

## My Sweet Sibling and I- A Capstone Project

Chloe Koeppen<sup>1</sup>, Jessica Rispoli, MS, CGC<sup>1</sup>, Julie Raskin, CEO<sup>2</sup>, Abby Turnwald, MS, CGC<sup>3</sup>, & Victoria Sanders, MS, CGC<sup>4</sup>

1. Rutgers Genetic Counseling Master's Program 2. Congenital Hyperinsulinism International 3. Cincinnati Children's Hospital Medical Center 4. Children's Hospital of Philadelphia

### BACKGROUND

- Congenital Hyperinsulinism [HI] is a rare genetic disorder where beta cells secrete too much insulin (1,4).
- This condition affects 1 in 25,000 babies annually and can result in hypoglycemia leading to seizures, brain damage, and even death (3).
- While those with HI face significant challenges, their siblings also experience unique difficulties such as emotional distress, adjustment problems, and taking on caregiver responsibilities (2,5).
- These challenges may be partly attributed to a lack of communication and understanding about HI within the family structure (6).
- This resource aims to help families navigate the complexities of genetic conditions, including providing support to siblings who may be struggling with their emotions.
- The ultimate goal of this project is to publish this book as a long-term resource for anyone in the HI community, including CHI and clinics treating patients with HI.

### REFERENCES

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### METHODS

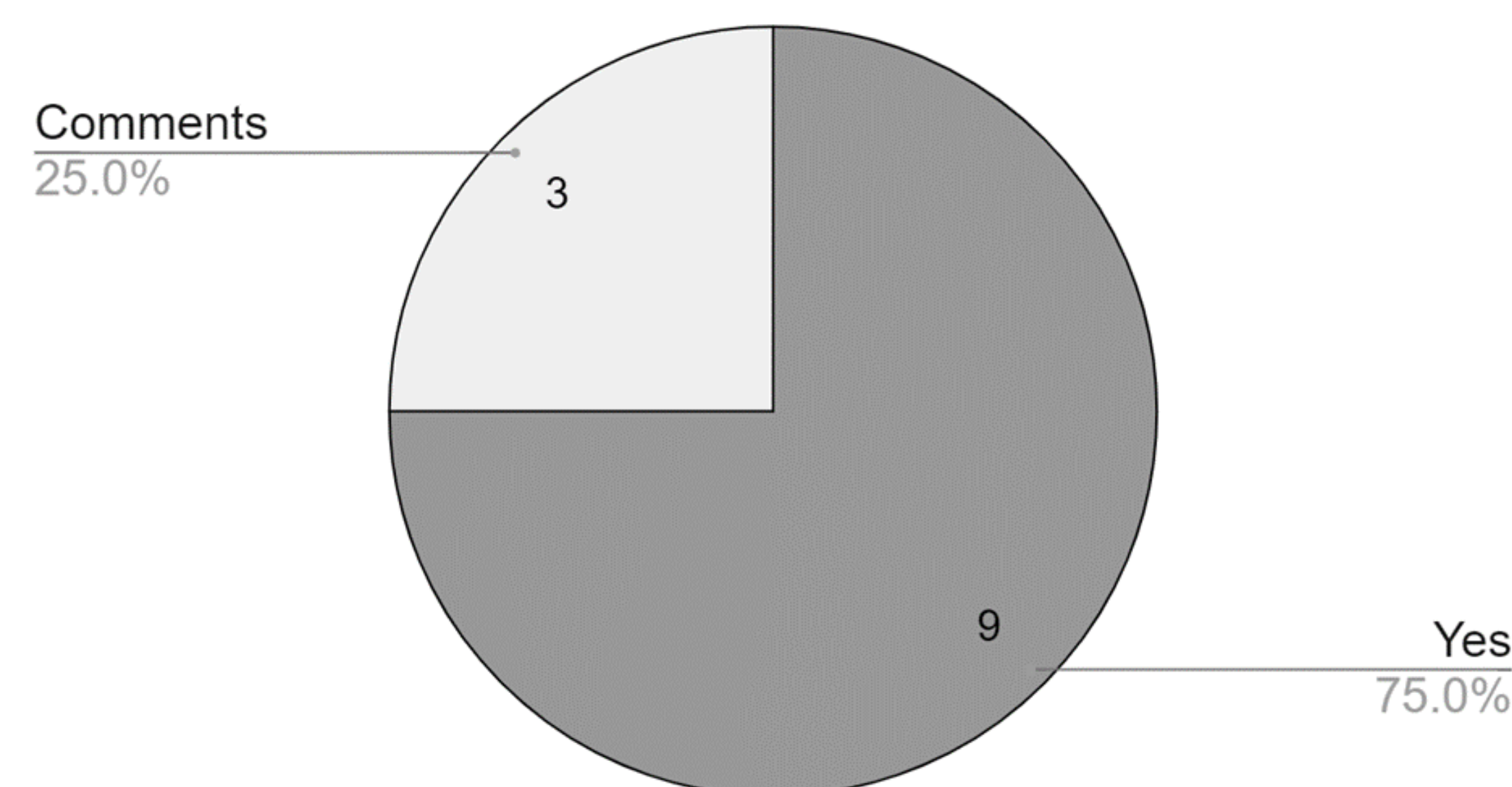
- The children's book is 25-facing pages long and was based on a literature review, CHI conference, and relevant webinars.
- To evaluate its effectiveness, 12 participants were provided with the storyline and asked to complete a Qualtrics survey to assess if the material was satisfactory.
- Participants were recruited from a leading nonprofit organization known as Congenital Hyperinsulinism International.
- This feedback was utilized to inform appropriate modifications to the final product to ensure it is meeting the needs of its readers.

### RESULTS

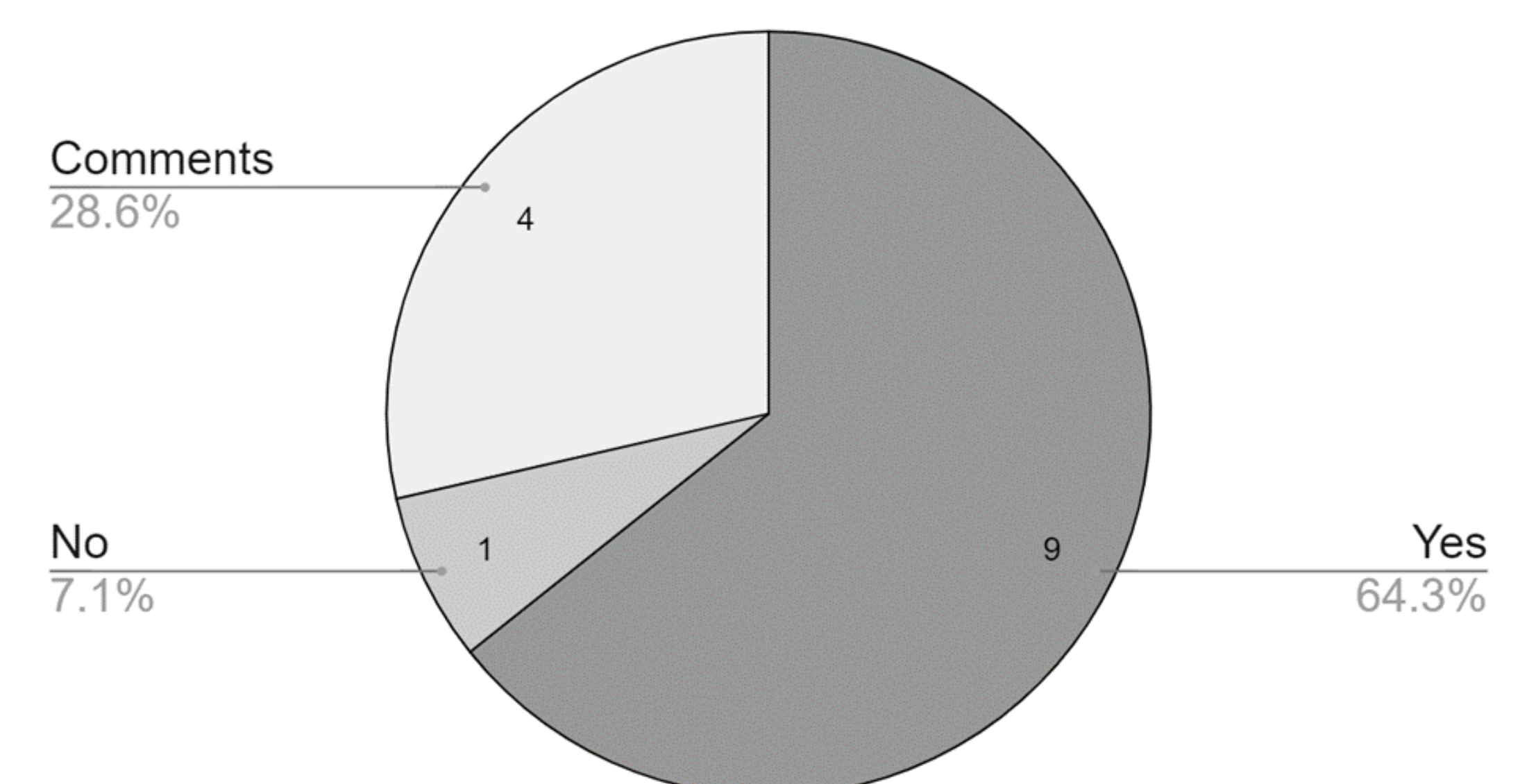
- The distribution metrics revealed a 70% response rate.
- Q1 received 9 responses of "Yes" and 3 responses of "Comments". Of note, the "Comment" responses all marked Q1 as "Yes".
- Q2 received 9 responses of "Yes", 1 response of "No", and 4 responses of "Comments". One participant selected both "Yes" and "No" for their response. Three participants selected both "Yes" and "Comments".
- The results indicated that the book met the project's stated goals, and we believe it will be a beneficial tool for families seeking to foster healthy relationships between children with genetic conditions and their siblings.

### QUALTRICS SURVEY RESPONSES

Q1 - Was this material satisfactory in helping demystify the disease for siblings in order to maintain healthy relationships with those with HI?



Q2 - Was the material satisfactory in helping educate children on congenital hyperinsulinism?



### CONCLUSIONS

- Based on the feedback gathered from our survey participants, it was clear that this resource was highly valued.
- The majority, if not all, of the survey respondents expressed gratitude and recognized the value of the children's book in demystifying the disease, which helps siblings maintain healthy relationships, and educating them on HI. I am confident in concluding that our research goal for this project has been achieved.
- Future Direction: One possibility is to expand our children's novels into a book series that addresses other important areas of a child's life, such as friendships or school.