National Research Registry

Interim Progress Report
Introduction

Starting on July 1, 2018, LLS worked in collaboration with the International Waldenstrom Macroglobulinemia Foundation (IWMF) and the CLL Society to invite patients to share their medical records with LLS researchers via a secure medical records submission process.

The following report shows preliminary results regarding metrics of participants and the status of record sharing, as well as the breakdown of whether treatment records originated at an academic or a community practice setting.

From the total of 244 signed consents, 170 individuals shared their medical records via the secure LLS Registry upload process. 210 total records were shared, with an average of 1.2 records per patient:

- **Academic medical center** - 91 records
- **Community practice** - 119 records

59 CLL* patients shared a total of 77 records, with an average of 1.3 records per patient:

- **Academic medical center** - 43 records
- **Community practice** - 34 records

27 records were rejected for processing, with an average of 1.17 records per patient:

- **Academic medical center** - 9 records
- **Community practice** - 18 records

41 other blood cancers were not analyzed, with an average of 1.2 records per patient:

- **Academic medical center** - 15 records
- **Community practice** - 26 records

*Chronic Lymphocytic Leukemia*
Chronic Lymphocytic Leukemia

Has cytogenetic analysis been done?

70% of patients confirmed that this test had been done

When was cytogenetic analysis performed?

- Day of Diagnosis
- Prior to Diagnosis
- After Diagnosis

41% patients use or used Ibrutinib

In patients diagnosed since 2017, no FCR or chemo was used for initial treatment. The conclusion is that initial treatment of CLL is currently treated by targeted therapy as opposed to chemotherapy.

Other gene sequencing analysis noted these mutation types:
Registry results to date are encouraging. Seventy percent (70%) of patients who agreed and signed consent shared their medical records.

Registry results to date are also encouraging in that the study hypothesis allowed for patients to share more than one portal record available for analysis. The overall ratio was 1.16 records set shared per patient.

Creating a blood cancer registry by asking patients to share medical records has been shown to be effective. Direct patient survey follow-up has also been shown to be an effective method of gathering data.

Additionally, please note that to date:

- There are no reported adverse events or adverse outcomes associated with participation in the LLS Registry.
- There are no unanticipated problems involving risks to subjects or others.
- There have been no subject withdrawals.
- There have been no complaints about the research.
- There have been no amendments or modifications to the protocol.