

**Recognizing and Comprehensively Treating Sleep Disordered Breathing in Children  
with Primary Bedwetting:  
Illuminating the Disparities and the Solutions**

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### **Abstract**

Bedwetting and sleep disordered breathing (SDB) in children are often related conditions. The goal was to assess parents' awareness of the connection as well as to investigate if SDB is adequately assessed and treated in children who wet the bed. A survey questionnaire was conducted to a closed Facebook group of parents who have children and teens that wet the bed. Based on parental feedback, a review of the literature, a case story review, and an interview with an expert in the field of SDB, the findings confirm that sleep disordered breathing (SDB) is an under recognized and an under diagnosed condition in children who wet the bed. Children who suffer with bedwetting need to be comprehensively assessed and treated for SDB at an early age using a multidisciplinary approach of healthcare providers that specialize in airway to prevent physical, emotional, and psychosocial distress.

Bedwetting, SDB and the connections between these disorders are defined and discussed followed by an exploration of multiple factors that contribute to the lack of comprehensive assessment and treatment in children and teens who wet the bed.

The model of healthcare that has a focus on airway health is a comprehensive solution to the assessment and treatment of SDB. A multidisciplinary team approach is described, including the importance and role of each provider within the team. A literature review on the outcomes of bedwetting resolution by treating SDB reveals qualitative evidence that treating SDB is effective at resolving bedwetting. Limitations of the data are discussed as well as the need for future peer review studies to look at bedwetting outcomes in children who have been comprehensively treated for SDB.

## **Recognizing and Comprehensively Treating Sleep Disordered Breathing in Children with Primary Bedwetting:**

### **Illuminating the Disparities and the Solutions**

#### **Introduction**

Most children do not think twice about joining their friends for sleepovers, week-long summer camps or moving away to college. These outings and important life events can be some of the most memorable times in a child's life. For some though, these exact occasions invoke anxiety and stress. Nick, a 12-year-old boy, had a common childhood problem, he wet the bed (Appendix B).

In his case, bedwetting was a symptom of poor sleep due to his inability to breathe properly at night. The connection between bedwetting and sleep apnea and other sleep breathing issues is well established in the literature. In a recent article, Neveus et al. (2020), reported that "there is a link between [bedwetting] and heavy snoring or sleep apneas in a subgroup of [bedwetting] children" (p. 12). However, Nick's mom, Sara, had never heard of the bedwetting/sleep breathing connection until, by chance, she found Joyce, an orofacial myofunctional therapist (OMT), who not only knew of the connection but also knew how to screen Nick for sleep breathing problems (Appendix B). Like Sara, many parents are not familiar with the connection between bedwetting and sleep disordered breathing (SDB). According to a survey posted to a closed Facebook group of parents who have children and teens that wet the bed, of 48 respondents, 33% have never heard of the connection, 52% have heard of it, but did not know much about it, and only 14% were familiar with the connection (Appendix A). Nick was fortunate to find Joyce. His bedwetting came to a halt the day he had his SDB issues treated (Appendix B). So why then, do kids like Nick, needlessly suffer with

bedwetting and SDB problems? Why are these kids falling through the cracks of our healthcare system? Children that wet the bed and have SDB issues are not only suffering from the consequences of bedwetting but also from the ill health effects of poor fragmented sleep. Sleep disordered breathing is under recognized and under diagnosed condition in children who wet the bed. Children with bedwetting need early assessments and treatments for SDB by a multidisciplinary team of healthcare providers that specialize in airway health in order to prevent physical, emotional, and psychosocial distress.

## **Background**

### **Bedwetting**

Bedwetting is a childhood condition that is more common than people realize. According to Baird et al. (2014), “An estimated 5 to 7 million children in the United States [wet the bed]” (p. 560). Zaffanello et al. (2017) described bedwetting as a “complex disorder that is characterized by intermittent urinary incontinence during sleep in a child at least five years of age” (p. 2). Nick suffered from primary nocturnal enuresis (primary bedwetting) until the age of 12. His mom, Sara, reported that he wet his bed 6 nights a week (Appendix B). Nick suffered from primary bedwetting which differs from other variations of bedwetting. Zaffanello et al. (2017) defined primary bedwetting as children who have never been dry at night for six consecutive months (p. 2).

Although the underlying causes of bedwetting are not fully understood according to Zaffanello et al., there is a genetic component. According to Hoffman (2012), the majority of bedwetting is inherited with “3 out of 4 kids either have a parent or first-degree relative who wet the bed in childhood.” In addition, Neveus et al. (2020) described the cause of bedwetting

to be a “mismatch between [nighttime] urine production, [nighttime] bladder storage capacity and the ability to arouse from sleep” (p. 11).

In the review article of the updated standardization document for the treatment and management of bedwetting, Neveus et al. (2020) lists the alarm and a medication called desmopressin, as initial therapies in the treatment of bedwetting. Other therapies are offered if the initial therapy fails to work. It states that other conditions commonly coexist in children with bedwetting. The updated recommendations discuss the need to evaluate and treat comorbidities, such as constipation, psychiatric conditions, urinary tract infections and sleep apneas and heavy snoring, all of which can have an influence on the effectiveness of bedwetting treatments (pp. 11-12).

It is important for parents and healthcare practitioners to comprehensively address the child’s bedwetting early on because the psychosocial effects of bedwetting can be profound and long lasting even after the condition has ceased. In Hornsby’s (2020) interview, O’Connor described her history of childhood bedwetting and the psychosocial and emotional ramifications she suffered and how even today she still experiences feelings of shame and embarrassment. O’Connor remarked, “I actually still have some scars” (Hornsby, 2020). Furthermore, according to Grzeda et al. (2017), bedwetting is associated with poor self-image and self-esteem and “females had increased levels of depressive symptoms” (p. 656). Their findings indicated that being found out, the anxiety of participating in overnight social activities, parental stress, all influence the child's psychosocial development. It is obvious that early intervention and treatments are necessary to spare the child from psychological and social stress associated with bedwetting.

## **Sleep Disordered Breathing**

There is a silent pandemic occurring in our children. Sleep disordered breathing (SDB) is often unrecognized by parents and healthcare practitioners. The high health toll to our children from SDB is unacceptable and preventable. There needs to be a shift among parents and the healthcare profession in recognizing and treating SDB. The shift begins with being aware of what SDB is, what the signs and symptoms are, why early recognition of SDB is important and knowing the four root causes of SDB.

Fully understanding sleep disordered breathing is necessary in being able to recognize if a child is suffering the ill health effects from poor, fragmented sleep. According to McIntosh, a pediatric ear, nose, throat (ENT) doctor specializing in airway health, SDB describes a broad spectrum of breathing problems while asleep (O'Connor, 2020). In his interview he gave a detailed description of the sleep breathing conditions within the spectrum of SDB (Figure 1). He began with obstructive sleep apnea by defining the word *apnea*: “a” meaning “without” and the “pnea” meaning “breath.” McIntosh continued, “It is a physical obstruction where [the child] is not able to get a breath in. It is the equivalent to being choked from the inside” (O'Connor, 2020). Next, he described Upper Airway Resistance Syndrome (UARS) as a situation wherein the child struggles to take a breath in due to a partial airway obstruction. Both snoring and mouth breathing are sleep disordered breathing conditions as well. Regular snoring is defined as four or more nights per week. He added that heavy breathing falls under the category of snoring and that neither snoring nor heavy breathing is graded; “it is either a yes or a no” (O'Connor, 2020). Lastly, he stated that “mouth breathing is not normal and has impacts on the physiology” (O'Connor, 2020).

### **Figure 1**

*Sleep Disordered Breathing Problems*

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|--|
| <b>Obstructive Sleep Apnea (OSA)</b>           |
| <b>Upper Airway Resistance Syndrome (UARS)</b> |
| <b>Snoring and Heavy Breathing</b>             |
| <b>Mouth Breathing</b>                         |

Beyond understanding the definition of SDB, it is important for healthcare professionals (and parents) to be attuned to SDB in children. They need to be able to recognize multiple signs and “symptoms of SDB and OSA in children [including] snoring, restless sleep, excessive sleepiness, teeth grinding and jaw clenching, migraines, bedwetting, and irritability” (Medical X press, 2019). Furthermore, SDB can lower IQ and “[exacerbate] attention-deficit hyperactivity disorder” (Zaffenello et al., 2017, p. 2). According to McIntosh, bedwetting is just one clue that a child may have SDB (O’Connor, 2020). Knowing the signs and symptoms of SDB is key in connecting them to the underlying cause: sleep disordered breathing.

Unfortunately, SDB in children is under recognized. The article titled, “Up to 15% of Children Have Sleep Apnea, yet 90% Go Undiagnosed,” sums up the severity of the problem, SDB is “grossly underdiagnosed” (Alexander et al., 2019, as cited by Medical X press, 2019). This is statistical evidence that healthcare professionals do not always connect the dots to realize that behavioral, emotional, and learning issues are correlated with fragmented, nonrestorative sleep. If healthcare professionals are not attuned to SDB in children, then it is clear to see how SDB is not getting diagnosed in children who wet the bed.

Since early recognition of SDB in children who wet the bed is critical to the health and development of the child there needs to be an urgency in recognizing and treating the

condition. Gelb and Hindin (2016) stated that research “shows that deep uninterrupted sleep of adequate duration is necessary to keep our bodies healthy” and is “intimately tied to maintaining healthy brain chemistry” (p. 40). Another source, Alexander et al., (2019), as cited by Medical X press (2019), echoed the importance and urgency of treating SDB in children and teens. Without proper restorative sleep, night after night, children suffer on multiple levels. Researchers explain that neurocognitive development, cellular regeneration, and tissue and bone growth all occur during the deep sleep stage. The author continued the explanation, “when breathing is obstructed in the upper airway, the brain switches back from deep to light sleep in order to resume normal breathing- barring the mind and body from critical restorative processes.” Moreover, McIntosh remarked that in all forms of SDB, the child’s sleep is disrupted and that “the net outcome is lower blood oxygen levels to the point it impacts sleep quality” and subsequently daytime function, behavior, emotions, and learning. (O’Connor, 2020). He continued, pointing out that a child’s brain, heart, blood vessels, and hormones are impacted by poor sleep. McIntosh remarked, “In brain scans, we can actually see change in the brain not functioning properly- parts of the brain dying off” (O’Connor, 2020). He pointed out that children are getting high blood pressure, and this can set them up for a lifetime of cardiovascular issues.

While recognizing the signs and symptoms of SDB are important to obtain early intervention of SDB, it is also necessary for practitioners and parents alike to understand the root causes of SDB to ensure that the child gets a comprehensive assessment of SDB.

McIntosh explained the four root causes of SDB, all of which need to be assessed and treated to obtain full resolution of SDB (O’Connor, 2020). He explained that SDB stems from either a structural and/or a functional issue with the airway. The first and most dominant issue is an

obstruction of the airway from enlarged tonsils and/or adenoids. Second, nasal congestion from allergies must also be considered. Third, children with a small airway, because of a small jaw, can suffer from SDB. McIntosh noted that “The jaw may not grow properly; [it may be necessary] to involve a dentist to develop the jaw forward and apart” (O’Connor, 2020). The fourth root cause of SDB relates to function; it is poor muscle tone and muscle dysfunction associated with the muscles of the face, mouth, and airway. McIntosh stated, “When you breathe in, the muscles- instead of holding the throat open- can collapse to some degree” (O’Connor, 2020). In addition to the muscles of the throat, the function of the tongue and how it rests in the mouth and its range of motion are all important considerations in assessing SDB. In the book, *Tongue Tied*, the author described the condition of tongue-tie as “a tight string of tissue under the tongue that can prevent the tongue from functioning properly” (Baxter, 2018, p. 2). Later in the book Baxter (2018) explained that a tongue that is restricted from being able to rest in the roof of the mouth “leads to an open mouth posture and changes in facial growth that can result in a long face pattern” (p. 175).

As demonstrated, there are many factors to consider in assessing SDB. A small airway and/or obstructions to the airway are considered structural root causes whereas lack of muscle tone and muscle dysfunction are functional root causes. Comprehensive assessments and subsequent treatments of SDB can be complicated. Therefore, it is crucial to understand what SDB is as well as to know the signs, symptoms, and root causes to ensure children receive comprehensive care.

### **The Connection**

#### **Bedwetting: A Symptom of SDB**

Although under recognized by both healthcare professionals and parents, the connection between bedwetting and SDB is well documented in the literature. Sakellaropoulou et al. (2012) provide “statistically significant association” in the results section that link sleep apnea, snoring, nasal congestion, enlarged tonsil and adenoid size and mouth breathing to bedwetting (p. 523). The statistical evidence gives validity and strength to the connection of the conditions. Another study looking at the relationship between the two conditions reported that sleep disordered breathing is common in children and teens who wet the bed. “More specifically, [bedwetting] has been reported in 8 to 47% of children with obstructive sleep disordered breathing” (Zaffanello et al., 2017, p. 4). Furthermore, the authors reported that children who do not respond to the first line treatments of desmopressin and/or alarms have shown a higher rate of obstructive SDB. They indicated that “The most important symptoms and signs - breathing through the mouth, tonsillar size and nasal congestion- correlated with [bedwetting] in children who do not respond to standard treatment” (Zaffanello et al., p. 3). To comprehensively treat bedwetting, healthcare practitioners and parents need to fully understand and accept the evidence of the connection; bedwetting is a sign and symptom of SDB.

The cascade of events that connect SDB and bedwetting is complex, yet the established pathophysiology is proof of the causal effect. In McIntosh’s interview, he described the pathophysiology of the connection as a combination of five events that “collectively [create] the perfect storm for bedwetting” (O’Connor, 2020). First, mouth breathing, during the day and at night, creates a dry mouth and throat. This triggers a thirst response which results in more fluid intake and consequently more urine output. Second, he described how lower blood oxygen levels, because of SDB, creates a stress/panic response in

the body. Rather than the “rest and digest” parasympathetic nervous system being activated, the ‘fight or flight’ sympathetic nervous system is activated. McIntosh compared the body’s response as similar to what happens when a person takes a big exam and their palms get sweaty and their heart rate increases. The third event, the release of adrenaline results in a scenario where not only does the heart rate rise, but blood pressure does as well. Additionally, the tone in the muscles, including the wall of the bladder, increases resulting in a bladder that needs to be emptied. When the blood pressure rises, the body responds with two hormonal changes, (the fourth event), in an effort to reduce blood pressure by reducing the blood volume. McIntosh explained that the receptors in the atrium of the heart respond to counteract the rise in pressure by releasing atrial natriuretic hormone (ANP). This, in turn, influences the kidneys to excrete more sodium (and water) which leads to an increase in urine production. Additionally, there is a decrease in antidiuretic hormone (ADH) causing a loss of water volume, resulting in more urine volume. The changes in levels of both ANP and ADH result in an increase of urine volume. Lastly, the child is difficult to rouse because of chronic poor sleep quality. He or she is tired during the day and exhausted at night (O’Connor, 2020). The succession of these five events have a result of the child wetting the bed. As McIntosh described, the pathophysiology of bedwetting can be traced to SDB. If the connection between bedwetting and sleep disordered breathing is indisputable, then why are so many children with SDB and bedwetting not getting properly assessed and treated for their SDB?

## **The Problems**

### **The Overarching Issues**

Many children are needlessly suffering from both disorders. Nick suffered until the age of 12 before his SDB was recognized and addressed (Appendix B). Why is SDB under

recognized and under diagnosed in children who wet the bed? The answers to this question are complex and multifactorial stemming from the broad overarching issues all the way down to incomplete patient care.

The overarching issues that contribute to the under recognition of SDB in children with bedwetting are attributable to mainstream westernized healthcare, lack of parent awareness, lack of reliable parent resources, and social stigma.

The first problem leading to the lack of diagnosis of SDB in these children relates to how western medicine is practiced. In their book, *Gasp*, Gelb and Hindin (2017) pointed out that the model of mainstream healthcare has a focus on treating a patient's symptoms rather than the underlying causes and prevention of their health issues. They indicated that "most of modern medicine has not considered sleep disordered breathing and its effects on the body and brain" (Gelb & Hindin, p. 41). The authors use an Aesop's Fable as an analogy that accurately depicts the core problem with mainstream healthcare:

Modern Medicine is approached like The Five Blind Men  
and the Elephant: One feels the trunk, one the tail, one the  
tusk, one the leg, and one the ear, but no one sees The  
Whole Elephant. (p. 43)

Bedwetting and SDB are complex multifactorial conditions. The analogy is applicable to any under diagnosed or misdiagnosed health condition including bedwetting and SDB. Without a collaborative team of healthcare providers that see the big picture, it is no wonder SDB is underrecognized. The specialists look narrowly at the problems of SDB and bedwetting through their own lens; they all may fail to recognize the underlying symptoms of either condition. The dentist fails to consider the airway, only focusing on the health of the

teeth and bite. The ENT dismisses a child's enlarged tonsils and adenoids. The urologist tests for urinary tract pathologies but finds none. The psychiatrist prescribes medication to treat symptoms of ADHD in children that suffer from SDB, and lastly, the pediatrician treats the symptoms of bedwetting with a medication or recommends a bedwetting alarm. As the authors state, there is a critical missing link: putting all the pieces together to look at the "elephant" or "big picture" of the patient (Gelb & Hindin, 2016, p. 44). When children with bedwetting are assessed and treated in a compartmentalized fashion, the connection of bedwetting as a sign and symptom of SDB is missed.

The second problem that contributes to the lack of recognition and underdiagnosis of SDB is denoted in how different scholarly articles discuss the connection. Bedwetting articles are not congruent with those of sleep medicine. According to McIntosh (O'Connor, 2020) and Medical X press (2019), bedwetting is a symptom of SDB. The other sources that discuss the management of bedwetting identify SDB as a "Comorbidity" or coexisting condition to bedwetting (Neveus et al., 2020, p.11). Although the differences in descriptions are subtle, they are, nonetheless, incongruent. Upon examination of the following two differing sources, it is apparent that treating SDB as a comorbidity of bedwetting rather than a symptom of bedwetting results in the under recognition and underdiagnosis of SDB in children with bedwetting.

The first example conveys a cause-and-effect explanation where bedwetting is a symptom of sleep disordered breathing and sleep deprivation. In Kotagal et al. (2011), the authors categorized bedwetting as a parasomnia: "The American Academy of Sleep Medicine has defined parasomnias as "undesirable physical events or experiences that occur during entry into sleep, within sleep or during arousals from sleep" (p. 113). The cause of

parasomnias is complex but essentially, they are a part of the nervous system, an activation of central pattern generators (CPG) that causes them. The authors state that “[CPG’s] can be activated by sleep disordered breathing, sleep deprivation, [acid] reflux, periodic limb movement activity, stress, fever, and epilepsy” (Kotagal et al., p. 113). The section on “bedwetting” states that obstructive sleep apnea “has been associated with enuresis, and often its correction leads to resolution of enuresis as well” (Kotagal et al., p. 119). Similar to McIntosh’s pathophysiological cause and effect explanation between SDB and bedwetting, this section of the book also validates the connection.

In contrast, Neveus et al. (2020), reported that the International Children’s Continence Society’s (ICCS) updated standardization document on management and treatment of bedwetting does not convey a cause-and-effect connection but rather a coexistence of separate but possibly related conditions. According to Neveus et al, (2020), “the most important comorbid conditions to take into account are psychiatric disorders, constipation, urinary tract infections and snoring or sleep apneas” (p. 10). Categorizing SDB as a comorbid condition brings to light the issues of mainstream medicine where each condition is compartmentalized and therefore separately assessed and treated. This approach lessens the validity of the connection and negates the importance of an early, comprehensive assessment of SDB in the treatment of bedwetting. Furthermore, Neveus et al. (2020) noted that psychiatric disorders, such as behavioral, emotional and ADHD as a comorbid condition to consider in the treatment of bedwetting, even though these are well documented symptoms of SDB.

In addition to differing views in the literature, a third problem is that many pediatricians fail to recognize that bedwetting and SDB are related. The net result is that children who wet the bed do not get screened or assessed for SDB. The possible reason could

be that the connection is relatively new. In Hornsby (2020), the interviewer commented that it has only been in the literature for about the past 10 years. According to Hornsby and Burhenne (2020), SDB nor the signs and symptoms were a part of either of their formal dental education. Although it is difficult to know how long it takes research evidence to be implemented in mainstream healthcare one source reported that it is “frequently stated that it takes an average of 17 years for research evidence to reach clinical practice” (Morris et al., 2011). Based on this, it makes sense why the evidence of the connection between SDB and bedwetting have not yet been fully accepted into clinical practice.

The shortcomings in mainstream healthcare are major issues in why SDB in children with bedwetting is under recognized and under diagnosed, yet the lack of awareness among parents and social stigma around bedwetting each play a role as well. When a child’s doctor is unaware of the SDB/bedwetting connection then the parent is often also unaware. The parent survey (Appendix A) indicated that 33% had never heard of the connection. Parents trust their child’s doctor for guidance and solutions to health issues, including bedwetting. Many doctors view bedwetting as a benign condition that has no health implications (healthychildren.org., 2013), therefore the parent is unfortunately unaware that SDB may be the cause of their child's bedwetting. Nick’s story (Appendix B) illustrates how his SDB got missed early on due to the lack of awareness by both Nick’s pediatrician and his parents. According to Nick’s mom, his pediatrician offered no treatments for his bedwetting and no consideration was made to the connection of SDB and bedwetting. The only thing they were told is that he would eventually outgrow it.

Unfortunately, Nick’s story is all too common. The parent survey revealed that 46% of parents are dissatisfied and 33% are very dissatisfied with their child’s pediatrician in terms of

helping with their child's bedwetting. Of the 48 respondents, 28 added comments to why they are dissatisfied with the care they are receiving (Appendix A). Most comments echoed sentiments similar to this sampling:

- "Our pediatrician didn't think it's an issue until 18"
- "I had to do the research myself to find out about sleep disordered breathing. The pediatrician gave me no guidance or information other than "he will grow out of it eventually""
- "Lack of education and options for service. They were out of ideas after meds didn't work."

Based on the parent survey and Nick's story, it is clear that pediatrician's often do not offer any treatments for bedwetting and that SDB is not consistently screened or even mentioned as a possible underlying cause of bedwetting. Parents are left feeling unsupported and consequently feel they need to fend for themselves in helping their child.

When searching the internet for answers to their children's bedwetting, parents can easily be misguided and confused by the inconsistent advice and recommendations. Although some sites provide educational resources, many have an underlying agenda to sell desperate parents *the* bedwetting solution. Sites offering help may be outdated, incomplete, and/or offer solutions that are not scientifically proven. Many bedwetting websites fail to mention SDB as a possible factor in bedwetting. The article, *Bedwetting*, featured by [healthychildren.org](http://healthychildren.org), (2013), is one example where parents will find an incomplete and out of date article. Not only is there no mention of the bedwetting/SDB connection, the article states that "bedwetting is not a serious medical condition" ([healthychildren.org](http://healthychildren.org), 2013), Arguably, it is a sign of a serious medical condition if the child's bedwetting is a symptom of SDB. Additionally, with

good intention, it advises that “your child’s doctor is the best source of advice for bedwetting” (healthychildren.org., 2013).

Parents and families respond differently in how they approach bedwetting. Social stigma around bedwetting keeps some parents and families from talking about the problem and even seeking help for their child. According to Barone, (2015), despite how common of a problem bedwetting is, parents do not talk about it. “It’s like a hidden family secret, in many cases. We keep it quiet and typically do not discuss it at lunch” (Barone, 2015, pp. 39-40). The author described that he would have parents come to him with their teenagers, seeking help for the first time. When children and families do not seek help or talk about it there is no chance in recognizing and diagnosing SDB as a cause to bedwetting.

All the overarching issues collectively result in the under recognition and under diagnosis of SDB in children who wet the bed. Consequently, the first hurdle to treating SDB is recognizing its presence. The next steps include assessment and treatment. Unfortunately, recognizing the presence of SDB does not always lead to proper assessment or treatment.

### **Incomplete Assessments and Treatments**

Incomplete assessments and treatments of SDB in children with bedwetting result in unresolved SDB and consequently, unresolved bedwetting. Without a full assessment, one or more of the root causes may be missed. A comprehensive assessment for SDB may involve several diagnostic tests by one or more healthcare providers. In an introductory course in orofacial myofunctional therapy the diagnostic tests and evaluations were discussed in lecture. The following protocols may include:

- A CBTC (cone beam computed tomography) scan. A 3-D image used to assess the size of the airway and check for obstructions, such as enlarged tonsils and adenoids
- An assessment of the tonsils and adenoids by and ENT
- A sleep study to diagnose obstructive sleep apnea
- Evaluation for muscle dysfunctions of the face and mouth and breathing issues, evaluated by an orofacial myofunctional therapist (OMT) or other providers specializing in SDB
- An evaluation of the tongue for tongue-tie, performed by a dentist or ENT doctor that specializes in tongue-tie

Depending on the child's signs and symptoms, some or all these tests may be necessary to assess SDB (S. Hornsby, Personal Communication, April 1, 2020).

Unfortunately, the tests and exams that screen for SDB are infrequently utilized in children with bedwetting. As a case in point, surveyed parents were asked which assessments their children have had or were recommended to have. Of the 46 parents that responded to the question, only 2% reported that their children have had a CBCT scan, 28% have had an evaluation for enlarged tonsils and adenoids, just 6% have been referred for, or have had, a sleep study, only 2% have seen a myofunctional therapist, and just 11% have been evaluated for a tongue tie (Appendix A). It is unclear by these results if each parent's child had one, or more than one, of the tests, however the low percentages are indicative of the overall lack of assessment or incomplete assessment of SDB.

In his interview, McIntosh conveyed that a sleep study is a tool that has benefits and limitations in assessing SDB. Parents need to know its limitations. A sleep study functions as

a starting point in assessing SDB, but should not be the end point (O'Connor, 2020). In Nick's case, the sleep study was beneficial because it diagnosed his sleep apnea (Appendix B), but for some children, a sleep study does not identify SDB. When asked about the effectiveness of sleep studies for children, McIntosh explained that a sleep study is a good guide for obstructive sleep apnea but "it doesn't tell about the spectrum of problems we want to know about. A normal sleep study does not mean normal breathing. We need to look at SDB or not, not obstructive sleep apnea or not" (O'Connor, 2020). A child suffering from bedwetting that has a "normal" sleep study, but mouth breathes will get missed and consequently undiagnosed if the sleep diagnosis is based solely on a sleep study.

Despite the limitations of sleep studies, it is an effective tool in screening children for sleep apnea, yet many children who wet the bed are not getting referred for a sleep study as evidenced by the parent survey (Appendix A). Of the 48 respondents, 94% of parents indicated that their child has never had or been referred for a sleep study. The results illustrate the overall lack of addressing even sleep apnea as a possible cause of bedwetting.

In addition to a sleep study as a diagnostic tool, the evaluation of the child's tonsils and adenoids should be considered as a possible obstruction to the airway. According to McIntosh, of children with bedwetting, 40% who have SDB due to enlarged tonsils and adenoids (T&A) will no longer wet the bed once their T&A are removed. He commented, "It's a plumbing problem" (O'Connor, 2020). He explained that not all ENT doctors recognize the sleep health benefits of removing enlarged T&A. They may be of an older school mindset and consequently will only advise removing T&A if the child suffers from tonsillitis. He stressed the importance of finding an ENT doctor that has an interest in airway health to assess T&A (O'Connor, 2020).

While it is encouraging to know that 40% of children stop wetting the bed after T&A removal, why is it that 60% are not getting the same results? Many of these children continue to suffer due to residual SDB according to (Guilleminault & Sullivan, 2014, p. 2). A sleep study and tonsil/adenoid assessment and removal are important considerations in assessing and treating SDB, but mainstream healthcare is still not looking at the big picture.

The discrepancy in how SDB is being assessed and treated, versus how it needs to be assessed and treated, results in incomplete treatment of SDB in children. Here again, recommendations in scholarly articles differ between the two camps: sleep medicine and bedwetting. Current protocols for assessing and treating SDB as a comorbidity of bedwetting fall short of those that discuss assessing and treating SDB as a cause of bedwetting. Because scholarly articles on bedwetting are incomplete and vague in addressing the connection and how to comprehensively assess and treat, children with SDB are continually missed or under diagnosed. As an illustration, three articles were examined. One discusses the importance of treating the full spectrum of SDB, including mouth breathing, whereas the other two offer recommendations on how to assess and treat bedwetting that fall short of complete assessment and treatment.

In the first article, Guilleminault and Sullivan (2016) conveyed that SDB can persist or return after tonsil and adenoid removal. They stated that “even with early intervention, a large portion of children with SDB will redevelop SDB overtime” (p. 2). Furthermore, they note that children who continue to have chronic mouth breathing after T&A removal may be referred for other SDB therapies, such as myofunctional therapy, allergy treatments, orthodontic expansion of the upper jaw, and CPAP. Guilleminault and Sullivan (2016)

concluded that eliminating mouth breathing by restoring nasal breathing should be the “finish line” for treating sleep disordered breathing in children. (p. 4).

In contrast, the first article addressing bedwetting, “Management and Treatment of Nocturnal Enuresis- an Updated Standardization Document from the International Children’s Continenence Society” (ICCS) by Neveus et al. (2020), fails to acknowledge the full spectrum of SDB when assessing a child with bedwetting. “The ICCS has produced clinical guidelines which can function as a checklist” in assessing and treating bedwetting. (Neveus et al. p. 10). Under the section of “History,” the fifth item to consider is, “Sleep problems. Is there a consistent heavy snoring or sleep apneas? Daytime sleepiness” (Neveus et al., p. 12)? Based on this criterion, children who snore lightly, have UARS, or breathe through their mouth may not be diagnosed with sleep disordered breathing. Furthermore, SDB is only mentioned in one sentence in the remainder of the article. Under the section titled, “Management of therapy-resistant children,” the last sentence reads, “There is a subgroup that may need surgical treatment for sleep disordered breathing” (Neveus et al. p. 15). According to their recommendation, assessing and treating sleep apnea should be considered only after initial therapy fails. While the inclusion of sleep apnea and heavy snoring to the recent ICCS document is progress from previous guideline documents, it, unfortunately, it still falls short in its comprehensiveness and importance in evaluating SDB as an underlying cause to bedwetting.

The second article on bedwetting by Baird et al. (2014), offers recommendations and includes a flow chart from assessment through treatment for the physician to follow, however the problem here is that SDB is not included as a part of the initial evaluation section. Additionally, “Obstructive sleep apnea” is last on the list of considerations within their

diagnostic flowchart. The recommendation is to “consider referral for [a sleep study]” Baird et al. p. 4). In Table 2 of their article, obstructive sleep apnea is listed under “Common Comorbidities and Differential Diagnosis of Enuresis in Children” (Baird et al., 2014, p. 3). Interestingly, that table indicates that sleep apnea has a 10-54% prevalence in children with bedwetting and yet it is excluded from the initial evaluation section. Like the ICCS’s updated standardization document, the article offers a limited definition of SDB and gives its importance low priority in both assessment and treatment (Baird et al., 2014).

The comparison of the three articles reveals a large gap in properly addressing SDB in children with bedwetting. Neither article on the management and treatment of bedwetting offered comprehensive protocols to ensure complete assessment or treatments of SDB. They both fail to make the direct connection between bedwetting and SDB, leaving holes in the system of complete care. On the other hand, Guilleminault and Sullivan (2016) get it right. They discuss all aspects of SDB that may need attention and treatment. Moreover, they offer an end goal in which SDB is fully treated; nasal breathing all day and all night, a proven deterrent to bedwetting.

## **Solutions and Answers**

### **Accessing Comprehensive Care for SDB**

As illustrated, bedwetting and SDB are complex multifactorial conditions that require a big picture approach to ensure comprehensive care. Although relatively new and unheard of, a system consisting of a team of collaborative healthcare providers is already available for parents and children to obtain comprehensive care for SDB. In their book, the authors described the registered trademark term “Airway Centric” as a “revolutionary system aimed at recognizing and correcting [sleep disordered breathing]” (Gelb & Hindin, 2016, p.42). This

model of care focuses on seeing the big picture at all ages of people's lives. The main focus is on airway health, as breath and oxygen are at the core of “all health and well-being” (Gelb & Hindin, p. 3). The importance of a team approach in treating SDB in children is echoed by White (Alexander et al., 2019, as cited in Medical X press, [2019](#)) when “[he] says a referral to a multidisciplinary team is ideal. This typically includes a pediatric ENT, sleep specialist, dentist trained in craniofacial development, and a myofunctional therapist.”

Unfortunately, finding healthcare practitioners that focus on airway health can be a challenge. The authors of *Gasp* indicate that “85% of practitioners will not be aware of the ‘hidden airway’ paradigm, which explains why 85% of the population of airway, [SDB] patients are still unrecognized and undiagnosed” (Gelb and Hindin, 2016, p. 187).

How does a parent go about finding a healthcare provider that can assess SDB and the airway? McIntosh recommended finding a pediatric ENT that specializes in sleep health as a starting point; he explained that as an “airway” ENT can assess all root causes of SDB (O’Connor, 2020). Burhenne, a dentist specializing in airway, typically refers his patients to a myofunctional therapist for a screening. He states, “It’s an easy [and affordable] way of knowing if you need help.” (Burhenne, 2020). If an “airway” ENT, dentist, or orthodontist are not in close proximity a myofunctional therapist can do an in person or telehealth intake screening for SDB. In the article, “Myofunctional Therapy: A Novel Treatment of Pediatric Sleep-Disordered Breathing,” the authors described the myofunctional assessment as a thorough medical and developmental history and comprehensive screening for face, mouth and tongue muscle dysfunction, “with an emphasis on SDB risk factors” (Moeller et al., 2014). If the child is found to have SDB, the myofunctional therapist can provide therapy if

needed but also, they can network to find and refer to other “airway” healthcare providers necessary for comprehensive care.

Finding providers that specialize in airway health and SDB can be tricky, but not impossible. The Breathe Institute ([www.thebreatheinstitute.com](http://www.thebreatheinstitute.com)), led by Dr. Soroush Zaghi, an ENT doctor and forefront researcher in airway and sleep health, is a great resource for finding a list of doctors, dentists, orthodontists, and myofunctional therapists healthcare who have trained and studied at the institute (The Breathe Institute). Additionally, Gelb and Hindin (2016) name organizations that serve as a resource in locating providers. The Academy of Orofacial Myofunctional ([www.aomtinfo.org](http://www.aomtinfo.org)) and the International Association of Orofacial Myology ([www.iaom.com](http://www.iaom.com)) both have provider directories for finding a myofunctional therapist. The authors recommend finding an “Airway Centered Practitioner,” on the *Foundation for Airway Health* website ([www.airwayhealth.org](http://www.airwayhealth.org)) or the *American Academy of Physiological Medicine and Dentistry* website ([www.AAPMD.org](http://www.AAPMD.org)) (p. 187). For finding an orthodontist, Gelb and Hindin recommend the *Foundation for Airway Health* as a resource. The authors stress the importance of expanding the upper jaw out and forward to grow the airway and advised against an orthodontist who recommends a treatment plan that involves extraction of permanent teeth. They commented that “jaws can be expanded at a young age in a matter of months” (Gelb & Hindin, 2016, p. 188).

Many people have never heard of orofacial myofunctional therapy (OMT) or the term orofacial myofunctional dysfunction (OMD). In an interview with Burhenne, therapist Sarah Hornsby described myofunctional therapy as “physical therapy” for the muscles of the face and mouth. “I teach people exercises to retrain the brain, neuromuscular education to restore

normal healthy function” (Burhenne, 2020). She goes on to stress the importance of comprehensively addressing SDB and the four goals to be achieved in treating OMD:

1. Breathe through your nose - all day and all night
2. Lips together- all day and all night
3. Full tongue resting in the palate- all day and all night
4. Swallow without a tongue thrust

The role of the myofunctional therapist as a part of the “airway” team can be key to ensuring comprehensive care of SDB. Nick’s story (Appendix B) is a prime example of how a myofunctional therapist can function as a “gatekeeper” in the coordination of care from start to finish.

After Nick’s initial assessment appointment, Joyce, his therapist, established several issues that contributed to his SDB and its related signs and symptoms. In his health history she identified that Nick has seasonal allergies, he takes Claritin, he had trouble breastfeeding, and he has primary bedwetting. Further, she concluded that he was breathing through his mouth while asleep, and that he had a tongue thrust when he swallowed. Under the dental/orthodontic screening she noted he had a “deep bite,” a slightly retruded lower jaw, and a slightly narrow and high palate. She categorized his tonsils as slightly enlarged and noted the inability to breathe freely through his left nostril. Based on measurements and the appearance of his tongue, she determined that he had a tongue tie. She evaluated his posture and documented he had a “forward head posture.” Nick’s assessment illustrates a thoroughness on the part of his therapist to look at multiple possible factors contributing to his SDB.

From the information she gathered, Joyce was able to establish what further diagnostic tests and exams would be necessary. Following are her notes in managing Nick’s care:

After my initial assessment, I referred [REDACTED] for a home sleep study. After we received those results, I referred him to an ENT that has experience with myofunctional disorders. The ENT was trained by Dr. [REDACTED] in lingual functional frenuloplasty. However, [REDACTED] had his tongue tie released while sedated due to him needing his adenoids removed and nasal turbinate reduction at the same time. I did about 4 sessions of therapy with [REDACTED] prior to the surgery to prepare him for the tongue tie release. His mom told me his bedwetting reduced just with therapy to get him nasal breathing and getting his tongue up (Appendix B).

Joyce provided Nick with comprehensive care, making sure that all of his airway needs were addressed to fully resolve his SDB.

Nick's story has a happy ending (Appendix B). With comprehensive assessments and treatments, not only was his SDB fully resolved, but his bedwetting was as well. Nick's mom wrote:

Before our son's surgery he started exercises with the myofunctional therapist. It was at this time that his nighttime wetting started to decrease from about 6 times a week to 3-4. Then after surgery, it was completely gone! The dark circles under his eyes are lighter and he has remained cavity free.

We are so grateful that the myofunctional therapist was educated about tongue ties and the symptoms of a dysfunctional airway. We were able to get to the root cause of many of these seemingly unrelated symptoms that our son was experiencing. I think our son's future health has been preserved by addressing these issues now. He is happy and confident and looking forward to getting braces in a couple of months.

-Sara (Appendix B)

## Going Forward

Nick's story provides qualitative evidence that bedwetting resolves when SDB is comprehensively treated, but is there significant quantitative evidence to show that the treatment of SDB resolves bedwetting? The answer is no. However, that does not mean that treating SDB does not resolve bedwetting. To establish data on comprehensive SDB treatment and bedwetting outcomes, future peer reviewed prospective research studies should be conducted. So far, the relationship has been minimally studied. In Zaffanello et al. (2017), the section, "Can treatment of [SDB] resolve [bedwetting]?", the authors report that there have been some studies conducted that look at this relationship. However, they note that "some limitations of these studies should be addressed. In particular, none of the outcome studies were peer reviewed, randomised or quasi-randomised and controlled" (p. 5). Despite these limitations, the studies showed that SDB treatments did resolve bedwetting. One of the problems though, is how the researchers have studied the relationship.

True to the five blind men analogy, research has only studied one SDB treatment at a time in relation to bedwetting outcomes. A case in point, like the 40% success rate in bedwetting resolution of children with T&A removal, one study looked at just orthodontics and bedwetting outcomes. Another study looked at allergy treatment and bedwetting outcomes. A study conducted by Neveus et al. (2014), only looked at the relationship between an orthodontic procedure called rapid maxillary expansion and bedwetting. Although the study concludes that "orthodontic widening of the palate may be curative in a subgroup of children with therapy-resistant enuresis," (Neveus et al., 2014) its narrow focus fails to advance the goal of comprehensive SDB treatment in relation to bedwetting outcomes.

Admittedly, studying the relationship between comprehensive SDB and bedwetting outcomes could prove to be difficult. For instance, how would a study of this nature be conducted and controlled? One possible solution would be to have a group of “airway” providers enrolled in tracking children with bedwetting based on fully treating their SDB. An OMT, like Joyce in Nick’s treatment, may be the ideal “airway” practitioner to track such outcomes. If the current model of healthcare is to adopt an “airway” centered approach to addressing bedwetting, then it is imperative that research provide reliable quantitative scientific evidence on bedwetting outcomes with comprehensive treatment of SDB.

Beyond the need to acquire quantitative evidence on the relationship between comprehensive treatment of SDB and bedwetting outcomes, there needs to be revolutionary change in how both bedwetting, SDB, and the connection of the two are viewed, assessed, and treated. Children need and deserve to have a childhood free from the health effects of SDB and bedwetting. Unfortunately, changing a model of healthcare that is well ingrained does not happen overnight. It is a long slow process that begins with educating parents and healthcare about SDB and how bedwetting can be a sign of bigger health problems. According to Gelb and Hindin (2016), observation is key.

Parents are the first caretakers, who need to observe their child with sensitivity to airway function, followed by obstetricians, pediatricians, lactation consultants, doulas, midwives, pediatric ENT’s, pediatric sleep specialists, myofunctional therapists, oral surgeons, pediatric dentists, and orthodontists (p. 42).

The Airway Centric approach calls upon these healthcare providers to incorporate airway health and prevention into the scope of their practice. Moreover, it is a role model that needs to be the start in the shift of how healthcare is addressed (Gelb & Hindin, 2016, p. 44.)

A push for change is critical in turning the tide in how mainstream healthcare handles SDB and bedwetting. Children deserve a model of healthcare that focuses on the prevention of disease and the treatment of underlying issues and symptoms rather than on the symptoms alone. Change can start with awareness among parents and healthcare providers. Parents need to be made aware of SDB and its signs and symptoms as they relate to not only bedwetting, but other psychological and physical ailments. Likewise, healthcare providers need to be aware of the studies and findings that validate the causal relationship between bedwetting and SDB.

Parents have a responsibility to be proactive in advocating for the wellbeing of their child's health. Hearing “they will eventually outgrow bedwetting” from a pediatrician is unacceptable. That type of response requires pushing back and demanding more testing or it requires finding a new doctor who understands the connection of SDB and bedwetting. Parents with children that wet the bed need to insist that their child be comprehensively evaluated for SDB by an “airway” provider. It is time for parents to start talking about bedwetting and seeking help for their children. Social stigma around bedwetting is inhibiting children from getting the help they need.

In addition to comprehensively assessing the bedwetting, including SDB, the child may need professional support to deal with the shame, embarrassment, and self-esteem issues caused by bedwetting. Similarly, parents face their own emotions and stress from their child's bedwetting. Online support from closed Facebook groups offer parent to parent support, where group members post questions and share successes and failures. Groups like these are helpful for a parent to realize how common the problem of bedwetting is and to not feel so alone.

### **Conclusion**

Thankfully, the underlying cause of Nick's bedwetting was recognized by a healthcare provider who viewed his bedwetting and SDB from a big picture perspective, though sadly and most often, the five blind men keep doing the same old thing with limited results in addressing SDB (Appendix B). Meanwhile, millions of children continue to be denied the health benefits of restorative sleep and the confidence and comfort of dry sheets in the morning. Instead of staring through a narrow lens, mainstream healthcare needs to step back from its myopic view to see the suffering child through a wide-angle lens exposing the underlying causes of bedwetting and SDB. The happy ending to Nick's story paints a picture of how mainstream healthcare can and needs to function to fully assess and treat both conditions.

For the sake of these children and their families, change is needed. That change starts with knowledge and awareness for parents and healthcare alike. Change starts with peer reviewed research and data. Change happens by squashing stigma. Change happens by acting. McIntosh stated it perfectly, "It's one thing to have the knowledge but the other thing is you gotta do something about it. There's no good knowing these things and then not acting on it. If your child cannot breathe properly, that's a serious problem" (O'Connor, 2020).



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## Appendix A

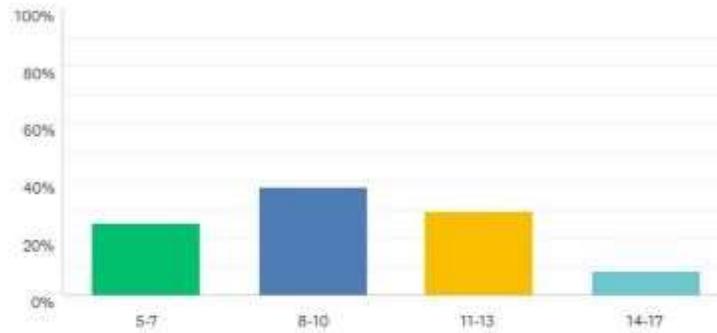
Parent Survey

Parent Questionnaire of Children/Teens with Primary Bed Wetting

SurveyMonkey

Q1 How old is your son or daughter?

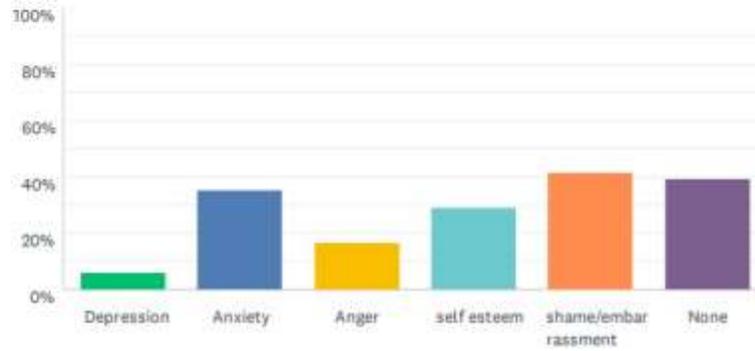
Answered: 48 Skipped: 0



| ANSWER CHOICES | RESPONSES |           |
|----------------|-----------|-----------|
| 5-7            | 25.00%    | 12        |
| 8-10           | 37.50%    | 18        |
| 11-13          | 29.17%    | 14        |
| 14-17          | 8.33%     | 4         |
| <b>TOTAL</b>   |           | <b>48</b> |

**Q2 What, if any, psycho social challenges does your child struggle with that may be related to bed wetting? Check all that apply.**

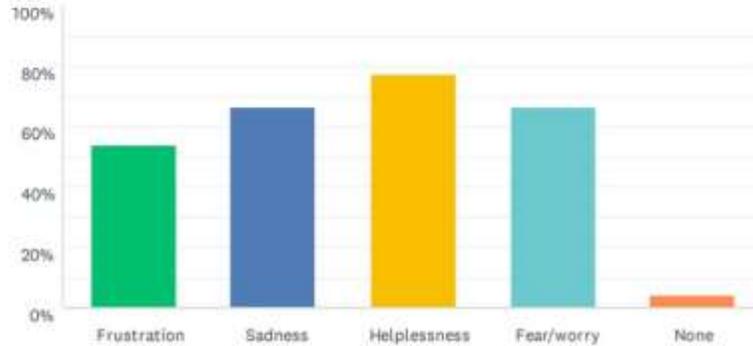
Answered: 48 Skipped: 0



| ANSWER CHOICES        | RESPONSES |    |
|-----------------------|-----------|----|
| Depression            | 6.25%     | 3  |
| Anxiety               | 35.42%    | 17 |
| Anger                 | 16.67%    | 8  |
| self esteem           | 29.17%    | 14 |
| shame/embarrassment   | 41.67%    | 20 |
| None                  | 39.58%    | 19 |
| Total Respondents: 48 |           |    |

**Q3 As a parent, what emotions do you experience around your child's bed wetting? Check all that apply.**

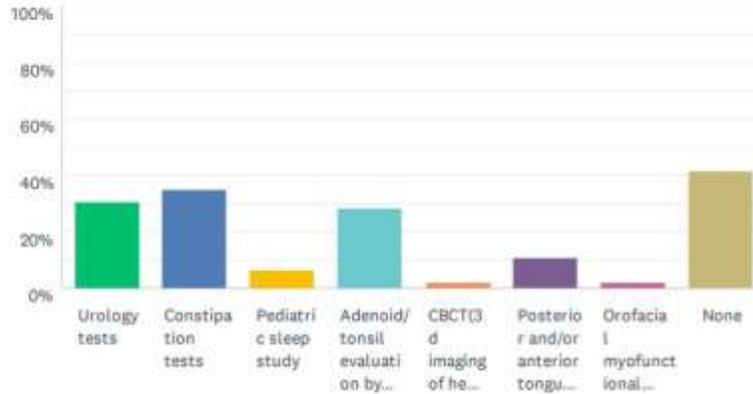
Answered: 48 Skipped: 0



| ANSWER CHOICES        | RESPONSES |    |
|-----------------------|-----------|----|
| Frustration           | 54.17%    | 26 |
| Sadness               | 66.67%    | 32 |
| Helplessness          | 77.08%    | 37 |
| Fear/worry            | 66.67%    | 32 |
| None                  | 4.17%     | 2  |
| Total Respondents: 48 |           |    |

**Q4 What referrals have been made and/or tests/evaluations have been done specific to bed wetting, by your child's pediatrician, pediatric dentist or orthodontist, or bed wetting clinic? Check all that apply**

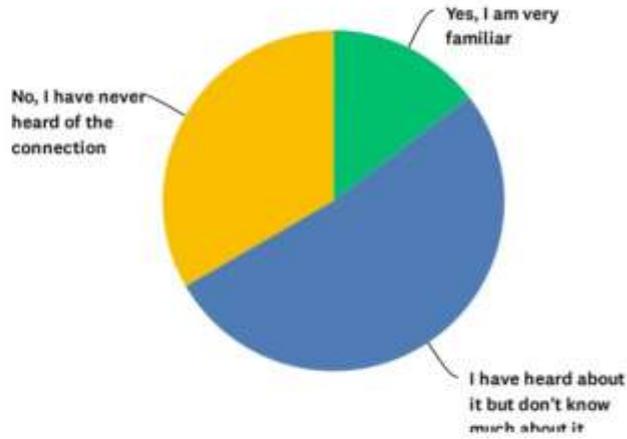
Answered: 46 Skipped: 2



| ANSWER CHOICES   | RESPONSES |    |
|--|-----------|----|
| Urology tests  | 30.43%    | 14 |
| Constipation tests   | 34.78%    | 16 |
| Pediatric sleep study  | 6.52%     | 3  |
| Adenoid/tonsil evaluation by ENT(ear, nose, throat) doctor                         | 28.26%    | 13 |
| CBCT(3 d imaging of head and neck) for airway structure evaluation                 | 2.17%     | 1  |
| Posterior and/or anterior tongue tie(by ENT or dentist specializing in tongue tie) | 10.87%    | 5  |
| Orofacial myofunctional therapy( tongue thrust therapy)                            | 2.17%     | 1  |
| None   | 41.30%    | 19 |
| Total Respondents: 46  |           |    |

### Q5 Do you know about the connection between bed wetting and sleep disordered breathing?

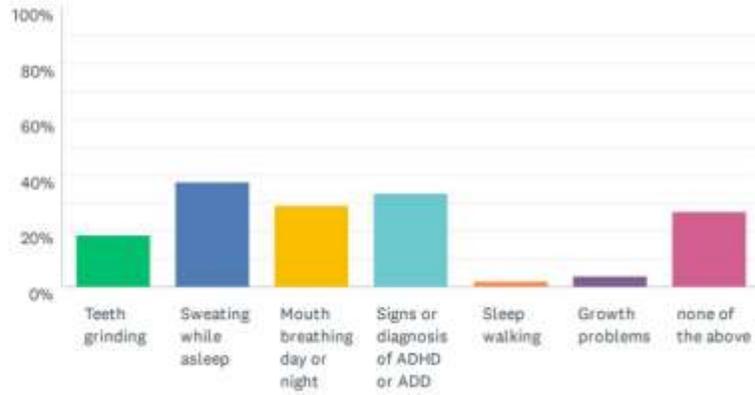
Answered: 48 Skipped: 0



| ANSWER CHOICES                                     | RESPONSES |
|--|-----------|
| Yes, I am very familiar                            | 14.58% 7  |
| I have heard about it but don't know much about it | 52.08% 25 |
| No, I have never heard of the connection           | 33.33% 16 |
| TOTAL  | 48        |

**Q6 Does your child have any of the following symptoms? Check all that apply.**

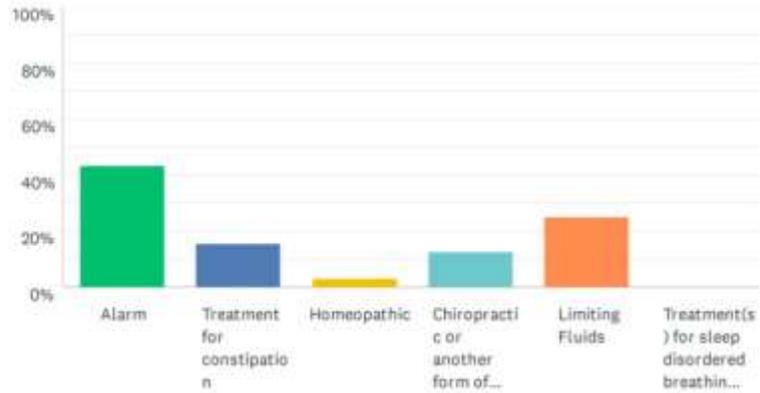
Answered: 48 Skipped: 0



| ANSWER CHOICES                    | RESPONSES |    |
|-----------------------------------|-----------|----|
| Teeth grinding                    | 18.75%    | 9  |
| Sweating while asleep             | 37.50%    | 18 |
| Mouth breathing day or night      | 29.17%    | 14 |
| Signs or diagnosis of ADHD or ADD | 33.33%    | 16 |
| Sleep walking                     | 2.08%     | 1  |
| Growth problems                   | 4.17%     | 2  |
| none of the above                 | 27.08%    | 13 |
| Total Respondents: 48             |           |    |

**Q7 Of the treatments listed that you have tried, which one has your child shown the most improvement or full resolution?**

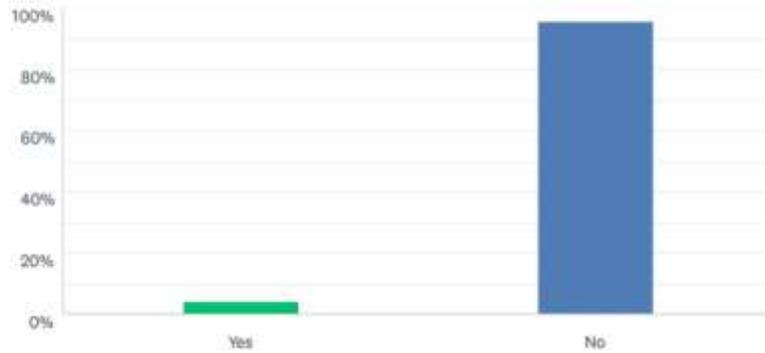
Answered: 32 Skipped: 16



| ANSWER CHOICES  | RESPONSES |
|---|-----------|
| Alarm   | 43.75% 14 |
| Treatment for constipation  | 15.63% 5  |
| Homeopathic   | 3.13% 1   |
| Chiropractic or another form of body work   | 12.50% 4  |
| Limiting Fluids   | 25.00% 8  |
| Treatment(s) for sleep disordered breathing and/or mouth breathing( sleep disordered breathing includes sleep apnea, snoring , any audible sleep breathing) | 0.00% 0   |
| <b>TOTAL</b>  | <b>32</b> |

**Q8 Has your child been formally evaluated with a pediatric sleep study for sleep apnea and all forms of sleep disordered breathing ?**

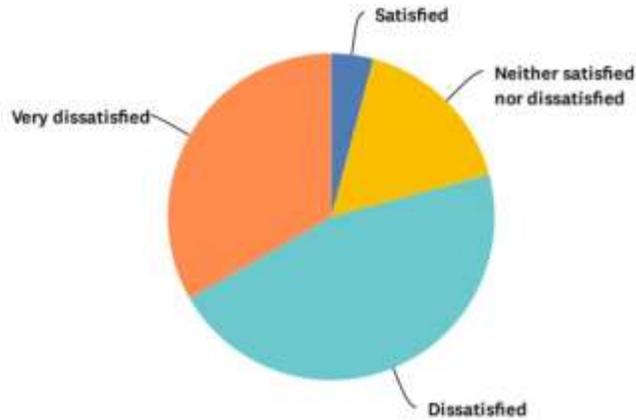
Answered: 48 Skipped: 0



| ANSWER CHOICES        | RESPONSES |    |
|-----------------------|-----------|----|
| Yes                   | 4.17%     | 2  |
| No                    | 95.83%    | 46 |
| Total Respondents: 48 |           |    |

**Q9 Are you satisfied with the resources available and the healthcare profession in terms of helping you address your child's bed wetting?**

Answered: 48 Skipped: 0



| ANSWER CHOICES                     | RESPONSES |    |
|------------------------------------|-----------|----|
| Very satisfied                     | 0.00%     | 0  |
| Satisfied                          | 4.17%     | 2  |
| Neither satisfied nor dissatisfied | 16.67%    | 8  |
| Dissatisfied                       | 45.83%    | 22 |
| Very dissatisfied                  | 33.33%    | 16 |
| TOTAL                              |           | 48 |

## Parent comments associated to survey question #9

1. "We haven't sought specific help from the NHS yet as we are trying the alarm first so I cannot comment on this."
2. "The lack of information. Being told to wait by GPs"
3. "Cure not available"
4. "Practitioners first say "he'll outgrow it", then when he's older, guess at solutions. I feel there should be a medical checklist to work through from pediatricians that does NOT involve drugs. (We have tried 'everything' except the antidepressant and Desmo that can have fatal side effects). I feel there is a different solution for kids that have primary enuresis vs secondary enuresis. I feel urologists check the mechanical parts and dismiss it as constipation when they can't find anything else to explain it. (My child has NOT been constipated every day of his life!) I do feel there is something related to sleep/brain/breathing, and we've scratched the surface, but the remedies we've tried haven't changed anything. I'm very hesitant to do a sleep study, because I've been told the results tell you only how many times apnea kicked in, then you're told to remove tonsils/adenoids (which seems wrong to me to remove body parts) and/or get a cpap (which I'm sure tags my 12 y/o on insurance as high risk for the rest of his life). I'm also curious about stages of sleep because I learned more about brain waves (alpha, theta, etc) when we did brain mapping therapy. My son sleeps like a rock (and never woke up for alarms), but I'm told sleep studies don't gather that information (i.e., how many times a night and how long you are in REM

sleep). I do think the deep sleep, lack of vasopressin, ADD symptoms, and bed wetting could relate back to disordered sleeping/breathing. We are actually having a consultation for a second tongue tie reversal tomorrow. Myofunctional therapy would again be required, so I'm hoping to make some progress this time!"

5. "Even the "experts" say she'll grow out of it as there has been a slight improvement with Desmopressin. 2 years later not much has changed"
6. "Only had one appt with dr , children is almost 8 so will increase my search for help"
7. "My pediatrician has told me that it is something my child will grow out of. We have tried medication.: that didn't help.. they didn't seem too interested in referring us on to anything else. We have started the Therapee alarm.. we have been doing it less than two weeks but my child has had a few dry nights. I am hopeful that my child will conquer this. I don't put too much pressure on them to feel like they have to succeed. We do the best we can."
8. "They tell me she will just grow out of it"
9. "No progress in treating this. Spend tons of money on urologists who just tell you they'll grow out of it."
10. "He's only recently turned 6, so his doctor isn't concerned. But maybe we should be?"
11. "That he's 17 and still have no other answers than he will outgrow it"
12. "The fact that they discharged us due to pandemic"
13. "Our pediatrician didn't think it's an issue until 18 years of age"

14. "The only help that our pediatrician has offered is monitoring constipation and Desmopressin."
15. "Now the medication works in keeping her dry at night. Have been on medication for 3 years no one is interested in finding the reason why she still isn't dry at night and still has severe urgency during the day. They've treated the symptoms not cured the issue."
16. "medication was the only thing offered and no tests were carried out or offered.my son tried medication for around 9 months but it stopped being effective."
17. "my consultant never contacts me i have not had an appointment from him in over 18months all i see is a nurse for urology scan and uroflow to b told same rubbish month after month"
18. "I had to do the research myself to find out about sleep disordered breathing. The pediatrician gave me no guidance or information other than "he will grow out of it eventually."
19. "Lack of education and options for service. They were out of ideas after meds didn't work"
20. "No help available other than medication which does not address the problem. No tests carried out"
21. "I feel that I've had to do all my own research and that our GP here in New Zealand believes he will just grow out if it"
22. "I feel that we are navigating this alone. It takes YEARS to get anything accomplished in the healthcare system."

23. "Lack of knowledge by professionals"
24. "All my pediatrician says is she will grow out of it"
25. "Constantly being told he will outgrow it and no suggestions"
26. "Not enough being done to find the reason why my 11 year old is still bedwetting. Not enough help and support available to us from the NHS (we live in the UK)"
27. "The medication prescribed is the only intervention we have been offered"
28. "Lack of help on the nhs"

**APPENDIX B**

## Case Story

Email correspondence with orofacial myofunctional therapist

RE: Bedwetting/SDB/OMT Case Study

7/16/20

Ann,

I have talked with my patient and his mother. They do not mind me sharing all of his information with you. They have given me permission several other times as I have shared his case with study groups. I am attaching this patient's myofunctional exam findings and photos (I know you said you didn't need photos, but they are already attached to the exam). I will also attach his sleep study results.

I believe [REDACTED] was 12 when I saw him first. I actually saw his brother first who was referred by their orthodontist. His brother had a cross bite. When I did the evaluation on the brother, the Mom and Dad said all of the sleep symptoms sounded more like their son [REDACTED]. I go through a power point at my evaluations where I discuss OMD symptoms in kids. So they brought him in later for an evaluation. I am not sure what exact things they had tried for the bedwetting prior. His mom just told me she had asked every doctor [REDACTED] had ever been to if they knew why he was wetting the bed. She said every doctor said that some kids just do and that he would eventually outgrow it.

After my initial assessment, I referred [REDACTED] for a home sleep study. After we received those results I referred him to an ENT that has experience with myofunctional disorders. The ENT was trained by Dr. [REDACTED] in lingual functional frenuloplasty. However, [REDACTED] had his tongue tie released while sedated due to him needing his adenoids removed and nasal turbinate reduction at the same time. I did about 4 sessions of therapy with [REDACTED] prior to the surgery to prepare him for the tongue tie release. His mom told me his bedwetting reduced just with therapy to get him nasal breathing and getting his tongue up.

[REDACTED] did not have any behavior issues. He was a very calm young man. However, after resolving his bedwetting his mother said he was more confident. I had her write a testimonial for one of the presentations I did. I will post it below:

“Before our son’s surgery he started exercises with the myofunctional therapist. It was at this time that his nighttime wetting started to decrease from about 6 times a week to 3-4. Then after surgery, It was completely gone! The dark circles under his eyes are lighter and he has remained cavity free.

We are so grateful that the myofunctional therapist was educated about tongue ties and the symptoms of a dysfunctional airway. We were able to get to the root cause of many of these seemingly unrelated symptoms that our son was experiencing. I think our son’s future health has been preserved by addressing these issues now. He is happy and confident and looking forward to getting braces in a couple of months. “

-Sara

Patient Name: [REDACTED]  
DOB: 05/25/2007  
Date of Exam : 05/01/2019

Medical Hx:  
• Seasonal/Environmental Allergies  
• Congenital Hernia Repair

Medications:  
• Claritin

Other significant history:  
• Was breastfed - did have latching issues  
• Nocturnal Enuresis



## Myofunctional Findings

### SPEECH

Pt does mumble and has issues with voice projection.

### SLEEP

Pt tends to sleep with mouth open. Pt wakes with dry mouth and sore throat. Pt has nocturnal enuresis approximately every 2-3 nights.

### ORAL POSTURE

Pt has open mouth posture mostly at night. Pt tends to drool at night. Pt's nose tends to stay clogged. Pt states the tip of his tongue rests on his lower teeth. Pt feels the back of his tongue rests in between his upper and lower teeth.

### EATING, DRINKING, SWALLOWING

Pt has a tongue thrust swallow.

### DENTAL/ORTHODONTIC

Pt has a deep bite. Pt has 4mm of overjet. Pt is skeletal Class II. Pt is slightly retrognathic. Pt has not been evaluated by ortho yet.

### NASAL PATENCY

Restricted airflow in left nostril

### PALATE

Slightly narrow and vaulted

### TONSILS

Grade II

---

**MALLAMPATI**

Grade III

**UVULA**

WNL

**TONGUE**

Pt has a heart shaped tip with a slight midline groove. Pt's tongue rolls some when lateralizing. Pt has difficulty placing tip of tongue to tip of lip and the upper lip rolls under. Pt has difficulty raising posterior portion of tongue to suction & hold.

**LINGUAL FRENUM**

Pt has a Grade 2 Functioning Tongue Tie (66% TRMR). Pt has 57% TRMR with suction & hold. Patient's frenum attaches into the anterior third of the tongue and into the alveolar crest. Pt has "Eiffel Tower" tie. The floor of pt's mouth elevates when raising tongue. Kotlow's Free Tongue Measurement is 10mm.

**LIP FRENUM**

Pt has maxillary labial frenum that we will monitor for now.

**FACIAL DEVELOPMENT**

Retrognathic chin

**POSTURE**

Forward head posture

**TREATMENT RECOMMENDATIONS**

- Referral to ENT to evaluate nasal patency and airway.
- Referral for Sleep Evaluation
- Tongue Tie Release with Dr. [REDACTED]
- 12 Sessions of Myofunctional Therapy to treat mouth breathing, sleep issues, and tongue posture.
- Ortho Referral to Dr. [REDACTED]

**Patient Photos**







## Pediatric Home Sleep Test Screening Report

| Home Sleep Test Report |            | Study Date: 5/14/2019 |                |
|------------------------|------------|-----------------------|----------------|
| Patient Name:          | [REDACTED] | Recording Device:     | Alice NightOne |
| Sex:                   | M          | Height:               |                |
| D.O.B.:                | 5/25/2007  | Weight:               |                |
| Age:                   | 11 years   | B.M.I.:               |                |

| Times and Durations    |             |                             |               |
|------------------------|-------------|-----------------------------|---------------|
| Lights off clock time: | 10:10:03 PM | Total Recording Time (TRT): | 717.8 minutes |
| Lights on clock time:  | 10:07:51 AM | Time In Bed (TIB):          | 717.8 minutes |

This study has been found to be technically adequate for interpretation.

| Summary |            |     |            |     |            |              |           |
|---------|------------|-----|------------|-----|------------|--------------|-----------|
| AHI     | <b>2.0</b> | OAI | <b>2.0</b> | CAI | <b>0.0</b> | Lowest Desat | <b>91</b> |

AHI is the number of apneas and hypopneas per hour. OAI is the number of obstructive apneas per hour. CAI is the number of central apneas per hour. Lowest Desat is the lowest blood oxygen level that lasted at least 2 seconds

| RESPIRATORY EVENTS |                |                   |                     |                    |                         |            |            |            |            |
|--------------------|----------------|-------------------|---------------------|--------------------|-------------------------|------------|------------|------------|------------|
|                    | Index (#/hour) | Total # of Events | Mean duration (sec) | Max duration (sec) | # of Events by Position |            |            |            |            |
|                    |                |                   |                     |                    | Supine                  | Prone      | Left       | Right      | Up         |
| Central Apneas     | 0.0            | 0                 | 0.0                 | 0.0                | 0                       | 0          | 0          | 0          | 0          |
| Obstructive Apneas | 2.0            | 24                | 10.2                | 14.0               | 24                      | 0          | 0          | 0          | 0          |
| Mixed Apneas       | 0.0            | 0                 | 0.0                 | 0.0                | 0                       | 0          | 0          | 0          | 0          |
| Hypopneas          | 0.0            | 0                 | 0.0                 | 0.0                | 0                       | 0          | 0          | 0          | 0          |
| Apneas + Hypopneas | 2.0            | 24                | 10.2                | 14.0               | 24                      | 0          | 0          | 0          | 0          |
| <b>Total</b>       | <b>2.0</b>     | <b>24</b>         | <b>10.2</b>         | <b>14.0</b>        | <b>24</b>               | <b>0</b>   | <b>0</b>   | <b>0</b>   | <b>0</b>   |
| Time in Position   |                |                   |                     |                    | 430.0                   | 63.8       | 192.6      | 10.5       | 7.6        |
| AHI in Position    |                |                   |                     |                    | <b>3.2</b>              | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> |

*Hypopnea is defined as an abnormal respiratory event lasting at least 2 breaths associated with at least a 30% reduction in airflow as compared to baseline, and with at least a 3% decrease in oxygen saturation.*

Patient: 

## Home Sleep Test Report

| Oximetry Summary                  |            |           |
|-----------------------------------|------------|-----------|
|                                   | Dur. (min) | % TIB     |
| <90 %                             | 15.5       | 2.2       |
| <85 %                             | 10.9       | 1.5       |
| <80 %                             | 0.0        | 0.0       |
| <70 %                             | 0.0        | 0.0       |
| Total Dur (min) < 89              |            | 15.5 min  |
| <b>Average (%)</b>                |            | <b>96</b> |
| Total # of Desats                 |            | 4         |
| Desat Index (#/hour)              |            | 0.4       |
| Desat Max (%)                     |            | 7         |
| Desat Max dur (sec)               |            | 28.0      |
| <b>Lowest SpO2 % during sleep</b> |            | <b>91</b> |
| Duration of Min SpO2 (sec)        |            | 192       |

| Heart Rate Stats        |            |
|-------------------------|------------|
| Mean HR during sleep    | 73.5 (BPM) |
| Highest HR during sleep | 106 (BPM)  |
| Highest HR during TIB   | 106 (BPM)  |

| Snoring Summary             |              |
|-----------------------------|--------------|
| Total Snoring Episodes      | 157          |
| Total Duration with Snoring | 22.9 minutes |
| Mean Duration of Snoring    | 8.7 seconds  |
| Percentage of Snoring       | 3.3 %        |



## Pediatric Home Sleep Test Screening Report

**BACKGROUND:**

1. Patient's breathing rate was noted to be approximately 16 breaths per minute – 18 breaths per minute
2. 2 missed breaths were defined as  $\geq 8$  seconds; based upon the average length of 2 breaths during baseline breathing. Pediatric apneas were scored by notation of 2 missed breaths
3. Pediatric hypopneas were scored by notation of  $\geq 30\%$  decrease in amplitude of flow waveform for 2 missed breaths with associated oxygen desaturation  $\geq 3\%$
4. Flow limitation is deemed significant if sigh breath is noted post limitation, SpO<sub>2</sub> plethysmography waveform has decrease in amplitude post limitation, and/or if pulse rate fluctuates  $\geq 4$  beats per minute
5. SpO<sub>2</sub> plethysmography waveform reduction equals reduced oxygenated blood to the periphery
6. AHI  $\leq 1$  is normal, AHI 1-5 is mild, AHI 5-10 is moderate, AHI  $> 10$  is severe.
7. This report is not a diagnosis, rather a screening mechanism not unlike overnight oximetry

**IMPRESSION:**

1. Mild obstructive sleep apnea with an overall AHI 2.0 events per hour.
2. Frequent flow limitation noted; consistently accompanied by SpO<sub>2</sub> plethysmography waveform reduction and pulse rate variance of  $\geq 5$  beats per minute
3. Mild to moderate sigh breaths (gasping) were noted post flow limitation and were concurrent with pulse rate variance and SpO<sub>2</sub> plethysmography waveform reduction
4. Snoring noted consistently throughout the study
5. Respiratory events, to include flow limitation were noted almost exclusively while supine

**POSSIBLE SYMPTOMS:**

1. Excessive daytime sleepiness, nocturnal enuresis, somniloquy, somnambulism, headaches, attention deficit, impaired cognition, hyperactivity, allergies, frequent rhinorrhea, ear infection, reduced hearing, cold extremities

**POSSIBLE SIGNS:**

1. Forward head posture, mouth breathing, increased buccal space, crossbite, vaulted palate, enlarged turbinates, nasal septal defect, adenoid face, retrognathia, sunken orbits, bruxism, drooling, inability to see airway with mouth open, V-shaped uvula

**RECOMMENDATION:**

1. Follow up with myofunctional therapist
2. Evaluate for mid-face deficiency
3. Evaluate for soft tissue abnormality

*Scored, reviewed, and electronically signed by:*

 RRT, RPSGT

Date: 05/18/2019