

PCORnet PPRN Child Sleep Health Study
Summary for the International WAGR Syndrome Association

June 2018

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Recruitment Summary

Methods

Staff at the International WAGR Syndrome Association identified potentially eligible participants (parents of children aged 5-7 and child-parent dyads, including children aged 8-17) from research and network registries. Potentially eligible parents and guardians were sent an email that described the study and provided a link to the online questionnaire through which parents, and if applicable, their children completed the sleep health measures. A description of the study, and the study link, was also included in newsletters and on social media pages. Before enrollment, parents completed a questionnaire to assess their/their child's eligibility for study participation.

Participants

Recruitment and Enrollment of WAGR Syndrome Child Participants

Participant population: Children with WAGR syndrome (International WAGR Syndrome Association), aged 8-17 years

Date	Total Eligible (N)	Began questionnaire (N)	Did not complete (N)	Response Rate (%)
4/30/17	3	2	0	66.7%

Recruitment and Enrollment of WAGR Syndrome Parent Participants

Participant population: Parents of children with WAGR syndrome (International WAGR Syndrome Association), aged 5-17 years

Date	Total Eligible (N)	Began questionnaire (N)	Did not complete (N)	Response Rate (%)
4/30/17	35	35	7	80.0%

Parent Ineligibility

- adult participant was not the parent or legal guardian of the child: 0
- parent did not read or speak English: 1
- child was not between the ages of 5 and 17: 1

Child Ineligibility

- parent did not provide permission for child to complete survey: 14
- child did not read or speak English: 2
- child not between 8 and 17: 13
- child had intellectual or developmental delay that prevented him/her from answering survey questions: 10

Table 1. WAGR Syndrome Participant Sample Characteristics

Characteristic	WAGR Children n (%)	US Children n (%)	WAGR Parents n (%)	US Parents n (%)
Overall	2	1104	28	1477
Child Age				
5-7 years	-	-	7 (25.0%)	373 (25.3%)
8-12 years	2 (100%)	604 (54.71%)	12 (42.9%)	604 (40.9%)
13-17 years	0 (0%)	500 (45.29%)	9 (32.1%)	500 (33.9%)
Child Female Gender	0 (0%)	540 (48.9%)	13 (46.4%)	720 (48.7%)
Child Race				
White	2 (100%)	833 (75.5%)	27 (96.4%)	1118 (75.7%)
African American/Black	0 (0%)	103 (9.3%)	0 (0.0%)	137 (9.3%)
Asian	0 (0%)	38 (3.4%)	0 (0.0%)	52 (3.5%)
Other/More Than One	0 (0%)	130 (11.8%)	1 (3.6%)	170 (11.5%)
Child Hispanic Ethnicity	0 (0%)	220 (19.9%)	0 (0%)	293 (19.8%)
Parental Education Attainment				
Less than high school	1 (50%)	65 (5.9%)	5 (17.9%)	77 (5.2%)
High School	0 (0%)	317 (28.7%)	2 (7.1%)	386 (26.1%)
Some College	1 (50%)	341 (30.9%)	12 (42.9%)	448 (30.3%)
College or Higher	0 (0%)	381 (34.5%)	9 (32.1%)	566 (38.3%)
Financial Strain*	0 (0%)	383 (34.7%)	6 (21.4%)	511 (34.6%)
Food Insecure	0 (0%)	106 (9.6%)	0 (0%)	147 (9.95%)
Obesity (>=95 age-sex BMI percentile)	2 (100%)	161 (16%)	17 (63.0%)	226 (17%)
Currently takes melatonin for sleep	0 (0%)	67 (6.07%)	11 (39.3%)	84 (5.69%)
Currently takes other medicine for sleep	0 (0%)	24 (2.17%)	3 (10.7%)	27 (1.83%)
Names of medication			Clonidine, 1 (3.6%) Guanfacine, 1 (3.6%) Promethazine, 1(3.6%)	
Has a doctor ever diagnosed your child with sleep apnea	1 (50%)	n/a	8 (28.6%)	n/a
Has your child had his/her tonsils and/or adenoids removed	2 (100%)	n/a	16 (57.1%)	n/a
Does your child currently take medicine for ADHD (Attention Deficit Hyperactivity Disorder)?	0 (0%)	n/a	6 (21.4%)	n/a
Average weekday bedtime (range)	8-12 years: 10:00-10:29pm 13-17 years: N/A	8-12 years: 9:00-9:29pm 13-17 years: 10:00-10:29pm	5-7 years: 8:30-8:59pm 8-12 years: 8:00-8:29pm 13-17 years: 9:00-9:29pm	5-7 years: 8:00-8:29pm 8-12 years: 9:00-9:29pm 13-17 years: 9:30-9:59pm
Average weekday wake time (range)	8-12 years: 6:30-6:59am 13-17 years: N/A	8-12 years: 6:30-6:59am 13-17 years: 6:30-6:59am	5-7 years: 6:30-6:59am 8-12 years: 6:00-6:29am 13-17 years: 6:00-6:29am	5-7 years: 7:00-7:29am 8-12 years: 6:30-6:59am 13-17 years: 6:30-6:59am

Average weekday sleep duration	8-12 years: 10.5 13-17 years: N/A	8-12 years: 9.5 13-17 years: 8.5	5-7 years: 10 8-12 years: 10 13-17 years: 9	5-7 years: 10.5 8-12 years: 9.5 13-17 years: 8.5
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WAGR Syndrome Sample-Specific Analyses

Questions

Has a doctor ever diagnosed your child with sleep apnea [yes, no]
Has your child had his/her tonsils and/or adenoids removed [yes, no]
Does your child currently take medicine for ADHD (Attention Deficit Hyperactivity Disorder)? [yes, no]
Sleep medication questions:
Does your child currently take melatonin to help him/her sleep?
Does your child currently take any other medication to help him/her sleep?
What is the name of the medication?

Appendix A: Questionnaire Items

Eligibility

<i>Question</i>	<i>Response options</i>
What is your child's age?	[younger than 5, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18 or older]
Does your child have a cognitive limitation or developmental delay that would prevent him/her from answering survey questions about his/her sleep?	[Yes-No]

Sociodemographic Questions

What is your child's date of birth? [__/__/____]
What is your child's gender? [Male, female, other]
What is your gender? [Male, female, other]
Please check one or more categories below to indicate what race(s) you consider your child to be. [White, Black or African American, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian (type in race), Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander (type in race), Other race (type in race)]
Please check one or more categories below to indicate what race(s) you consider yourself to be. [White, Black or African American, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian (type in race), Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander (type in race), Other race (type in race)]
This is about Hispanic ethnicity. Is your child of Spanish, Hispanic, or Latino descent? [No, he/she is not, Yes, Mexican, Mexican-American, Chicano, Yes, Puerto Rican, Yes, Cuban, Yes, Central American, Yes, South American, Yes, Caribbean, Yes, Other Spanish/Hispanic/Latino]
This is about Hispanic ethnicity. Are you of Spanish, Hispanic, or Latino descent? [No, I am not, Yes, Mexican, Mexican-American, Chicano, Yes, Puerto Rican, Yes, Cuban, Yes, Central American, Yes, South American, Yes, Caribbean, Yes, Other Spanish/Hispanic/Latino]
What is your child's height? [open response (feet and inches)]
What is your child's weight? [open response (pounds)]
In which state do you live? [select from 50 US states, or not in the US option]
Your child's grade level in fall 2016: [preschool, pre-K, kindergarten, 1st, 2nd, 3rd, 4th, 5th, 6th, 7th, 8th, 9th, 10th, 11th, 12th, college, my child is not in school]
What is the highest level of education you have completed? [No formal education, 1st/2nd/3rd/4th, 5th/6th, 7th/8th, 9th, 10th, 11th, 12th grade no diploma, high school graduate, some college (no degree), associate's degree, bachelor's degree, Master's degree, Professional or doctorate degree]
How hard is it for you to pay for the very basics like food, housing, medical care, and heating? [Not hard at all, Somewhat hard, Very hard]

Which of the following describes the amount of food your household has to eat: [Often not enough to eat, sometimes not enough to eat, enough to eat]

What is your primary email address (note: this information will not be shared with others, or used to contact you about future studies)?

Health Questions

How many seizures has your child had in the past 6 months? [None, 1-2, 3-5, 6-12, 13-24, 25-100, More than 100]

How often does your child have seizures during the night (while in bed) or while sleeping? [At least once per week, 1-3 times a month, 6-10 times per year, Less than 6 times per year, Never or almost never]

How many different drugs to control seizures is your child currently taking daily? [1, 2, 3, 4, 5, 6, 7, 8, 9, 10, more than 10]

Sleep medication questions:

Does your child currently take melatonin to help him/her sleep?

Does your child currently take any other medication to help him/her sleep?

What is the name of the medication?

PRO Measures

PROMIS Fatigue items

Being tired made it hard for me to play or go out with my friends as much as I'd like. [never, almost never, sometimes, often, almost always]/ Being tired made it hard for my child to play or go out with his/her friends as much as he/she would like. [never, almost never, sometimes, often, almost always]

I felt weak. [never, almost never, sometimes, often, almost always]/ My child felt weak. [never, almost never, sometimes, often, almost always]

I got tired easily. [never, almost never, sometimes, often, almost always]/ My child got tired easily. [never, almost never, sometimes, often, almost always]

I was so tired it was hard for me to pay attention. [never, almost never, sometimes, often, almost always]/ My child was so tired it was hard for him/her to pay attention. [never, almost never, sometimes, often, almost always]

Sleep Disturbance: (In the past 7 days . . .)

I had difficulty falling asleep (SQ005) [never, almost never, sometimes, almost always, always]/ My child had difficulty falling asleep (SQ005) [never, almost never, sometimes, almost always, always]

I slept through the night (SQ020) [never, almost never, sometimes, almost always, always]/ My child slept through the night (SQ020) [never, almost never, sometimes, almost always, always]

I had a problem with my sleep (SQ041) [never, almost never, sometimes, almost always, always]/ My child had a problem with his/her sleep (SQ041) [never, almost never, sometimes, almost always, always]

I had trouble sleeping (SQ042) [never, almost never, sometimes, almost always, always]/ My child had trouble sleeping (SQ042) [never, almost never, sometimes, almost always, always]
It took me a long time to fall asleep (SQ017) [never, almost never, sometimes, almost always, always]/ It took my child a long time to fall asleep (SQ017) [never, almost never, sometimes, almost always, always]
I worried about not being able to fall asleep (SQ010) [never, almost never, sometimes, almost always, always]/ My child worried about not being able to fall asleep (SQ010) [never, almost never, sometimes, almost always, always]
I woke up at night and had trouble falling back to sleep (SQ022) [never, almost never, sometimes, almost always, always]/ My child woke up at night and had trouble falling back to sleep (SQ022) [never, almost never, sometimes, almost always, always]
I tossed and turned at night (SQ036) [never, almost never, sometimes, almost always, always]/ My child tossed and turned at night (SQ036) [never, almost never, sometimes, almost always, always]

Sleep-Related Impairment: (In the past 7 days . . .)
I was sleepy during the daytime (W001) [never, almost never, sometimes, almost always, always] / My child was sleepy during the daytime (W001) [never, almost never, sometimes, almost always, always]
I had a hard time concentrating because I was sleepy (W011) [never, almost never, sometimes, almost always, always] / My child had a hard time concentrating because he/she was sleepy (W011) [never, almost never, sometimes, almost always, always]
I had a hard time getting things done because I was sleepy (W028) [never, almost never, sometimes, almost always, always] / My child had a hard time getting things done because he/she was sleepy (W028) [never, almost never, sometimes, almost always, always]
I had problems during the day because of poor sleep (W029) [never, almost never, sometimes, almost always, always] / My child had problems during the day because of poor sleep (W029) [never, almost never, sometimes, almost always, always]
I had trouble staying awake during the day (W002) [never, almost never, sometimes, almost always, always] / My child had trouble staying awake during the day (W002) [never, almost never, sometimes, almost always, always]
It was hard to have fun because I was sleepy (W030) [never, almost never, sometimes, almost always, always] / It was hard for my child to have fun because he/she was sleepy (W030) [never, almost never, sometimes, almost always, always]
I could not keep my eyes open during the day (W036) [never, almost never, sometimes, almost always, always] / My child could not keep his/her eyes open during the day (W036) [never, almost never, sometimes, almost always, always]
I was in a bad mood because I was sleepy (W015) [never, almost never, sometimes, almost always, always] / My child was in a bad mood because he/she was sleepy (W015) [never, almost never, sometimes, almost always, always]

Sleep Practices: (In the past 7 days . . .)

I followed a bedtime routine before falling asleep (SP028) [never, almost never, sometimes, almost always, always] / My child followed a bedtime routine before falling asleep (SP028) [never, almost never, sometimes, almost always, always]

I watched TV shows or videos just before falling asleep (SP025) [never, almost never, sometimes, almost always, always] / My child watched TV shows or videos just before falling asleep (SP025) [never, almost never, sometimes, almost always, always]

I played video or computer games just before falling asleep (SP026) [never, almost never, sometimes, almost always, always] / My child played video or computer games just before falling asleep (SP026) [never, almost never, sometimes, almost always, always]

I tried to fall asleep at about the same time every night (SP006) [never, almost never, sometimes, almost always, always] / My child tried to fall asleep at about the same time every night (SP006) [never, almost never, sometimes, almost always, always]

I needed someone with me to fall asleep (SP018) [never, almost never, sometimes, almost always, always] / My child needed someone with him/her to fall asleep (SP018) [never, almost never, sometimes, almost always, always]

I used my phone, computer, or other electronic device just before falling asleep (SP024) [never, almost never, sometimes, almost always, always] / My child used his/her phone, computer, or other electronic device just before falling asleep (SP024) [never, almost never, sometimes, almost always, always]

I woke up at about the same time every morning (SP007) [never, almost never, sometimes, almost always, always] / My child woke up at about the same time every morning (SP007) [never, almost never, sometimes, almost always, always]

Timing:

What time do you try to fall asleep on weekday nights? (SP002) [before 7:00pm, 7:00pm-7:29pm, 7:30pm-7:59pm, 8:00pm-8:29pm, 8:30pm-8:59pm, 9:00pm-9:29pm, 9:30pm-9:59pm, 10:00pm-10:29pm, 10:30pm-10:59pm, 11:00pm-11:29pm, 11:30pm-11:59pm, after midnight] / What time does your child try to fall asleep on weekday nights? (SP002) [before 7:00pm, 7:00pm-7:29pm, 7:30pm-7:59pm, 8:00pm-8:29pm, 8:30pm-8:59pm, 9:00pm-9:29pm, 9:30pm-9:59pm, 10:00pm-10:29pm, 10:30pm-10:59pm, 11:00pm-11:29pm, 11:30pm-11:59pm, after midnight]

What time do you wake up on weekdays? (SP003) [before 5:00am, 5:00am-5:29am, 5:30am-5:59am, 6:00am-6:29am, 6:30am-6:59am, 7:00am-7:29am, 7:30am-7:59am, 8:00am-8:29am, 8:30am-8:59am, 9:00am-9:29am, 9:30am-9:59am, 10:00am-10:29am, 10:30am-10:59am, 11:00am-11:29am, 11:30am-11:59am, after 12:00pm] / What time does your child wake up on weekdays? (SP003) [before 5:00am, 5:00am-5:29am, 5:30am-5:59am, 6:00am-6:29am, 6:30am-6:59am, 7:00am-7:29am, 7:30am-7:59am, 8:00am-8:29am, 8:30am-8:59am, 9:00am-9:29am, 9:30am-9:59am, 10:00am-10:29am, 10:30am-10:59am, 11:00am-11:29am, 11:30am-11:59am, after 12:00pm]

Appendix B: Data Set

Identifying Variables

- Child's first name [name_child]
- Date of birth [child_dob]
- State of residence [state_residence]

Condition-Specific Variables

- Has a doctor ever diagnosed your child with sleep apnea? [sleep_apnea]
- Has your child had his/her tonsils and/or adenoids removed? [tonsils_adenoids]
- Does your child currently take medicine for ADHD (Attention Deficit Hyperactivity Disorder)? [medicine_adhd]