### My Sleep Study



Produced by the Down Syndrome Program and The Center for Pediatric Sleep Disorders



The Down Syndrome Program has developed this booklet to help prepare children and young adults for their upcoming sleep studies. The hope is that improved preparation before arriving will help improve the experience of having a sleep study.



We have developed a story that your son or daughter can read (or have read aloud to him or her) to help prepare. Through its pictures and descriptions, the story provides a walk-through of a night in the sleep laboratory. Our goal is to help your child become familiar with the sleep lab procedure, so that the night of the appointment will be as comfortable as possible.

We recommend that you begin to use the sleep study story four to six weeks before your scheduled appointment, with increasing frequency as the date approaches. We also recommend that you try to simulate the conditions and stimuli your son or daughter will encounter. On the next page is a suggested schedule.

### 4 to 6 weeks before:

• Read the story once a week. Either read it together, or have your child read it by himself or herself.

### 2 to 3 weeks before:

- Read the story twice a week. Either read it together, or have your child read it by himself or herself.
- Use stickers to practice having electrodes placed on the head and body.
- For younger children, practice putting stickers on a stuffed doll or toy car.

### 1 week before:

- Read the story each night. Either read it together, or have your child read it by himself or herself.
- Use stickers to practice having electrodes placed on the head and body.
- Place tape on your child's index finger to simulate the sensor placed on fingers.

The schedule above is just an example of how you can help prepare your child for their sleep study. In the end, what is most important will be helping your son or daughter feel familiar with the procedure. That way, when the time comes, it will not be as foreign or uncomfortable.

If you have questions or concerns, please call the Down Syndrome Program at 857-213-4329

### Good luck and we look forward to seeing you soon!

-The Down Syndrome Program Staff

# I will arrive at Boston Children's Hospital





## I will take the elevator to the 9th floor.



I will meet the sleep technician who will be my friendly helper.

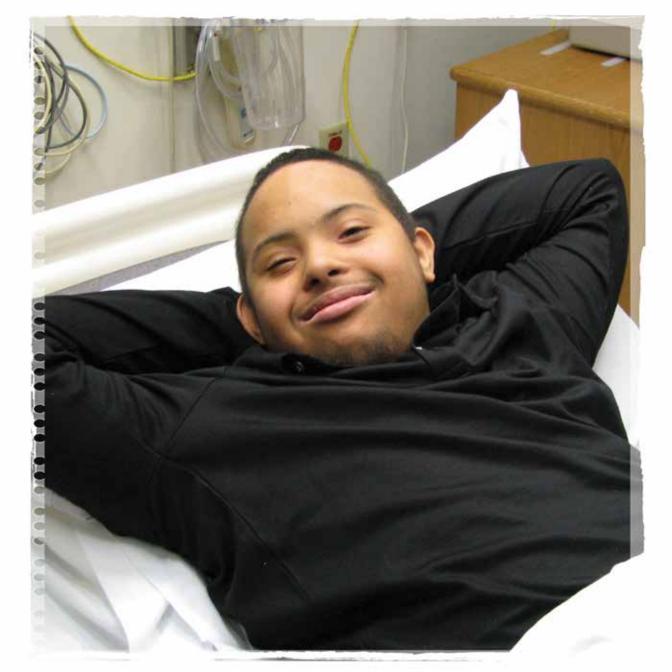


## My friendly helper will show me my room.



### This will be my bed.

AAAAAAAAA



# My mom or dad will sleep next to me in a separate bed.



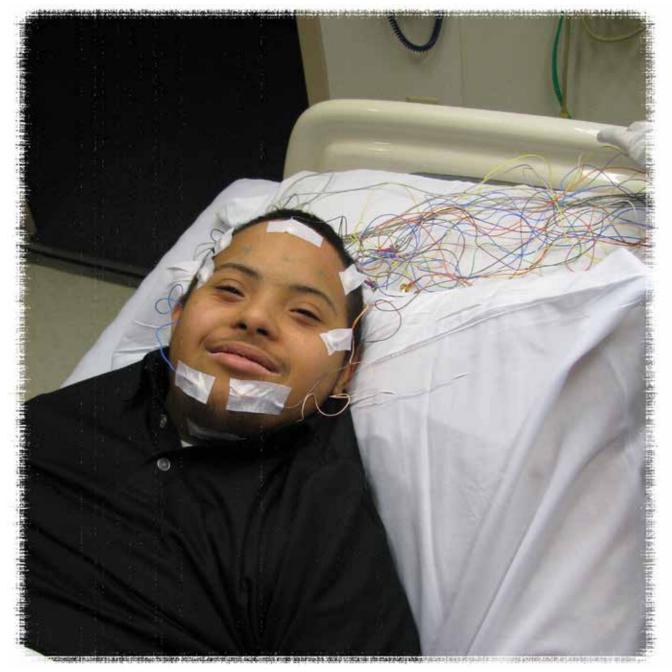
# My friendly helper will measure my head.



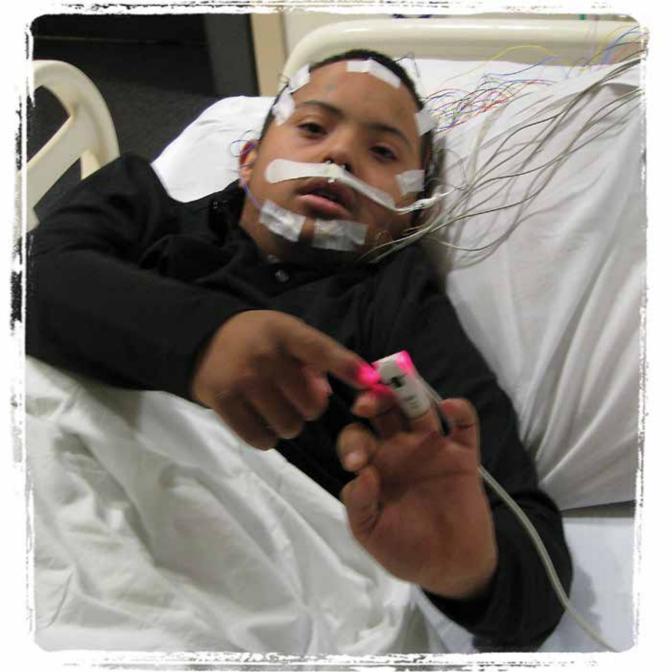
My friendly helper will get me ready; I can play or watch a video while I'm getting ready.



## My friendly helper will put stickers on me.



My friendly helper will put a light on my finger that glows in the dark. It will be fun!



My friendly helper will help me put on two sleep belts.

AAAAAAAAAA



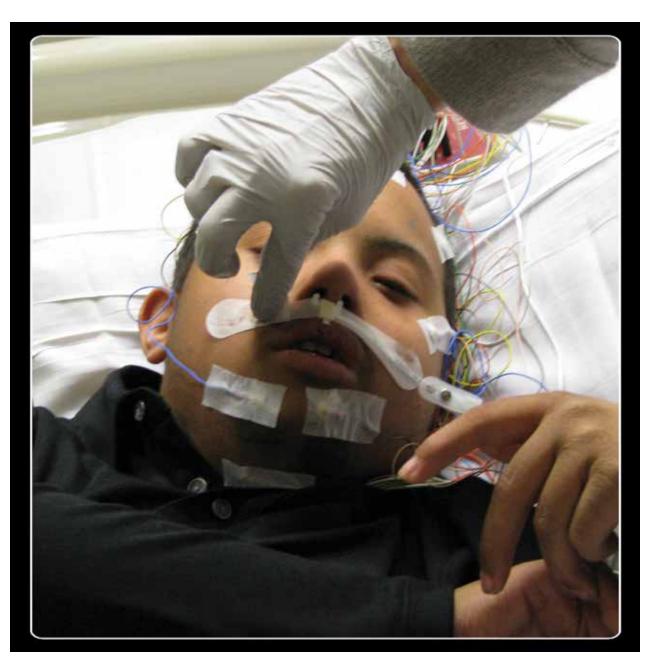
# I am ready for bedtime! My friendly helper will turn off the lights.



### My friendly helper will be at her desk nearby all night.







There might be a special light to help my friendly helper see in the dark.



My friendly helper will wake me up early in the morning to help get ready to go home.

AAAAAAAAA



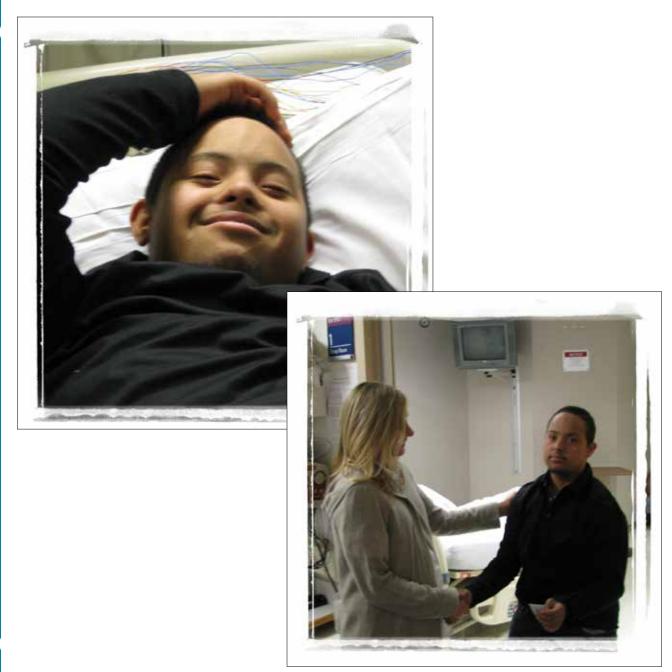
### My friendly helper will use something wet to take off my stickers.





My friendly helper also will take off my belts and the light on my finger.





## I did a great job!

### [spot for my photo!]

My Sleep Study was written and produced by the Boston Children's Hospital Down Syndrome Program, including Gil Weintraub (research assistant 2010-2011), Angela Lombardo, Down Syndrome Program Coordinator and Emily Jean Davidson, MD, MPH, Down Syndrome Program Clinical Director.

Special thanks to Isaiah Lombardo and Michelle San Giuliano, sleep technician, for participating in the story and to Lauren Voelz, Research Coordinator for the Predicting Obstructive Sleep Apnea in Down Syndrome, for her involvement and support in the production of the story. This booklet was supported by a generous philanthropic donation to the Down Syndrome Program. For more information about supporting the Down Syndrome Program, please contact the Program Coordinator at 857-218-4239 or the Children's Hospital Trust at 617-355-6890. For more information on creating your own "Social Stories" to help prepare children for unfamiliar events, please see the work of Carol Gray at the Gray Center www. thegraycenter.org.



