

Psychogenic nonepileptic seizures (PNES) in Schools:

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Disclosures

I have no actual or potential conflicts of interest in relation to this presentation.

I receive royalties for intellectual property (“The Psychogenic non-epileptic seizures Pocketbook” and nonepilepticseizureseducation.com)

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Psychogenic nonepileptic seizures

- Definition of PNES
- Prognosis and risk factors
- How is the diagnosis made?
- Returning to school as part of the Recovery process

What are psychogenic nonepileptic seizures (PNES)?

- AKA dissociative seizures, functional seizures, stress seizures, nonepileptic attacks, and an abandoned term □ pseudoseizures

PNES: Resemble an epileptic seizure (involuntary movements of body parts, alteration of consciousness, paralysis, vocalizations) but **not associated with abnormal electrical activity in the brain.**

Epilepsy: diagnosis is given after the patient has more than one seizure and these are unprovoked (e.g., drug or alcohol induced). **Associated with abnormal electrical activity in the brain.**





PNES-misdiagnosis

PNES are often misdiagnosed as epilepsy

- PNES is often bounced back and forth between neurology and psychiatry/psychology = “**ping pong**” **effect.**
- **Keep a PNES rule out in mind**

Prognosis in youth with PNES

- Youth with PNES have better prognosis compared to adults
- Remission rates as high as percentages in the 70s
- Early behavioral intervention is key
- Treatment of comorbidities, if present, is essential.





Myths associated with PNES in teens:

- The stressors or conflicts that cause it are easily identified.
 - PNES is always caused by trauma
 - Patients present with easily identifiable psychiatric issues
 - Patients are faking symptoms to get attention
 - Patients can control their symptoms.
-



Risk Factors for PNES in Youth

- Epilepsy
- History of unexplained medical symptoms
- Family dysfunction, unrealistic parent expectations
- Traumatic life events - bullying, family, social problems, abuse, serious illnesses, exposure to violence
- Subtle to moderate undiagnosed learning difficulties, including language difficulties
- History of psychopathology - anxiety, depression, post-traumatic stress disorder, or ADHD



Networks of Care (how the diagnosis happened and who was involved)

- Primary team involved in diagnosis often hospital-based
 - Epileptologist or other medical specialties
 - Behavioral health team
e.g., psychiatry, psychology & social work
 - Nurse practitioner (epilepsy)

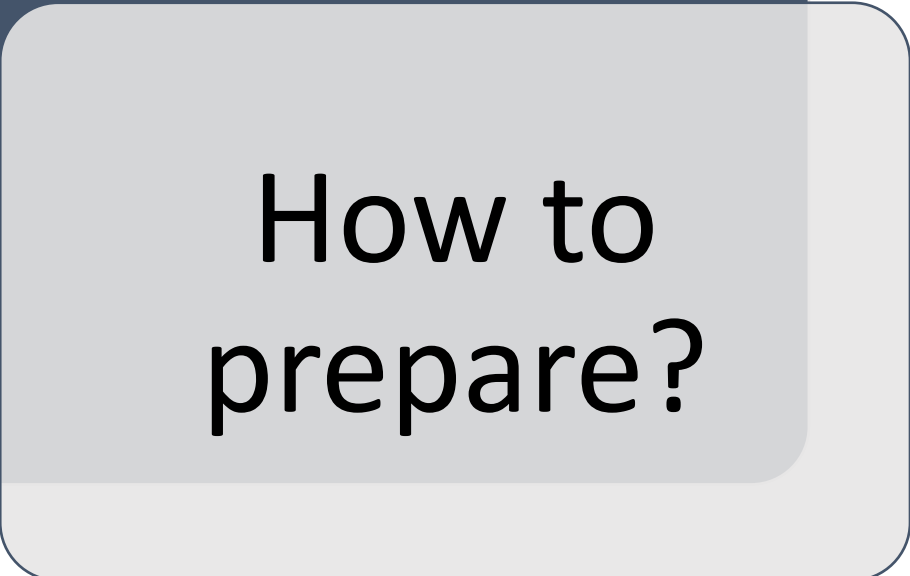
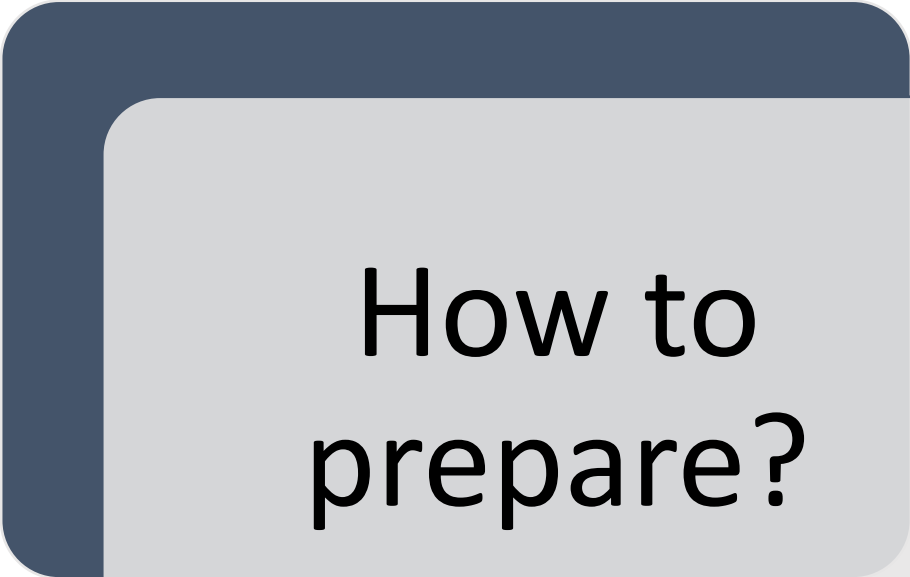
How is PNES diagnosed?

- The gold standard for diagnosis: Video-EEG during which all “typical” events are recorded, no associated epileptiform discharges are noted, before, during or after the event
- In hospital or at home (ambulatory V-EEG). Typically, 3 days duration (3-5 in hospital).

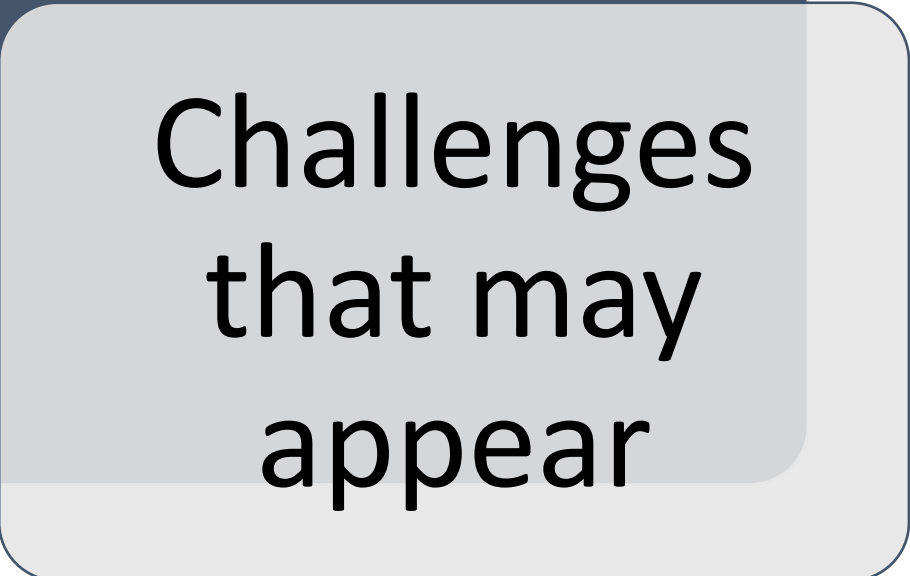
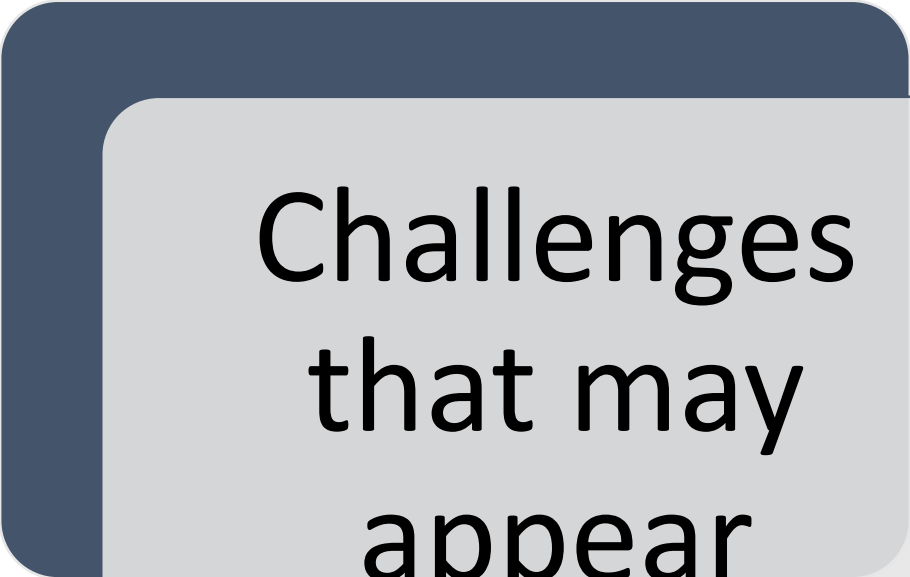




Returning to school



How to
prepare?



Challenges
that may
appear

Returning to School With PNES


- After diagnosis returning to “normal” functioning as soon as possible is a primary goal
- For most young people school is their “normal” and also usually involves some level of stress
- Depending upon how the diagnosis occurred, families may have more or less information about the diagnosis and how to respond to it
- The school can become an important aide in promoting return to “normal” as well as assisting the family in connecting with information to better understand the diagnosis and treatment.



Common Issues that come up for School Staff

- Few have heard of PNES
- Rarely receive adequate information about diagnosis
- Parents may not be comfortable disclosing information about student's diagnosis due to stigma of mental illness
- School staff may perceive the child as “faking” events



A large orange circle is positioned on the left side of the slide, containing the text 'How and when to return to school?'.

How and when to return to school?

- Return to school as soon as possible
- Prior to this: Arrange a meeting with relevant school staff, parents, and the child to create a seizure action plan

The meeting:

- Parents and child should meet with school nurse, counselor and other staff who work with the child prior to return to school
- A plan should be created for how to respond to PNES that may occur during the school day
- The student should have some accommodation for work and navigating the school day as needed to reduce stress upon return

The primary goal upon returning to school is being successful in managing episodes at school. Learning and social interaction will come but that should not be the main focus



Document during the meeting:

- How long do the events last?
- What is observed during them?
- What is their level of awareness?
- Does the person experience injuries when having their PNES?
- Does the person have a warning/what is the warning that an episode is about to start?



PNES Action Plan

Individualize action plan for PNES

Key components:

- Person's typical PNES event, any epilepsy seizures or other events
- Medical history (i.e., comorbidities)
- Behavioral steps to reinforce during event
- When to use rescue therapy if prescribed
- When to call and NOT TO call EMS (911)
- [Response plan template](#)



Walk through Steps of the Action Plan during Meeting:

- Encourage person with PNES to notify teacher or aide if they feel event coming on
- Ensure safety (provide recommendations for how teacher should respond if in the classroom)
- Stay in classroom if possible
 - Allow them to move to a quiet area
- If needed, assist person to nurse's office or another quiet area
- Decrease external stimuli as much as possible



Recovery: How to Help After an Event

Assess child's safety and ability to resume activity – ideally child should return to classroom activity as soon as possible

Notify parents of event if requested

Record in communication log or seizure event diary

Important for child to stay in school after an event to minimize adverse effects of PNES

Encourage child/youth use relaxation or distraction activities, but do not do the activity with them

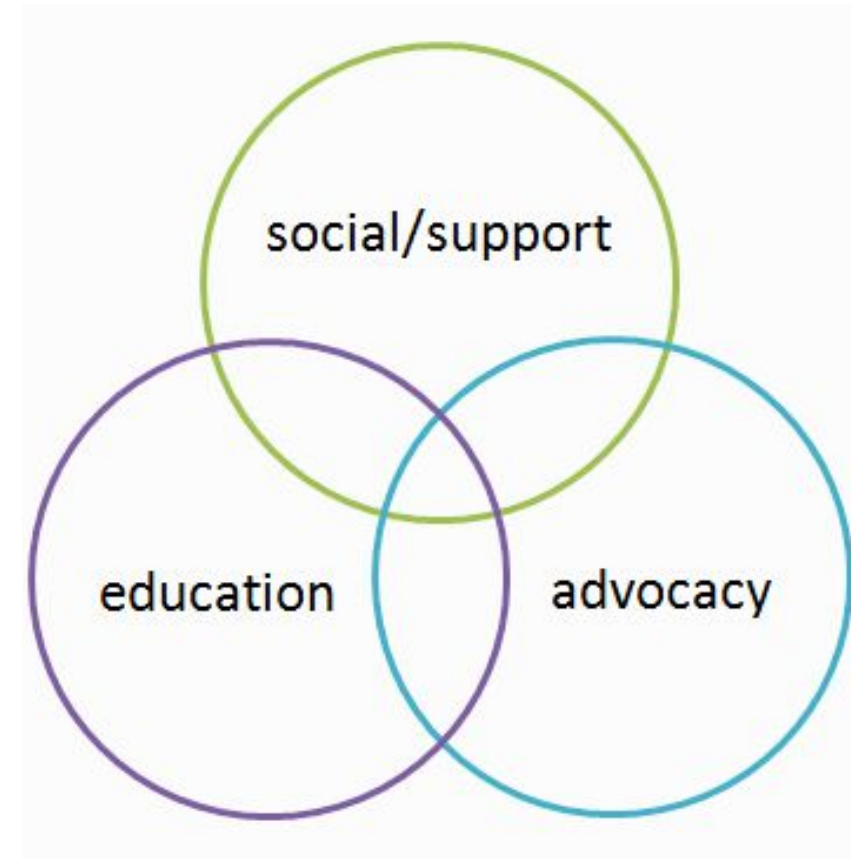
Avoid giving extra attention - event will pass quicker in a quiet environment free from extra stimulation

Do not call EMS for clearly defined PNES unless injury or other medical problems occur



Supportive Services for School Setting

- Individualized Education Plan (IEP)
- Consider 504 Plan accommodations
 - Plan visits to school counselor
 - Change classroom seating
 - Create break times to provide student relaxation and quiet time
- Consider need for modifications to student's schedule
 - Include time in special education room if FS is very frequent or affects learning



Training of School Personnel

- Ensure that substitute teachers, coaches, and other school personnel know how to use action plan
- Teach paraprofessionals to manage episodes and allow teacher to return to other students
- Work with teacher, family and student on how to talk with other students – same as for student with epilepsy



The background features two large, decorative, curved lines. One line, on the left, is a light green color and curves from the top left towards the center. The other line, on the right, is a light blue color and curves from the top right towards the center. Both lines have a soft, blurred, and layered appearance, giving them a sense of depth and movement.

The Challenge of Peer Interaction

PNES and Peer Relationships

- Most people respond well to a leader, the school staff (nurse, teacher, principal) are the leaders in the school and should take charge when PNES occur
- Instruct other students to continue working, teacher/aide/nurse respond to student with PNES- not another student
- Present a calm and strong response in order to calm the other students and draw attention away from the student with PNES
- Develop a system for assisting the student to leave if needed prior to a PNES to minimize disruption to the classroom and allow youth with PNES to manage it without distraction (i.e. sitting in the hallway, going to a back corner of room and sitting on the floor, or going to nurse or counseling office)



Managing Peer Relationships

- Help the youth develop narrative about their illness
 - Gives them a way of managing questions
- Role-play to prepare for interactions
- Encourage limits in amount of information shared
 - Full story to 2-3 best friends
 - Partial story to 3-4 more
 - General story to everyone else



Conclusion



- Youth with PNES should return to their typical school setting as quickly as possible following diagnosis
- Engagement with the school staff in developing a response plan for managing episodes at school is necessary
- Train staff in the response and encourage them to present a calm and planned approach to the PNES
- Assist the student with PNES in developing ways of addressing questions from peers about their episodes.

Conclusion:

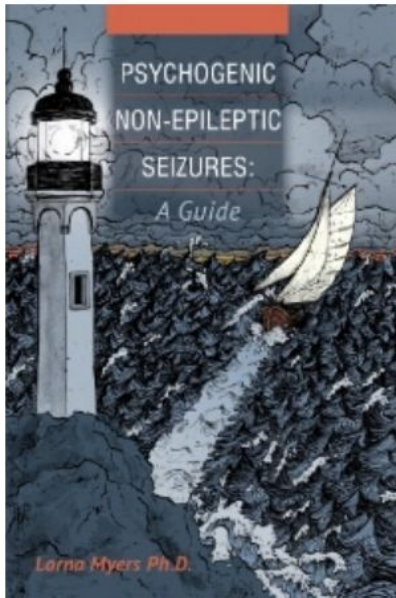
- Youth return to school following PNES diagnosis and will likely still be experiencing symptoms
- PNES can be managed safely in a school setting
- Understanding the diagnosis and its origins can help school staff better approach student
- School staff are one of the most important components in helping the student gain control of their PNES



PNES scholarship

Lorna Myers PNES Scholarship Fund

Applications Now Being Accepted



The application deadline for the 2024-2025 School Year is **April 30, 2024**.

Announcements about recipients for the 2024-2025 School Year will be made in June 2024.

The application process includes the following:

Lorna Myers PNES Scholarship Announcement 2024

Lorna Myers PNES Scholarship Application 2024

Provider Statement – Lorna Myers PNES Scholarship – 2024

Reference Form- Lorna Myers PNES Scholarship 2024

If you have questions about the application process, please email Lisa Gallipoli at lisa.gallipoli@epilepsyallianceamerica.org.



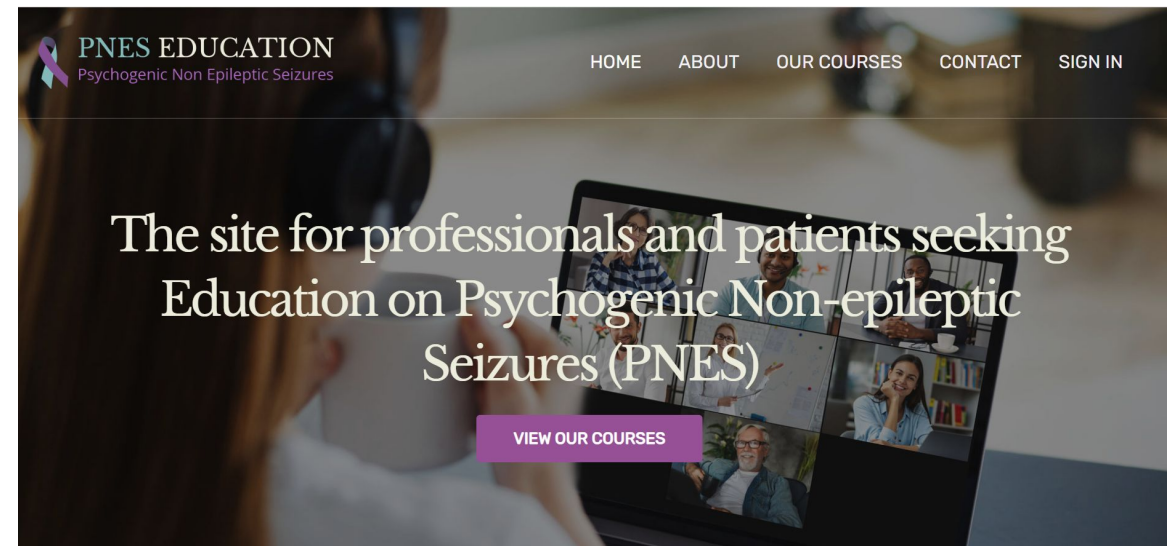
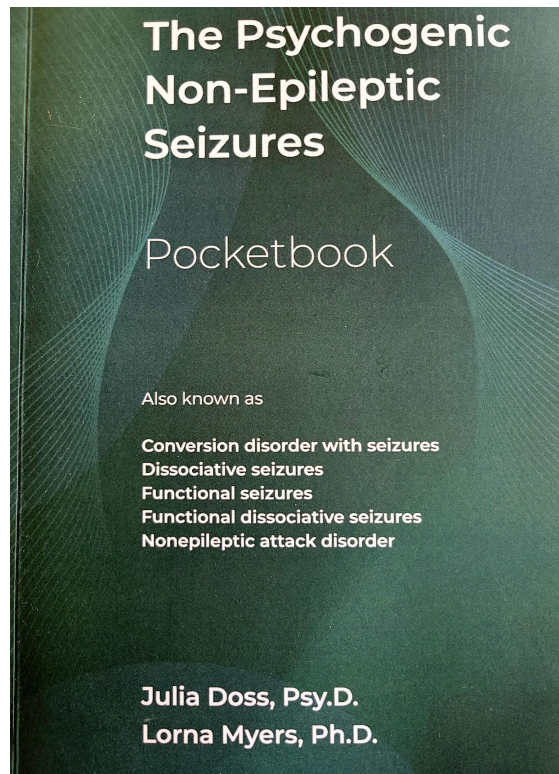
Patricia Gibson and Dr. Lorna Myers at American Epilepsy Society meeting – December 2023

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Professional Resources

- Pocketbook with chapters on how to manage pediatric PNES, maintain safety, and assist the child to maintain normalcy.
- Website with brief courses for school nurses and other school staff working with youth with PNES.
- <https://nonepilepticseizureseducation.com/>





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