

The activities promoted by ASPE on the Purple Day in Brazil: a letter to Cassidy Megan

As atividades promovidas pela ASPE para o Dia Roxo, no Brasil: uma carta para Cassidy Megan

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RESUMO

A epilepsia é a doença neurológica crônica mais comum no mundo e afeta todas as idades, raças e classes sociais. Desde 2002, a Organização não Governamental (OnG) Assistência à Saúde de Pacientes com Epilepsia (ASPE) desenvolve ações de conscientização sobre epilepsia no Brasil, sendo ela a executora oficial do Projeto Demonstrativo sobre Epilepsia no Brasil parte integrante da Campanha Global 'Epilepsia fora das Sombras' da Organização Mundial de Saúde, da Liga Internacional Contra Epilepsia e da Associação Mundial de Pacientes com Epilepsia (OMS/ILAE/IBE). Buscando ampliar as ações de divulgação para o ano de 2014, a ASPE em parceria com a Fundação Internacional Anita Kaufmann promoveu o Purple Day, celebrado no dia 26 de março, no Brasil. O Purple Day teve início em 2008 com a manifestação de uma menina de 9 anos, Cassidy Megan, de Nova Escócia, Canadá, com o objetivo de aumentar a conscientização sobre a epilepsia. A escolha do roxo remete à lavanda, a cor internacional da epilepsia, dado ao fato que a flor lavanda remete a um sentimento de isolamento, solidão, frequentemente vivenciado pelas pessoas com epilepsia. A presente carta tem por objetivo descrever à Cassidy Megan sobre as atividades realizadas no Purple Day.

Palavras-chave: epilepsia, conscientização, comunicação

ABSTRACT

Epilepsy is the most common chronic neurological disease worldwide and affects all ages, races and social classes. Since 2002, the nongovernmental organization (NGO) "Assistência à Saúde do Paciente com Epilepsia" (ASPE) undertakes activities to raise awareness about epilepsy in Brazil, as the official executor of Demonstrative Project on Epilepsy in Brazil, part of the World Health Organization Global Campaign 'Epilepsy Out of Shadows', the International League Against Epilepsy and the International Bureau for Epilepsy (ILAE IBE WHO). To expand its actions on 2014, ASPE in partnership with the Anita Kaufmann Foundation promoted the Purple Day, celebrated on March 26th, in Brazil. The Purple Day began in 2008 with the initiative of a 9-year-old girl, Cassidy Megan of Nova Scotia, Canada, with the goal of raising awareness about epilepsy. The choice of purple refers to the color of lavender fields, to the feeling of isolation linked to this flower, often experienced by people with epilepsy. This letter aims to describe directly to Cassidy Megan about the activities promoted on the Purple Day.

Keywords: epilepsy, awareness, communication

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Campinas, Brazil.
March 26th, 2014.

Dear Cassidy Megan,

In this letter, I would like to tell you about Purple Day in my city, in Brazil. But, first, I shall tell you a bit about myself.

I had just graduated in Nursing and started my Masters in Neuroscience, when I was invited to be part of a volunteer organization in Epilepsy, called 'Assistência à Saúde do Paciente com Epilepsia' (ASPE). In English, it would be 'Healthcare Assistance to the Patient with Epilepsy'.

As a volunteer, I went to a very poor community in Brazil's countryside to talk about Epilepsy. There, people with Epilepsy amazed me with their willpower and strength to overcome so many barriers in life. I thought I would be

teaching there, but I was the one learning. As a nurse and as a human being, I would do anything to break down these barriers. To knock out prejudice, fear, shame and solitude. I came back home with all these wishes in my mind.

The organization I told you about, ASPE, was created in 2002 with this same purpose. As part of a World Health Organization campaign called 'Epilepsy Out of Shadows', ASPE was founded to promote Epilepsy awareness in Brazil, starting at University of Campinas.

This year, the founding chairman of ASPE, Prof. Li Li Min, told me about you. A 9-years-old girl from Canada who stood up to talk about Epilepsy on the 26th of March. Then, he said, the color of lavender fields, purple, was chosen to represent this day, recalling the solitude faced by those with Epilepsy. And, by gathering to talk about it, we shall send this loneliness away!

Figure 1 - Group Meeting for Preparation



I am happy to tell you that this day was all about purple and smiling people in Brazil. We started joining the ones with the same purpose: patients, healthcare professionals, students, reporters (Fig.1). Suddenly, Purple Day was all over the news. Through TV channels, several newspapers and magazines, social networks, all available through web,

we invited people to wear purple and join us. We even gave our voice for the Purple Day and recorded a song about it. I hope you like it! Watch this video: <https://www.youtube.com/watch?v=pu9GCAGDZ5k> (Youtube: Purple Day 2014. ASPE Wears Purple, Sings Along and Stands for Epilepsy Awareness).

Figure 2 - Campus Purple Lights



But we wanted the whole University wearing purple. What about brightening it on purple? Lights of the main centers in campus were covered in purple (Fig.2). Purple Day would last until night. Also, our ASPE president,

Mrs. Isilda, decorated the Hospital entrance with purple fabrics and posters, while others, nurses, doctors and students were distributing purple ribbons, leaflets and informations (Fig.3).

Figure 3 - Hospital Entrance in Purple preparation



Still, that wasn't enough. We wanted more noise. More purple. With a group of Medical students and with Alice, from ASPE, I simulated a seizure in the middle of the University restaurant (Fig.4). We did it during the busiest hour, lunchtime. I was afraid of performing it and I felt a great despair when pretending to lose control. Now, I understand a bit more of how difficult a seizure can be. It was extremely

important to have people I trusted by my side. By doing so, we were able to show to students how easily they could help and how naturally this situation should be seen. We definitely caught their attention. They had questions and they learnt about Epilepsy through our leaflets and our explanation (Fig.5). Other students were able to see it later on, when we released the video online, through social networks.

Figure 4 - Simulation at the University restaurant



In the evening, our founding chairman released his new book on Neuroscience and Epilepsy during a nice and pleasant event. Much more was said and heard about Epilepsy. People were gathered, laughing and taking pictures

together (Fig.6). The ones who posted pictures wearing purple on Facebook received a free copy of this book! 'Out of shadows', I may say, far from solitude. Purple Day extended throughout the night.

Figure 5 – Leaflets: ‘Keep Calm and wear Purple for Epilepsy on the 26th of March’



A dear friend of mine, who has Epilepsy, told me that she had never felt more welcome in life before. I didn't even know that she had Epilepsy. She was telling me for the first time, saying that we had no idea of how much it meant for her. I remembered of you, the reason why this beautiful day happened. Through this letter, I would like to congratulate you. Thank you for bringing so many people together. Thank you for allowing them to be heard, taken care of and, most important, to feel welcome as any of us should feel, every day.

That Purple Day may be remembered and disseminated all over the world. In Brazil, you can count on me and ASPE!

My best wishes and greatest admiration,

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Figure 6 - Me and my family together on the Purple Day



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