having a spell, but you are ok and safe."

After this brief reassurance it is best to stop interacting until the NES has stopped. If this occurs in class and does not last for an extended amount of time, it may be best just to watch him/her closely but continue on with class. Once the spell is over, if he/she would like, it may be helpful to leave him/her room for a few minutes to calm or rest.

3. Ensure that [Patient name] is in a position where he/she will not get hurt. Keep him/her away from sharp objects, and ensure his/her head is not hitting a hard surface. It is best to avoid holding or restraining during a spell. Do not place anything in the mouth; it is not possible for him/her to swallow the tongue.

4. It is not recommended that he/she be moved during a spell. If sent out of the room, this will draw attention to the situation and may increase stress and anxiety. Therefore, it is recommended that he/she stay in the room after the spell, if possible.

5. If [Patient name] experiences a spell at school, those in the room should be instructed to return to their normal activities without interacting with him/her, until it is finished.
   a. We encourage you to use language like "[Patient name] is having a spell, but is okay. Let's let him/her be, so that he/she is able to relax."
   b. If the person is at home, all others should leave the room during a spell except for the person who will monitor for safety.

6. It is not appropriate to give medications, to send away from class, call the paramedics, or encourage avoidance of certain activities in response to a typical NES. If [Patient name] is injured with an episode or is having an atypical episode, consider further medical evaluation.

After the NES:

1. Note what happened just before the NES started. Is there anything that could have caused an increase in stress?

2. It is important that "normal" activities typical for [Patient name] be resumed as soon as is possible to reinstate normalcy and minimize disruption to daily activities. Neutral, calm responses to these events will help him/her to feel calm.

3. If [patient name] appears stressed, worried, or fearful, it may be necessary to have a brief period of time before resuming normal activities (i.e. maybe a 10 to 15 minute break, but should not need more that that).

4. [Patient name] should not be removed from an activity or asked not to participate, because this will give the signal that something is wrong, or that he/she cannot do something. [Patient name] is still capable of engaging in normal daily activities, and this should be encouraged.

Resources:

1. Functional Neurologic Disorders Hope (nonprofit organization) Https://fndhope.org/

2. Patient workbook: Taking Control of Your Seizures by Joel M. Reiter, Donna Andrews, Charlotte Reiter, and W. Curt LaFrance, Jr.
https://global.oup.com/academic/product/taking-control-of-your-seizures-9780199335015?cc=us&lang=en&

3. Therapist guidebook: Treating Nonepileptic Seizures by W. Curt LaFrance, Jr and Jeffrey Peter Wincze
https://global.oup.com/academic/product/treating-nonepileptic-seizures-9780199307173?cc=us&lang=en&

Please call us with any questions/concerns, 254-724-5437.

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Your Provider
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