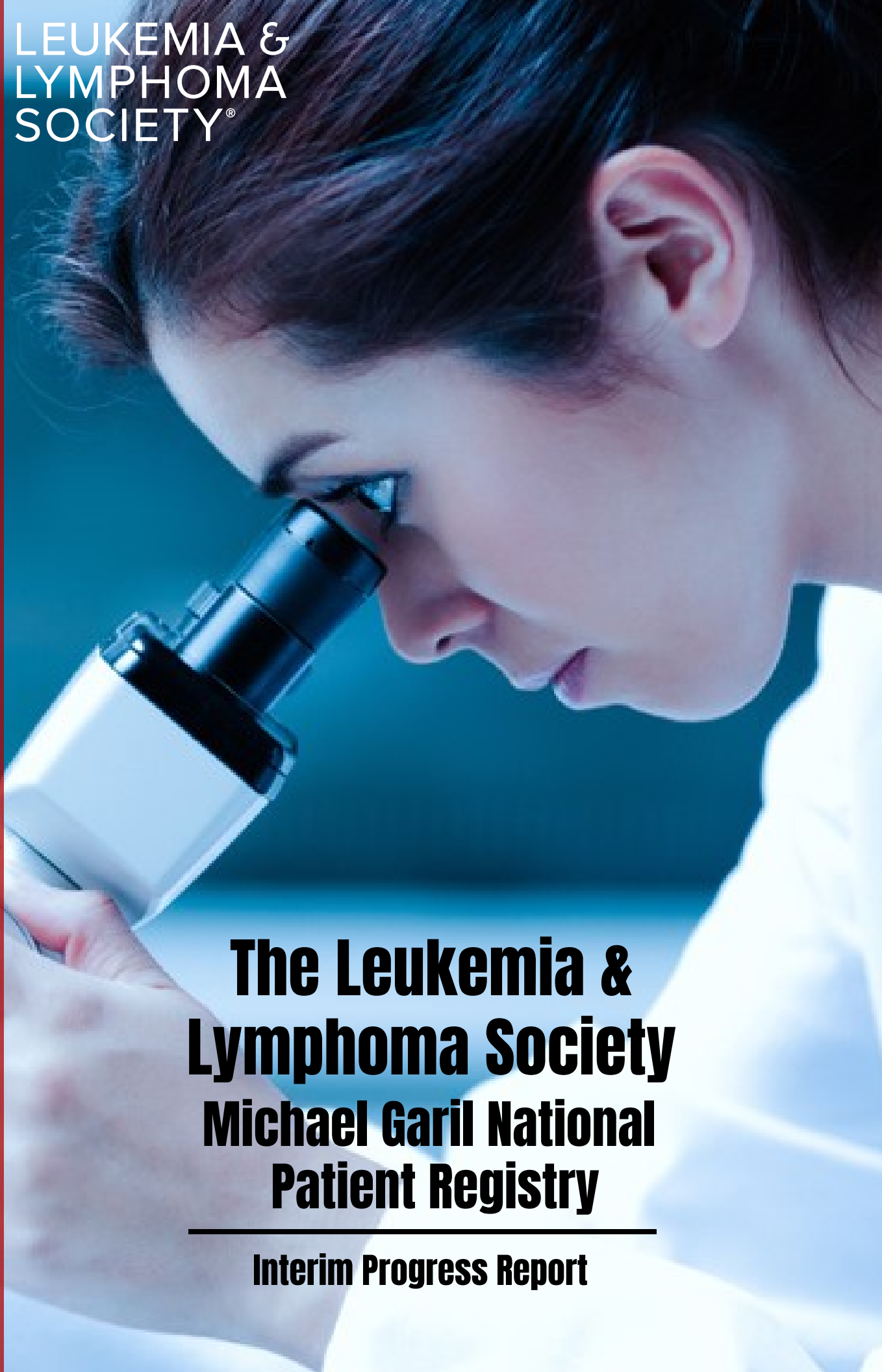
LEUKEMIA & LYMPHOMA SOCIETY®



The Leukemia & Lymphoma Society

Michael Garil National Patient Registry

Interim Progress Report

Introduction

Starting on July 1, 2018, LLS worked in collaboration with the International Waldenstrom's 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.

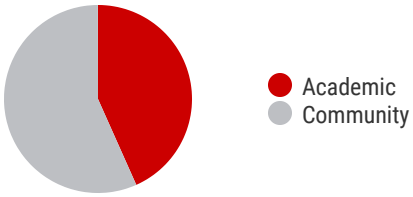
From the total of 244 signed consents,170 individuals shared their medical records via the secure LLS Registry upload process

Of the 170 individuals who shared their records, 69 were WM patients, and 70 were CLL patients and 31 represented other blood cancers.

170 Total patients*

210 **total records** were shared, with an average of 1.2 records per patient

Academic center - 91 records
Community practice - 119 records

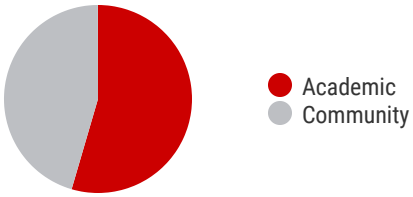


*Includes Chronic Lymphocytic Leukemia and Waldenstrom's Macroglobulinemia patients

69 CLL* patients

88 **total records** were shared, with an average of 1.27 records per patient

Academic center - 48 records
Community practice - 40 records

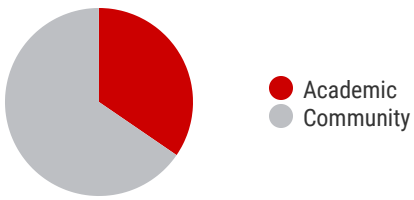


*Chronic Lymphocytic Leukemia

69 WM* patients

81 **total records** were shared, with an average of 1.17 records per patient

Academic center - 28 records
Community practice - 53 records



*Waldenstrom Macroglobulinemia

27 Records rejected for processing

Majority of rejections due to **no date of diagnosis** in records

Academic center - 9 records
Community practice - 18 records

41 Other blood cancers not analyzed

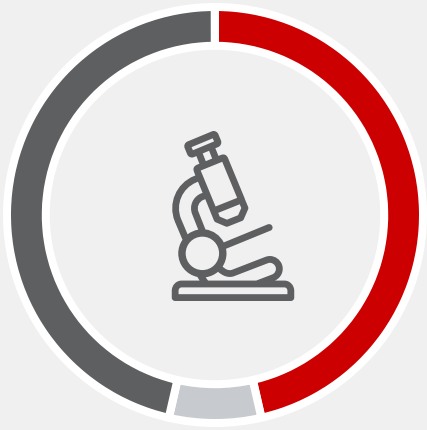
41 **total records** were shared, with an average of 1.2 records per patient

Academic center - 15 records
Community practice - 26 records

Chronic Lymphocytic Leukemia

Has cytogenetic analysis 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:

TP53
ATM
NOTCH 1
IVGH
MYD88
SF3B1

Waldenstrom's Macroglobulinemia

Treatment Status

- **9% (n=5)** Untreated and on Watch & Wait
- **64% (n=36)** Treated and now on Watch & Wait
- **27% (n=15)** continue in active treatment

Note: 13 of the 69 total WM patient participants records rejected for processing)

Most Common Treatments

Prior to 2015, treatments were primarily Cyclophosphamide combined with either Vincristine or Rituximab

Treatments after 2015 have switched to oral targeted therapy (example is Ibrutinib) either alone or in combination with Rituximab.

66%

of relapsed patients

are treated with Ibrutinib

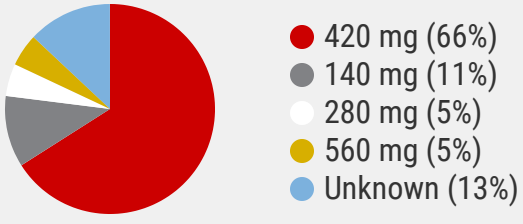
Is testing for Myd88 and CXCR4 routinely done?

15 tests for Myd88

4 tests for CXCR4

?

What is the most commonly prescribed Ibrutinib dose?



Summary

Registry results to date are encouraging. Seventy percent (70%) of patients who signed consents and agreed to participate were able to share their electronic 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