Seizure Monitoring Devices

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www.dravetfoundation.org

DRAVET® SYNDROME FOUNDATION

Seizure Monitoring Devices

- Devices used to help detect seizure activity, primarily at night or while sleeping
  - Video
  - Under mattress
  - Wearable
- Devices may detect movement, oxygen, heart rate, or respiration
- None of these devices will prevent a seizure
- All devices have limitations (missed seizures, false alarms, seizure types)
- Most of these devices are not FDA approved and are not considered medical devices, nor have they been shown to prevent SUDEP.

Before you decide:

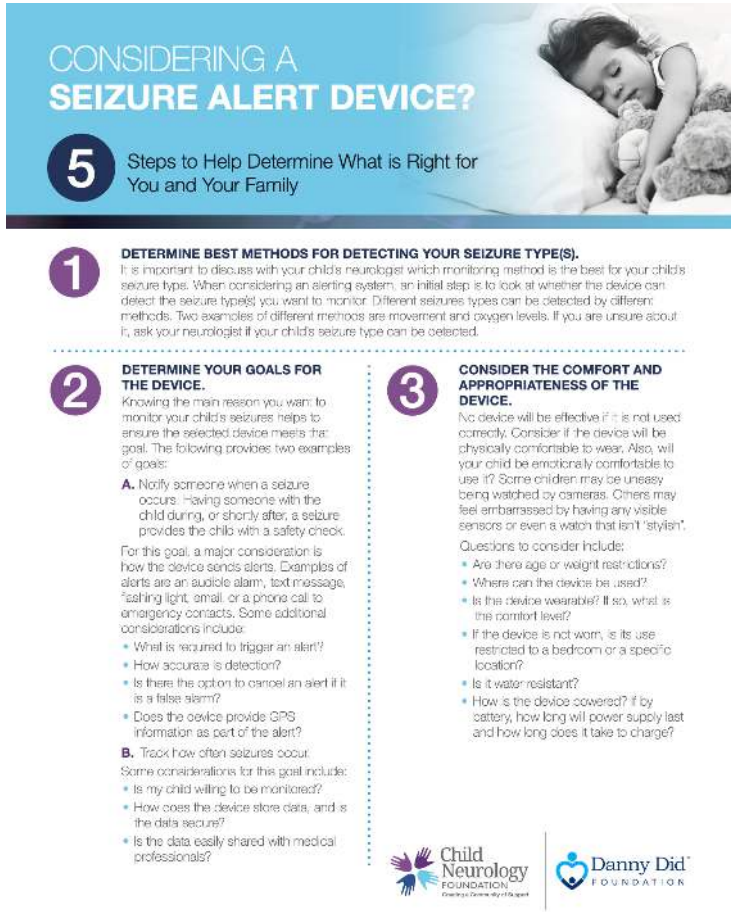
1) **Best method for detecting seizure type.**
Include a conversation with your child's neurologist when making a decision.

2) **Goals for device.**

3) **Appropriateness & Comfort.**

4) **Set up & Ease of Use.**

5) **Cost.**
Remember that both DSF and the DannyDid Foundation have assistance grants that may help cover costs for many of these devices


CONSIDERING A
SEIZURE ALERT DEVICE?

5 Steps to Help Determine What is Right for You and Your Family

1 **DETERMINE BEST METHODS FOR DETECTING YOUR SEIZURE TYPE(S).**
It is important to discuss with your child's neurologist which monitoring method is the best for your child's seizure type. When considering an alerting system, an initial step is to look at whether the device can detect the seizure type(s) you want to monitor. Different seizures types can be detected by different methods. Two examples of different methods are movement and oxygen levels. If you are unsure about it, ask your neurologist if your child's seizure type can be detected.

2 **DETERMINE YOUR GOALS FOR THE DEVICE.**
Knowing the main reason you want to monitor your child's seizures helps to ensure the selected device meets that goal. The following provides two examples of goals:

A. Notify someone when a seizure occurs. Having someone with the child during, or shortly after, a seizure provides the child with a safety check.

For this goal, a major consideration is how the device sends alerts. Examples of alerts are an audible alarm, text message, flashing light, email, or a phone call to emergency contacts. Some additional considerations include:

- What is required to trigger an alert?
- How accurate is detection?
- Is there the option to cancel an alert if it is a false alarm?
- Does the device provide GPS information as part of the alert?

B. Track how often seizures occur.

Some considerations for this goal include:

- Is my child willing to be monitored?
- How does the device store data, and is the data secure?
- Is the data easily shared with medical professionals?

3 **CONSIDER THE COMFORT AND APPROPRIATENESS OF THE DEVICE.**
No device will be effective if it is not used correctly. Consider if the device will be physically comfortable to wear. Also, will your child be emotionally comfortable to use it? Some children may be uneasy being watched by cameras. Others may feel embarrassed by having any visible sensors or even a watch that isn't "stylish".

Questions to consider include:

- Are there age or weight restrictions?
- Where can the device be used?
- Is the device wearable? If so, what is the comfort level?
- If the device is not worn, is its use restricted to a bedroom or a specific location?
- Is it water-resistant?
- How is the device powered? If by battery, how long will power supply last and how long does it take to charge?

Child Neurology FOUNDATION | Danny Did FOUNDATION

Dannydid.org

SAMi by Hipass Design

- Sleep Activity Monitor for iPhones
- Infrared camera
- Measures
  - motion
- Communicates with an Apple device, can see “live view” at any time; one iOS device MUST be in proximity (can bridge)
- Any age (privacy concerns)
- Adjustable triggers for alarms

Founder developed this device because his son had uncontrolled nighttime seizures

Not a medical device, not FDA-approved

Dannydid.org
samialert.com

Miku Smart Baby Monitor

- Not seizure specific
- Radar technology to detect breathing and sleeping patterns even in darkness
- Measures:
  - Breathing
  - Sleep patterns
  - Ambient temperature and humidity of room
- Some features can have alarms with smartphone
  - Apnea for 20 secs triggers an alarm
- Ages: 0-7+ years *(privacy concerns)*
- Hospital study validation in 13 patients looking at breathing
  (Aarts et al 2013 Early Human Development, doi: 10.1016/j.earlhumdev.2013.09.016)

Dannydid.org
Mikucare.com

Emfit Movement Monitor

- Movement detection (requires repetitive motion)
- Placed between mattress & box springs
- No age/weight restrictions (very large mattress might need two sensors)
- Studied at Le Bonheur's in-patient EEG facility: detected 9 out of 10 convulsive seizures
- Sometimes insurance has covered with prescription

Marketed in Europe as an Epileptic Seizure Alarm, in US not considered a medical device,.

Founder adapted an acoustic instrument monitor after having their own child with epilepsy

Dannydid.org
https://www.epiusa.net
http://shop-us.emfit.com/products/emfit-qs

Empatica Embrace 2 Watch

- Worn on wrist
- Measures:
  - Movement
  - temperature
- Tonic clonic/convulsive seizure longer >20 secs
- Must pair with a Bluetooth phone (w/in 30ft of device; can contact other caregivers from phone)
- Subscription plan required
- Alert sent to designated phone
- FDA Approved for Ages 6+
- Requires prescription

Dannydid.org
empatica.com

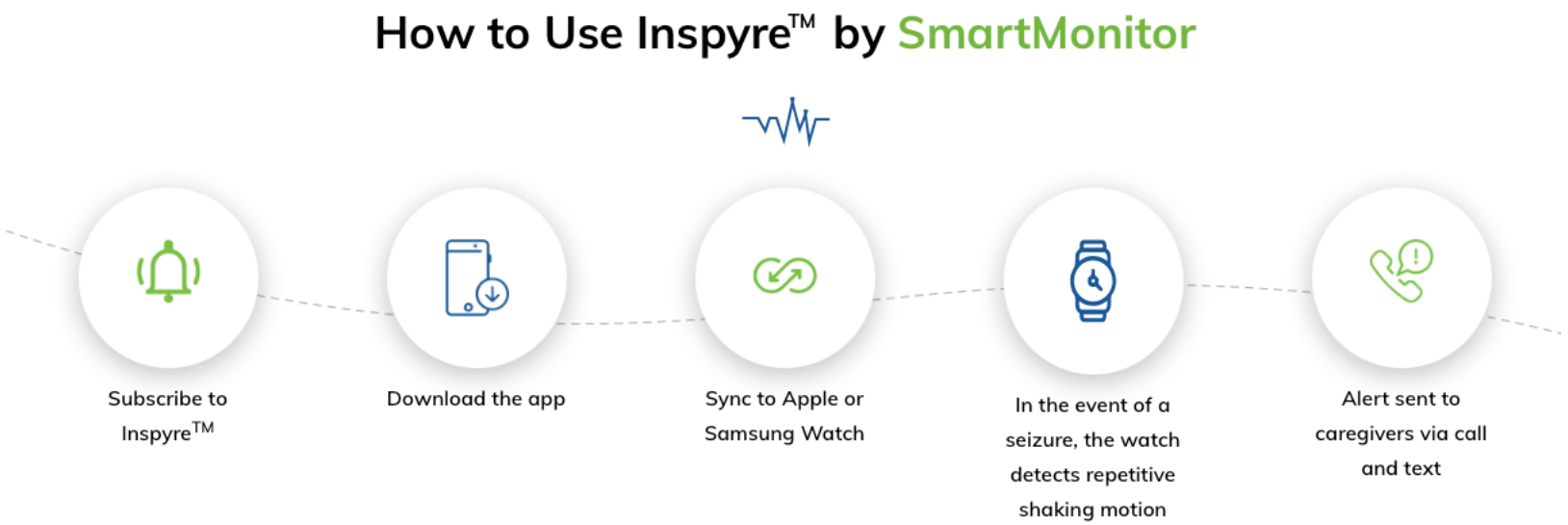
Pulse Oximeter

- Not seizure specific
- Measures:
  - heart rate
  - oxygen
- Requires a wired probe to be worn
- Any age
- Requires doctor prescription and DME provider
- Often covered by insurance

Dannydid.org
masimo.com/products/continuous/rad97/

Inspyre smartwatch App

- App for use on Apple Watch or Samsung Watch
- Detects repetitive/shaky movements
- Sends alert to a designated phone
- Requires a monthly subscription



Dannydid.org
Smart-monitor.com

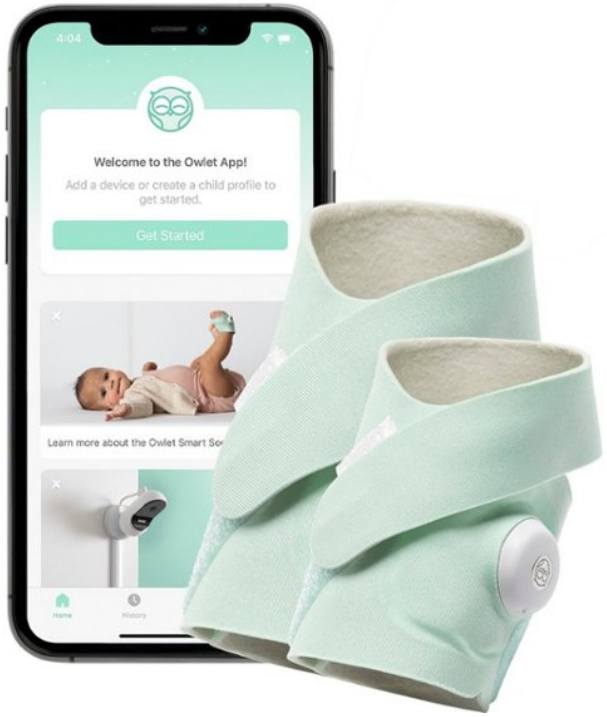
Neebo

- Not seizure specific
- Wear on wrist, arm, leg
- Measures:
  - Heart rate
  - Oxygen
  - Temperature at touch point
  - Audio
- Alert system to a Bluetooth paired iOS device (can bridge)
- Ages: Up to 5
- 3-day battery

neebomonitor.com

Owlet - Smart Sock Plus

- Not seizure specific
- Wear on foot
- Measures:
  - Heartrate
  - Oxygen
  - Sleep Patterns
- Alarms to a base station located close by, can also connect over WiFi to a smartphone
- Ages: Up to 5
- 16 hour battery
- *Also sell a companion camera*



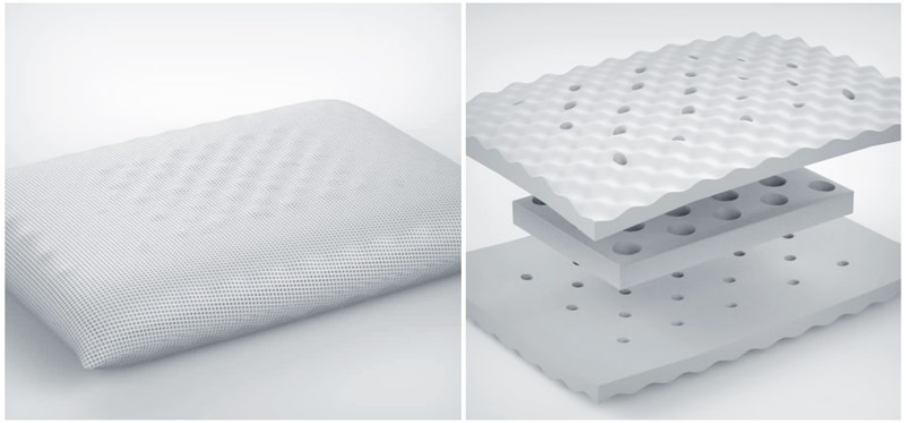
"The Smart Sock is an information-gathering product for use with healthy babies only. It is not a medical device"

Owletcare.com; cnet.com

Other Considerations

- Some families choose to use baby monitors or other video/audio devices
- Many families co-sleep

- Sleep-Safe Anti-Suffocation Pillow: “Epilepsy Safety Pillows”
  - Registered medical device categorized by the UK Medical and Healthcare Products Regulation Agency (not by FDA)
  - “Aero matrix” allows airflow throughout pillow to prevent suffocation



Dannydid.org
Sleep-safe.co.uk

Thank you

- Special thanks to the Danny Did Foundation for their excellent resources
  - Visit dannydid.org
  - Check out their “Dissecting Devices” webinar series for more in-depth information on specific devices

Questions? Email veronica@dravetfoundation.org

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