



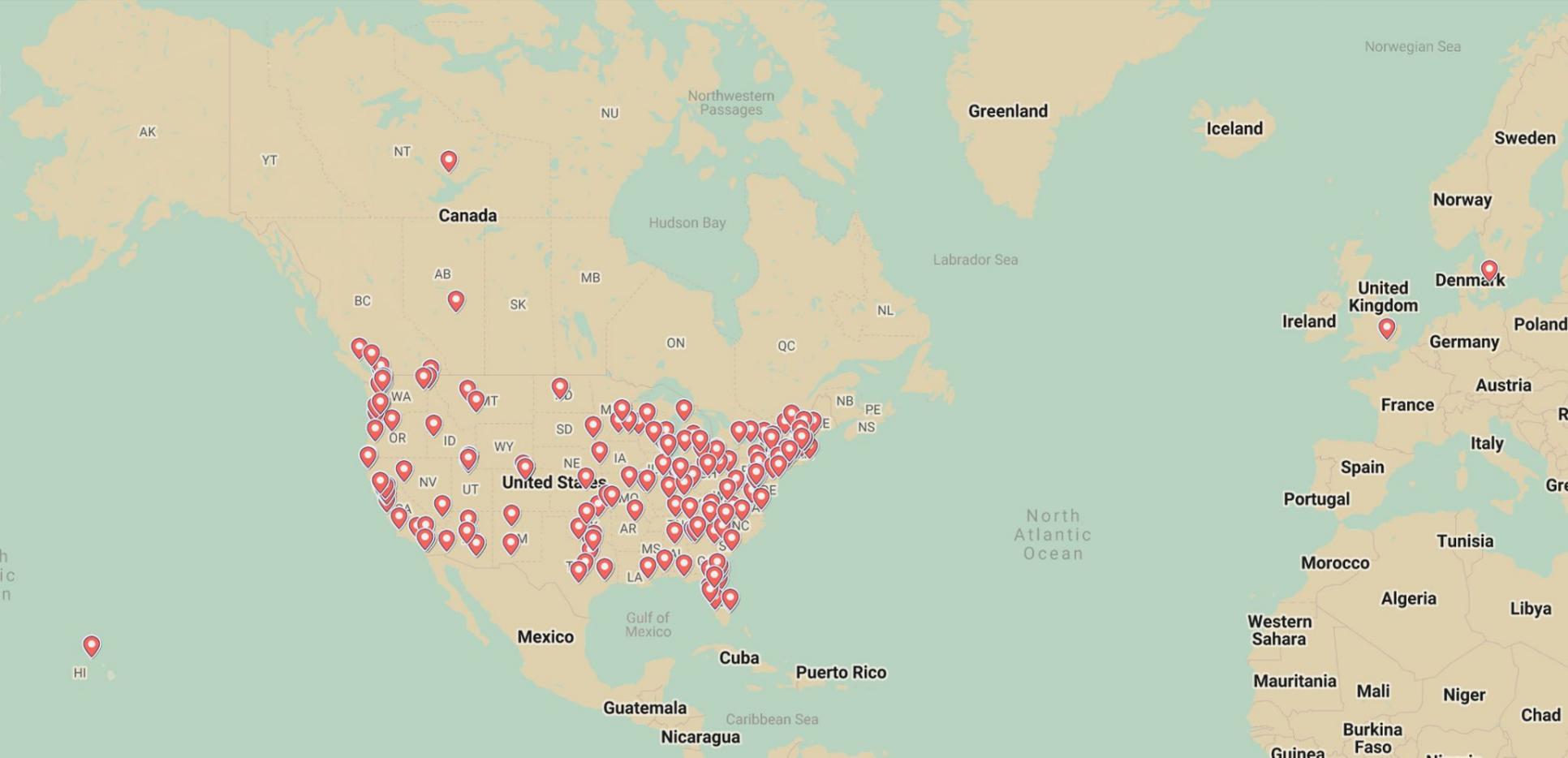
# NATIONAL RLS OPIOID REGISTRY

Massachusetts General Hospital

John Winkelman, MD, PhD  
Sleep Disorders Clinical Research Program

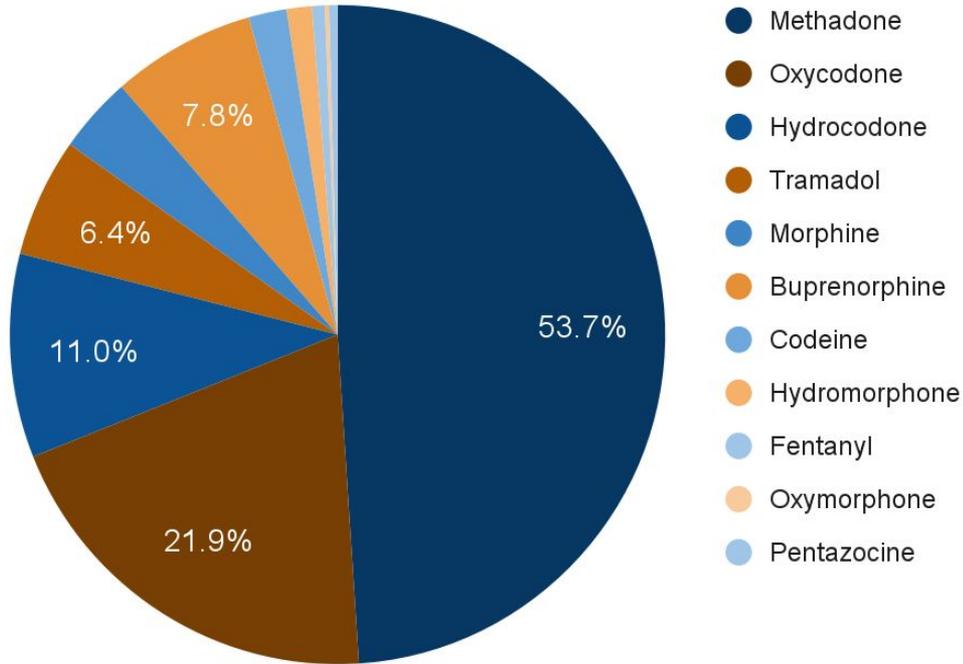
## RLS Registry 3-Year Update

# Where are participants located?



# What opioids are Registry participants taking?

3-Year Opioid Medications

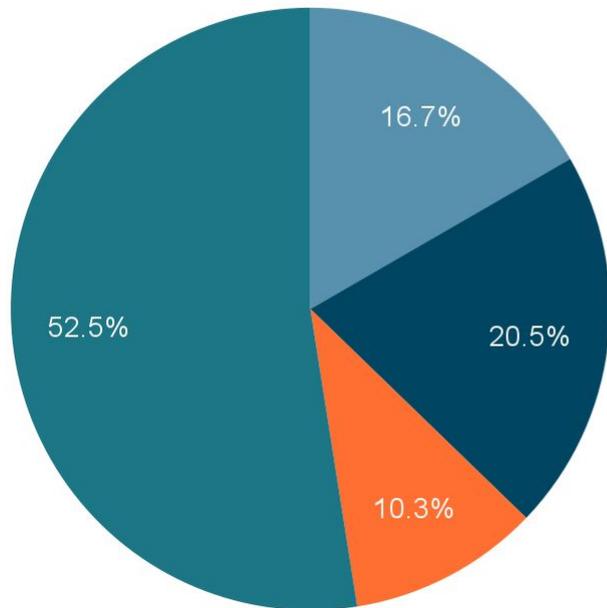


More than 50% of participants are taking low-dose methadone for RLS



# Almost Half of Participants Use a Second Type of RLS Medication

Other RLS Medications



- Pramipexole (Mirapex), Ropinirole (Requip), Rotigotine (Neupro patch), Levodopa (Sinemet) [DA]
- Gabapentin (Neurontin), Horizant, Pregabalin (Lyrica) [CCL]
- Both [DA & CCL]
- Opioid Only [No DA or CCL]

*A second (and occasionally third) type of medication are often used to manage RLS symptoms*



# Insomnia Severity

- The majority of participants **do not** have clinically significant insomnia
- There has been **little change** in insomnia severity since enrollment in the Registry



# RLS Severity

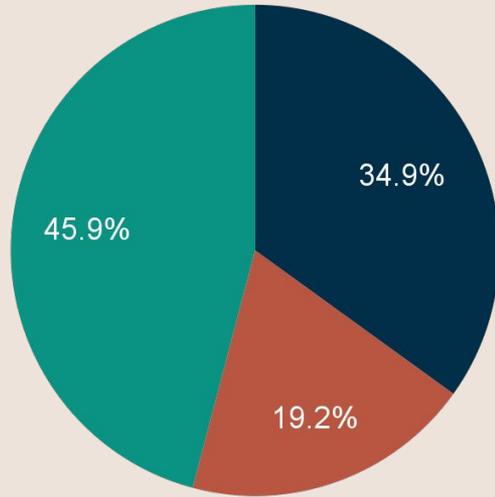
- A majority of participants have at least **moderate persistent RLS symptoms**
- There has been **little change** in RLS severity since enrollment in the Registry



# 3-Year Dose Updates



## Baseline to 3-Year Change in Dose



- Same Dose
- Decreased Dose
- Increased Dose

Top Two Opioids:	Median Dose:	Median Dose Change:
Methadone	10 mg	0 mg
Oxycodone & Oxycontin	15 mg	0 mg

# Who is most likely to increase their opioid dose?



Notable  
Anxiety at  
Time of  
Enrollment

Under One  
Year on Opioid  
at Time of  
Enrollment

Switched Opioid  
Medications  
Between  
Enrollment and  
3-Year Survey

# Conclusions

500 Total at Baseline

62 Incomplete

**438 Completed  
3-Year**

20 Lost Contact

14 No Longer in  
Study

28 Discontinued  
Opioid

*Response Rate:*

1-Year: **97.7%** → 2-Year: **94.9%** → 3-Year: **94.4%**

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Nearly everyone enrolled (94.4%) continues to participate. Our first enrollees have now completed their 5.5 -year surveys! Detailed progress is shown on the left.

**Thank you for your continued participation!**

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*How have we reported our findings recently?*

- Presented at **APSS SLEEP 2023**
  - Submitted to **World SLEEP 2023**
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*This study is not meant to be used as clinical guidance nor is it a reflection of individual experiences.*

If you have any questions or comments, please email [akilty@mgh.harvard.edu](mailto:akilty@mgh.harvard.edu) or call (617) 643 - 6026 to speak with Adysn, the Registry coordinator.