

Monday, July 21, 2014

This weekend “Hollywood” used “epilepsy” as a punchline in a movie and lost an actress whose parents speculate may have died as a result of an epileptic seizure.

Yes, we saw the opening of “Sex Tape” on Friday night and heard how the film used “epilepsy” as a punchline. In the case of “Sex Tape,” it felt more like a punch, because the reference minimized epilepsy and people with epilepsy.

In the film, a character played by Jason Segal finds himself in need of an explanation for his erratic behavior, which leaves him with cuts to his face and a dirty, disheveled appearance. When asked for an explanation he stops, collects himself and flatly uses having had a “fit” and “being epileptic” as an excuse.

(Note: We didn’t include the full quote because we don’t want to give it more life. If you want to know what was said without seeing the movie, you can contact us.)

Had Mr. Segal’s character actually had epilepsy and suffered a seizure as part of the storyline, it should have been portrayed as a cause for concern requiring appropriate seizure first aid. Using “being epileptic” as a comedic excuse was in poor taste.

Then, yesterday, we got the sad news that “The Patriot” actress, Skye McCole Bartusiak, who had recently been suffering from epileptic seizures, was found dead. According to news reports, her family speculates her death was seizure-related. This is a powerful reminder of the seriousness of epilepsy.

So why does “epilepsy” continue to be used as a joke? Will it take extremes, like injury and death in epilepsy, to make everyone stop using it as a punchline?

We want our TV and movie writers and producers to have more understanding and empathy about epilepsy. We want stronger “epilepsy filters” that screen out lines that are hurtful and negative and reinforce myths about epilepsy.

IF that’s what we want – we as the community of people affected by epilepsy also need to show our power and strength by speaking up loud and clear to spread awareness in order to increase the public’s understanding and empathy.

The Epilepsy Foundation of Greater Los Angeles is actively reaching out in Hollywood to educate studios and producers, because we want children to grow up in a world where epilepsy is taken seriously and garners greater public support for advocacy and research. We want TV shows and movies where people with epilepsy are part of the storyline but not the punchline. We want entertainment that fully includes people with epilepsy, and does not

leave them feeling ridiculed or minimized as the butt of a joke. Together with the community of families affected by epilepsy we want to help change the conversation about epilepsy – to help bring epilepsy and people with epilepsy out of the shadows.

As an organization, it's important for us to counter the events of this weekend with accurate epilepsy information that will hopefully make all of us more empathetic towards those living with epilepsy and lead to less injury and death due to seizures.

People familiar with epilepsy know that it is a disease/disorder of the brain and the seizures that people with epilepsy suffer are not funny and should not be taken lightly.

There are almost 3 million people in the U.S.A. and about 65 million in the world who are affected by epilepsy. In fact, 1 in 26 people will develop epilepsy during their lifetime, and anyone can develop epilepsy at any time. So chances are you will encounter someone having a convulsive seizure and we want you to know what to do.

The **5-S** of Seizure First Aid

1. **STOP** and calmly help the person
2. Make sure they are **SAFE**
3. Turn them on their **SIDE**
4. Put something **SOFT** under their head
5. **STAY** with them until they are fully aware

If the seizure lasts more than **5 minutes**, call 911.

Epilepsy affects more people than multiple sclerosis, muscular dystrophy, cerebral palsy and Parkinson's disease, combined. But even if epilepsy only affected 1 person it is still no excuse to use it recklessly as a punchline in a movie.

We found this powerful quote of Ellen DeGeneres and it says most of what we want said: *"Most comedy is based on getting a laugh at somebody else's expense. And I find that that's just a form of bullying in a major way. So I want to be an example that you can be funny and be kind, and make people laugh without hurting somebody else's feelings."*

The EPILEPSY FOUNDATION OF GREATER LOS ANGELES is leading the fight to END EPILEPSY® and the burden of seizures. Our fundraising and community efforts support care, advocacy and education, today, while investing in research and hope for tomorrow. Our organization is glad to consult on any movie to ensure accurate portrayal of epilepsy. We welcome calls from individuals affected by epilepsy because we are your allies in this fight. **Visit us online at ENDEPILEPSY.org and contact us at Help@EndEpilepsy.org and 1.800.564.0445**