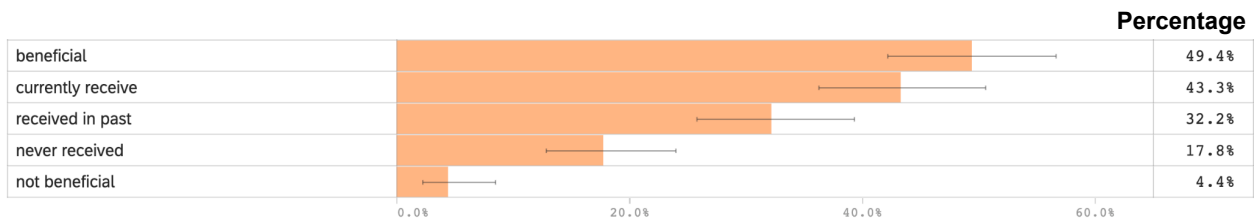


Collective Voices in Gut1 Deficiency Project Survey – Report

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 **Therapies**. n=180

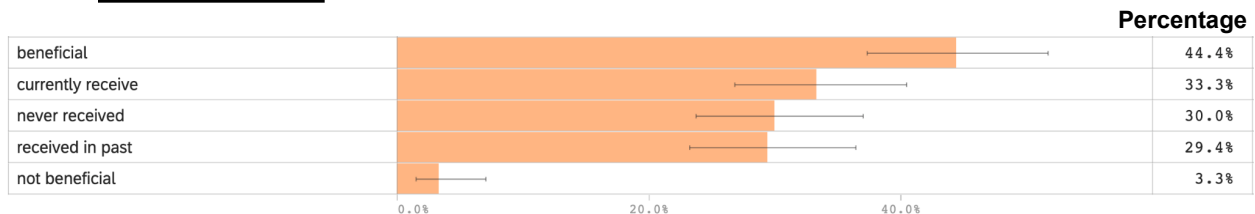
1. Have you ever received Speech/language therapy? If so please indicate whether it was beneficial or not.



43% of our surveyors are currently receiving speech/language therapy, while 32% have received this type of therapy in the past. 49% of the people either currently receiving speech therapy or who have received it in the past report that this type of therapy is beneficial, while only 4% report it not being beneficial. Interestingly 17% of surveyors report never receiving this type of therapy.

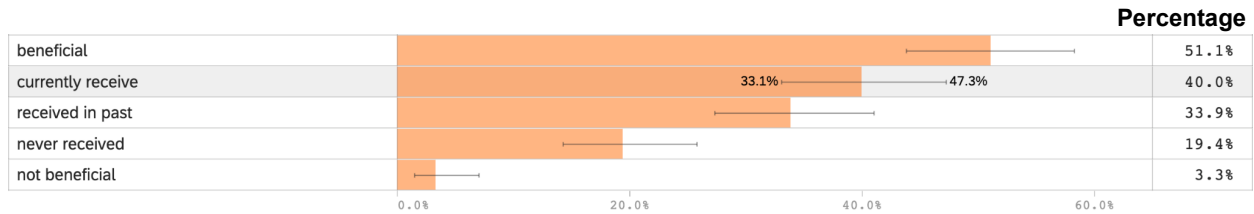
Speech/language difficulties is one of the top three symptoms patients and families report as having a negative impact on their quality of life.

2. Have you ever received occupational therapy? If so please indicate whether it was beneficial or not.



33% of our surveyors are currently receiving occupational therapy, while 29% have received this type of therapy in the past. 44% of the people either currently receiving occupational therapy or who have received it in the past report that this type of therapy is beneficial, while only 3% report it not being beneficial. The percentage of surveyors not receiving this type is 30%, much higher than the percentage of surveyors never receiving Speech/Language therapy.

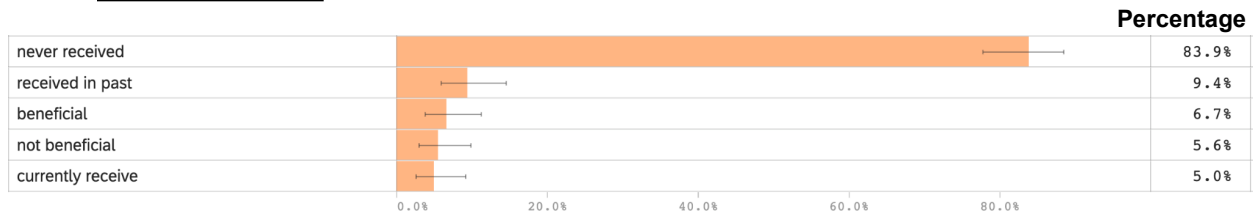
3. Have you ever received physical therapy? If so please indicate whether it was beneficial or not.



The percentage of surveyors currently receiving physical therapy is 40%, while the percentage of surveyors who have received this type of therapy is in the past is 34%. Most of them (51%) have also reported that occupational therapy is beneficial, while 3 % report it as not being beneficial.

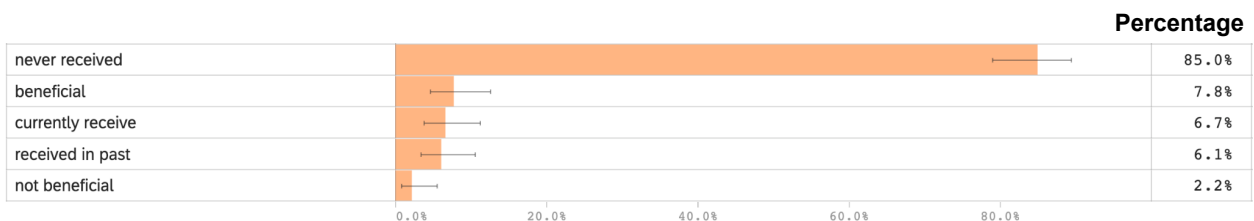
The percentage of surveyors never receiving occupational therapy is 19%.

4. Have you ever received chiropractic therapy? If so please indicate whether it was beneficial or not.



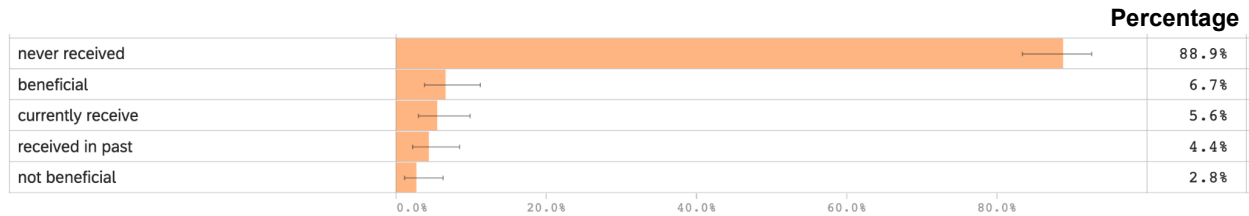
The great majority of our surveyors (84%) have never received this type of therapy. On the other hand, only 5% are currently receiving this therapy and 9% has received it in the past. From this group, 7% report this type of therapy as being beneficial while 6% report it as not being beneficial. This result makes it difficult to conclude whether this type of therapy is beneficial or not to our patients.

5. Have you ever received behavior therapy? If so please indicate whether it was beneficial or not.



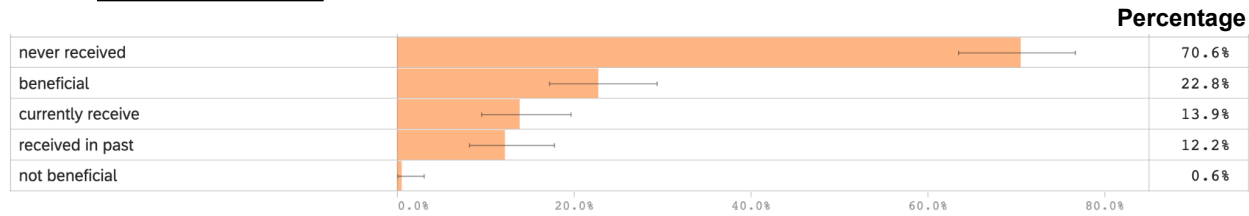
Most of the surveyed people (85%) report to never received behavior therapy. Currently, 7% of surveyors receive this type of therapy, while 6 % report to have received it in the past. From this group, 8% report behavior therapy as being beneficial, while 2% report not being beneficial.

6. Have you ever received vision therapy? If so please indicate whether it was beneficial or not.



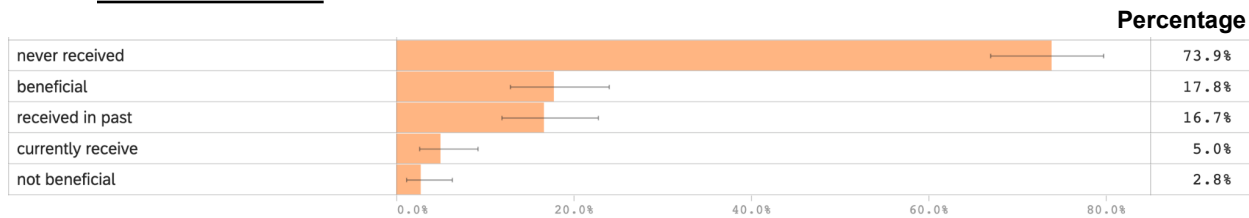
Most of the surveyed people (89%) report having never received vision therapy. Currently, 6% of surveyors receive this type of therapy, while 4% report to have received it in the past. From this group, 7% report vision therapy as being beneficial, while 3% report not being beneficial.

7. Have you ever received hippotherapy (horses)? If so please indicate whether it was beneficial or not.



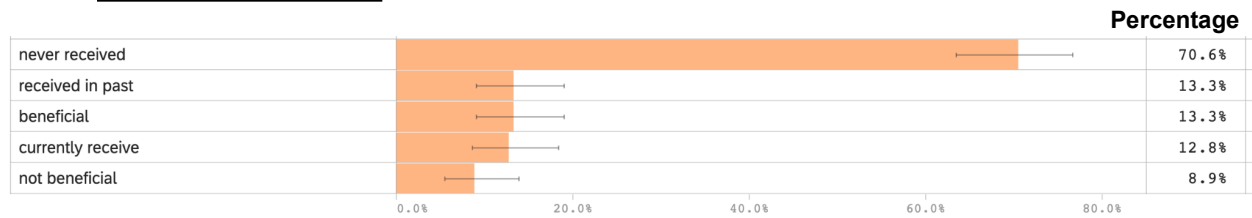
71% of our surveyors have never received hippotherapy, while 14% are currently receiving this type of therapy and 12% have received it in the past. 23% of the people who are either currently receiving hippotherapy or who have received it in the past report that this type of therapy is beneficial, while only 1% report it not being beneficial.

8. Have you ever received aqua therapy (water)? If so please indicate whether it was beneficial or not.



74% of our surveyors have never received aqua therapy, while 5% are currently receiving this type of therapy and 17% have received it in the past. 18% of the people who are either currently receiving aqua therapy or who have received it in the past report that this type of therapy is beneficial, while only 3% report it not being beneficial.

9. **Have you ever received psychotherapy/counseling? If so please indicate whether it was beneficial or not.**



Most of the surveyed people (71%) report to never received psychotherapy/counseling. Currently, 13% of surveyors receive this type of therapy, and 13 % report to have received it in the past. From this group, 13% report psychotherapy/counseling as being beneficial, while 9% report it not being beneficial.

OTHER THERAPIES???