

FUNCTIONAL NEUROLOGICAL SYMPTOM DISORDER, NON- EPILEPTIC SEIZURE (NES) ENTRY PACKET CHECKLIST

Ready to take control of your NES? To help get the most out of your treatment, please read the contents in the clinic entry packet. This checklist provides a guide through the documents included.

CONTENTS

- NES Welcome Letter
- NES Information Sheet
- Clinic Policies, Statements, and Guidelines
- Get to know your NES Team!
- 6 Week Group Therapy Agenda
- 12 Week Group Therapy Agenda
- NES Virtual Group Guidelines
- NES Seizure Diary (Example)
- Explanation of NES Standard of Care Scales (Questionnaires)
- Research in the NES Clinic
- NES Resources



Hello and welcome, to the University of Colorado, Neurosciences Center, NES

treatment clinic. NES is an acronym for non-epileptic seizures and is a term that is descriptive of what we know these seizures are *not*. Outwardly, patients have seizures which are initially diagnosed as epileptic, sometimes for years, but then are proved with scalp EEG to not be epileptic. An average of one third of the patients we evaluate in the Epilepsy Monitoring Unit (EMU) at the Anschutz Inpatient Pavilion have NES. Prior to 2016, we had no treatment pathway for NES patients, who included more than 200 patients diagnosed per year at our hospital alone.

NES is known by many names. In the United States (North America) the term psychogenic non-epileptic seizures (PNES) is commonly used. In the United Kingdom, dissociative seizures (DS) is more common. There are other derogatory and stigmatizing names for this disorder which most of our patients have unfortunately encountered. Our goal is to teach you more about what causes NES, to normalize this disorder and to provide an inclusive and welcoming environment in which to get well. We aim to help you to begin the process of gaining control of your seizures, by whatever name you call them.

In the fall of 2014, Dr. Alison Heru and I met to discuss how to create a treatment program for patients with functional neurological symptom disorder (FND) previously called conversion disorder. FND encompasses many different outwardly neurological signs and symptoms, like gait disturbance, paralysis, tremor, speech abnormalities and in the case of NES, attacks or seizures. Our goal was ambitious, to create a clinic to treat FND. What we wisely did, was to create a clinic to begin this work by focusing on patients with FND with attacks or seizures. We launched the NES clinic in August of 2016.

We modeled our treatment approach on the work of Dr. Curt LaFrance, first inviting him to come to Colorado and consult with us about his approach. After studying with him and absorbing his work, we analyzed the access which would be required to treat our patient population diagnosed in the EMU. We quickly realized that given our patient volume, a group approach would be needed. We created our current 6-week group curriculum using *Neurobehavioral Treatment (NBT)* from the book "*Taking Control of Your Seizures*" by Reiter, Andrews, Reiter and LaFrance in partnership with the group therapy experts from the University of Colorado, Department of Psychiatry.

As of 2020, we have treated nearly seven-hundred patients and we hope you will share in our enthusiasm as you come to know us and our program. We are honored to be a part of your recovery and have confidence that you will be successful in the pursuit of wellness.

So welcome and let us begin the process of recovery.



Laura A. Strom, MD, FAES
University of Colorado
Director, NES Clinic

Non-Epileptic Seizures (NES)

NES is a common illness and has many names: non-epileptic seizures, non-electrical seizures, dissociative attacks, functional seizures, psychogenic non-epileptic events, somatoform disorder, conversion disorder or psychogenic seizures to name a few. These events are outwardly similar to epileptic seizures but have a different underlying cause. They can involve anything from "zoning out" to fully blacking out and having violent movements similar to epileptic seizures. Sometimes, patients are told, incorrectly, that they have epileptic seizures, which can be confusing as very few patients have both. In some cases, patients with NES are given medicines for epilepsy. Making the right diagnosis is essential because medicines for epilepsy are not helpful for NES, which has a different treatment pathway. When epilepsy medications are used they are used for other indications (eg, migraine, mood disorder, neuropathic pain).

What's different about NES, and how is it treated?

Unlike epilepsy, NES is not accompanied by abnormal discharges on the EEG. NES is due to a temporary circuit disruption in the brain, akin to circuit overload. This makes it difficult, or often impossible, to stay aware and control what the body is doing during an event.

Our NES program has several components:

- A complete psychiatric assessment and neurological intake when needed
- Psychoeducational or psychodynamic group therapy
- Individual therapy
- Multi-family group therapy
- Medication management
- A treatment team of neurologists and psychiatrists
- Full patient participation in the decisions about your care

The individual, group and family interventions focus on teaching techniques to manage the triggers and warning signs of NES, and avoiding circuit overload.

What will my program of care look like?

- The NES team meets weekly and discusses the best individualized plan for each patient.
- A transition plan is developed for each patient.
- Our goal is to return you back to your primary care team after six months.
- We are optimistic that you will do well in our program.

University of Colorado Non-Epileptic Seizure Clinic

Practice Policies, Statements, & Guidelines

Welcome to the NES Clinic!

We are pleased to have the opportunity to serve and assist you on your journey to take control of your seizures. Please review the following guidelines and expectations for your participation in the NES Clinic.

Our goal is to provide timely appointments and access to our NES Team. Our clinic staff monitors missed appointments for all new and return patients. If you are unable to attend an appointment, we ask you to cancel your appointment at least 24 hours in advance. Advance notification of a cancellation provides us the opportunity to reassign the appointment time to someone else who may need it.

We understand that circumstances may prevent attendance at appointments, and you may not be able to cancel your appointment in time. However, if you do not call and cancel **four hours** prior to the appointment time, the University defines this as a no-show. Please review the following guidelines for a no-show in the NES Clinic:

New Visit: If a patient no-shows for a new visit three times, they may be dismissed from the clinic.

Follow Up Visits: If a patient no-shows for an individual follow up visit we will review the patient's adherence to prior visits to assess further scheduling. In general, if a patient no-shows three times to a follow up visit, we will not automatically reappoint the patient.

Group Visits: These appointments occur in series which build upon one another for treatment. Adherence to the prescribed numbers of appointments are needed for the treatment effect. If a patient **misses two or more visits** of the 6 Week Group (cancellation or no-show) they will be asked to attend the next available 6 Week Group. If a patient **misses three or more visits** of the 12 Week Group (cancellation or no-show) they will be asked to attend the next available 12 Week Group.

Discharge from Clinic: Following the first and second missed visit, the patient will receive a No Show/Cancellation reminder letter to their email. The letter will have the NES Clinic's Program Manager's and Neurology Clinic's contact information for the patient to reschedule. **PLEASE NOTE: If there is a pattern of no-shows and/or cancellations, the clinic may no longer be able to serve your needs and you can be discharged. A discharge letter will be sent from the clinic detailing your rights and next steps.**

Completion of Clinic: The NES Clinic is not a chronic care model. All patients will be asked to establish with additional providers outside of the NES Clinic to assist with ongoing care after the patient has completed treatment in the NES Clinic. Your readiness to complete treatment in the NES clinic will be discussed with your NES Clinic behavioral health provider. Once treatment is completed, a transition to outside care with the behavioral healthcare recommendations will be provided. These recommendations will be discussed with your ongoing care team.

Our goal is to provide every patient the highest level of care and service. We appreciate you helping us to serve your needs and the needs of all of our patients. Please direct your questions and concerns to our Program Manager, at 720-445-5345.

GET TO KNOW YOUR NES TEAM!

You may meet some or all of these individuals during your time with us.



Dr. Laura Strom - Neurologist/Epileptologist, Director

NES Clinic Roles: Individual evaluations and 6 Week group leader

Education: University of Pennsylvania

Started at University of Colorado: 1998

Years of NES Experience: 23

Fun Fact: Calls herself the knitting neurologist, likes to make jam.



Dr. Randi Libbon - Psychiatrist

NES Clinic Roles: Individual evaluations and 12 Week group leader

Education: University of Arizona College of Medicine

Started at University of Colorado: 2013

Years of NES Experience: 5

Fun Fact: Loves to bake sweets of all types.



Abbie Pennetti - Licensed Clinical Social Worker

NES Clinic Roles: Individual evaluations, 6 and 12 week group leader

Education: University of Pittsburgh School of Social Work

Started at University of Colorado: 2019

Years of NES Experience: 2

Fun Fact: Obsessed with Harry Potter.



Nicole Ralston - Physician Assistant

NES Clinic Role: EMU liasion, 6 Week group leader

Education: Red Rocks PA Program

Started at University of Colorado: 2019

Years of NES Experience: 2

Fun Fact: Colorado native.



Kim Ndahayo - Nurse Practitioner

NES Clinic Role: EMU liasion, 6 Week group leader

Education: Chamberlain University

Started at University of Colorado: 2020

Years of NES Experience: 2

Fun Fact: Has five boys and a black belt in Taekwondo.



Stacey Wilson - Physician Assistant

NES Clinic Role: EMU liaison, 6 Week group leader

Education: Red Rocks PA Program

Started at University of Colorado: 2016

Years of NES Experience: 4

Fun Fact: Has skydived over the Swiss Alps and backpacked Southern Europe.



Scott Pearson - Physician Assistant

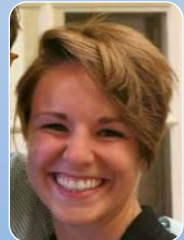
NES Clinic Role: EMU liaison, 6 Week group leader

Education: Red Rocks PA Program

Started at University of Colorado: 2018

Years of NES Experience: 10

Fun Fact: Went to high school with Neil Patrick Harris.



Meagan Watson - NES Clinic Program Manager and Development Specialist

NES Clinic Role: Patient coordination and clinic management

Education: Colby College

Started at University of Colorado: 2016

Years of NES Experience: 4

Fun Fact: Enjoys slacklining in the summer and skiing in the winter.



Travis Beckstead - Epilepsy and Seizure Program Manager

NES Clinic Role: Patient coordination and scheduling

Education: University of Utah

Started at University of Colorado: 2018

Years of NES Experience: 2.5

Fun Fact: Speaks Mandarin Chinese and is a proud Corgi Dad.



Sarah Baker - Professional Research Assistant

NES Clinic Role: Manage patient's clinical and research data

Education: Northeastern University

Started at University of Colorado: 2018

Years of NES Experience: 2

Fun Fact: Plays cornet and flugelhorn.



Holly Borland - Professional Research Assistant

NES Clinic Role: Manage patient's clinical and research data

Education: University of Colorado, Boulder

Started at the University of Colorado: 2019

Years of NES Experience: 1

Fun Fact: Has lived in Japan.

6 WEEK GROUP THERAPY AGENDA

University of Colorado Hospital Non-Epileptic Seizure Clinic		
Attendees:	People like you!	
Leaders:	NES Clinic providers. Please note: Depending on which group you are scheduled for you may be with providers you have met with in your individual sessions or not.	
Please complete before group visits:	<ol style="list-style-type: none"> 1. Read NES clinic expectation and guidelines. 2. Familiarize yourself with this NES packet. 3. Fill out/update seizure diary. 	
Date: ____/____/____	Week 1 – Getting Started! <ul style="list-style-type: none"> - Group member confidentiality - Expectations and outcomes - Defining NES - Mindfulness 	Virtual through Zoom Video-conferencing platform
Date: ____/____/____	Week 2 – Taking Control <ul style="list-style-type: none"> - Establish group goals - Triggers and stressors - Learn control - Empowerment and engagement - Expand knowledge of illness - Mindfulness 	Virtual through Zoom Video-conferencing platform
Date: ____/____/____	Week 3 – Acceptance and Responsibility <ul style="list-style-type: none"> - Sense of responsibility - Acceptance and coping mechanisms - Comorbidities - Mindfulness 	Virtual through Zoom Video-conferencing platform
Date: ____/____/____	Week 4 – The Mindful Pause <ul style="list-style-type: none"> - Reactions to stressors and triggers - Practice the mindful pause - You are not alone - Find support with resources - Mindfulness 	Virtual through Zoom Video-conferencing platform
Date: ____/____/____	Week 5 – Where to go from here? <ul style="list-style-type: none"> - Coping strategies - Support structures - Group reflection - Follow up with your appointments - Individual discussions 	Virtual through Zoom Video-conferencing platform
Please note this will be at a different time Date: ____/____/____	Week 6 – Multi-Family Group <ul style="list-style-type: none"> - Help communication between you and your family - Helping family understand NES - How has NES impacted or changed family functioning 	Virtual through Zoom Video-conferencing platform

NES Clinic Address and Contact Information:

Anschutz Outpatient Pavilion, 5th Floor Neurology

1635 Aurora Ct, Aurora CO 80045

(720) 848-2080

12 WEEK GROUP THERAPY AGENDA

University of Colorado Hospital Non-Epileptic Seizure Clinic		
Attendees:	People like you!	
Leaders:	NES Clinic behavioral health providers.	
Please bring:	All of your questions!	
Dates: ____/____/____ through ____/____/____	<p>Week 1-12</p> <p>In the 12 week group the weekly therapy agenda is patient needs driven. Review and think about the following questions:</p> <ol style="list-style-type: none"> 1. How do you connect your emotional and physical pain and why is that important? 2. What role has trauma played in the development of your NES? 3. What is the NES trying to communicate to yourself and your family? 4. Why does your body manifest stress with NES? 5. How do you communicate your needs to people in your support network including medical providers, therapists, friends, and family members? 	<p>Virtual through Zoom Video-conferencing platform</p>

NES Clinic Address and Contact Information:

Anschutz Outpatient Pavilion, 5th Floor Neurology
 1635 Aurora Ct, Aurora CO 80045
 (720) 848-2080

NES Clinic Virtual Group Visit Guidelines

These expectations are put in place for all virtual NES group to maximize your experience and eliminate any risk of loss of privacy for you or your group members.

Please review before your first group session.

1. Approach this group as you would if you were coming into clinic. Do not have other activities scheduled at the same time.
2. Remain in one room during the visit, just as you would for an in-person group setting.
3. Please dress appropriately just as you would for an in-person appointment. This is important to maintain a safe and comfortable space for all group participants.
4. Group participation requires both audio and video capabilities unless there are technological challenges requiring you to call in to the session. If you are regularly unable to utilize both audio and video settings, we will meet individually to address these concerns.
5. The location from which you choose to participate in group must be secure. Meaning others who live in the house are not able to hear or see the group. If you need to leave, mute your sound, and turn off the video. If others are in earshot (within the same living space) we require that you use headphones. This is especially important if there are children in the same area.
6. If you are responsible for the care of others in your household, plan for someone else, such as a spouse or other family member, to take on this duty during your group appointment. We understand this is not always possible. If you need to tend to your duty (you are the only one available) turn your video off and mute your sound while you tend to the needs of your household.
7. If others are in the room with you, you are moving about too frequently, or are distracted/not able to engage as you would if you were in person, we will place you in a virtual break out room to reduce distraction for the other group members, and a group leader will join you there to find a resolution.
8. If needed, we will place you in a break-out room to ensure the privacy of other group members. A group leader will join you to discuss a resolution to any difficulty you are having. When you are ready, we will rejoin the group setting to resume the appointment.

Thank you for reviewing and following these guidelines.

If you have any questions regarding these guidelines please contact Meagan Watson, NES Clinic Program Manager at 720-445-5345 or email Meagan.watson@cuanschutz.edu.

NES WEEKLY ONLINE SEIZURE DIARY

After your first visit with Dr. Strom in the NES Clinic, you will begin to receive an electronic seizure diary to your email. This diary will be sent **weekly** throughout the duration of your treatment in the NES Clinic. Until you are discharged from the NES Clinic, please continue to complete these diaries weekly – even when you are waiting for 6 and 12 Week Groups to begin!

The screenshots below show an example patient’s diary for Monday. Your diary will include the seizure types you agree on tracking with Dr. Strom and show the entire week, Monday – Sunday.

To the right of each day, you will see drop downs for you to indicate the number of that type of seizure you had that day. If you did not have any, please indicate “0”. You will also see drop downs for healthcare visits including Emergency Room (ER), Procedures, and Other visits. Please navigate to those drop downs if you have any of the visits indicated on the list. If you did not have any, leave it blank.

Finally, you will see two free text boxes at the bottom of each day. The Notes section is for you to describe your seizures and/or write down anything you think is important in relation to the seizures. The Triggers and Stressors text box is for you to write down anything you feel contributed to you having the seizures that day.

On the online diary there is a floating, blue “Save” button. Be sure to save you progress if you will be entering seizures on a daily basis. ***If you do not press save, your information will be lost and must be re-entered.*** You can submit the diary at the bottom using the green “Submit” button.

University of Colorado | Anschutz Medical Campus Department of Neurology

NES Weekly Seizure Diary

Start Date: 1/25/2021 End Date: 1/31/2021

SEIZURE TYPES:

A: Convulsion

B: Twitches

Please use the dropdown arrows to select how many seizures you have had of each type.

Day	Seizures	Healthcare Visits
Monday 1/25/2021	A: <input type="text"/>	ER: <input type="text"/>
	B: <input type="text"/>	ER: <input type="text"/>
		Procedure: <input type="text"/>
		Procedure: <input type="text"/>
		Other Visits: <input type="text"/>
		Other Visits: <input type="text"/>

Notes: (Suggestions: severity, impact on your day, impact on others, duration, time of day, location, precursor, improved with)

Triggers and Stressors:

Explanation of NES Standard of Care Scales (Questionnaires)

Brief Illness Perception Questionnaire:

This scale is only 8 questions long and uses a slider bar so that you can rank from zero to the highest ranking depending upon the question. This questionnaire explores how you feel about your illness, in this case non-epileptic seizures. Answer these questions from the perspective of your NES. If you have epilepsy as well, answer these questions just in terms of your NES.

The Brief COPE Questionnaire:

This scale is 28 questions and is located on 2 pages of the online questionnaire packet. This questionnaire is designed to help us understand your style of coping with stress and asks you to rate how often you do any of these specific activities from never (I haven't been doing this at all) to often (I've been doing this a lot). We are specifically interested in knowing how you are coping with the stress of having NES.

Childhood Traumatic Events Scale:

This scale asks you to answer questions in two parts. The first set of 7 questions asks you to reflect on life events during the first 17 years of your life. The second set of 7 questions asks you to reflect on any life events in the last 3 years. Please rate all situations on a 1 to 7 scales, 1 meaning not at all traumatic, and 7 meaning very traumatic. **Please note:** these questions can be trigger so please reach out to the NES team if you are having trouble answered certain questions of completing the scale.

The Family Assessment Device (FAD):

The FAD helps us to understand what impact family life may be having on your life. Some people are living in circumstances without family. Everyone should answer these questions in terms of however they define their family. Even if your family is remote from you. This questionnaire is 12 questions long.

The PTSD Rating Interview (SPRINT):

This scale asks you to identify an event in your life you found most distressing and traumatic. This is hard sometimes but it is very rare that someone cannot think of at least one traumatic experience. This questionnaire has 10 questions. Please make sure to identify which event you are answering the questions about in the empty field on the top of the page.

The Dissociative Experiences Scale (DES):

This scale has 10 questions. Not everyone has these experiences and in that case the drop down box will allow you to put in 0% or Never for any that do not apply. Each question describes a setting and asks you **IN** that setting how often the experience produces the result also described in each question.

The Quality of Life in Epilepsy (QOLIE-10):

QOLIE-10 is sometimes confusing for our patients with NES and those with NES and epilepsy together. This scale is designed for patients with epileptic seizures but has also proven very useful in

understanding the problems that people have with their NON-epileptic seizures. We would like you to answer these questions with your NES in mind if you have both. Please just replace any instance of epilepsy you encounter with the work non-epileptic seizures. We have permission to use this questionnaire but do not have permission to change this wording. There are 10 parts with 39 questions total in this questionnaire.

Generalized Anxiety Disorder (GAD-7 scale):

This scale is only 7 questions long on one page. The items ask you to rate how much you have been bothered by a set of problems, like being anxious or annoyed. The questionnaire is designed to determine if anxiety (feeling very worried) is playing a part in your NES or in your life in general. It is important to understand anxiety in order to make forward progress.

The Chronic Pain Grade Questionnaire:

This scale is a tool to determine how much or little pain is a factor in your everyday life. The questionnaire helps to determine how severe pain is for you. There are 7 questions to answer in this questionnaire all on one page. Pain is a common problem in general and will need to be addressed as part of a complete treatment program. The questionnaire uses a slide bar so that you can move your answer from 0 which is No Pain, all the way to 10 which is Pain as bad as could be.

The Patient Health Questionnaire (PHQ-9):

This scale is a way to measure how mood may be having an impact on patient health. The questionnaire looks at the last 2 weeks of daily life and asks you to rate problems with energy, concentration, sleep, eating, etc on a scale of not at all a problem to being a problem nearly every day. There are only 10 questions with the final question asking you to rate how difficult these problems have made it for you to work and take care of your home life including relationships with others.

These scales have been sent to the email address you provided to the NES Team or the email you have on file in your electronic medical record at the University Hospital. We know these take time and may be triggering, but please fill them out to the best of your ability as it helps our team best direct your care.

If you do not receive these scales within a week of your diagnosis or have any questions about them please reach out to the NES Team at (720) 445-5345

RESEARCH IN THE NES CLINIC

Throughout the duration of your time in the NES Clinic you may be asked if you would like to speak with one of our research assistants or learners working with the NES Team. A “learner” is a provider in training that is interested in working with and helping the NES population. This could include a medical student, resident, fellow, public health student, or other behavioral healthcare providers interested in learning how to improve their knowledge and skills surrounding the NES population.

All research assistants and learners are trained to maintain patient privacy and abide to HIPAA laws and regulations mandated by the Colorado Institutional Review Board (COMIRB) when conducting clinical research.

Most often, research in the NES Clinic involves filling out questionnaires. These questionnaires are in addition to the standard of care questionnaires you will receive from the NES Clinic providers that help them and you follow your treatment progress.

All research in the NES Clinic is 100% voluntary and will not affect your treatment. If you do not want to participate in research, please let our program manager know and she will inform the research assistants and learners to remove you from the list of interested patients.

NES Clinic Program Manager, Meagan Watson

Phone: 720-445-5345 Email: Meagan.watson@cuanschutz.edu



HELPFUL RESOURCES:

PRINT RESOURCES AND FND WORKBOOKS

1. Overcoming functional neurological symptoms: a five areas approach

Author: Professor Christopher Williams

2. Taking Control of Your Seizures Workbook

Author: Joel M. Reiter

3. Gates and Rowan's Nonepileptic Seizures

Authors: Steven C. Schachter and W. Curt LaFrance Jr.

4. Psychogenic Non-Epileptic Seizures: A Guide

Author: Lorna Myers, PhD

5. In Our Words: Personal Accounts of Living with Non-Epileptic Seizures

Author: Markus Reuber

6. View From The Floor: Psychogenic Non-Epileptic Seizures: A Patient's Perspective

Author: Kate Berger and Lorna Myers (Foreward)

7. Lowering the Shield – Overcoming Psychogenic Nonepileptic Seizures

Author: John Dougherty

8. Your Memory: How It Works and How to Improve It

Author: Kenneth Higbee, PhD

9. The Memory Book: The Classic Guide to Improving Your Memory at Work, at School, and at Play

Author: Harry Lorayne

10. Treating Memory Impairments: A Memory Book and Other Strategies

Author: Vicki S. Dohrmann



COMMUNITY RESOURCES

Epilepsy Foundation

<https://www.epilepsy.com/learn/types-seizures/non epileptic-seizures-or-events>

Help Guide – Trusted mental health and wellness

helpguide.org

National Center for PTSD

ptsd.va.gov

Anxiety and Depression Association of America

adaa.org

The Center for Trauma and Resilience

traumahealth.org

UCCS Veterans Health and Trauma Clinic

<https://www.uccs.edu/healthcircle/veterans-health-and-trauma-clinic>

National Alliance for Mental Illness

<https://www.nami.org/find-support/nami-programs/nami-connection>

Colorado Crisis Center

<https://coloradocrisisservices.org/>

ONLINE RESOURCES

1. <https://Nestreatmentucd.org>
2. <https://fndhope.org/>
3. <https://nonpilepticseizures.com>
4. <https://www.neurosymbols.org/>
5. <http://www.nonpilepticattackdisorder.org.uk/>
6. <https://www.aafp.org/afp/2005/0901/p849.html>
7. <https://emedicine.medscape.com/article/1184694-overview>