

Frequency of Hypoglycemia in HI Global Registry Participants

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Objectives

The objective of this study was to investigate the frequency of self-reported low-blood sugar, below 70 mg/dL, based on the other disease and management characteristics of individuals living with HI.

Congenital Hyperinsulinism (HI)

- HI is the most frequent cause of severe, persistent hypoglycemia in neonates, infants, and children.
- In most countries, the estimated incidence of HI is approximately 1/25,000 to 1/50,000 birth, classifying it as a rare disease.
- Controlling blood sugar and preventing lows, is a critical feature of HI management.

Methods

The HI Global Registry (HIGR) is an online platform consisting of 13 surveys capturing the experience of living with HI. Respondents are adults with HI or parents of children with HI.

This study utilized data collected from 2018 through April 2021 using the HIGR.

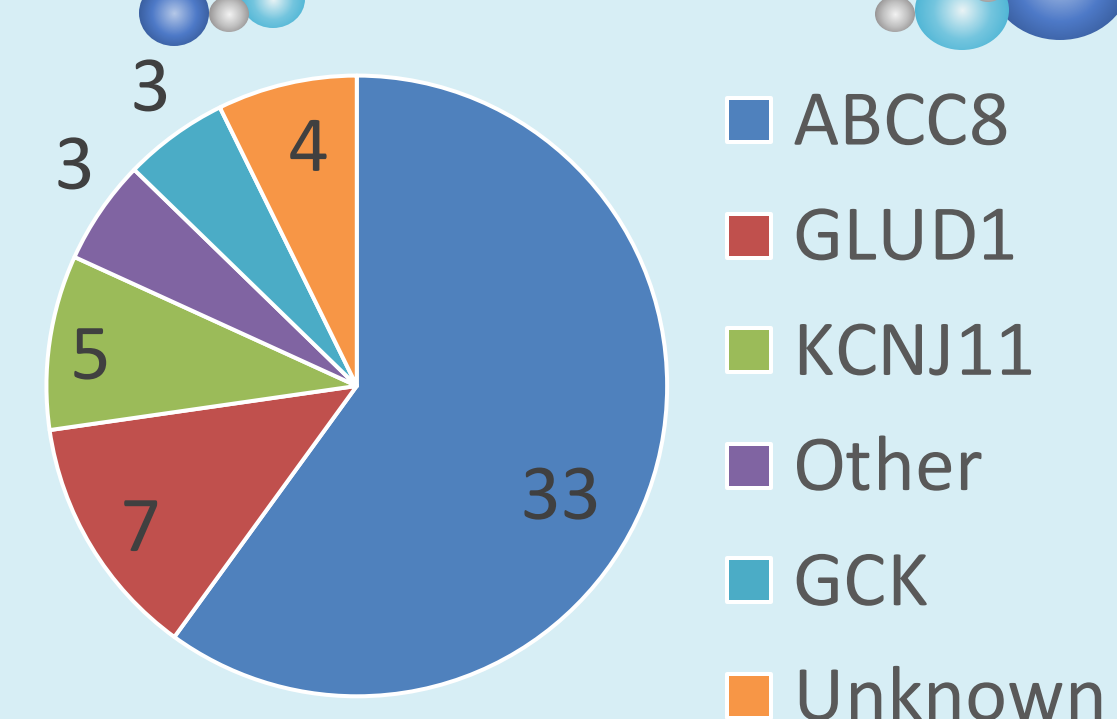
The frequency of blood sugar lows is reported as a categorical variable with options ranging from infrequently to more than once a day.

All other variables were categorical, and data analysis was conducted in Stata and chi-square analysis was completed.

Chi-square analysis was completed to investigate statistically significant differences by groups.

Genetics

A total of 84 people reported on the results of genetic testing. Of those, 53 reported a positive results for a change/mutation in at least HI-related gene.



Sample Characteristics

There were a total of 120 people who reported on the frequency of low-blood sugar. We then excluded individuals who reported they have been diagnosed with diabetes (8) or where their HI has “resolved” (4).

In some cases these individuals may not have answered the additional surveys or questions being reported, therefore the sample for each question does not always equal 108.

In the future, we will present data on frequency of lows by HI subtype.

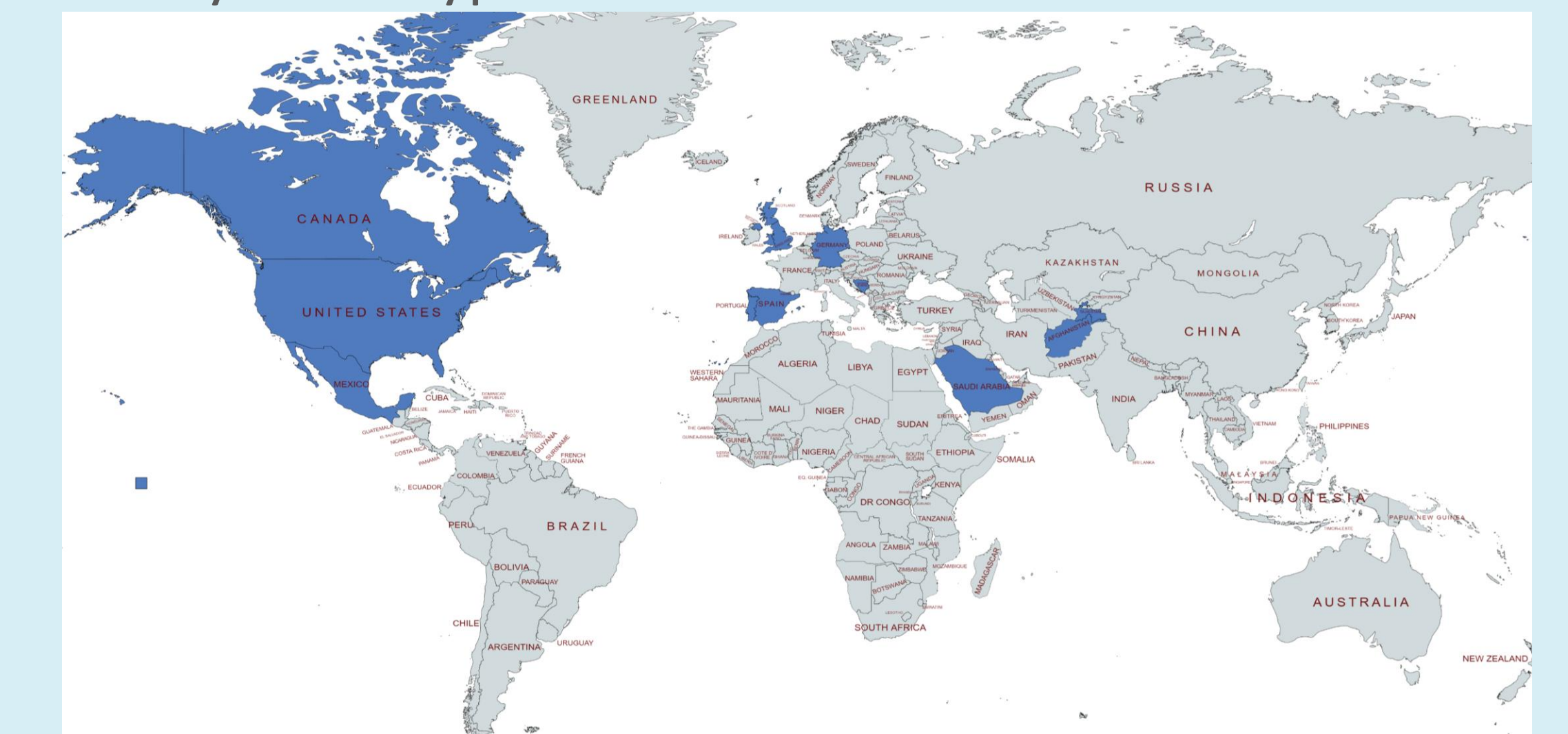


Figure 1: Countries Represented in this sample

Secondary Diagnoses

- 90 individuals in this data set answered questions about secondary diagnoses.
- The most common secondary diagnoses were GE reflux (12), heart-related condition (12), epilepsy (11), and asthma (6)

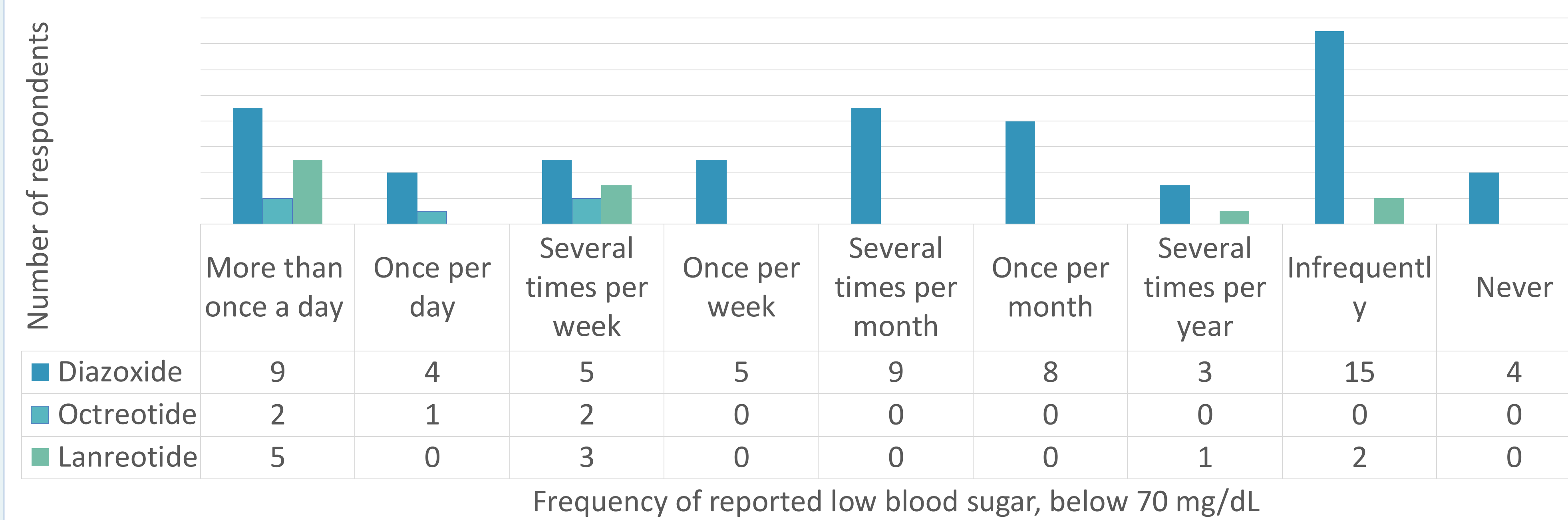
Conclusions

Even individuals on medications for HI or who are feeding frequently still experience episodes of hypoglycemia. However, none of the results were statistically significant by group.

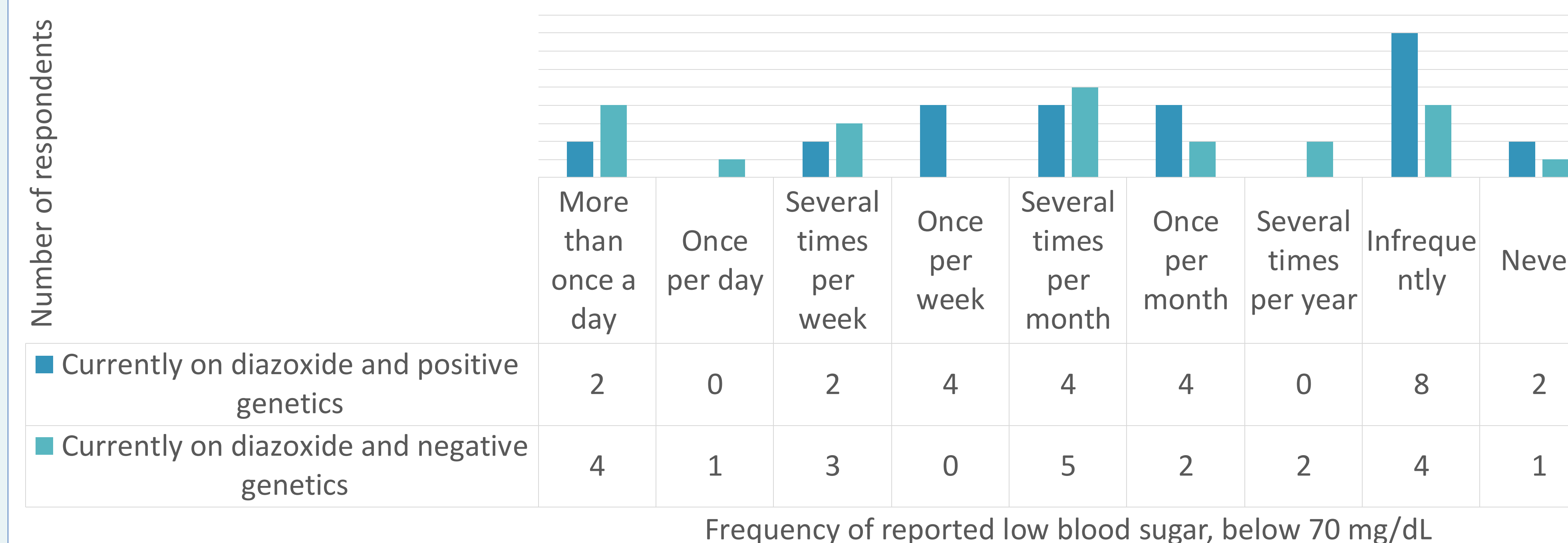
This speaks to the unmet need for better HI medications and more effective strategies to manage frequent lows.



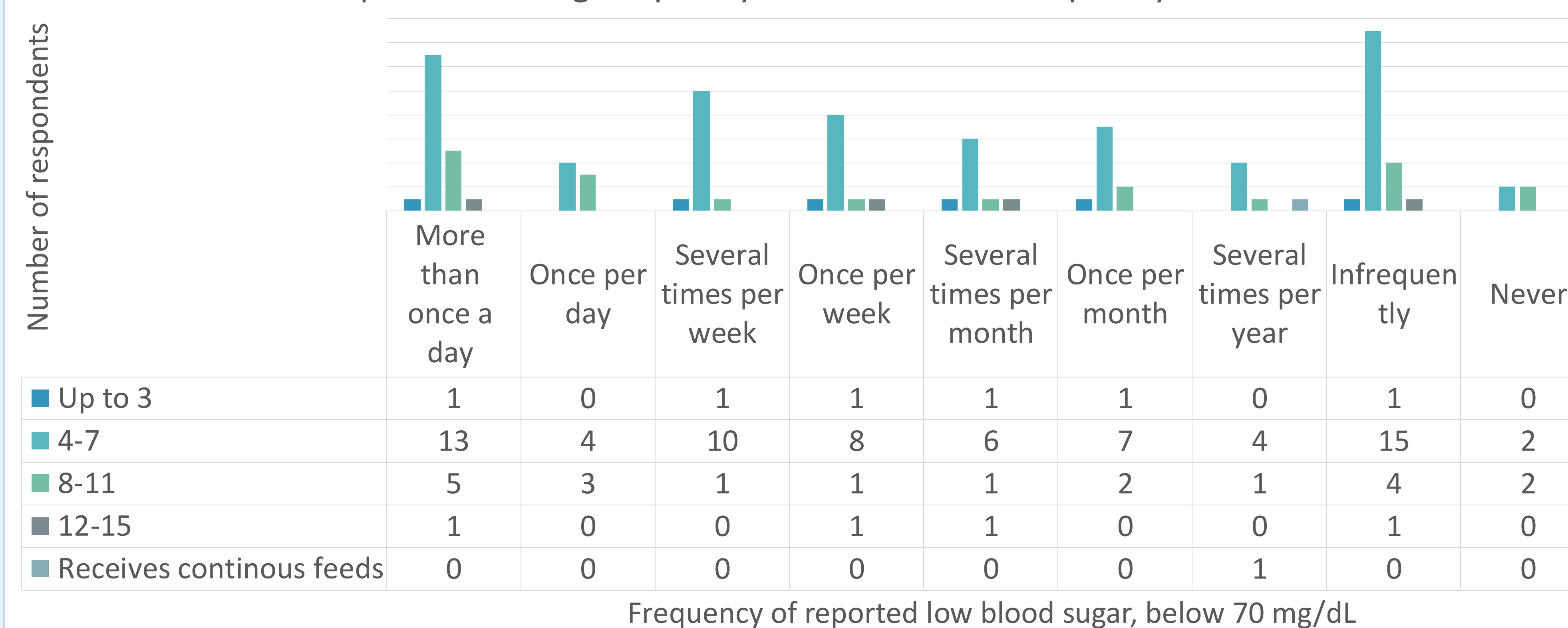
Reported frequency of lows and current medication use



Frequency of lows for individuals currently taking diazoxide by genetic results



Reported feeding frequency in 24 hours and frequency of lows



Frequency of lows for those continuously using a CGM

