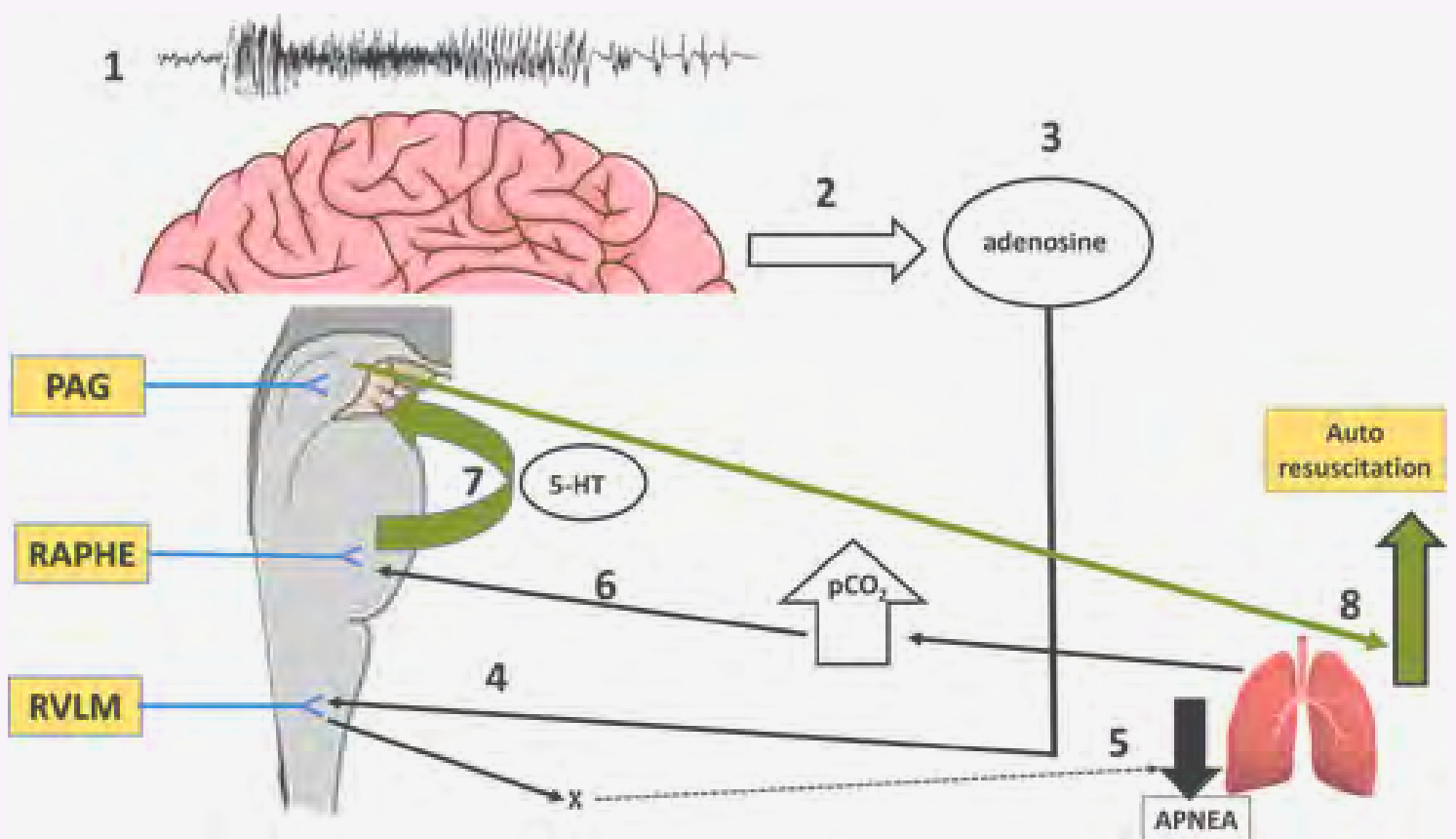


Epilepsy India

Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



Undefined Adenosine Hypothesis of SUDEP

(Explanation on back cover)

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Dear EI Family!

Hope you are having a wonderful festival season.

This issue of Epilepsy India is focused on a very important aspect of epilepsy care which has a tendency to be discussed lesser than needed, many times due to the discomfort of giving news of a serious outcome which is considered uncommon; but nonetheless needs much more awareness and planning. We are talking about the discussion about Sudden Unexpected Death in Epilepsy (SUDEP). We feature a guest article from Joanne Doody, co-founder of Peter Doody Foundation, who has been working tirelessly as an advocate for SUDEP awareness.

The Cover picture graphic is also about SUDEP and denotes the 'Unified Adenosine Hypothesis of SUDEP' with explanation on the back cover.

In addition to this there are chapter reports, which serve as an inspiration for other members to organize epilepsy care activities in their own chapters.

We encourage our members to submit more articles for publishing, especially the lived experiences by people with epilepsy, their caregivers and the epilepsy warriors.

Param & Joy

Hello, my name is Joanne and I am the co-founder of the Peter Doody Foundation. The charity was registered in 2019 following the death of our son. Peter's cause of death was Sudden Unexpected Death in Epilepsy (SUDEP) which is when a person with epilepsy dies suddenly and prematurely and no reason for death is found.

Peter was our first born, big brother to Harry and loved deeply by many. He was kind, caring, thoughtful, sensitive, and funny and wanted to make life better for others whenever he could. A talented musician, music producer and there wasn't much he didn't know about technology! He had a wonderful enquiring mind. It is engraved on his headstone that he was too beautiful for this earth and he truly was. We have always preferred to say however "Peter is", not "was". We believe fervently that Peter still exists but not in the way we long for.

Peter was 17 years old when he was diagnosed and died when he was just 21. Tragically we were never informed about SUDEP until the point where it was too late and aside from the limited support we were able to give during those four years, he received minimal support elsewhere.

This led to the advent of our charity. We felt that transitional care from paediatric to adult services fell short and we wanted to look at how we could support. For those living with epilepsy the condition can have a profound effect, feeling isolated, stigmatised and confused, affecting mental as well as physical health. Our support crucially also extends to family members and friends. I find it incredulous that a parent, sibling, partner will witness their loved one having seizures then attend school, work, etc. in a potentially traumatised state with nowhere to turn for help.

As registered stakeholders with the National Institute of Clinical Excellence (NICE), we have continued in our aim to educate on SUDEP. This includes lobbying parliament and collaborating with other national and global epilepsy charities to get a clear message out there. That clinicians must inform of SUDEP of time of diagnosis and to have a patient's understanding of this checked upon at regular intervals.

In a recent film I made with the aim to stop SUDEP silence (use links below to watch), I refer to and acknowledge a considered unconscious bias around this. Would I really have wanted to know about SUDEP when Peter was alive? The answer is unequivocally yes. Of course, we would have been fearful and anxious as would have Peter, but, ultimately, we would have been empowered to help keep him safe. Any feelings of anxiety we may have felt at the time pale into insignificance compared to the trauma and finality of losing Peter forever.

If we had known about SUDEP we would have understood the seriousness of his condition. We believe it would have made a significant impact on medication adherence, for one. It would have also enabled us, as a family, to take safeguarding measures knowing about SUDEP and the risks associated with sleep seizures. We would have made adaptations to his sleeping arrangements and used a seizure detection device and an anti-suffocation pillow. We would have also had a far better understanding of Peter's vulnerability whilst being away from home at university.

What we would like to see happen in the future around SUDEP communication is for people living with epilepsy to be informed about SUDEP in clear terms. To not avoid using the word SUDEP, and what that means, by only talking about generic 'risk'. We would also like to see a comprehensive person-centred care plan with clear set pathways inclusive of an individual SUDEP plan.

We are often asked how clinicians should deliver the SUDEP conversation. First and foremost, SUDEP just simply needs to be spoken. Similarly to discussions Oncologists and Cardiologists have with their

patients, the informing of SUDEP will be extremely difficult and challenging, however this information must be given. There is no easy way, it is as simple as that. It just takes courage, kindness and time.

Explaining the mechanisms of SUDEP to the best of current understanding (heart and respiratory failure) is empowering and builds a clearer picture and increased understanding of this complex neurological condition. It would be wrong to assume that people automatically understand this. Another way to assist patients and families would be to inform of the varying aids and seizure detection devices which can increase the chances of a person being attended to when having a potentially dangerous seizure.

It goes without saying that to achieve optimal SUDEP care, there is a great need for increased appointment times and availability of epilepsy specialists and nurses. But the present lack of time and resources mustn't continue to be a reason not to inform patients about it. As parents who are now experiencing the finality of this unimaginable loss, we would simply ask clinicians to please have the courage to inform and discuss SUDEP. We ask you to please push past any personal anxiety or lack of appointment time so that patients and families get a fighting chance to keep their child/loved one alive.

My personal opinion is that people living with epilepsy are among the most courageous. I can't even begin to imagine how it must be to manage this complex neurological condition. From personal experience being Peter's mum and in the work I have done these past five years running an epilepsy charity, I feel that persons living with epilepsy are not getting the optimal care and support they should. This has to change now.

We will continue in the work we do and regrettably needs to be done, but as Peter's mum, I take comfort in my son's continuing legacy, having already brought about positive changes for those living with epilepsy and even more to come.

To find out more about the Stop SUDEP Silence film and our campaign please visit: www.peterdoodyfoundation.org

-Joanne Doody



Links to 'Stop SUDEP Silence'

Trailer: <https://youtu.be/QSDsllzBySc>

Film: https://youtu.be/wYIAR_jSZk8



Epilepsy Camp Report

*Contributed by: Dr Archana Verma, Consultant Neurologist
MGM Medical College, Indore*

Dr. Archana Verma, a neurologist from Indore, has been conducting an Epilepsy Camp at Geeta Bhawan Mandir every third Thursday since December 2021. There are 226 registered patients who come from all over MP, many cities of Rajasthan and Maharashtra. Antiepileptic drugs that cost almost Rs 1 lakh per month are given to them for free. A team of 20-25 volunteers and duty doctors(residents) give free services for consultation, drug distribution and operational management at camp.

Among the services offered in the camp are free antiepileptic medication distribution, free iron, calcium, and folic acid, free consultations, handicap certificates for patients with refractory epilepsy, marriage and pregnancy counselling, and fitness certifications for employment and school education.

AED are made available and supported financially by the kind donations of medical professionals, pharmaceutical companies, pharmacies, and some business firms like Moyra Sariya, among others.



Samman's Impact: Six Months of Support, Awareness, and Growth

Contributed by: Pooja Mehta

In the past six months, Samman has worked tirelessly to support individuals with epilepsy, both on the ground and online. Through a variety of activities, we've aimed to make a real difference in people's lives by providing care, raising awareness, and fostering empowerment.

Our rural medical camps in Dahanu and Dharampur have been central to this effort, offering essential healthcare services to hundreds of patients. From medical evaluations to therapy and even surgeries, these camps ensure that people in rural areas get the support they need.

Along with conducting Support group meetings at ADAPT, our office we've also conducted hospital support groups across Mumbai at places like KEM Hospital, Fortis Hospital, SRCC Children's Hospital, KDAH and Wockhardt Hospital. These meetings offer a safe space for people living with epilepsy to share their experiences, learn to manage the condition better, and connect with others who understand what they're going through.

In addition to health-related support, we organized a soft skills workshop for our members, led by a trained professional from within Samman. This workshop provided participants with valuable life and professional skills, and we celebrated their achievements with a graduation ceremony.



We launched online yoga sessions held twice a month, promoting physical and mental wellness for our members by offering them a space for relaxation and mindfulness. Additionally, we organized storytelling and crafts workshops at ADAPT for children with disabilities, encouraging them to express themselves creatively and joyfully.

Our work hasn't been limited to offline activities. In the past three months, Samman's social media presence has grown significantly. In the last three months alone we've reached nearly 90,000 accounts on Instagram and garnered over 1,87,000 views, spreading awareness and encouraging conversation about epilepsy on a larger scale.

In just six months, we've been able to make an impact through healthcare, education, wellness, and awareness. Samman remains dedicated to supporting individuals with epilepsy and creating a more informed, compassionate world.



Explanation of Cover Picture

Postictal apnea leading to terminal cardiac arrest is thought to be the commonest mechanism for SUDEP in witnessed cases. Seizures induce the production of adenosine leading in turn to termination of seizures.

However, adenosine also depresses respiration. This effect is mediated, partly, by inhibition of neuronal activity in subcortical structures that modulate respiration, including the periaqueductal gray (PAG). Serotonin is also released during seizures. In juxtaposition to adenosine, it enhances respiration in response to elevated carbon dioxide level that often occur postictally.

Reference:

Faingold CL, Feng HJ. A unified hypothesis of SUDEP: Seizure-induced respiratory depression induced by adenosine may lead to SUDEP but can be prevented by autoresuscitation and other restorative respiratory response mechanisms mediated by the action of serotonin on the periaqueductal gray. Epilepsia. 2023 Apr;64(4):779-796. doi: 10.1111/epi.17521. Epub 2023 Feb 15. PMID: 36715572; PMCID: PMC10673689.