Joint Decision Making

Patient & Family
- Adherence: Clinical and/or Insurance
- Severity of Underlying Disease
- Severity of daytime Dysfunction without treatment
- Local availability of alternate devices or treatments
- Acute /Chronic symptoms of foam toxicity
- AHI
- O2
- CO2
- Sleep quality
- Overall medical complexity
- EDS
- Drowsy driving
- School performance
- Behavior

Medical Team

- The factors included here for decision making are common ones, but not an exhaustive list
- Decision making in each case should be approached individually
- Listed (and unlisted) factors, will have different weights in each patient
Does the child using recalled device have any of these diagnosis/comorbidities?

- Neuromuscular disorder with hypoventilation
- CSA or Hypoventilation Disorder (e.g. CCHS, ROHHAD, Rett syndrome, Prader-Willi Syndrome, Chiari Malformation)
- Chronic Lung Disease with chronic respiratory failure
- Cardiovascular disease and/or Pulmonary Hypertension requiring PAP therapy
- Severe Upper Airway Obstruction with gas exchange abnormalities

Does the child have marked improvement in daytime and/or nighttime dysfunction related to using recalled device?

- Yes
  - Suggest to continue using PAP device until it is replaced or repaired, or make an appointment to discuss alternative treatment options with child and family

- No
  - Suggest to discontinue device
  - Register for repair or replacement
  - Get a replacement device if possible
  - Discuss alternative treatments with child/family if they are uncomfortable with current options
  - Offer a school note to family/child about PAP therapy suspension

Does the child have marked improvement in daytime and/or nighttime dysfunction related to using recalled device?

- Yes
  - Suggest to continue using PAP device until it is replaced or repaired, or make an appointment to discuss alternative treatment options with child and family

- No
  - Suggest to discontinue device
  - Register for repair or replacement
  - Get a replacement device if possible
  - Discuss alternative treatments with child/family if they are uncomfortable with current options
  - Offer a school note to family/child about PAP therapy suspension

- Document patients decision or stated intention in medical chart or EHR
Recommendations: Shared Decision Making

This statement only serves as suggestions for guidance and clinicians should:
• Always consider the specific sleep breathing disorder and incorporate the opinions of patient and families when making recommendations.
  • E.g. - continuing PAP devices to prevent tracheostomy, and patients & families may opt to continue PAP to avoid tracheostomy
  • E.g. – a child with Prader-Willi syndrome using a PAP device to continue growth hormone therapy
• Acknowledge with patients and families that discontinuing PAP therapy, regardless of the severity of the underlying disorder, affects patients differently, as sleep disorders have variable presentations/phenotypes.
  • Possible risks of discontinuing PAP therapy in children include daytime dysfunction, severe daytime sleepiness, decreased mood or mood lability, inattention, hyperactivity, learning dysfunction, behavioral disturbance.
  • Long term risk of temporary discontinuation of PAP therapy in children is unclear.
• Acknowledge with patients and families that discontinuing PAP therapy may have an impact long term with maintaining adherence to PAP, and may result in children discontinuing PAP altogether.
• Provide guidance to alternative therapies at all times, as well as closely monitor patients for risks related to untreated sleep disordered breathing should children and/or families opt to discontinue PAP until a replacement device is available.