

--- Talking Points for Narcolepsy Patient Email Response ---

Reminders:

Email your response by July 2, 2010 to NCSDR-RFI2010@spmail.nih.gov

Subject line: NOT-HL-11-107: Request for Information (RFI): Sleep Disorders
Research Plan

The purpose of your email to NIH is to tell the government officials who will be formulating the Sleep Disorders Research Plan for the next 5 or so years what research is most important to you.

Opening paragraph Provide a frame of reference so the reader can put your comments in perspective.

Example

I have narcolepsy with mild cataplexy. I was diagnosed 14 years ago at age 17. For the first few years I tried many medications but none were very helpful. I lost several jobs due to breakthrough narcolepsy symptoms. Newer treatments enabled me to earn a 4-year college degree in 5 years. I am able to work at the cost of having no life outside of work. I would like to marry and have a family but until I can function for a full 16 hours a day, this goal is beyond reach.

Comments/Recommendations

Narcolepsy Network has identified the following to be the areas most in need of research. Use as many or as few as you wish, edited or verbatim, based on what is personally important or relevant to you. You may elaborate further, provide personal examples and/or add other points that meet the guidelines of the RFI.

1. Narcolepsy research must continue to be funded until both the disease process and full effects of the disorder are understood so that better treatments and preventions can be developed. This includes not only narcolepsy with cataplexy but also narcolepsy without cataplexy and idiopathic hypersomnia, for which there have been no advances to date.
2. Studying narcolepsy, its causes, prevention, disease process and definitive treatment should have application to the causes, treatments and prevention of other neurological, auto-immune and/or metabolic diseases.
3. Early diagnosis is essential. Pediatricians, Family Practitioners, General Practitioners, Physicians Assistants and other Primary Care Physicians as well as most nursing staff must be sufficiently educated about sleep and sleep disorders to recognize the symptoms and refer the patient to a sleep physician. Annual checkups should include screening for sleep disorders.

4. The incidences of misdiagnosed narcolepsy indicate that too many sleep physicians do not have sufficient understanding of narcolepsy, particularly in the area of differential diagnosis. One possible remedy would be for narcolepsy experts to develop a continuing education program to be offered online that would be mandatory in order to maintain certification.
5. Too many patients are initially prescribed older, less effective treatments such as SSRIs for cataplexy. Few sleep physicians are aware that SSNRIs, particularly atomoxetine, are often a superior alternative to wakefulness and cataplexy medications for hypocretin-deficient narcolepsy.
6. People with hypocretin-deficient narcolepsy are at high risk for obesity and Type II diabetes. Current narcolepsy treatment focuses only on the sleep/wake cycle. Metabolism in narcolepsy needs to be better understood and preventative measures and/or medications incorporated into the treatment plan.
7. Narcolepsy and Pregnancy: The trends toward earlier diagnosis of narcolepsy and the need for two-incomes to support a household has increased the numbers of women who must choose to forgo children or risk taking medications that might harm their babies. A study is needed to assess outcomes in the children of women who have taken narcolepsy medications during pregnancy to add to the scant body of existing knowledge. These children should be followed at least through puberty to allow time for possible medical, psychological and cognitive issues to be identified.
8. Health insurance coverage and affordability of medications: Health insurance costs are predicted to increase as recently enacted health care measures are implemented. Most narcolepsy treatments are already very costly. A segment of the narcoleptic population cannot presently afford the most effective treatments under their health insurance coverage. This segment is likely to grow over the coming years as health care reforms are phased in. This situation requires monitoring and intervention.

Conclusion Summarize in a sentence or two. You may wish to thank NIH for the opportunity to submit comments.

Sign-off – Identifying information is not required. NIH will confirm receipt of your email but will not respond to your specific comments.