Dear Parent,

My name is Dr. Alfred J. Lewy, and I am a professor of Biological Psychiatry and Director of the Sleep and Mood Disorders Laboratory at Oregon Health & Science University. I am writing to ask for your help in reaching **blind youth without light perception (children ages 5-8 and young adults ages 17-20)** who may be interested in contributing to a research opportunity funded by the National Institutes of Health. Below is a letter of support from Carol Castellano, President of the National Organization of Parents of Blind Children at the National Federation of the Blind:

Dear Friends:

The National Organization of Parents of Blind Children is helping to find participants for an important research study on sleep cycles in blind children and youth. This project has the real potential to help families whose children are having difficulty with sleep patterns. Children and youth with and without sleep difficulties are needed for the study.

If you are interested in finding out more about the project, please call Stevie Hodge, Research Assistant, at (503) 494-1402 or e-mail her at sleeplab@ohsu.edu.

Carol Castellano, President
National Organization of Parents of Blind Children
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The body clocks of sighted individuals are synchronized to a daily 24-hour cycle by the perpetual rising and setting of the sun, a process that is not always possible for blind individuals who are unable to see light through their eyes. Entirely blind people sometimes have natural body rhythms that free-run, meaning that their rhythms drift each day, similar to the experience of jet lag when traveling. This can lead to sleep complaints and difficulty staying alert during the day and can also contribute to social and academic challenges. (For more information on this phenomenon, type “circadian rhythms in the blind” into your internet search engine.) Through decades of research, we have learned that we can adjust these body rhythms with low doses of melatonin—a naturally occurring hormone produced in the brain. We think that understanding this problem better and confirming melatonin as an inexpensive, low-risk, and effective treatment will be invaluable to the social and academic functioning of blind children not only in the United States but also worldwide. Our research group has been studying sleep disorders in the blind in the Portland area for almost thirty years. We have recently simplified our procedures so that individuals can participate in our studies from home,
allowing us to include contributors from anywhere in the nation. In this project, we will measure body rhythms by using wristwatch-style activity monitors, sleep journals, and by periodically measuring melatonin levels in saliva. Sleep quality and daytime functioning will be measured by simple questionnaires completed by participants, teachers, or parents. Daytime saliva collection sessions will occur in participants’ homes and will be scheduled at their convenience. For participants with qualifying body rhythms, we will offer the option of taking a daily low-dose of melatonin in an effort to confirm that it can be used to adjust these irregular body rhythms in children and adolescents, as it does in adults. All costs associated with this study, including pill costs, will be covered by the investigators.

The success of our research and the opportunity to positively impact the health, social, and academic functioning of blind children and young adults worldwide is dependent upon your help. If you have any questions about our project, would like to participate, or have any suggestions as to how we might reach interested families, please contact Stevie Hodge, Research Assistant, at sleeplab@ohsu.edu or (503) 494-1402. Thank you in advance for your support.

Sincerely,

[Signature]

Dr. Alfred J. Lewy, MD, PhD
Director, Sleep and Mood Disorders Laboratory
Oregon Health & Science University
Principal Investigator
eIRB #4664