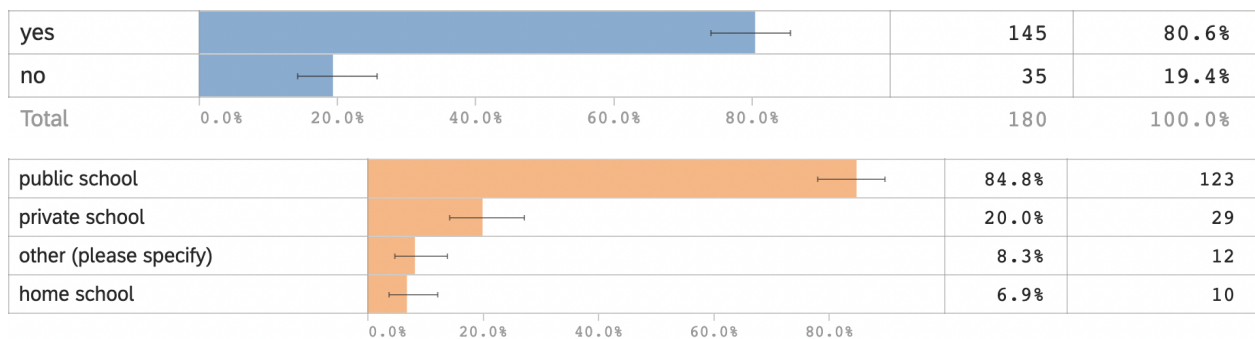


## Collective Voices in Gut1 Deficiency Project Survey – Report

The Glut1 Deficiency Collective Voices Project was designed to have a better understanding of the patient and family experience across a broad range of areas. The goals for the survey were to better define the range of symptoms, identify gaps in treatment and patient care, identify the gaps in knowledge and understanding of this disease, better understand disease burdens, identify the most important components of a future natural history study, develop and prioritize a patient-led strategic research plan, and to develop better and more effective clinical trials for potential future treatments.

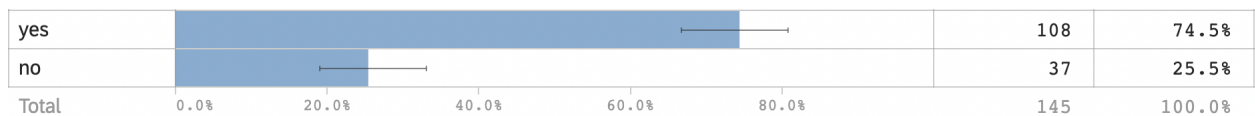
This time we are reporting the section about **School & Learning**.

### 1. Have you attended school?



80% of our patients report having attended school, with the vast majority attending public school as opposed to private or homeschool.

### 2. Have you received special education services?



Of those that have attended school, the majority (75%) have received special education services.

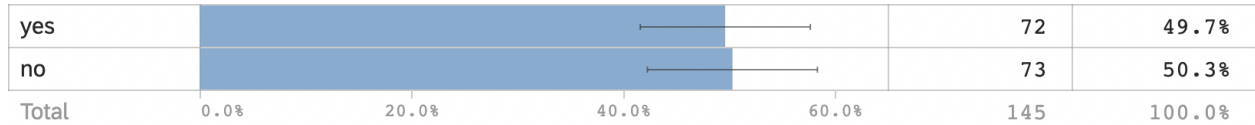
### 3. Have you consistently performed academically at grade level?



Although the majority of respondents do not report consistently performing academically at grade level, around 30% do. This further highlights the cognitive variability seen in Glut1

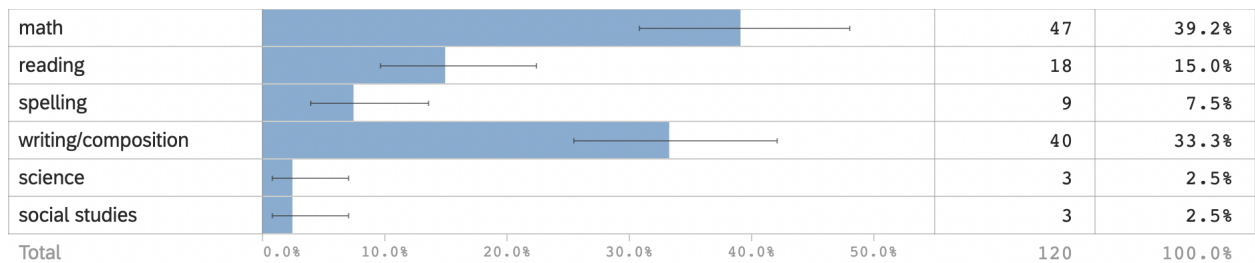
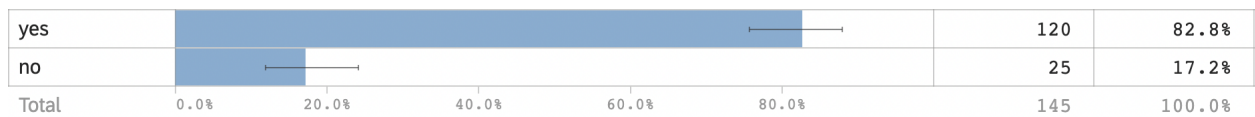
patients. Interestingly, these percentages weren't affected by different types of diet or the presence of SLC2A1 gene mutation.

**4. Has there been a full time nurse in your school?**



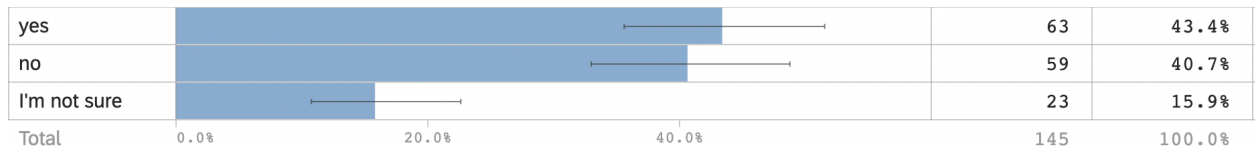
The availability of a full time nurse in schools was mixed among our respondents, with 50% having one and 50% not.

**5. Have certain subjects in school been more difficult than others?**



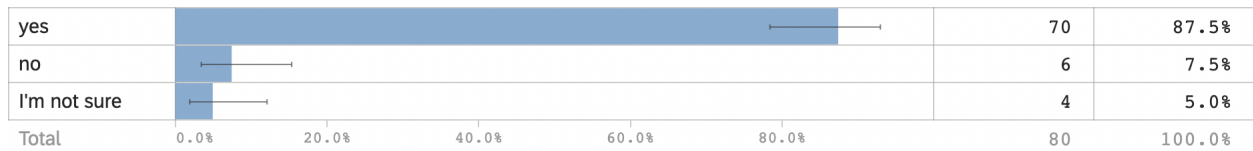
The majority of respondents feel that certain subjects- particularly math and writing/composition- caused the most difficulty. Science and social studies, on the other hand, were found to be the least difficult subjects.

**6. Have you had difficulty finding a good curriculum fit in the school program (level of support, level of difficulty, individualized enough, challenging enough, etc.)?**



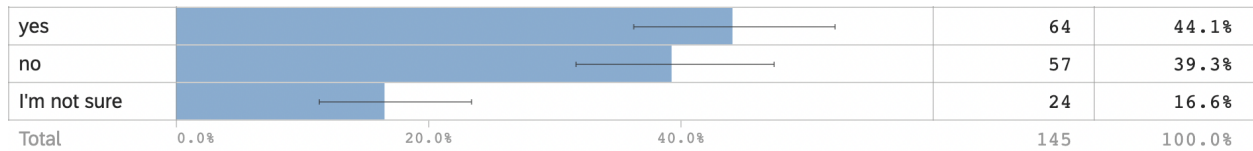
The ability to find a good curriculum fit in school has been split among our respondents, with 43% reporting difficulties. This shows the need there is among the Glut1 community for a better schooling environment that fosters success.

### 7. Have you had neuropsychological testing?



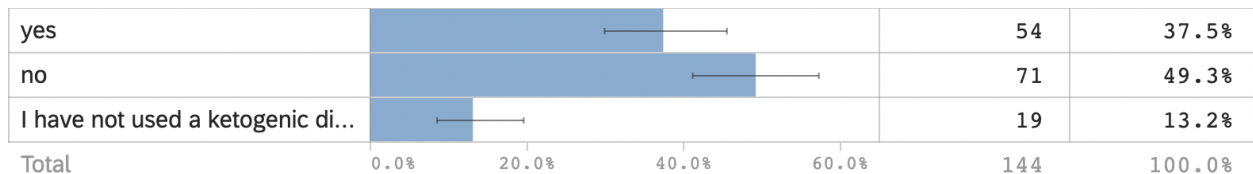
The majority of respondents have had neuropsychological testing which did reveal deficits in learning and memory, visual-spatial, and motor function.

### 8. Have you been given an IQ score?



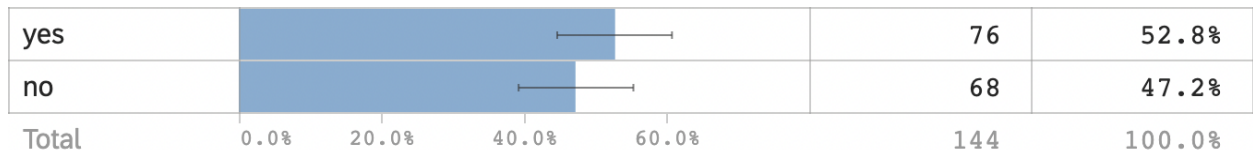
44% of our respondents have been given an IQ. These IQ scores ranged from 36-112, with an average score of 76 and a mode of 55.

### 9. Have you had difficulties with ketogenic diet implementation/management while at school?



Of those who have used a ketogenic diet at school, the majority have not experienced difficulties with implementation/management while at school

### 10. Have you had difficulties meeting the energy demands of attending school?

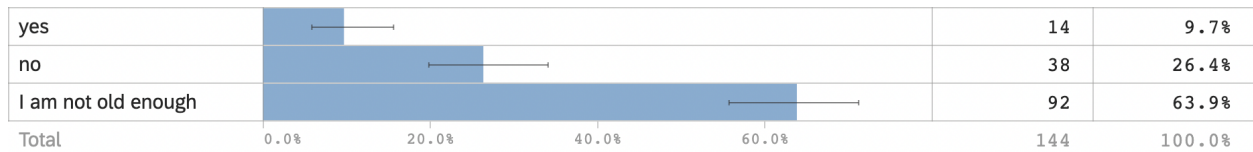


53% of respondents have reported difficulties meeting the energy demands of attending school. Of those that did not report difficulties with energy demands, 56% were on the ketogenic diet, 31% were on a modified ketogenic diet, 14% were on modified atkins diet, and 12.5% were on MCT ketogenic diet.

**11. Have you been happy with your overall school experience?**

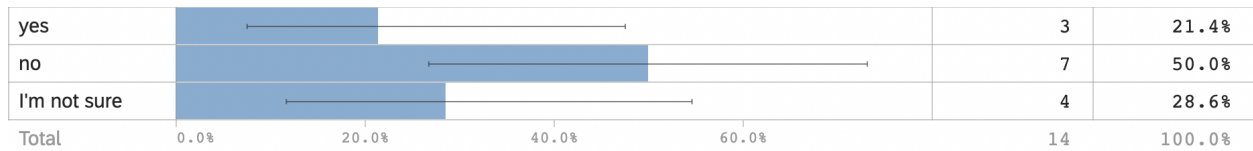
On a scale from 1-10, the average was 7 when reporting happiness with overall school experience. Individualized Education Programs (IEP), One-on-One assistance, speech therapy, and occupation therapy provided by school were the most beneficial programs reported by our respondents.

**12. Did you attend college or vocational school?**



Of those respondents old enough to attend college or vocational school, only 10% have.

**13. Did you receive vocational rehabilitation or similar services?**



The majority of respondents did not report having received vocational rehabilitation or similar services.