



Kleine Levin Syndrome Foundation Registry

Welcome to the Kleine Levin Syndrome Foundation Registry. This document will provide tips on how to navigate through the registry. The Table of Contents below can direct you to guidance on a specific section.

If you have questions that aren't answered here, please feel free to contact the Kleine-Levin Syndrome Foundation Patient Registry support at registry@klsfoundation.org.

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1. Getting Started

You can access the registry using the link: <https://kls.beneufit.com/> or from the Kleine Levin Syndrome Foundation website (<https://klsfoundation.org/>). It is recommended that you save the link as a browser favorite and/or a shortcut on your desktop to help save you time with subsequent logins.

If you leave the system and need to get back in at any time, go to <https://kls.beneufit.com/> and enter your email address and password. Upon repeat logins, the system will take you to where you left off to enter or update data.

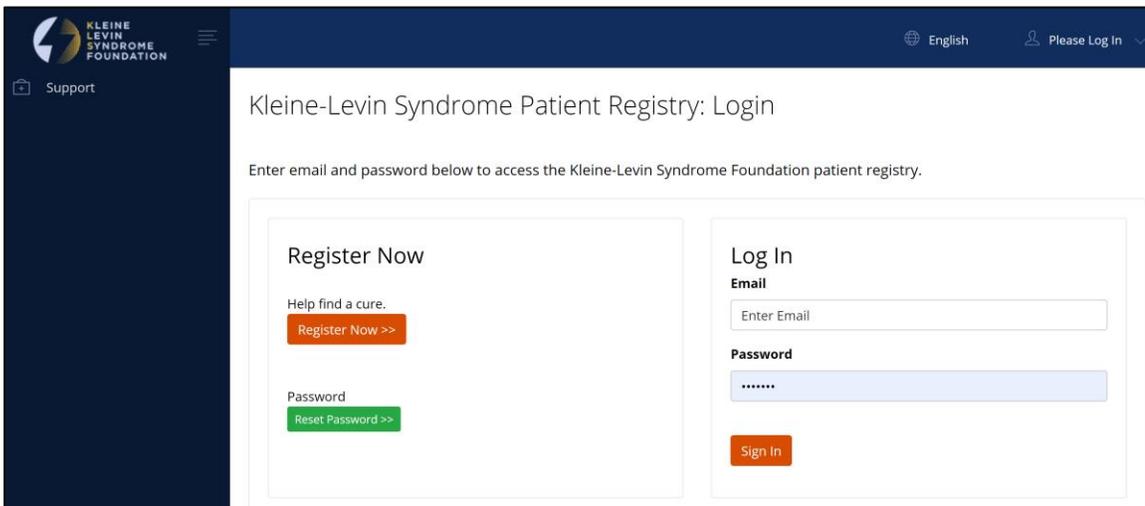
Word to the wise: DO NOT USE THE BACK KEY ON YOUR COMPUTER, as this may result in an error and you will have to log back into the system.

2. First Time Login

The first thing you will see as you enter the Registry is a Registration Page. Please click on “Register Now”.



Enter your email address and choose a password. Make sure to remember this password, or keep it in a safe place.



After clicking on “Register Now”, you will be asked to fill out your name, contact information and role (relationship to the Patient).



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3. Research Subject Consent Form

Please complete the information at the top of the page, and read the Consent Form carefully. If you have any questions about the Consent, please contact the Kleine-Levin Syndrome Foundation Patient Registry support at registry@klsfoundation.org.

If you agree with the Consent, please click the “Agree” box all the way at the bottom and fill in YOUR name. If you are the parent or guardian, also fill in the name of the Patient. You will be able to download a copy of the consent form from the Dashboard, shown next.

As you proceed, you should see the Dashboard which provides some summary information about the community. To begin data entry, click on the ID, as shown below.

[Record Your First Episode Details >>](#)

Kleine-Levin Syndrome Patient Registry: Dashboard

Kleine-Levin Syndrome Patients

Click on the ID number or patient name to access the various sections of the registry and edit patient data.

| ID | Patient Name | Gender | Date of Birth | Consent Document |
|----|---------------------------|--------|---------------|-----------------------------------|
| 9 | test account test account | Male | 2021-01-01 | Download Document |

Demographics
Patient Country

Family Data
Grandparent's Birthplace

Disease History
Number of KLS Episodes



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You will be asked to complete five main sections of the Registry:

- Demographic Data
- Family Data
- General Health Data (including Health History, Medications, and Symptom Ranking)
- KLS History Data
- KLS Episode Tracker

4. Demographic Data

Once you have completed the Consent form and added the Patient, you will see a screen to enter Demographic data. You will need to enter data for all fields on the left side of the form before you can move on.

Please then complete as much as you can on the right side of the form. If you were diagnosed with KLS by a doctor, please select 'Yes' and the box will expand to provide the name, institution, country and contact information for the doctor who made the KLS diagnosis. If you have information about the Patient's pediatrician, please click on [+ Add Pediatrician](#) and some boxes will open to enter information. You can only enter one pediatrician, so please enter the pediatrician that played the most important role in the Patient's treatment. Similarly, you can click on the box [+ Add Genetic Counselor](#) to enter information about the Patient's primary genetic counselor, if applicable.

When you have completed the Demographics page, click on [Save Patient >>](#), and you will see a representation of Patients in the Registry so far, distributed by country. If you need to make any corrections to the data you entered, you can click "Go Back" to return to the Demographics page and add or correct the data, but **don't hit the back key on your computer.**

Click on [Next >>](#) at the bottom of the page to move on to the next section.



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5. Family Data

Please fill out the Family Data section as completely as possible. If you have a copy of DNA testing, please click on “Choose Files” and upload a file from your computer.

If you have a genetic report done by physician or a genealogy DNA testing company (i.e. Family Tree DNA, 23andme, Ancestry DNA, My Heritage), upload report. If you only have a hard copy, scan or take a photo of the report and upload.

Choose Files No file chosen

Save Data

As you finish each section, please click “Save Data”. You will then see a bar chart showing a summary of data for the section. If you need to correct any data you entered, click on “Go Back”, but **don’t hit the back key on your computer**.

Click on **Next >>** at the bottom of the page to move on to the next section.

6. General Health Data

General Health Data is divided into three sections: General Health History, Medications, and Symptom Ranking. Please answer the General Health Data questions as completely as possible, and make sure to enter the Year of KLS Diagnosis.

a. History

For relevant medical history, check *all that apply*. If none of the listed medical history options applies, ***please check “none”***.

b. Medications

In this section, you will be asked to indicate which medications, if any, you have used or tried in an effort to manage KLS episodes. The medications that may be used in treating KLS are listed in the following categories:

- Stimulants
- Anti-Depressants
- Mood Stabilizers
- Neuroleptics
- Antivirals
- Anxiolytics
- Antiepileptic
- Diuretics



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- Sleeping Agents
- Antibiotics
- Other

You do NOT need to check each category and specific medication option. If you have not taken a specific medication, please skip over.

An example of how to enter these is shown below using the “Stimulant” category:

+ Medication

Which of the following medications have you used or tried in the past in an effort to manage your KLS episodes? Please rate what effect you believe each medication had in controlling your KLS symptoms and episodes.

STIMULANTS

- Armodafinil (Nuvigil) [Add Data](#)
- Atomoxetine HCL (Strattera) [Add Data](#)
- Bupropion (Wellbutrin) [Add Data](#)
- Demethylphenidate (Focalin) [Add Data](#)
- Dextroamphetamine (Dexedrine) [Add Data](#)
- D-L Amphetamine Salts (Adderal) [Add Data](#)
- Methamphetamine (Desoxyn) [Add Data](#)
- Methylphenidate (Ritalin, Ritalin SR, Ritalin LA, Concerta, Daytrana) [Add Data](#)
- Modafinil (Provigil) [Add Data](#)
- Pitolisant (Wakix) [Add Data](#)
- Other [Add Data](#)

If any of the drugs were used, then click on [Add Data](#), and a window will open (as shown next) where you can enter details.



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STIMULANTS

Armodafinil (Nuvigil) [Add Data](#)

| | | |
|------------------------|---------------------|----------|
| Duration of Use | Dosage | |
| Select Number | Select Dose | |
| Select Period | Select Units | |
| Effect on KLS Episodes | | |
| Sleepiness | Cognition | Appetite |
| Sexual Urge | Prevent New Episode | |
| End Current Episode | | |

Click on “Select Number” to record the duration of use in days, weeks, months or years. You can then indicate if the number you entered is in days, weeks, months or years in “Select Period”.

Then click on each of the items in the “Effect on KLS Episodes” and a new window with choices will open. Select **one** correct response for each item.

- Sleepiness: Mildly Improved
- Sleepiness: Improved
- Sleepiness: Significantly Improved
- Sleepiness: No Change
- Sleepiness: Mildly Worse
- Sleepiness: Worse
- Sleepiness: Significantly Worse

Please make sure to enter all medications, including any that are not listed. You can enter any not listed in “Other” within each drug class.

Please use the “Other” section at the bottom of the list if none of the listed drug classes apply or if you don’t know the drug class of a medication you tried.



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OTHER

Immune Therapy [Add Data](#)

Intravenous Immune Globulin (IVIG) [Add Data](#)

Intravenous Steroids (Biaxin) [Add Data](#)

Other [Add Data](#)

a. Symptom Ranking

The final section within General Health Data is one where you rate the KLS symptoms that are most important for you to alleviate. Please put them in order by clicking on the item that is most important to you and dragging it to the top, then dragging the second most important to the spot second from the top, etc. When you feel the order is accurate, then click “Yes” at the bottom to agree to the order. Click on “Save Data” to complete the General Health Data section.

Please drag in order what you feel is most to least important for the patient to have gains in?

Reorder by dragging. 1 (on top) - most important; 10 (on bottom) - least important

Improving Sleep

Improving Speech

Improving Cognition

Improving Perception

Improving Physical Symptoms

Improving Appetite

Improving Behavior

Improving Sexuality

Improving Memory

Improving Recovery

I agree to this order.

Yes No

[Save Data >>](#)

You will then see a bar chart summarizing the number of KLS episodes for all Patients in the Registry. As with other sections, you can click “go back” if you need to correct anything on the prior form, or “next” to move on.



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7. KLS History Data

In this section, please think about **all of your KLS episodes** and try to provide **typical, or average** answers for your episodes. Don't worry about capturing the specific details of individual episodes—you will have an opportunity to do that later in the Episode Tracker.

Once you have completed all questions, click "Save Data". At this time, you will have completed the Basic Registry. A new form will pop up requesting you complete some information about specific KLS episodes.

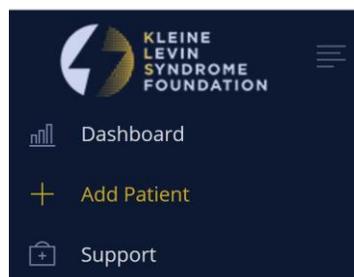
8. Kleine Levin Syndrome Episode Tracker

Here you will be encouraged to provide additional information about the Patient's:

- FIRST episode
- Most RECENT episode
- FUTURE episodes. Please return to the Registry to enter data on any new episodes as they occur. The episode tracker within the Registry can be used as a journal for you to track changes over time. Doing so will help the Foundation and researchers gain a better understanding of two critically important issues: KLS variability and progression over time and from one Patient to the next.

9. Add a Patient

If you have completed the basic registry for a first Patient and want to enter data for another Patient (for example, if you have two children with KLS), then you can enter data for both Patients using your same login by clicking on "+ Add Patient" in the upper left corner. You will be prompted to provide Informed Consent for a new Patient and will then be able to proceed with entering data for subsequent Patients.



THANK YOU FOR COMPLETING THE KLEINE LEVIN SYNDROME REGISTRY!