

## Pediatric Sleep Medicine: Priorities for Research, Patient Care, Policy and Education.

*A Report From the Conference Held February 19-20, 2005, Amelia Island, Florida*

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**Study Objective:** To achieve consensus among pediatric sleep medicine practitioners on recommendations for the advancement of the field in the areas of research, clinical practice, education, and public policy.

**Methods:** Leading pediatric sleep medicine researchers and clinicians, in collaboration with Brown Medical School, convened a conference to discuss the state of the field. Participants engaged in multiple discussion panels and work groups, ultimately creating recommendations to advance basic and clinical research, clinical practice, sleep education, and public policy.

**Results:** Participants reached agreement on the major challenges facing the field. Key points of consensus were the need to conduct long-term epidemiologic studies of sleep patterns and sleep disorders in children, standardize polysomnography and other sleep-measurement methodologies, examine the links between insufficient and disrupted sleep in the pediatric population and physical and mental health outcomes, and develop clinical standards of practice. Attendees also agreed on the need

to educate more medical health practitioners and the public on pediatric sleep. The importance of research on sleep in children and adolescents to inform public policy decisions was also endorsed.

**Conclusions:** Pediatric sleep medicine is a related, but unique, discipline within the broader field of sleep medicine. Additional research, both basic and clinical, on all aspects of children's sleep is necessary to elucidate the neurophysiologic basis of normal sleep development; to establish a solid foundation for the evaluation, diagnosis, and treatment of pediatric sleep disorders; and to formulate evidence-based public policy in sleep health.

**Keywords:** Pediatrics, research, patient care, education, policy

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Recognition of the significance of sleep to the overall health and well-being of children and adolescents is of relatively recent origin. Over the last few decades, there has been an explosion in information about sleep in children and the different developmental stages relative to sleep from birth through adolescence. Further study has led to the characterization of pediatric sleep disorders unique to different developmental stages (e.g., sleep onset association disorder in very young children, delayed sleep phase syndrome in adolescents), as well as disorders that are also observed in the adult population (e.g., restless leg syndrome, obstructive sleep apnea). Links between sleep disorders and other medical, psychiatric, and developmental disorders, including depression, attention-deficit/hyperactivity disorder (ADHD), neurodevelopmental disorders, and posttraumatic stress disorder, are

also beginning to be explored in the pediatric population.

In spite of substantial progress, there are still many open questions about fundamental aspects of the diagnosis and treatment of pediatric sleep disorders. There is still much to learn about the development of sleep in childhood and the linkage of various sleep disorders to negative health outcomes. The tools used to study adult sleep are not always appropriate for use in children, and a common definition of 'normal' sleep for any age range does not exist. Clinicians continue to struggle with the lack of standards of practice for the evaluation and treatment of these disorders, as well as reimbursement for care. Families, professionals who work with children, and healthcare practitioners are often unaware of basic information about the importance of healthy sleep and appropriate treatment options for children who are experiencing difficulties. Finally, public-policy decisions are frequently made without consideration of the impact that they will have on children's sleep practices.

Responding to these concerns, a national conference was organized, bringing together major stakeholders in these issues on February 19 and 20, 2005, in Amelia Island, Florida. The goals of the meeting were (1) to share information on the current state of the field of pediatric sleep in the following key areas: basic and clinical science, clinical practice, professional and public education, public policy, and organization of the field and (2) to develop recommendations for further action or research in each of these areas. More than 130 participants from the United States, as

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well as from other countries, including Canada, Israel, and China, attended the conference. They represented a broad range of disciplines involved in both research in and the clinical practice of pediatric sleep medicine in academic and community settings, including pediatric pulmonary medicine, child neurology, neurosurgery, pediatric critical care, developmental/behavioral pediatrics, child psychiatry, child psychology, and nursing. Representatives from the National Institutes of Health, patient education and advocacy groups, and industry also participated in the conference.

The conference agenda (see Appendix) began with plenary presentations providing a survey of pediatric sleep medicine, followed by a “research blitz” overview of pediatric sleep research programs in the United States and panel discussions focused on issues in public policy, clinical practice, and pediatric sleep education. The first day concluded with breakout discussion sessions on special topics in pediatric sleep medicine. On the second day of the conference, all conference participants were assigned to a working group in one of the following areas (basic and clinical research, clinical practice, education, policy, and organization). Each working group was charged with identifying a set of key issues in a specific area of pediatric sleep medicine and developing recommendations within their selected broad area to address them. At the conclusion of the conference, the working groups reconvened to present their recommendations to the entire group, providing the opportunity for all conference participants to be exposed to, and comment on, the efforts of each group. This report presents a summary of the current knowledge/status and identifies gaps in each of the general areas, as outlined in the presentations on day 1 and further refined within the working groups, and the consensus “work-in-progress” general and specific recommendations for future directions developed by the working groups in each category. The specific aims of this summary are to educate a wide variety of stakeholders and constituencies and to provide background information for groups that develop policies and guidelines relating to pediatric sleep medicine.

## I. RESEARCH

### A. Current Knowledge

The evolution of research in pediatric sleep medicine over the past half century may be illustrated by tracing the emergence of infant sleep research that began with the rigorous exploration of the field in the 1950s and 1960s. Milestones in infant sleep research include the identification of key research areas, such as the ontogeny of sleep-architecture development beginning in fetal life, the interaction between chronobiology and endocrine changes in neonates, the bidirectional relationship between maternal and infant sleep, and the effects of sleep deprivation and stress on infant sleep; development and refinement of specific research methodologies, such as time-lapse video recording of sleep in infants and the standardization of infant sleep-scoring terminology; creation of a nosology and classification systems of infant sleep disorders; and development of transactional models of infant sleep to describe the transition from parent-infant to self-regulation of sleep.

There has been an explosion of knowledge in these and many other aspects of pediatric sleep research, as indicated by the increase in PubMed pediatric sleep citations from 20 in the decade between 1970 and 1980 to 506 between 2000 and 2004. Both the scope and the fundamentally multidisciplinary nature of pedi-

atric sleep research are illustrated by the diversity and breadth of the research programs presented during the research blitz. Topics presented included the relationship between sleep and obesity in children (obstructive sleep apnea and metabolic syndrome, sleep-wake cycles in obese children with binge eating, and continuous positive airway pressure (CPAP) treatment for obese adolescents with obstructive sleep apnea); variables impacting on the development of sleep-disordered breathing in normal children (including pubertal status, specific anatomic factors, sleep architecture, second-hand smoke, sleeping position) and in special pediatric populations (obstructive sleep apnea in children with cleft palate and sickle cell disease, risk factors for cardiovascular disease in these patients); sleep problems in children with a variety of chronic medical disorders (including cystic fibrosis, Williams syndrome, traumatic brain injury, epilepsy, chronic headaches, juvenile rheumatoid arthritis, and hospitalized children); psychosocial comorbidities in children with sleep problems (e.g., poverty, family stress, ADHD); and treatment modalities for sleep problems (including chronobiologic interventions for childhood depression, surgical treatment of obstructive sleep apnea, iron therapy for restless legs syndrome/periodic limb movement disorder). Other research areas discussed included sleep and education (including parenting books as an intervention for sleep problems, impact of early school-start times on sleep, and psychological and academic outcomes of insufficient sleep), sleep issues in caregivers of chronically ill children, development of empirically based classification systems for sleep disorders, and clinical outcomes related to service-delivery systems. Multiple disciplines were represented in these research programs, ranging from pediatric neurology, neuropsychology, child psychology and psychiatry, and developmental/behavioral pediatrics to pediatric otolaryngology and rheumatology.

Any discussion of the topic of pediatric sleep clinical research must also take into consideration the methodologic and ethical challenges inherent in conducting research in children. Generally, in clinical research, for example, research topics are selected because they represent a significant problem for patients and, thus, counterbalance exposure to trial-related risk. This may involve, for example, limiting participation in trials to patients who had already attempted behavioral therapy without sufficient improvement. Cultural norms and values influence the choice of research topics and assumptions as well. Although studies conducted across the world indicate a fairly consistent prevalence rate of pediatric sleep problems, independent of the cultural variations in sleep practices, it is clear that cultural factors do interact with other variables in affecting problematic outcomes of sleep patterns and behaviors. Thus, it is critical to take specific cultural factors into account when making international or cross-cultural comparisons in pediatric sleep research or when stating purportedly generalizable conclusions.

### B. Research Gaps

- Although it is clear that substantial progress has been made to develop both basic and clinical research in pediatric sleep, much remains to be done. This is evidenced by the recommendations included in the National Center on Sleep Disorders Research 2003 research plan ([http://www.nhlbi.nih.gov/health/prof/sleep/res\\_plan/index.html](http://www.nhlbi.nih.gov/health/prof/sleep/res_plan/index.html)), which made specific recommendations for pediatric sleep research in the areas of

sleep deprivation, sleep-disordered breathing, insomnia, parasomnias, sleep in children with medical and neuropsychiatric disorders including ADHD, adolescent sleep, regulation of sleep in early childhood, and the linkages between sleep and early brain development, attention, and arousal. As stated in the 2003 National Institutes of Health Sleep Research Plan, “an improved understanding of all aspects of the neurobiology and function of sleep is needed,” particularly during the various developmental stages of sleep, beginning with the fetus and continuing through adolescence.

- Within specific patient populations, including special-needs children and children with medical and psychiatric disorders, research is needed to identify the prevalence of different types of sleep disorders and to investigate the neurobiologic and physiologic mechanisms of interaction between sleep regulation and primary medical, neurologic, and psychiatric conditions (for example, periodic limb movement disorder/restless legs syndrome and ADHD).
- There are a number of key research questions regarding the impact of cultural beliefs and practices on sleep in children. These include: Is there a universally applicable set of criteria defining “normal” sleep for children at various developmental stages? How do cultural factors (including specific ethnic identity, generation, level of acculturation) and social class interact in shaping children’s sleep, and is it possible to separate these influences? Can it be shown that any one approach to 1 or more specific pediatric sleep problems is “better,” irrespective of cultural setting?
- Short-term and long-term effectiveness of different treatment modalities (behavioral, pharmacologic, respiratory, surgical) for sleep disorders have to be evaluated. Clinical trials are needed to create an evidence base for pharmacologic treatment recommendations for pediatric sleep disorders. For example, currently, there are no pharmacologic agents that are approved by the Food and Drug Administration for use as hypnotics in the pediatric population, and safety and efficacy data are nonexistent.

### C. Research Recommendations

#### BASIC RESEARCH

Several key areas were identified as priorities in basic research in pediatric sleep:

- Extensive epidemiologic research is needed to characterize the genetic and environmental factors that are associated with both normal and abnormal sleep. As these relationships are better understood, basic researchers could be able to identify various biomarkers associated with different phenotypes of abnormal sleep that might help to identify different animal models for sleep research.
- A greater degree of productive collaboration of basic scientists with clinical researchers is needed, potentially leading to the development of translational research programs and solidly grounded approaches for improving children’s health through a combination of treatment and prevention.
- To meet these goals, research will need adequate funding and organizational support to further cooperation both among the community of basic researchers and with peers in clinical research.

#### CLINICAL RESEARCH

Several major themes were also identified as critical to advancing clinical research in the field of pediatric sleep medicine: (1) identification and characterization of normal sleep in children, as evaluated both by specific clinical outcomes and more-direct measures of sleep such as polysomnography (PSG); (2) further delineation of the causes and consequences of “abnormal” sleep (e.g., insufficient and/or fragmented sleep, circadian disruption); (3) the effects of different treatment options for specific sleep disorders, including pharmacologic management; and (4) specific recommendations were made regarding cross-cultural issues in pediatric sleep research and research in special populations.

- A multipronged approach is needed to address these issues, and availability of validated research tools was identified as a key component. In particular, additional tools for the assessment of daytime sleepiness in the pediatric population need to be developed and validated. Protocols should be developed for standardized neurocognitive and neurobehavioral assessment batteries to assess the impact of disturbed sleep at different developmental levels. In addition, clinical researchers would benefit from the availability of a website that would enable downloading of standardized clinical research tools.
- A national database for tracking both rare-case sleep disorders and ongoing, long-term, pediatric sleep studies should be created.
- Long-term cohort studies that could link sleep disorders with health outcomes and that could shed light on normal sleep development, the consequences of abnormal sleep, and treatment efficacy are needed. Efforts to fund these studies could potentially include efforts to embed sleep measures in other large-scale longitudinal pediatric studies.
- Multicenter, double-blind, placebo-controlled trials of sedative/hypnotics in children with symptoms of acute or chronic insomnia, including in children with special needs, need to be conducted.
- Cross-cultural issues identified as needing further research or clarification include: evaluation of cross-cultural applicability of established quantitative and qualitative sleep instruments, longitudinal assessment of specific cultures aimed at tracking changes in cultural norms and sleep patterns/sleep behavior; and development of standardized and culturally sensitive definitions of sleep practices such as cosleeping and napping.

## II. CLINICAL ISSUES

### A. Current Status

A number of target clinical issues in pediatric sleep medicine were presented, including (1) the management of pediatric sleep disorders in special populations, specifically in tandem with other common medical and psychiatric comorbidities, including in children with special needs, (2) challenges in pediatric sleep medicine healthcare delivery, including the coordination of the various disciplines involved in the care of children with sleep problems), (3) cultural considerations in working with various populations, (4) the use of PSG as a diagnostic tool in pediatric sleep medicine, and (5) the use of CPAP in the pediatric population.

## SPECIAL POPULATIONS

There is compelling evidence of a bidirectional interaction between the neurophysiologic systems that regulate sleep and affective, behavioral, and cognitive development in children and adolescents. Therefore, not only do children with existing psychiatric and neurologic disorders more frequently experience sleep disorders, but normal children whose sleep problems disrupt their mood or behavior run a higher risk for developing consequent psychiatric disorders. Studies of the general population of school-aged children have linked sleeping problems with anxiety, depression, aggressive behavior, attention problems, and mental distress. Restless legs syndrome, snoring, and sleep-disordered breathing have been correlated with hyperactivity and ADHD. Children with special needs may be defined as those with chronic medical, developmental, neurologic, emotional, or behavioral morbidities. These children often experience significant, chronic sleep disorders that complicate their lives and place additional strains on their families. Parents of children with pervasive developmental disorders, for example, have reported high rates of sleep disturbances in their children, including difficulty settling to sleep, prolonged and frequent awakening, shortened sleep duration, irregular sleep patterns, and parasomnias.

## HEALTHCARE DELIVERY

At present, parents turn to a collection of individuals for assistance with their children's sleep problems. These individuals might include sleep specialists, pediatricians, nurses, and psychologists. Having many different sources of potential assistance is positive for families, provided that the individual they select to assist them has an appropriate level of knowledge and is capable of either diagnosing sleep disorders related to medical issues or referring the family to an appropriate physician for diagnosis when behavioral sleep disorders have been ruled out. Pediatricians typically serve as the first line of defense for children's health problems. They are usually under significant time pressures, attempting to juggle both the specific treatment objectives that triggered a patient's visit, as well as conducting any one of a sizable number of recommended therapeutic screens and patient-education interventions. Incorporating a sleep screen into this context necessitates a simple process that can be used to quickly identify patients with significant sleep problems without requiring an excessive amount of time for patients who are not affected.

## CULTURAL ISSUES

Sleep practices are strongly influenced by cultural norms and setting. Thus, sleep behaviors of both adults and children may be considered to be a result of interactions among biologic, psychological, developmental, environmental, and sociocultural influences. Clinical advice also needs to be tailored to the cultural values and practices of particular families.

## POLYSOMNOGRAPHY

The overwhelming majority of PSG studies in children are performed to diagnose sleep-disordered breathing. However, there is limited evidence about how these disorders should be defined and relatively little evidence linking PSG parameters to clinical outcomes. Specifically, there is significant uncertainty about which physiologic data should be acquired by what set of equipment, the

best method for scoring PSGs, and how to interpret PSG results. Interpreting PSGs presents difficulties in defining what is normal, determining the threshold of abnormal results that indicates morbidity, and identifying which PSG data will be the best predictor of health outcomes.

## CONTINUOUS POSITIVE AIRWAY PRESSURE

There are a number of issues currently limiting effective pediatric CPAP, including variations between clinicians and sleep centers in the definition and recommended treatment of sleep-disordered breathing, challenges in conducting CPAP titration of children in the lab, lack of availability of pediatric masks and units developed specifically for children, difficulties in training the patient's family on its usage and care, compliance issues related to specific populations (e.g., children with developmental disabilities, adolescents), and barriers to ensuring that insurance coverage is available.

**B. Clinical Gaps**

- The absence of pediatric standards of practice for the evaluation and treatment of pediatric sleep patients ensures that there will continue to be variation in the evaluation, diagnosis, and treatment of these disorders and a corresponding unevenness in health outcomes.
- Despite the prevalence and significant impact of sleep disorders on health and development, the lack of outcome data regarding treatments for sleep problems in children and adolescents with psychiatric disorders has resulted in the use of interventions that are primarily based on generalized empirical evidence or on anecdotal clinical experience.
- Clinically, the utility of PSG in children is somewhat unclear. As yet, there have been no studies providing a clear link between clinical symptoms, PSG results, and health outcomes. As a result, different practitioners evaluating the same patient may make different diagnoses and advise very different courses of action. Furthermore, most PSG labs are not set up to accommodate children, so obtaining PSG results is somewhat problematic for pediatric patients. Further complicating the issue, different labs have chosen to utilize different measurement equipment and even score results from the same equipment using dissimilar methodologies.

**C. Clinical Recommendations**

- New techniques should be developed to monitor sleep-specific features responsible for clinically significant and reversible morbidities. The evidence base would be significantly enhanced by efforts to develop age-specific norms and pairing of diagnostic data with clinically meaningful outcome data.
- Patient care for special-needs children would be improved by the development of brief screening tools for use during regular office visits and guidelines for assessment and treatment of sleep disorders, including behavioral or cognitive-behavioral interventions.
- The availability of pediatric sleep medicine services would be enhanced by developing information sources for referrals to nearby sleep centers that provide necessary expertise, and the implementation of programs to minimize and pre-

vent chronic sleep disorders in inpatient settings (pediatric intensive care units, neonatal intensive care units, hospital wards).

- Clinical assessment tools should be culturally sensitive, available in different languages, and appropriate for a variety of literacy levels.
- The methodologic evidence base for pediatric PSG needs to be expanded in order to establish age-specific norms, to pair diagnostic and outcomes data, and to standardize PSG equipment usage and scoring. Specifically, information in this area would provide a useful basis for agreeing upon a “common language” for PSG signals, sensors, and scoring. Finally, pediatric diagnoses would be improved by identifying a cost-effective screening mechanism utilized prior to PSG and improving access to sleep health care.
- Regarding the use of CPAP in children, specific negative clinical outcomes associated with sleep-disordered breathing that are improved with CPAP need to be identified. To maximize CPAP compliance, it would be beneficial to increase the number of mask-interface devices available for use in children. Pediatric CPAP program development needs to occur at both the local and national level and to include advocacy for funding of CPAP by insurance providers.

### III. EDUCATION

#### A. Current Status

Discussion of education issues in pediatric sleep medicine was focused around 4 distinct constituencies: graduate and postgraduate medical trainees, graduate psychology students, nursing students, and the general public.

##### PHYSICIAN TRAINEES

The Accreditation Council on Graduate Medical Education has recently adopted program requirements governing accreditation of sleep medicine fellowships, and several programs have been accredited. Many individuals and organizations also have been working to enhance undergraduate, graduate, and postgraduate curriculum with sleep medicine content. These efforts have culminated in the active planning for a future board examination to be administered by the American Board of Internal Medicine. Individuals passing this examination will receive a certificate indicating sleep medicine specialization from the American Board of Internal Medicine, the American Board of Psychiatry and Neurology, American Board of Pediatrics, or the American Board of Otolaryngology.

Furthermore, there is compelling evidence that sleep disorders leading to meaningful negative health outcomes are widely underdiagnosed in both adults and children. This underdiagnosis is correlated with a deficient focus on teaching about sleep disorders in most medical schools and internship and residency programs. Efforts like the past National Center on Sleep Disorders Research/National Heart, Lung, and Blood Institute Sleep Academic Award Program serve to develop pediatric sleep medicine curriculum and promote the cooperation necessary to advance the field. Core curricula in pediatric sleep medicine have been developed that focus on the assessment and management of common pediatric sleep disorders and clinical skills development (including screening; diagnostic algorithms; use of sleep diagnostic tools like PSG

or sleep diaries; and behavioral, pharmacologic, and chronobiologic treatment strategies). Several studies have been conducted on the effectiveness of different pediatric sleep-medicine training schemes, such as the use of a simple sleep screening tool in the pediatric practice setting. These evaluations have found that relatively simple interventions result in an increase in physician awareness of the health impacts of pediatric sleep, and efforts in clinical practice settings have been shown to significantly increase the frequency of screening and treatment of sleep disorders

##### GRADUATE PSYCHOLOGY EDUCATION

Certification guidelines for practitioners and accreditation guidelines for behavioral sleep-medicine training programs were both published in early 2005 by the American Academy of Sleep Medicine. These guidelines should provide much-needed support for sleep medicine specialists who are continuing to attempt to integrate basic information on behavioral sleep medicine into the academic coursework, clinical practicum training, and clinical internship training of a larger number of general psychology programs.

##### GRADUATE NURSING EDUCATION

Until recently, there have been few attempts to establish a curriculum for educating nursing students to identify and treat sleep disorders in either the adult or pediatric populations. A few states have elected to incorporate sleep education into both lectures and nursing rotations, but this not the norm nationwide. In 2004, a group of nurses specializing in the field of sleep and circadian-rhythm disorders published a paper containing a series of recommendations regarding the inclusion of sleep medicine into nursing education programs. Enhancing the nursing curriculum in this manner would provide important benefits to families, since nurses often act as the first line of medical care, providing advice to parents on many aspects of their children’s health. More generally, a larger number of trained nurses would help the field of pediatric sleep medicine because their involvement with research projects and epidemiologic studies is critical to the advancement of the field.

##### PUBLIC EDUCATION

Parents face a bewildering array of information sources that address sleep in children. Several dozen books are exclusively dedicated to this topic, while hundreds more general parenting books have a chapter on sleep. Advice is offered by the mainstream media, as well as by magazines and television shows targeting parents. Thousands of internet sites purport to do the same. This vast quantity of material is testament to the fact that parents are extremely interested in helping all members of their family get an adequate night’s sleep and are willing to seek out assistance to achieve this goal. It should be noted that National Institutes of Health, American Academy of Sleep Medicine, and National Sleep Foundation have conducted successful education campaigns on general issues in sleep for younger children.

#### B. Education Gaps

- As with any new field of study, there are significant barriers to expand the dissemination of sleep education. In addition to the challenges of finding qualified faculty and squeezing

additional coursework into an already packed curriculum, the interdisciplinary nature of sleep medicine and the medical community's limited awareness of the link between sleep and health outcomes have limited efforts to expose more students to the fundamentals of sleep medicine.

- In spite of recent progress, much work remains to be done to ensure the spread of knowledge of this vital field throughout medical schools and the community of practicing physicians.
- General sleep education is not a standard part of most graduate psychology programs, and it almost goes without saying that pediatric sleep receives even less attention. Not surprisingly, this lack of emphasis is evidenced by the extremely limited coverage of sleep in the leading psychology textbooks. Further indication of this omission comes from a 2000 survey that found that only 17 North American universities with graduate psychology programs offered a specialization in behavioral sleep medicine. This small number of educational offerings corresponds to an even smaller number of internship programs.

### C. Education Recommendations

Broadly speaking, the educational efforts should be focused on 3 groups: (1) pediatric sleep medicine trainees, including medical and psychology postgraduate trainees; (2) healthcare providers both in training and in practice, including primary care physicians, pediatricians, obstetricians, psychologists and nurses; and (3) the general populace, including parents, children, teachers, and social workers. All audiences need to be educated about the basics of healthy sleep and simple methods to recognize common, treatable, sleep problems in children.

#### POSTGRADUATE SLEEP TRAINING

- An up-to-date, centralized listing of sleep-training sites with pediatric-specific information would help alleviate difficulties involved in finding pediatric sleep medicine education opportunities.
- Trainees would benefit from a core reading list on the subject, as well as the creation of additional comprehensive texts such as the recently published *Principles and Practice of Pediatric Sleep Medicine*.
- Access to a network of pediatric sleep specialists could help trainees connect with potential mentors, especially trainees at institutions with limited programs in this area.
- Trainees in pediatric sleep are in need of additional funding. This funding could take the form of either individual student grants from a foundation or academic institution or broader grants from national funding sources (e.g., National Institutes of Health, American Academy of Sleep Medicine, National Sleep Foundation, non-profit foundations, and private industry) secured by experienced faculty members to support entire training programs.

#### HEALTHCARE PROVIDERS

- Organizationally, education efforts targeting medical practitioners would benefit from a website containing information on pediatric sleep education, a standardized curriculum, and downloadable age-appropriate assessment tools.

- Basic cultural-competence information should be incorporated into education and training materials developed for sleep medicine instruction for healthcare professionals and sleep researchers. Culturally appropriate definitions of "healthy sleep" for use in public, parent, and health-professions' education need to be developed, including descriptions of culture-specific norms, values, and preferences.
- Additional efforts should be made to publish review and original research articles on pediatric sleep topics in journals beyond those targeting sleep specialists.

#### PUBLIC EDUCATION

- Education efforts for the general public could include the placement of sleep-assessment tools into maternity and well-child information packets, training for Lamaze instructors, mass-media campaigns, and efforts to incorporate sleep-hygiene information into science and/or health classes for children and teenagers.
- Including more information on sleep-disordered breathing, as well as sleep issues present in older children and adolescents, would enhance public education in pediatric sleep. Future efforts could also target new audiences, including non-English-speaking families, older children and adolescents, and teachers.
- Education efforts focused on sleep disorders in special-needs children should target the caregivers who are serving this population. Sleep-education materials for parents and special-education teachers should be developed in order to increase their awareness of the effects of sleep disruptions on these children's learning abilities and daytime behavior.
- Education courses on sleep disorders should be introduced into the training of other healthcare professionals, such as clinical psychologists, social workers, occupational therapists, physical therapists, speech and language therapists, respiratory therapists, and nurses.
- Efficient and convenient dissemination of knowledge with sharing of experience among pediatric sleep-health specialists would be desirable.

## IV. PUBLIC POLICY

### A. Current Status

There are multiple public-policy choices that impact pediatric sleep behaviors. Issues involving school policies include school start times, caffeine usage, and scheduling extracurricular activities. Broader societal issues include drowsy driving, work hours for adolescents, and the scheduling of television programs that target children. The major public-policy issues discussed included napping in young children, school start times for adolescents, and drowsy driving.

#### NAPPING

Children take naps for 3 reasons: in response to inadequate sleep, as part of a biphasic sleep cycle, and in preparation for a period of sustained wakefulness. Although research conducted with adult subjects has demonstrated that napping is associated with improvements in memory and other measures of neuropsychological performance, the role that napping plays in child development is largely unexplored. Multiple studies have indicated that

children begin to give up napping around 3 years of age; however, it is not clear whether children are spontaneously discontinuing napping because it has become unnecessary for them, or if naps are forcibly eliminated by parents, daycare, preschool, and kindergarten.

As women's participation in the workforce has increased over the past 30 years, there has been a corresponding rise in the number of young children in daycare and preschool. Thus, children's freedom to continue napping is governed by the policies of these care-giving organizations. Initiatives like the Federal No Child Left Behind Act and the introduction of school vouchers have placed school districts under substantial pressure to improve test scores. These factors have led some school districts to reduce or eliminate naptime in their preschool and/or kindergarten programs to increase the time dedicated to "learning." Understanding the effects of napping on child development is thus more important than ever, since moves to reduce napping in young children may actually be counterproductive to achieving education goals.

#### SCHOOL START TIMES

On average, adolescents require more than 9 hours of sleep nightly to be adequately rested. Achieving this goal is challenging under normal circumstances and becomes even more so if their schooling begins too early in the morning. Recent research indicates that the mean start time of high schools in the United States was 8 am in 1975, shifting back to 7:30 am in 1996. This earlier opening bell forces adolescents to go to bed earlier to be able to get enough sleep, a behavior that is contrary to their circadian rhythm and social structures.

In response to concerns about the amount of sleep students were getting, a small number of school districts across the country have responded by delaying their starting time for their high schools and/or middle schools. Initial evaluations of the results from these changes have been positive. In one effort, Minneapolis students in grades 9 to 12 obtained approximately 1 hour of additional sleep on school nights after their school start time was delayed from 7:15 am to 8:40 am. Studies of the Minneapolis school districts and others making similar changes have found that delays in school start times are associated with increases in total sleep time and attendance rates, decreases in tardiness, and improvements in academic performance.

#### DROWSY DRIVING

A study of data from the National Highway Traffic Safety Administration found that drowsy driving is responsible for approximately 100,000 accidents, resulting in more than 70,000 injuries and fatalities each year. Several groups of individuals exhibit higher frequencies of drowsy-driving behavior, including young people, shift workers, and commercial drivers. Even though this behavior occurs across the general population, young people between the ages of 16 and 29 years comprise the largest at-risk group and are responsible for two thirds of all drowsy-driving crashes—4 times the number of drowsy-driving crashes caused by individuals over the age of 30 years.

Young people seem to be at higher risk for this behavior for several reasons. They frequently experience chronic sleep deprivation because of cultural and lifestyle factors, including early school start times. Additionally, they tend to be less experienced drivers and are more likely to engage in risk taking behaviors.

Finally, younger drivers are more likely to drive at night and, relative to older drivers, are more likely to experiment with alcohol and drugs that act synergistically with sleepiness. In 2002, the National Sleep Foundation convened the National Summit to Prevent Drowsy Driving to develop an action plan addressing this issue. Summit participants endorsed a set of public-policy and research recommendations aimed at reducing drowsy driving behavior.

#### A. Policy Gaps

- Better understanding of childhood sleep needs is necessary to develop guidelines on the establishment of naptime, the timing of naps, and nap duration at the state and federal level and in partnership with education associations.
- In spite of the potential benefits accruing from a later school start time for teenagers, there are a number of barriers school districts face to implementing this change. These include logistical arrangements involved in coordinating bus service for an entire school district, the existence of younger children in a variety of childcare situations, and coordination of athletics and other after-school activities. Additional studies of the effects of school start time will be necessary to better understand the tradeoffs faced.
- Additional research needs to further explore risk factors for drowsy driving, including a link between drowsy-driving crashes and early school-start times.

#### B. Policy Recommendations

- Dissemination and implementation of public-education and policy interventions need to include a child focus.
- Education efforts would be most likely to succeed if their design reflected learnings from existing, successful, public-health campaigns. Thus, partnering with existing, established education programs is also recommended.
- Many school districts are aware of the positive evidence associated with a delayed school-start time for adolescents and are trying to make decisions that minimize disruption while resulting in the best possible outcome for all involved. This presents a unique opportunity for sleep researchers and clinicians to participate in these policy discussions as they continue to occur at the state and local levels and to ensure that decision makers have the necessary facts to inform their choices.

### V. ORGANIZATION

#### A. Current Status

Pediatric sleep medicine is a related, but unique, discipline within the broader field of sleep medicine due to its unique focus on children's health and development. Emergence of the field of pediatric sleep medicine as a separate discipline began in the 1950s and 1960s.

#### B. Organization Gaps

- Many questions remain about the best mechanisms for identifying, supporting, enhancing cohesion of, and communicating with all the individuals and various disciplines involved in research, clinical practice, education activities, and advo-

cacy in pediatric sleep medicine.

- Additional venues are needed to share information specific to pediatric sleep with the appropriate constituents and for more in-depth discussion of controversial issues within the field.

### C. Organization Recommendations

- The field of pediatric sleep needs to define and establish a professional and research identity both within and separate from the field of adult sleep medicine.
- Recognition of pediatric sleep medicine within the medical community would be enhanced by the development of a more-precise definition of the field, the unique body of knowledge that constitutes the field, and its scope.
- Additional opportunities must be provided to pediatric sleep medicine at all levels (including trainees) for networking and mentorship
- Standards of practice and a robust nosology based on clinical research (as it becomes available) must be developed and disseminated.
- The primary organization supporting pediatric sleep medicine should develop a website that would act as a repository of information and as a mechanism for communication between parties interested in pediatric sleep.
- Increasing the representation and visibility of pediatric sleep medicine within other specialties (e.g., ambulatory and developmental/behavioral pediatrics, pulmonary medicine, child neurology, child psychiatry) should be a top priority. This will necessitate the availability of key individuals within those fields to advance pediatric sleep interests.
- Long-term goals might include the eventual development of a separate organization, either within or independent from larger pediatric, psychology, or sleep professional organizations, devoted to pediatric sleep medicine.

## VI. SUMMARY

Relative to more-established medical specialties, pediatric sleep medicine is still in its infancy. A 2-day conference was convened to discuss the current state of the field and develop recommendations for its advancement. Overall, conference participants were unanimous in the sentiment that more research is necessary to create a solid foundation for the diagnosis, evaluation, and treatment of pediatric sleep disorders.

Discussion revolved around 5 primary areas, including research, clinical issues, healthcare practitioner and public education, policy issues, and organizational issues. For example, the challenges inherent in a lack of PSG standardization and standards of practice were reviewed. A discussion of the challenges faced by clinicians emphasized the complexity of simultaneously managing sleep disorders along with common comorbidities. The state of sleep-medicine education for physicians, psychologists, nurses, and the public was examined. At present, most healthcare practitioners receive very limited training in pediatric sleep medicine. Efforts underway to increase their exposure are promising but largely still limited in scope. A discussion of public policy focused on the potential developmental and safety implications of napping policies in elementary schools, school start times for adolescents, and the drowsy driving behavior of adolescents and young adults. All 3 areas would benefit from additional research to support fact-based policy choices and preventions mechanisms.

Consensus recommendations emerged from the conference. Participants agreed on the need for large-scale epidemiologic studies to provide a foundation for both basic and clinical research. The development of an age-appropriate definition of normal sleep and a standardized methodology for PSG are needed. The linkage of these sleep parameters to health outcomes for both normal and special-needs children are essential. Furthermore, standards of practice were identified as important goals necessary for the advancement of both clinical research and practice. Further research to support treatment choices, including behavioral therapy, CPAP, and pharmacologics, was advocated. The importance of ensuring that screening and education efforts are conducted with appropriate awareness of and respect for different cultural practices was also discussed. Conferees recommended escalating efforts to train both medical practitioners and the public about the importance of sleep in children and agreed that new public-policy initiatives should learn from, and potentially partner with, existing sleep campaigns. Finally, participants expressed the need for additional support for furthering pediatric sleep medicine, with further discussion required on the best structure to meet this need.

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Planning Committee: Co-Chairs: Judith Owens and Jodi Mindell; Ronald Chervin, David Gozal, Rafael Pelayo, Stephen Sheldon, Amy Wolfson

Presenters: Thomas Anders, Jeff Blumer, Ronald Chervin, Darrell Drobnich, Jeffrey Durmer, Richard Ferber, Daniel Glaze, Mark Goetting, Christian Guilliminault, Timothy Hoban, Carl Hunt, Anna Ivanenko, Sharon Keenan, Valerie Kirk, Brett Kuhn, Daniel Lewin, Lisa Meltzer, Cynthia Nichols, Bonnie O'Connor, Judith Owens, Carole Marcus, Jodi Mindell, Tonya Palermo, Carol Rosen, Stephen Sheldon, Daniel Taylor, Manisha Witmans, Amy Wolfson.

Working Group leaders: John Carroll, Ronald Chervin, Ronald Dahl, Richard Ferber, Mark Goetting, Christian Guillemineault, Carl Hunt, Sharon Keenan, Monique LeBourgeois, Rafael Pelayo, Stephen Sheldon, Amy Wolfson.

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## APPENDIX

## AGENDA

Pediatric Sleep Medicine  
Priorities for Research, Patient care, Policy and Education

**Saturday, February 19, 2005**

- 8:45 AM – 9:00 AM Welcome and Opening Remarks  
Dr. Jodi A Mindell, Dr. Judith A. Owens
- 9:00 AM – 9:30 AM Pediatric Sleep Medicine: Past, Present, and Future  
Dr. Thomas F. Anders
- 9:30 AM – 10:15 AM Research Program Blitz  
Moderator: Dr. Amy Wolfson
- 10:30 AM – 11:00 AM Methodological Issues in Pediatric Sleep Research  
Dr. Ronald D. Chervin
- 11:00 AM – 11:30 AM Funding Issues and Future Directions in  
Pediatric Sleep Research  
Dr. Carl E. Hunt
- 11:30 AM – 12:30 PM PANEL DISCUSSION  
15 min each + 15 min Q&A
- PUBLIC POLICY ISSUES  
Chair: Dr. Amy Wolfson
- School Start Times – Dr. Amy Wolfson  
Napping - Dr. Daniel S. Lewin  
Drowsy Driving in Adolescents – Darrel Drobnich

**Saturday, February 19, 2005**

- 1:30 PM – 2:45 PM PANEL DISCUSSION  
15 minutes each + 15 minutes Q&A
- CLINICAL ISSUES IN PEDIATRIC SLEEP MEDICINE  
Chair: Dr. Manisha Witmans
- Dr. Richard Ferber, Pediatric Sleep Specialist  
Dr. Timothy Hoban, Neurologist  
Dr. Anna Ivanenko, Psychiatrist  
Dr. Tonya M. Palermo, Psychologist  
Dr. Manisha Witmans, Pulmonologist
- 2:45 PM – 4:00 PM PANEL DISCUSSION  
15 minutes each + 15 minutes Q&A
- PEDIATRIC SLEEP EDUCATION  
Chair: Dr. Stephen Sheldon
- Postgraduate & Fellowship Training –Dr. Stephen H. Sheldon  
Graduate Training (Medical) – Dr. Judith Owens  
Graduate Training (Nursing, etc.) – Dr. Christian Guilleminault  
Graduate Training (Psychology) – Dr. Brett Kuhn  
Public Education – Dr. Jodi Mindell
- 4:00 PM – 4:30 PM Education Poster Session

**Saturday, February 19, 2005**

4:30 PM – 5:45 PM            CONCURRENT BREAKOUT SESSIONS

- I. PSG Standards - Dr. Carole Marcus, Dr. Carol Rosen
- II. Clinical Trials - Dr. Jeffrey Blumer, Dr. Daniel Glaze
- III. Cross-Cultural Perspectives – Dr. Bonnie O’Connor, Dr. Judy Owens
- IV. Trainee Issues – Dr. Jeffrey Durmer, Dr. Lisa Meltzer, Dr. Dan Taylor
- V. Sleep in Special Needs Populations - Dr. Mark Goetting, Dr. Anna Ivanenko
- VI. Pediatric CPAP –Dr. Valerie Kirk, Dr. Cindy Nichols

**Sunday, February 20, 2005**

8:30 AM – 10:00 AM            CONCURRENT WORKING GROUPS

- a. Basic Research - Dr. John Carroll, Dr. Christian Guilleminault
- b. Clinical Research - Dr. Ronald Chervin, Dr. Ronald Dahl
- c. Clinical Issues - Dr. Richard Ferber, Mark Goetting
- d. Education - Dr. Sharon Keenan, Dr. Monique LeBourgeois
- e. Policy - Dr. Carl Hunt, Dr. Amy Wolfson
- f. Organizational Issues - Dr. Rafael Pelayo, Dr. Stephen Sheldon

10:45 AM – 11:45 AM            Working Group Presentations

11:45 AM – 12:30 AM            Discussion

12:30 PM                            Conference Adjournment

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