

## KLS FOUNDATION 2011 REPORT

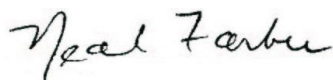
Dear Supporters and Friends of the KLS Foundation:

This has been an incredibly exciting year for the Kleine-Levin Syndrome (KLS) Foundation and the KLS Community. The First International KLS Conference exceeded all expectations and recreated the positive energy we all need to remain focused on our goal of supporting KLS families and finding a cure. The KLS Foundation welcomed its first formally affiliated KLS Foundation Chapter in the United Kingdom created by our newest Board Member, Caron Krieger. There continue to be grass-roots fundraising initiatives around the country and media attention around the world. With the help of our generous donors, the KLS Foundation has been able to grant seed funding for new KLS research at labs and universities around the world, and the Foundation has been able to support work in five labs dedicated to KLS research. These grants have enabled our researchers to move their projects forward and be the seed investment in securing additional funding from other agencies, such as the National Institutes of Health (NIH) in Washington, DC and overseas equivalents. Through the efforts of the KLS Foundation we have contributed a total of \$263,210.00 to research projects throughout the world.

The KLS Foundation works to support KLS patients, their families and friends, and to educate doctors and healthcare professionals about KLS for earlier recognition and faster diagnosis. All of our efforts are accomplished with minimal overhead expenses and no paid staff, allowing nearly all of our funds to be allocated to research and activities to provide support and raise awareness. The expansion of technology continues to make the world a smaller place and allow for the increased sharing of information. The Foundation is excited about the recent launch of the [KLS Foundation Facebook page](#) and continues to look for ways to better share information with the KLS Community. We hope that our efforts continue to have a positive impact on the KLS community around the world.

With your support in 2011, the KLS Foundation was able to make a difference in the lives of those affected by KLS. You showed your belief in the work that we all do together. As we enter a new year, we ask that you keep believing in the difference we can all make. We need your help to continue the work that is outlined in this report. Thank you for your continued support.

Sincerely,



Neal Farber, PhD - Co-President



Stephen Maier, CPA - Co-President

## KLS CONFERENCE

A long-held dream of the KLS Foundation Board of Directors has been bringing together the community of families touched by this rare and powerful disorder. That dream finally bore fruit at a three-day conference held in San Francisco, California in August 2011 thanks to the generous support of friends of the KLS Foundation and the hard work of dedicated volunteers.

The dual hopes of attracting a handful of KLS researchers and physicians to exchange ideas while offering a few interested KLS patients and families the opportunity to meet one another, share their experiences, and lend mutual support blossomed into the First International KLS Conference. Over 200 KLS patients, parents, grandparents, siblings and friends learned about this rare medical condition and supported their loved ones who suffer from it. Ten prominent scientists and clinicians from around the world came to present their research findings and share ideas.

The atmosphere was giddy with anticipation as families and teens began to arrive. There were hugs and tears of joy and relief as friendships born in online KLS support networks came face-to-face for the first time. The sentiments expressed throughout the conference reflected

how empowering it was for participants to finally be able to discuss KLS with others who have also lived through the fears, frustrations, medical and social issues presented by this difficult illness. Teenagers saw that there were others who understood their unique and painful experiences and were overwhelmed to finally be with friends who could understand what they had been through. They no longer felt alone in living with KLS.

KLS families participated in sessions addressing strategies and practical tools needed to manage and live with KLS, including a review of medications and treatments, how to best care for someone in a KLS episode, best practices for dealing with the educational system, and tips for running a KLS fundraiser. An inspirational panel featured successful young adults who bravely face the challenges of life with KLS and remain healthy, strong and determined to help others.

A second track of the conference was geared towards medical professionals. Researchers from around the world dedicated to the investigation of KLS gathered for the first time to share their knowledge and ideas. Keynote presentations were delivered by Dr. Emmanuel Mignot (Stanford University) on the genetics of

*Thank you for turning my family's life around, you will never know how much you helped us.*

*Attending the Conference was LIFE CHANGING. I'm not alone!*

- Overheard at the KLS Conference



Keynote speaker  
Dr. Emmanuel Mignot

KLS and by Dr. Isabelle Arnulf (Pitié-Salpêtrière Hospital; Paris, France) on an overview of the clinical picture of KLS. The Foundation is extremely appreciative of other speakers who came from Canada, China, Israel, Germany, Sweden and Taiwan to share their research findings. Topics ranged from “Long term follow-up clinical study of KLS in Taiwan,” to “Viral Infections and KLS” and “Cognitive dysfunction and neuroanatomic correlates in Scandinavian KLS patients.” The opportunity for mutual learning and discussion about the future of KLS research was beneficial to all, and these collaborations will enhance the scope and pace of KLS research. The KLS Foundation has already learned of new investigator requests for continued funding to expand KLS research programs.

The success of the First International KLS Conference ignited new and bigger dreams for the future of the KLS Foundation. We hope it will be the first of many successful worldwide



Some of the KLS patients at the first international KLS conference

events in pursuit of the KLS Foundation’s goals of providing information and support to those diagnosed with KLS and their families, helping in the diagnosis and care of those affected by KLS, supporting research programs, and finding effective treatment and ultimately a cure for Kleine-Levin Syndrome.

Information about obtaining a video of the conference is available [by clicking here](#).



The Board of the KLS Foundation



A full house at the KLS Conference

## FUNDRAISING

One of the critical missions of the KLS Foundation is to encourage and financially support scientific research to find effective treatment and ultimately a cure for KLS. With the help of generous donors who have opened their hearts and their wallets during past fundraising campaigns, this collective dream is now becoming a reality. Today with support from grants from the KLS Foundation researchers from top universities in the United States—including Stanford University and the University of California—and prestigious hospitals around the world—including the Sleep Disorders Unit of the Pitié-Salpêtrière Hospital (Paris France), the University of Linköping (Sweden) and the Dana Children's Hospital, Tel Aviv Sourasky Medical Center (Israel)—focus their work on possible causes of KLS.



One enterprising young KLS patient decided to take matters into her own hands, and onto the hands of others. Alanna Wong of Seattle Washington designed and sells KLS wristbands to spread awareness about KLS. The silver wristbands represents the silver lining of hope, happiness, health, wealth and love that Wong believes all KLS sufferers deserve. 100% of the net proceeds go to the KLS Foundation. Hundreds of bracelets have been sold resulting in over \$3,000 in cumulative

donations to the Foundation.

The third KLS Fundraiser at The Montvale Plaza in Stoneham, Massachusetts was a big success. Three hundred friends and family of the Penney family, whose son Joe has KLS, came out to support the cause and enjoy a spectacular night of dinner, dancing and an opportunity to win wonderful donated prizes including landscaping services, Red Sox, Bruins, and Celtics tickets, and gift certificates to local restaurants. The dance floor was filled all evening, as guests enjoyed the music of a live band. Christine and Joe Penney spoke about how their son Joe deals with KLS and how it has impacted his life as well as the challenges faced by adolescents with KLS and their families. Over \$10,000 was raised for the KLS Foundation that evening.

*Fundraising is an important way that friends and supporters of the KLS Foundation can be involved and make a difference in furthering our goals. Some of the successful grass-roots fundraising campaigns are highlighted here.*

The 4<sup>th</sup> annual “Walk for Ryan” KLS Fundraiser took place in April 2011 in Lancaster, SC. KLS Foundation board member Donna White led the initiative to honor the memory of her son Ryan, who struggled with KLS and tragically died of unrelated health complications. The fundraiser took place at the local high school in conjunction with a track meet between four area high schools. A spirited crowd supported the community effort and enjoyed races, activities for children, BBQ and festive music. KLS Foundation board member Dani Farber spoke about the Foundation’s mission, and White led a symbolic lap around the racetrack to honor Ryan’s memory and exhibit the community’s spirit to fight KLS. Over \$3,000 was raised for the KLS Foundation.



It may seem counter-intuitive to combine KLS patients, long-distance running, and fundraising, but one KLS family member found a creative way to do just that in support of the Foundation's fundraising goals. Inspired by the New York ‘Run for KLS Kids’ run by Danielle Farber in 2006, Oren Poleg, husband of KLS patient Arielle (Farber) Poleg, successfully ran the Marine Corp Marathon in Washington DC. His charity run raised \$12,000 for the KLS Foundation.

KLS families are finding creative ways to remember the needs of the KLS Foundation at special moments. Foundation board member Dani Farber and his wife Danielle made a donation to the KLS Foundation in honor of each of their wedding guests. A beautiful note at each dinner place setting informed the guests of the donation. The Fisch-Sabul family in San Diego, California sent out invitations for Lindsay’s Bat Mitzvah that included a note with the URL for the KLS Foundation and a request for donations in her honor. Lindsay raised over \$1,000.00 for the Foundation this way. Oren and Arielle Poleg chose to make a donation to the KLS Foundation in lieu of party favors for their wedding guests. The bottom of their wedding menu told each guest that a donation to the KLS Foundation had been made in their honor.

## NEW CHAPTER AFFILIATES

2011 saw the setting up of KLS Support UK by three mothers of children with KLS, amongst them KLS Foundation Board member Caron Krieger. KLS patients and families in the United Kingdom now have a local network linked to the US based KLS Foundation that can provide support and information tailored to the British KLS community. The aim of the group is to support families with KLS in Britain, raise awareness of KLS—particularly amongst the medical community—and support the work of the KLS Foundation, including its research into the causes of KLS. Professor Paul Gringras and Professor Matthew Walker have agreed to be Medical Advisers to KLS Support UK. An information booth was set up at the British Sleep Society Conference in Cambridge in September to raise awareness. KLS Support UK intends to apply for registration as a UK Charity.

[Click here](#) to visit the new affiliate group or [click here](#) to visit the KLS Support UK Facebook page.

*Other KLS groups and websites are emerging around the world including in Belgium, Sweden, France and Austria.*

## KLS IN THE MEDIA

One of the most effective ways to build awareness of Kleine-Levin Syndrome is through the media. The KLS Foundation works hard to encourage the media to bring attention to KLS through responsible, non-sensationalized coverage of this rare and intriguing illness. Many mainstream television shows and newspapers have run stories about KLS. Each time one of them airs, the KLS Foundation receives an increased number of telephone calls and emails from relieved parents who think they have stumbled across the long-missing answer to the mystery of what is plaguing their undiagnosed child. These news pieces are also helpful because they are seen by doctors and medical professionals who might not be aware of KLS, and they provide an opportunity for one more health care provider to become educated and familiar with KLS. Kudos to the brave young patients who have allowed the media into their lives in an effort to raise awareness.

Recent media coverage about KLS includes local newspaper articles, a show on the Discovery Health Channel “Mystery ER” program, MSNBC’s Today Health, and a segment on the Dr. Oz show. A full list of recent media links is available [here](#).

*Foundation Board Member Lori Haller and Foundation Advisory Board Member Gaylene Fisch, RN, have presented workshops on KLS at two hospitals, including a presentation at a medical Grand Rounds.*

In addition to traditional media sources, KLS has also made major inroads in the world of social media since the last KLS Foundation annual report. Numerous Facebook groups have sprouted up, allowing patients and parents to find other members of the KLS community and support one another in meaningful ways.

*The KLS Foundation’s Facebook page [can be found here](#). KLS patient Alanna Wong also hosts a website called [KLS Life](#) where she discusses her own life and profiles several other patients, sharing their extraordinary stories with the world.*



## PARTICIPATE IN RESEARCH PROGRAM

**You can help find a cure for KLS** by participating in the KLS research program. A blood sample taken at any time from an individual with KLS will tremendously help research studies underway.

The KLS Foundation is working closely with Dr. Emmanuel Mignot and his sleep research lab at Stanford University in California to discover the underlying cause and better understand KLS. Dr. Mignot's lab is assembling a valuable resource for KLS research: a collection of blood samples, swabs and detailed questionnaire data from individuals with KLS and their relatives. Hundreds of volunteers have participated in this effort by completing questionnaires and submitting samples. The research has provided some promising leads. Additional volunteers are very much needed to further these studies and to confirm preliminary findings. Collecting blood samples is vital to the progress of KLS research.

Recent medical and technological advances have allowed researchers to identify new genes and new pathways in many diseases, leading to exciting developments in understanding and treating illnesses. There may be some genetic factors that increase the risk of developing KLS, and these new advanced techniques may finally help gain a better understanding of KLS. Genetic studies require large numbers of patients, and the current set of available KLS blood samples is almost large enough to allow researchers to identify possible KLS susceptibility genes.

Because KLS is so rare, a challenging factor in KLS research is the limited sample pool. Every single patient and family member that participates in this research study is greatly helping the cause to conquer KLS. For these studies, it does not matter if you have not had a KLS episode in years.

*One mission of the KLS Foundation is to support scientific research, to find effective treatment and ultimately a cure for KLS. Before the KLS Foundation was established, there was little KLS research being conducted.*

*There are several challenges in trying to study KLS. KLS is a rare, "orphan disease" and a very unusual medical disorder. The cause of KLS is unknown; all medical tests are "normal" and an accurate diagnosis is difficult. The nature of the illness (episodic and self-limiting over time) and the small patient population add to the challenges.*

*There are several hypotheses (scientific guesses) about KLS and the Foundation has been working with leading research groups to investigate many of these. Researchers are asking is KLS genetic? Is it caused by a virus? Is it immune mediated? Hormonal? Environmental? Are there neuro-anatomical changes?*

*Another mystery of KLS is the diversity of the patients, indeed KLS has been identified in all continents, climates, geography and major ethnic groups of the world. This is reflected in the interest of KLS research groups in North America, Europe, Asia and the Middle East*

**The KLS Foundation strongly encourages everyone who qualifies to participate.** Participation is simple and there is no financial cost to volunteers in the study. The lab provides all sample collection kits and return mailers. If you are able to participate in the KLS Research Study, or if you know somebody that may be interested, please contact the Stanford University lab:

Tom Rico  
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Palo Alto, CA, 94304  
E-mail: [tomrico@stanford.edu](mailto:tomrico@stanford.edu)  
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You will be asked to complete a research questionnaire regarding KLS. If you are willing to provide blood samples you will be asked to complete a consent form. Once the form is complete blood sampling kits (with pre-paid FedEx return) will be mailed to you. Dr. Mignot's research team is skilled in arranging, collecting and processing samples, making participation fast and easy.

Please keep in mind that there are various other research programs underway requiring different samples taken at specific times from KLS patients, parents, siblings, and friends. Samples collected at designated times around an episode are very valuable and very much needed. For particular studies, samples submitted by patients accompanied by a blood sample from parents and family members are especially helpful. For other studies, samples from the same patient are needed from a healthy period and during a KLS episode. For a third study, throat and nasal swabs are needed to be taken as close as possible to the beginning of an episode.

## NOTABLE KLS PUBLICATIONS

*One positive impact of the KLS Foundation is that through the internet, networking and the media, KLS studies can now be conducted on larger groups of identified KLS patients. Previously, most information about KLS was published as "case reports," observations of 1-2 individuals with KLS. Now, by having larger groups of KLS patients participate in a study, the accuracy and insight provided by the information is greatly enhanced. Several such studies on groups of KLS patients have been conducted that now provide important information about KLS not only for the medical research community, but also valuable information for families, healthcare professionals, and schools or employers. A list of these studies and recent review articles based on observations and conclusions from larger groups of KLS cases is available on the KLS Foundation website. [Click here](#) to access it and [click here](#) to access a more comprehensive bibliography of all papers published on KLS.*

## FINANCIAL REPORT

2011 was a very busy fundraising year, resulting in a total of \$49,103.86 contributed to the KLS Foundation. As a result, the Foundation was able to provide financial support to scientific research efforts including the provision of research funding at the University of California, San Francisco. The Foundation was also able to support the First International KLS Conference, bringing in top researchers from around the world to attend the conference, discuss KLS and present their scientific findings to date.

*The KLS Foundation gratefully acknowledges the support of each and every donor whose gift has enabled the Foundation to continue our mission to fund research, educate families and physicians about KLS, and provide assistance and guidance to families & caregivers.*

*Special thanks to the following trailblazers whose giving history has been exceptionally generous*

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## OUR MISSION

THE KLS FOUNDATION PROVIDES INFORMATION AND SUPPORT TO THOSE DIAGNOSED WITH KLS AND THEIR FAMILIES. THE FOUNDATION EXCHANGES INFORMATION WITH PATIENTS AND THE MEDICAL COMMUNITY TO HELP IN THE DIAGNOSES AND CARE OF THOSE AFFECTED BY KLS, AND SUPPORTS RESEARCH PROGRAMS. OUR GOALS ARE TO RAISE AWARENESS, SUPPORT SCIENTIFIC RESEARCH, TO FIND EFFECTIVE TREATMENT AND ULTIMATELY A CURE FOR KLEINE-LEVINE SYNDROME.

**Kleine-Levin Syndrome (KLS)** is a rare and complex neurological disorder characterized by periods of excessive sleep and altered behavior. The disorder strikes adolescents primarily. KLS is cyclical: episodes begin with little warning and persist for days, weeks or months, during which time all normal daily activities stop. In between episodes patients appear completely healthy with no evidence of behavioral or physical dysfunction. At the onset of an episode patients become progressively drowsy and sleep for most of the day and night (hypersomnolence). When awake, the patient's demeanor is changed, often appearing "spacey" or childlike. Patients experience confusion, disorientation, complete lack of energy (lethargy), and lack of emotions (apathy). Most report that everything seems out of focus, and that they are hypersensitive to noise and light. In some cases, food cravings (compulsive hyperphagia) are exhibited. Patients cannot attend school, work or care for themselves while in an episode. Most are bedridden, tired and uncommunicative even when awake. KLS episodes may continue to reoccur for a decade or longer.