

## 2008 ANNUAL REPORT

The Kleine-Levin Syndrome (KLS) Foundation is proud of the significant progress made this year in furthering our mission. In this Foundation Report, we reflect on the significant growth and impact the KLS Foundation has had since its founding in 1999.

Kleine-Levin Syndrome (KLS) is a life-alternating illness that mostly affects teenagers and young adults. The focus of the KLS Foundation over the last few years has been on providing information and support to KLS patients and families, helping to educate the medical community about KLS, raising funds, and promoting KLS research programs.

Generating top-quality research interest in a rare illness like KLS is not easy. The KLS Foundation set out to initiate KLS research programs by providing “seed” funding. This has blossomed into larger programs at leading academic and hospital centers around the world, including Stanford University in California, the Tel Aviv Medical Center in Israel, the University of California San Francisco and the Hôpital Pitié-Salpêtrière in Paris. These efforts culminated this past year in Prof. Emmanuel Mignot of Stanford University receiving the first NIH grant for KLS research, a very competitive five-year research award.

The Foundation continues its efforts to raise awareness and share up-to-date information regarding KLS and ongoing research efforts. We continue to look for opportunities to plug into professional networks through conferences and group meetings, to improve the quality of information available and the Foundation website.

The KLS Foundation is committed to supporting those with KLS, to expanding the community’s knowledge and understanding about KLS and to foster further research into the cause, treatment and ultimate cure for KLS.

Our success in the past few years could not have been possible without the tremendous support of our members, their friends and families, and all of the supporters of the KLS Foundation. On behalf of the KLS Board of Directors we thank you for your generous support.

Neal Farber, PhD Stephen Maier, CPA  
Co-President KLS Foundation Co-President KLS Foundation

\*\*\*

### **Newly formed KLS Advisory Board**

The KLS Foundation expanded this year by creating a KLS Advisory Board and welcoming three new advisory board members. These individuals are dedicated to the mission of the KLS Foundation and are a great asset to the Foundation.

The new advisory board members are:

Gaylene Fisch, RN, BSN, CNOR

Gaylene's 15 year-old son Brian Sabul had his first episode of KLS in April of 2007. Gaylene credits the KLS Foundation with helping Brian receive an accurate diagnosis within weeks of his first episode, attesting to the value of the education and outreach provided by the KLS Foundation. Gaylene is a Registered Nurse and is working with Board member Lori Haller to present KLS information to pediatricians, neurologists, behavioral physicians and other doctors.

#### Donna White

Donna's son Ryan McKinney suffered from KLS without a diagnosis for over seven years. Ryan tragically died of a heart attack from an unrelated medical condition in 2006 and his death inspired Donna to raise awareness of KLS in the hopes that other children would not continue to suffer from this devastating syndrome. In 2007, Donna organized the first annual "Walking for Ryan Festival" in South Carolina to raise funds for KLS research. Donna is an ESL instructor and bilingual Spanish translator for the Lancaster County School District and founder of the South Carolina Chapter of the KLS Foundation.

#### Christine Penney

Christine is the mother of Joseph Penney who had his first KLS episode in December 2005, at the age of 16. Contact with the KLS Foundation became an invaluable support system for the Penney family. Christine actively volunteers for a variety of school and local organizations. She is also an advocate for raising KLS awareness in her community and has organized two very successful fundraisers for the KLS Foundation.

#### **You are invited to join our effort**

If you are interested in joining our dedicated group of volunteers, please contact Lucinda Maier at: [facts@klsfoundation.org](mailto:facts@klsfoundation.org). We are always in need of individuals who can share their creativity, talents or professional skills with the KLS Foundation.

#### **RAISING AWARENESS**

##### **KLS in the Media**

The unusual, unexplained symptoms and compelling stories of KLS patients continue to generate interest by various media outlets. Production of medical television programs about KLS continue both in the US and in Europe. With the assistance of the KLS Foundation, British television company ITV Productions aired a documentary about KLS in Europe on July 31, 2008.

As an indirect benefit, the film brought the Wong family from Seattle, Washington to Boston for a day of filming at the home of the Farbers, allowing Alanna Wong and her parents to meet another KLS family for the first time.

Tanis Burnett, a KLS patient in Canada, and a child of the internet age has produced a series of video blogs and a music video depicting her experience of life with KLS. The Foundation's website has been updated to include links to these videos.

During the year there have also been a number of articles about KLS printed in magazines and newspapers. A full list of these articles is available on the KLS Foundation web site, <http://www.kleinelevin.com>

## **Conferences and Professional Networks**

KLS Foundation board members have organized informational meetings at local hospitals as well as attended meetings of local chapters of the American Academy of Pediatrics. The Foundation continues to identify ways to further inform the medical community about KLS and to decrease the time between the onset of KLS to accurate diagnosis.

Rafael Pelayo, MD, Director of Pediatric Sleep Service at Lucile Packard Children's Hospital at Stanford University presented a talk entitled "Comparison of Narcolepsy and Kleine Levin Syndrome" during the Annual Pediatric Sleep Medicine Conference held March 2008 at Amelia Island, Florida. This conference focused on the "Next Steps in Research, Patient Care, Policy and Education" and was sponsored by the Medical School of Brown University.

## **WEBSITE**

During the spring of 2007 the KLS Foundation partnered with NetRaising to upgrade and help maintain the <https://klsfoundation.org> website.

New additions to the website include:

1. Diaries that share first person experiences of KLS patients and their families. Many families have said these diaries are valuable in helping them begin to understand KLS.
2. A comprehensive bibliography of KLS medical and scientific articles beginning in 1925 (mostly single case reports), as well as a list of research papers in which a cohort of KLS patients was more extensively studied.
3. A new chat room with improved functionality, security and monitoring.
4. Online donation capabilities to facilitate tax-deductable donations to the Foundation.

## **FUNDRAISING**

Fundraising continues to build momentum. Local fundraising events held in 2006 helped to launch larger events in 2007 and 2008 including the following:

Sunday at the Cinema: Over 200 friends and supporters of the KLS Foundation attended a benefit for the Kleine Levin Syndrome Foundation entitled Sunday at the Cinema on April 29, 2007. The benefit was organized by caring friends of the Farber family, whose son and daughter had episodes of KLS for over ten years. The event began with a festive reception followed by a presentation about KLS and the screening of the award winning Korean film "Spring, Summer, Fall, Winter ... and Spring."

Sunday at the Cinema was a huge success. It heightened awareness about KLS, educated the Boston community and raised over \$70,000 for KLS research. The community was honored to have an opportunity to make a difference in the lives of children and families suffering from KLS.

Walking For Ryan: Organized by Donna White in memory of her son Ryan McKinney, this fundraiser raised awareness about KLS and approximately \$10,000 for KLS medical research. On March 31, 2007, the Lancaster, South Carolina community enjoyed many activities at the track and field recreational center. Donna, KLS Foundation Board of Directors representative Dani Farber and US Olympic gold medalist sprinter Shawn Crawford led the

community around the track in a symbolic lap for Ryan and KLS research. In 2008 the Walking for Ryan fundraiser raised another \$5000 for KLS.

Montvale Plaza Event: Joe and Christine Penney and their friends organized a KLS fundraiser held on April 6, 2007 at the Montvale Plaza in Stoneham, Massachusetts. The evening included dinner and dancing, a stand up comedian and a very successful silent auction. The 2007 Montvale Plaza Fundraiser raised nearly \$40,000 for the KLS Foundation. A second Montvale Plaza Fundraiser in 2008 brought in another \$23,500 for KLS.

Both 'Walking for Ryan' and the Montvale Plaza fundraisers will become annual KLS Fundraisers with successive events planned for 2008.

The KLS Foundation is available to offer assistance or speakers for KLS fundraisers you wish to organize in your community.

## **RESEARCH**

Stanford University's KLS research program continues to investigate the nature of KLS. A detailed report on current research is available at: <http://www.kleinelevin.com>

## **FINANCIALS**

Fundraising efforts raised approximately \$137,000 and \$64,000 in 2007 and 2006, respectively. The Foundation continues to utilize the vast majority of donated funds to directly support research, education and awareness efforts, with a minimal amount used for Foundation administrative expenses.