

What to Do If You Are Reported to Child Protective Services

Tuberous sclerosis complex (TSC) manifestations – ranging from seizures, no sleep, no appetite, medication refusal, to self-injurious behaviors – can cause acting out, bruises, cuts, and even broken bones. Therefore, someone not knowledgeable about TSC may come to a wrong conclusion about why these behaviors are accruing and/or how these injuries occurred. Many professionals who come in contact with your child (such as teachers, administrators, counselors, school nurses, emergency room doctors, etc.) are “mandated reporters,” which means they are required under the law to report any suspected child abuse cases to Child Protective Services (CPS). Below are examples of stories recently shared on social media and/or to TS Alliance staff:

- A four-month-old had experienced a seizure; the parent took her to the local hospital. The local hospital did a CT scan and “spots” were found on her brain, leading to an inaccurate “shaken baby syndrome” diagnosis. Because the local medical community was not familiar with TSC, they considered no other possibility. Unfortunately, the child was taken from the parent, and the parent was referred to CPS.
- A new principal noticed a shagreen patch on the lower back of a student with TSC. He reported to CPS because he concluded it was scar tissue caused by the parents beating him.
- A parent was referred to CPS because of medical neglect by the school nurse. The child was refusing to take his medication, although the parents and doctors were trying everything possible.

These examples above are real stories about real families. Being reported to CPS can be overwhelming and can happen to almost anyone. Bruises, marks, refusing to eat, medication changes, medication interactions, and acting-out behaviors are all considered warning signs of abuse. Professionals who are not knowledgeable about TSC manifestations may assume the worst. Below are a few proactive actions you can take.

Make a journal and note in writing:

- Provide the school nurse with the “TS Alliance Healthcare Packet” (also available in an ePacket).
- Keep a record of seizure activity either by documentation or using a resource like www.seizuretracker.com.
- Take pictures of bruises, cuts, or broken bones and note time, place, situation and reason for the injuries.
- Get documentation from the physician when medication changes occur.
- Get documentation from the doctor when self-injurious behaviors are occurring (possible reasons for the behavior).

Talk to and educate all professionals working with your child about TSC. Provide a link to the TS Alliance website at www.tsalliance.org and download and print our “Introduction to TSC” booklet at <http://online.fliphtml5.com/tosk/lmdw/>.

If you are referred to CPS, here are some suggestions to help CPS understand TSC manifestations:

- Provide a printed copy of “Introduction to TSC” mentioned above.
- Download information about all your child’s TSC manifestations from www.tsalliance.org.
- Provide a letter from your child’s neurologist explaining your child’s specific manifestations and possible reasons for injuries or neglect issues reported.
- Provide them contact information for a TS Alliance Support Services staff member at 1-800-225-6872 or info@tsalliance.org.

If you are reported to CPS it means the professional working with your child cares and takes his/her role as a mandated reporter seriously. Remember a report filed means an investigation but not a crime. Your job at this point is to **educate the CPS investigator** and remember he/she knows nothing about TSC.



Tuberous Sclerosis Alliance

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