

What is LLS Community?

LLS Community is the Leukemia & Lymphoma Society's online space for patients, caregivers, and supporters. With more than 6,000 members, the LLS Community is a place for blood cancer patients to talk to others with the same or similar diagnosis and get disease updates from a trusted source. The LLS Community website is private and requires a user ID and password. All communication runs through an encrypted browser session, and any information stored on the LLS Community database is stored in an encrypted manner.

Do I have to be a member of LLS Community to join the LLS Patient Registry?

Yes, you must first register with LLS Community at <http://lls.org/community>. From there, you can opt-in to join the LLS Research Registry. LLS Community is an online space for people living with or supporting someone with blood cancer. This way, if we derive a result from our research, we can report the results directly back to our community. Your personal identifying information on LLS Community will not be linked to your LLS Patient Registry data.

What are the benefits to me of joining the LLS Patient Registry?

By joining the LLS Patient Registry you are “paying it forward” and your medical records are part of research that will help improve care and lead to better options for patients like you.

Is it difficult to join the LLS Patient Registry?

No, participating in the LLS Patient Registry just takes a few clicks. Many people who feel that they are not computer savvy find the site easy to use. If you need one-on-one help, contact 1-844-696-7228 or email [PACT@lls.org].

Do I have to upload my own medical records?

No, you will not have to upload your own medical records! Once you have joined the LLS Community and have “opted-in” to the LLS Patient Registry, you will be directed to a secure site, where you will authorize the connection between your medical provider's “portal” and LLS.

What is a portal?

A portal is basically an online resource where a patient can view his/her medical test results data, appointment schedules, medication list, visit summaries, and so on. Many hospitals and doctor's offices provide the opportunity for you to register for their online portal so that you can see your medical records online. This allows you to see your medical information from your own computer or hand-held device.

What if my doctor's office does not participate in an online portal?

While disconcerting, there are instances where a medical provider does have a portal system in place (which is meant to benefit the patient), but the patient is not yet aware of it – so, don't hesitate to ask them about it! Make sure to ask your doctor's office about it next time you visit.

What does "opt -in" mean?

The LLS Patient Registry is an opt-in service for patients, meaning we will ask for your permission to link your medical record data with LLS researchers.

How does LLS access my data?

When the LLS Research Registry receives your consent for participation, you will be directed to our site that allows you to select your provider's portal and enter your user ID and password credentials. From that point forward the program, on your behalf, will request a copy of your medical records on the portal and it will look for new records on a periodic basis. In many cases patients are cared for by more than one doctor or hospital and you can link as many portals to this process as needed so that all your data is in the LLS Patient Registry.

If I have data from several medical record portals, will this data be consolidated into one set of data for me?

Yes, all portal records will be consolidated into a single data file for research.

How is my information protected?

Your name is never associated with your records. Instead, your information is "de-identified."

How do my records become "de-identified?"

When an LLS researcher accesses the data in the LLS Patient Registry your record will have all your personal identifying data be removed and replaced with a numeric "key." In this way the researchers will not be able to link to any one individual.

How do I know my records are safe?

LLS Patient Registry is committed to safeguarding your personal content and employs a variety of measures that are designed to help protect your personal content from unauthorized access and disclosure. However, LLS Patient Registry CANNOT guarantee that any and all information or private communications will be protected from unauthorized disclosure or use. As with any online interaction, we encourage you to take steps to protect yourself against unauthorized access by signing off after using a shared computer, choosing a complex password that nobody else knows or can easily guess, and keeping your log-in and password private. If you receive an email asking you to "update" your information with respect to the service, do not reply and please contact LLS Patient Registry support.

Does the LLS Patient Registry store my portal password?

Yes, your credentials are stored in a strongly encrypted manner so that they can be used to update your medical records on a periodic basis.

Does the LLS Patient Registry store my medical records?

The LLS Patient Registry stores what is available to you on your provider's portal. These files are not your complete medical record as stored in your provider's office. They are the records made available to you, owned by you, and that you can share with anyone of your choosing.

Can I withdraw from the LLS Patient Registry at any time?

Yes, at any time, should you decide to end your relationship with LLS Patient Registry, you will be able to delete your account, at which time all of your accumulated records will be removed from our database.

Do I need to keep going back to the LLS Patient Registry every time my records change?

No. Once authorized, the LLS Patient Registry will routinely look for new input to your portal to add to the Registry. You don't need to do anything else unless you change your user ID and/or password for a given portal. If you go to a new hospital or medical practice, you will need to grant access to this new provider's portal.

What happens after I join the LLS Patient Registry?

After you opt-in to join LLS Research Registry and share your medical records on the secure platform, your health information will be de-identified and accessible to LLS researchers for further study.

Is the LLS Patient Registry compliant with the Health Insurance Portability and Accountability Act (HIPAA)?

Yes.

What type of Research can I expect that my data will be used for?

The LLS Patient Registry is focused on looking for patterns of care that may lead to better outcomes and fewer side effects. Initially, your data will be used to evaluate tests used for diagnosis, initial treatments based on the diagnosis, and ongoing results of care.

How will LLS share the research results with me...and on what frequency?

With a user account in the LLS Community, you will become a member of your disease specific discussion group. It is anticipated that when the research results are known and ready for publication, you will be able to see these results within your discussion group. The frequency of reporting is based on research and may vary between a few or many months depending on the study questions.

Will research be conducted specifically on my disease?

Yes, the LLS Patient Registry is beginning with disease specific research regarding the diagnosis and treatment patterns of Waldenstrom's Macroglobulinemia as well as Chronic Lymphocytic Leukemia.

Will research be conducted to find commonalities and/or differences among different and/or related blood cancers?

Yes, the goal of the LLS Patient Registry is to search for patterns of outcomes within a single blood cancer as well as across the spectrum of blood cancers. Ultimately, these patterns, whether showing positive outcomes vs. side effects, are important to understand and report as they relate to survivorship follow up.

What are LLS plans to allow me to access my own data in the Patient Registry?

Initially the data will be consolidated into one record set for research. We do anticipate that the data contained within the LLS Patient Registry will be made available to individuals via a web browser as well as a mobile application. We anticipate this service to become available in 2019.

Is there a cost to join the LLS Patient Registry?

No, there is no cost to participate in the LLS Research Registry.

Ready to share your medical data? [Click here to set up your record sharing](#)

If you still have questions please send an email to PACT@lls.org or call 1-844-696-7228 to speak to an LLS representative to learn more.