

RLS REGISTRY 5-YEAR UPDATE

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Registry participation at 5-years

Of the 500 people who initially enrolled in the RLS Registry, we have information on 410 participants at 5-years

Of those who are no longer participating in the RLS Registry:

38 participants
have
discontinued
their opioid

9 participants
voluntarily
withdrew from
the RLS Registry

20 participants
have lost contact

18 participants
are deceased

We are so thankful for the dedicated participation that each of our registrants contributes to the RLS Registry! Your contributions have helped us learn so much about the long-term treatment of RLS with opioids.

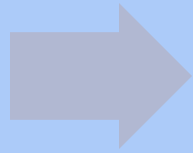
What opioids are participants taking?

Opioids (in order of frequency)	% of Participants	Median Dose (mg)
1. Methadone	53.17%	10
2. Oxycodone	16.34%	15
3. Hydrocodone	10.98%	10
4. Buprenorphine	10.98%	1.2
5. Tramadol	5.37%	112.5
6. Morphine	5.12%	30
7. Codeine	2.20%	50
8. Hydromorphone	1.46%	3

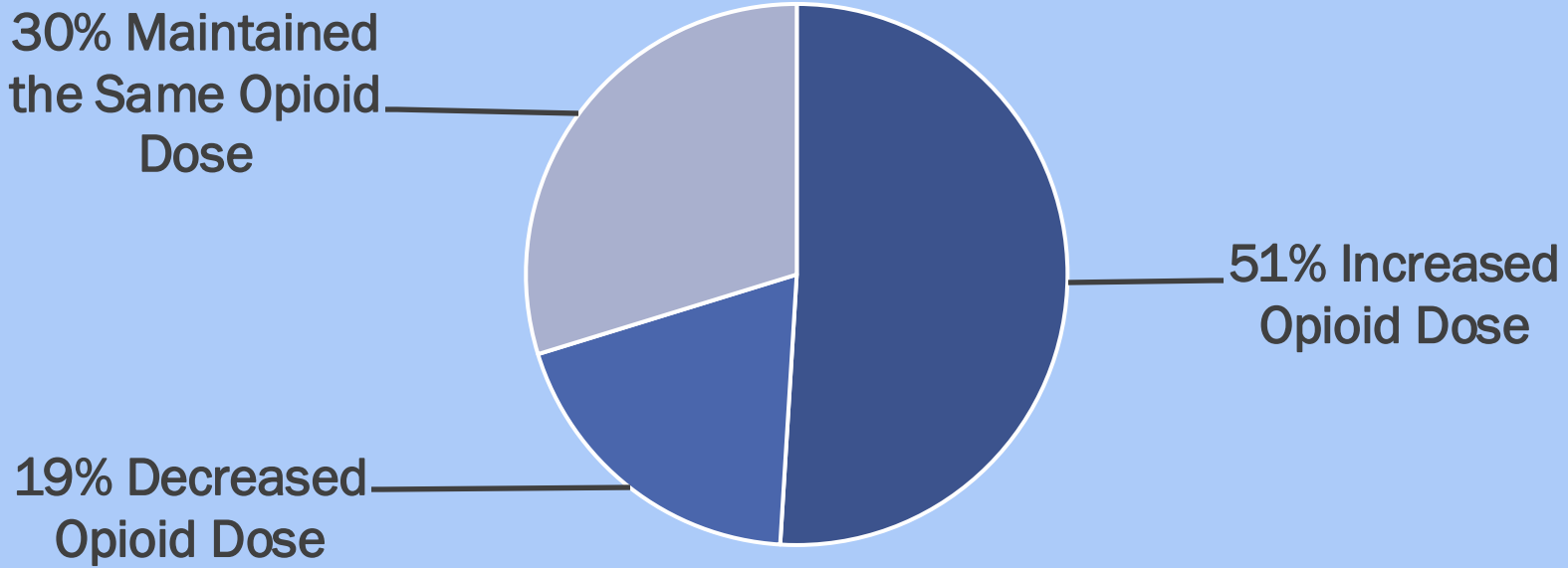
Slight increase in median opioid dose over 5-years

MME = Morphine Milligram Equivalents

Median Enrollment MME = **30**
(equal to 20 mg Oxycodone or 7.5 mg Methadone)



Median 5-Year MME = **36**
(equal to 24 mg Oxycodone or 9 mg Methadone)



What factors predicted large opioid dose increases from enrollment to 5-years ?

Strongest Predictor = 1

Weakest Predictor = 8

1. Switching to Buprenorphine

2. Adding/
Removing
Dopamine
Agonist*

3. Switching to Methadone

4. Taking Opioid for Another Pain Condition

5. Severe RLS at Baseline

6. Neuropathy

7. Higher Baseline Insomnia

8. Under One Year on Opioid at Baseline

**Dopamine Agonist medications include Pramipexole (Mirapex), Ropinirole (Requip), Rotigotine (Neupro), and Levodopa (Sinemet)*

What other changes have Registry participants seen over the last 5 years?



Although individual Registry participants may have seen changes, in general, the average RLS severity has remained stable over 5 years.



Anxiety and depression severity have also remained stable.



Insomnia severity has slightly improved from enrollment to 5-years in the RLS Registry.

7.6% of initial
Registry
participants
discontinued their
opioid medication...
why?

38% → Opioid Side Effects

22% → RLS Symptoms Controlled Without Opioid

16% → Switched to Non-Opioid

16% → Doctor Would No Longer Prescribe

13% → Opioid Was No Longer Effective

6% → Augmentation on Opioid

New RLS Treatment Guidelines from the American Academy of Sleep Medicine

Read the new guidelines here: [Treatment of restless legs syndrome and periodic limb movement disorder: an American Academy of Sleep Medicine clinical practice guideline](#)

Opioids were conditionally recommended for the treatment of RLS.

Dr. Winkelman's perspective on these guidelines: [New Treatment Guidelines for Restless Legs Syndrome and Shifting Away From Dopamine Agonists: John Winkelman, MD, PhD](#)

Thank you for your participation in the RLS Registry!



At 5-years, nearly all still-eligible participants initially enrolled in the Registry continue participation (**92.6%**). We hope to continue the Registry until 10-years!

We intend to present 5-year Registry information at the upcoming June 2024 National SLEEP meeting in Seattle, Washington! In addition, we are preparing a 5-year manuscript, which we plan to publish in a peer-reviewed academic journal.

This study is not meant to be used as clinical guidance.

Questions or comments? Please email akilty@mgh.harvard.edu or call (617) 643-6026.