

2005 KLS FOUNDATION ANNUAL REPORT

During 2005, the Kleine-Levin Syndrome Foundation, Inc. has continued to be an important network to identify and support individuals and families affected by Kleine Levin Syndrome (KLS). The Foundation exchanges information with patients and the medical community to help in the diagnosis and care of those affected by KLS. We are all very encouraged by the progress and activities of the Foundation during this past year:

- The KLS Foundation partnered with the Stanford University Sleep Center to establish a basic and clinical research program on KLS under the direction of Dr. Mignot. This has already resulted in the publication of a comprehensive medical review article on KLS (Arnulf, et al., "Kleine-Levin syndrome: a systematic review of 186 cases in the literature" *Brain*, 2005 Dec,128:2763-76). Over 100 KLS individuals and families participated in the KLS questionnaire and blood collection phase of the research.
- The Foundation has partially supported the Stanford University studies. This research program has already generated further research interest from groups in France and Israel. Research efforts are underway to explore possible causes of KLS, including autoimmune, genetic and viral causes.
- The Foundation web site continues to serve as a valuable information resource on KLS. During 2005, the number of hits to the website and the number of registered KLS individuals significantly increased. A chat room was added this past year and further enhancements to the website are planned for 2006.
- A scientific symposium on KLS is being organized for the June 2006 meeting of the Associated Professional Sleep Societies. This will be the first time a dedicated session on KLS will be held at a medical conference.
- The Foundation continues in its mission to educate the public and healthcare professionals about KLS. During 2005, the Foundation has presented at the Sleep Disorders Research Advisory Board meetings of the National Institute of Health. This past year stories on KLS were aired by Fox TV News affiliate in Los Angeles as well as on national CCN news. After each telecast the Foundation received numerous inquiries about KLS.
- The Medical Advisory Board and Board of Directors have been expanded during the year.
- Ongoing fundraising efforts raised over \$40,000 during 2005 and have raised over \$100,000 to date. Due to the relative rarity of KLS, the interest and available funding for initial research is a challenge. Through the end of 2005, the Foundation invested over \$70,000 of donations in research. Currently less than 5% of funds donated during 2004 and 2005 have been used to support the general and administrative activities of the foundation, including web site maintenance, with the remaining expenditures going directly to fund research efforts.
- The Foundation's goal is to raise \$300,000. This will enable the Foundation to continue to provide seed grants to generate research results. It is then expected that with some preliminary data, KLS researchers will be able to apply for more substantial government research grants.
- In the upcoming year we will be focusing our efforts in the following areas: continuing to support the research efforts at Stanford University as well as fostering research in other

laboratories both financially and through the participation of our community of contacts; increasing the exposure of KLS information to the medical community through continued participation in association meetings; seeking out additional media opportunities to facilitate the spread of information about KLS throughout the world; updating our website and chat room to provide additional functionality and information; and continuing our ongoing fundraising efforts.

- The Foundation continues to look for dedicated volunteers who are willing and able to donate their time and skills.

The website continues to be a valuable source of information for the KLS and medical communities, please be sure you are registered and check the site often for updates.

Thank you for your continued support.