



LEUKEMIA &
LYMPHOMA
SOCIETY®

A close-up, profile view of a woman with dark hair, wearing a white lab coat, looking through the eyepiece of a microscope. The background is a soft, out-of-focus blue. The overall image has a professional, scientific feel.

The Leukemia & Lymphoma Society Michael Garil National Patient Registry

Interim Progress Report
Waldenstrom's Macroglobulinemia

Introduction

Starting on July 1, 2018, LLS worked in collaboration with the International Waldenstrom's Macroglobulinemia Foundation (IWMMF) 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.



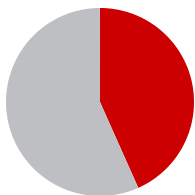
From the total of 244 signed consents, 170 individuals shared their medical records via the secure LLS Registry upload process

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



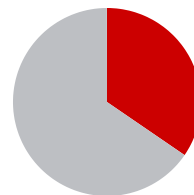
● Academic
● Community

*Includes Chronic Lymphocytic Leukemia and Waldenstrom's Macroglobulinemia patients

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



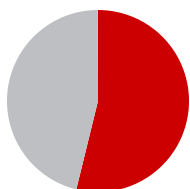
● Academic
● Community

*Waldenstrom Macroglobulinemia

13 WM Records rejected for processing

No date of diagnosis or recurrence can be found in the record - 7 records

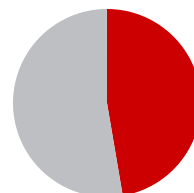
No mention of WM diagnosis at all - 6 records



● No date of diagnosis in record
● No mention of WM diagnosis

101 CLL and other blood cancer records analyzed




Academic center - 62 records
Community practice - 69 records



● Academic
● Community

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?



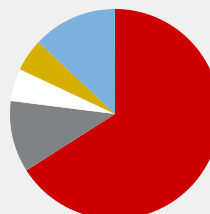
15 tests for
Myd88



4 tests for
CXCR4



What is the most commonly prescribed Ibrutinib dose?



- 420 mg (66%)
- 140 mg (11%)
- 280 mg (5%)
- 560 mg (5%)
- Unknown (13%)

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