

# **COVID-19 Experiences in Glut1 Deficiency**



COVID-19 EXPERIENCES IN GLUT1 DEFICIENCY

# Goals and Purposes

- **answer questions**
- **share concrete experiences**
- **help with decision-making ahead**



# Questions:

## Beginning of Pandemic:

- Are our patients at increased risk?
- Is Glut1 Deficiency an underlying condition?
- Are they more susceptible to contracting COVID-19?
- Should we be taking extra precautions?
- How will COVID-19 impact them if they get sick?
- Are they more likely to get severe illness if they do contract COVID-19?
- How does the ketogenic diet affect this?





# Questions:

## Beginning of Vaccine Rollouts:

- Should my child get vaccinated?
- How are other Glut1 patients handling the vaccines?
- Are there extra risks for side effects?
- Do the vaccines make Glut1 symptoms worse?
- Do the vaccines interfere with the diet?
- Are the experts recommending our patients get vaccinated?

**renewed questions now that younger children may soon be eligible**



# **Answers:**

## **come from patient experiences**

**a good time to ask**

- **COVID-19 has been here @ 20 months, vaccines @ 10 months**
- **Experienced multiple waves of cases in various seasons in various places**
- **Various phases and levels of precautions**
- **Various opportunities for exposure as more regular activities have returned**
- **New variants**



**Concerns:**

**"Glut1 is rare,  
COVID-19 is new."**

**the common theme**





# Concerns:

real and understandable

## Underlying Conditions: higher risk of severe illness

CDC list: neurological conditions, developmental disabilities

## Triggers: many noted symptom triggers in our community

Will COVID-19 illness trigger more Glut1 Deficiency symptoms?

Will vaccine side effects trigger more Glut1 Deficiency Symptoms?

## Keto Interference: impacts of sickness

Will illness or side effects interfere with being able to eat and maintain ketosis?

Will there be fallout?

not here to give medical advice - help provide you with information to make your decisions easier



# Patient/Family Results

**195 patient and family responses**

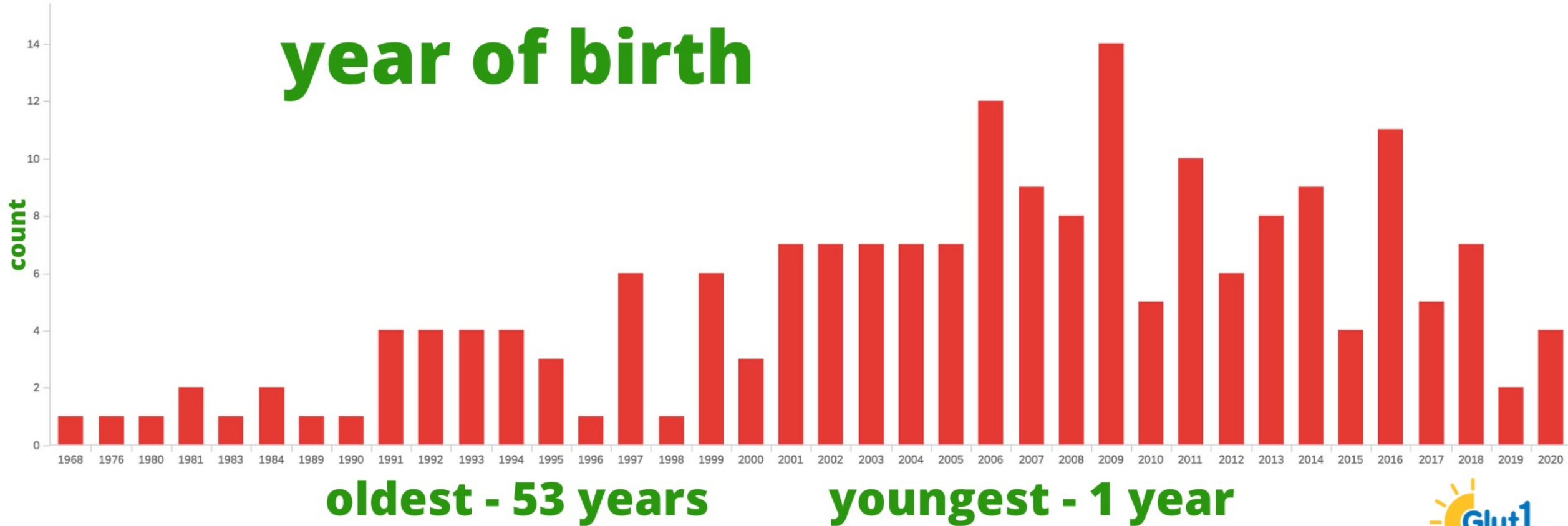


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# Patient Results

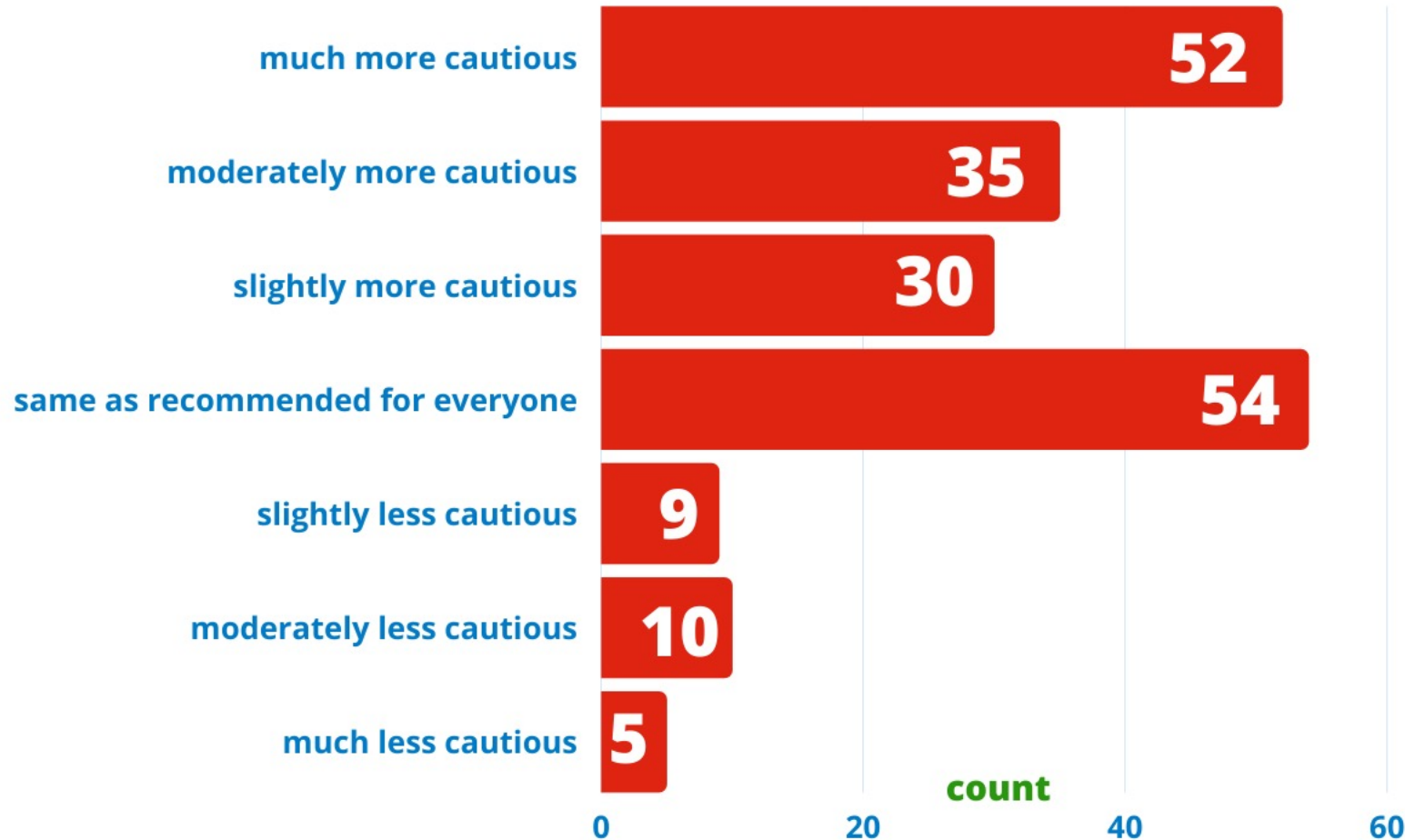
**year of birth**



# Patient Results

**precaution level compared to standard recommendations:**

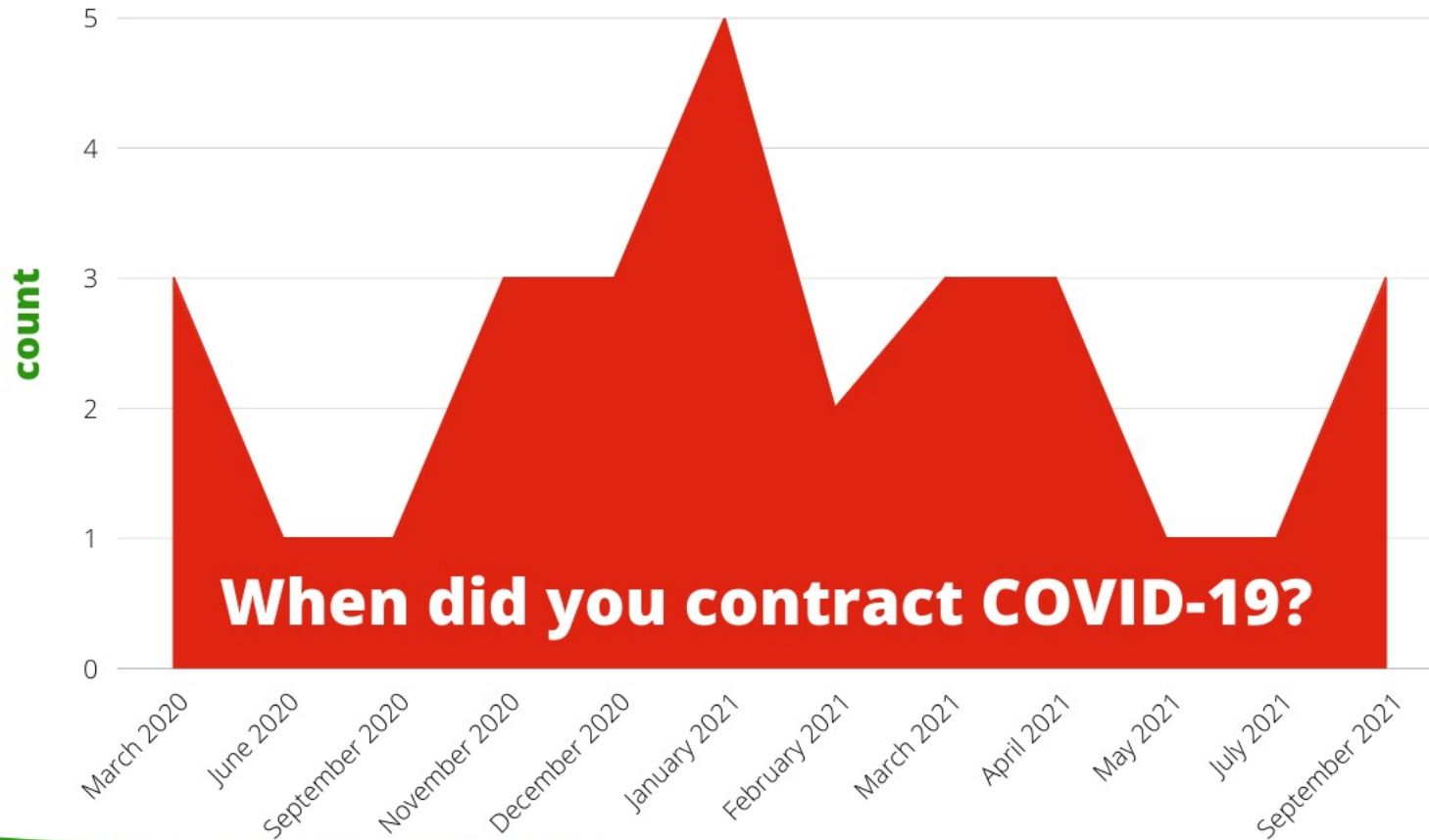
masking, social distancing, hand washing, etc.



- number of positive cases spread evenly across all levels of precaution taken
- stories shared about patients not contracting COVID-19 despite cases in multiple family members or classmates
- 11 patients reported additional underlying conditions, but none of those have contracted COVID-19



# Patient Results

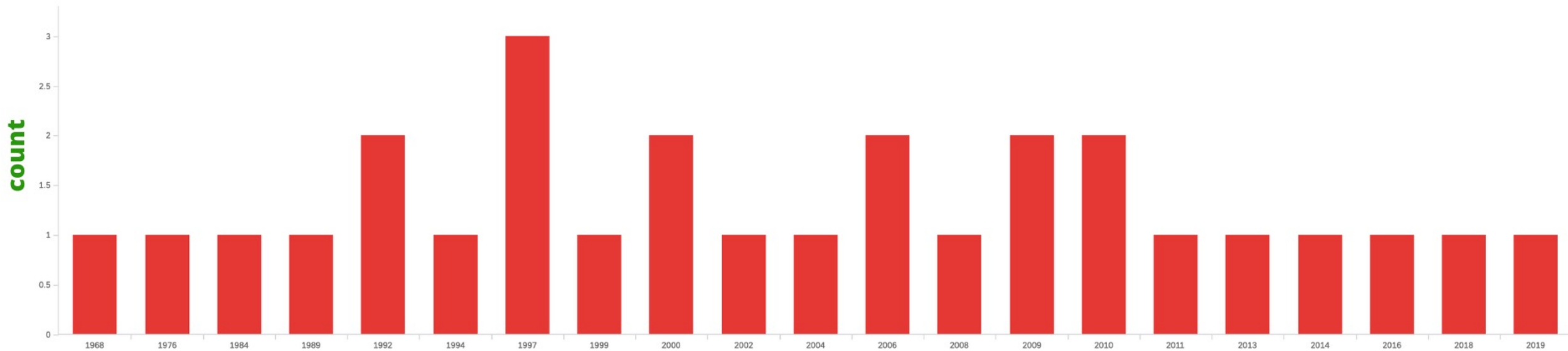


- **29 patients (15%) have tested positive for COVID-19**
- **none have had it more than once**
- **3 breakthrough cases after vaccination (Pfizer, mild illness)**



# Patient Results

ages of patients contracting COVID-19



year of birth

oldest - 53 years

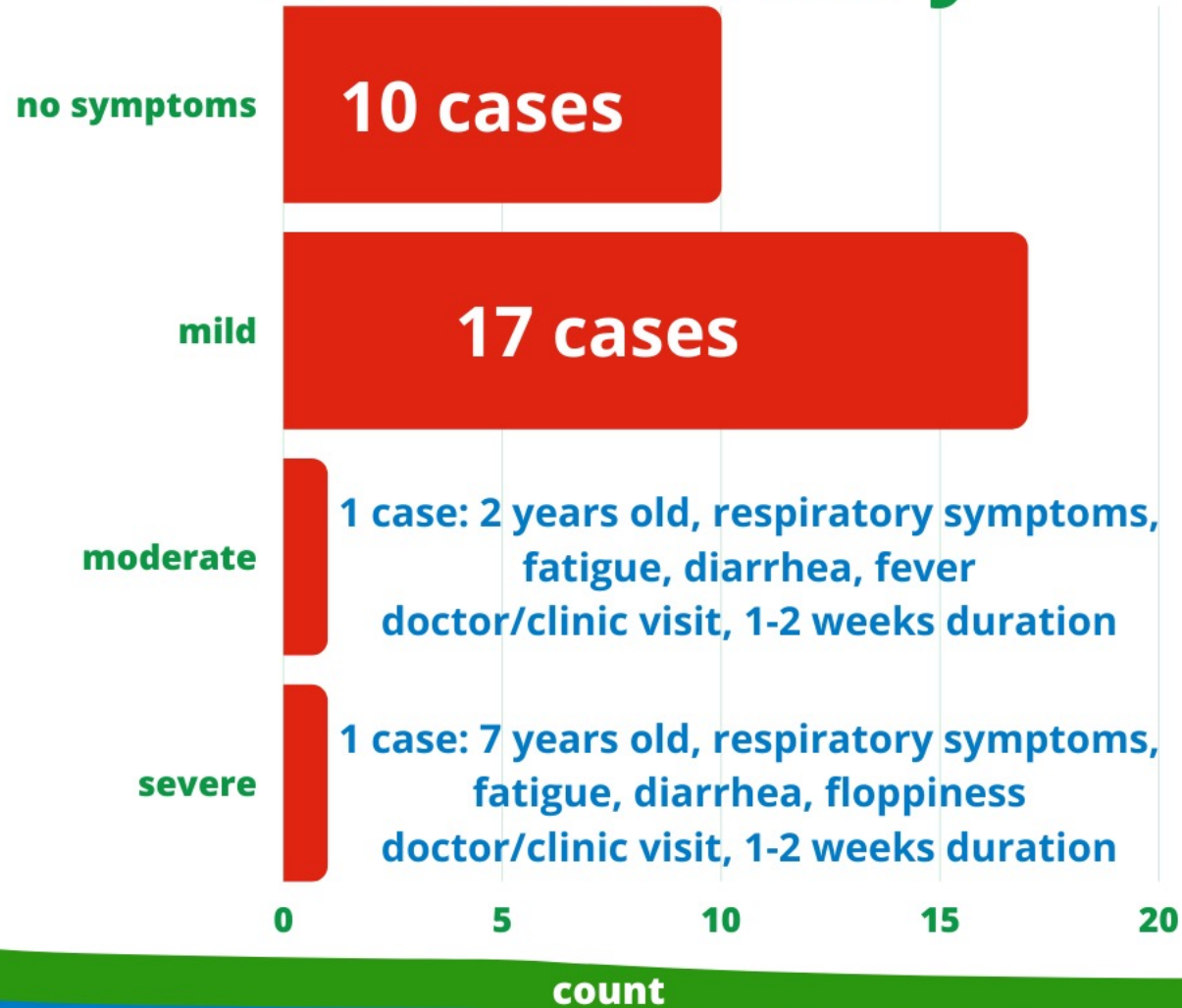
youngest - 2 years



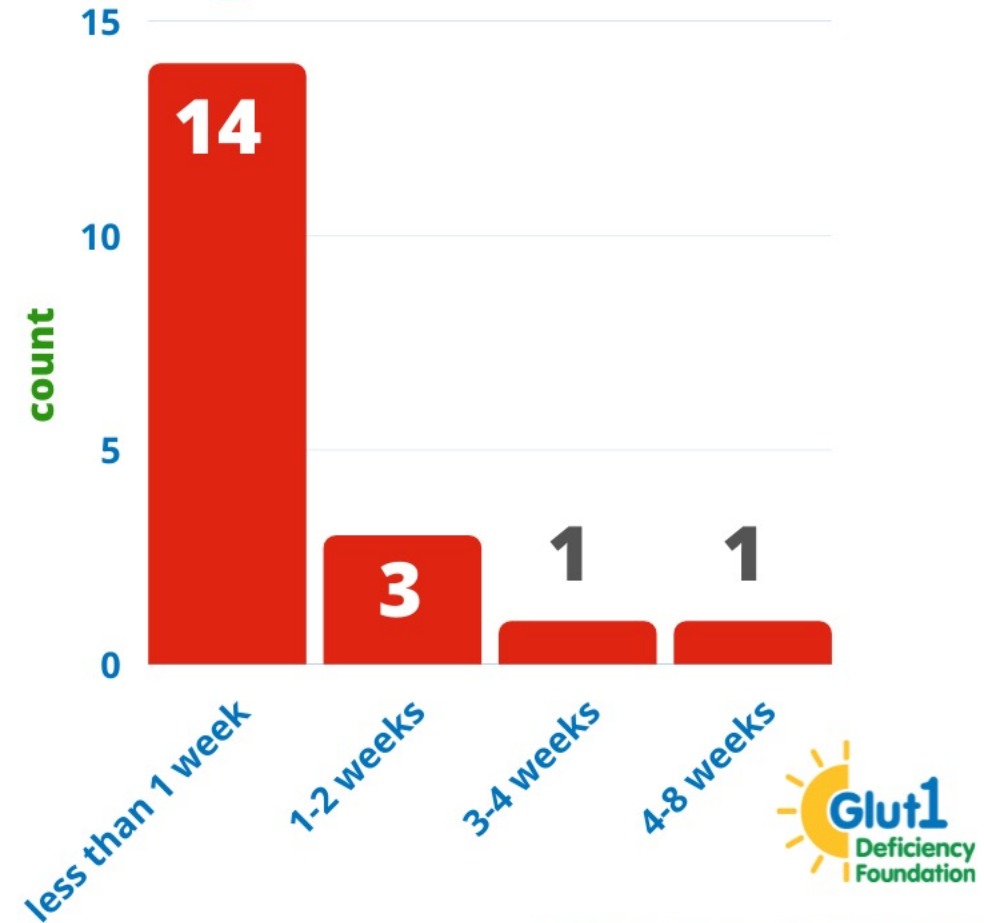
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# Patient Results

## illness severity

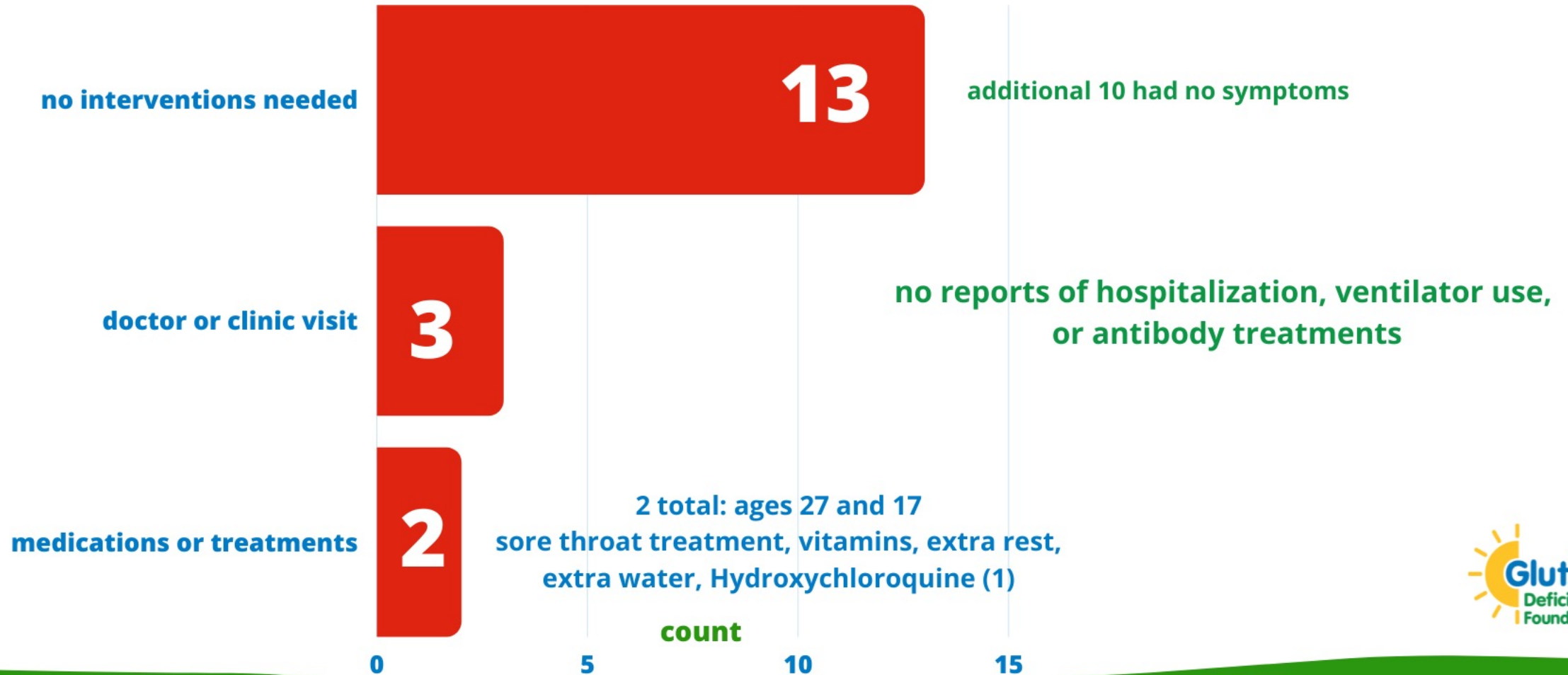


## length of illness



# Patient Results

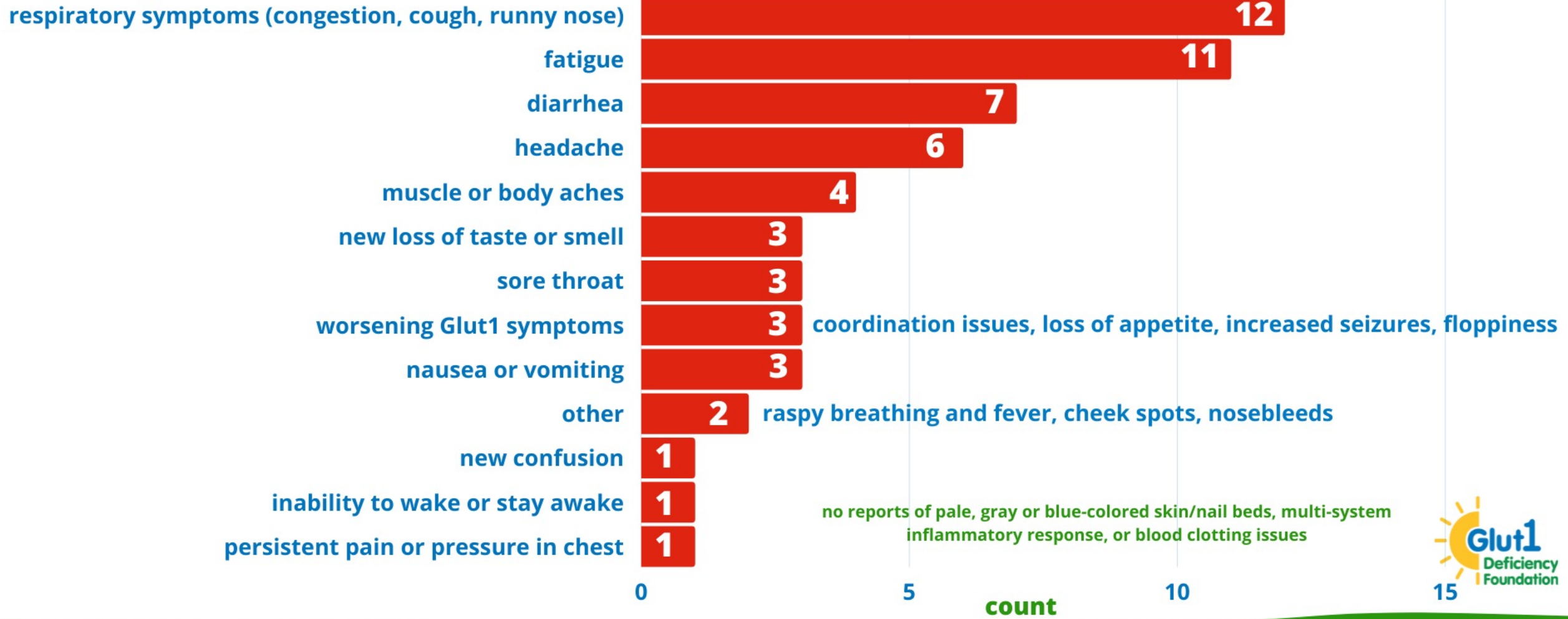
## interventions necessary





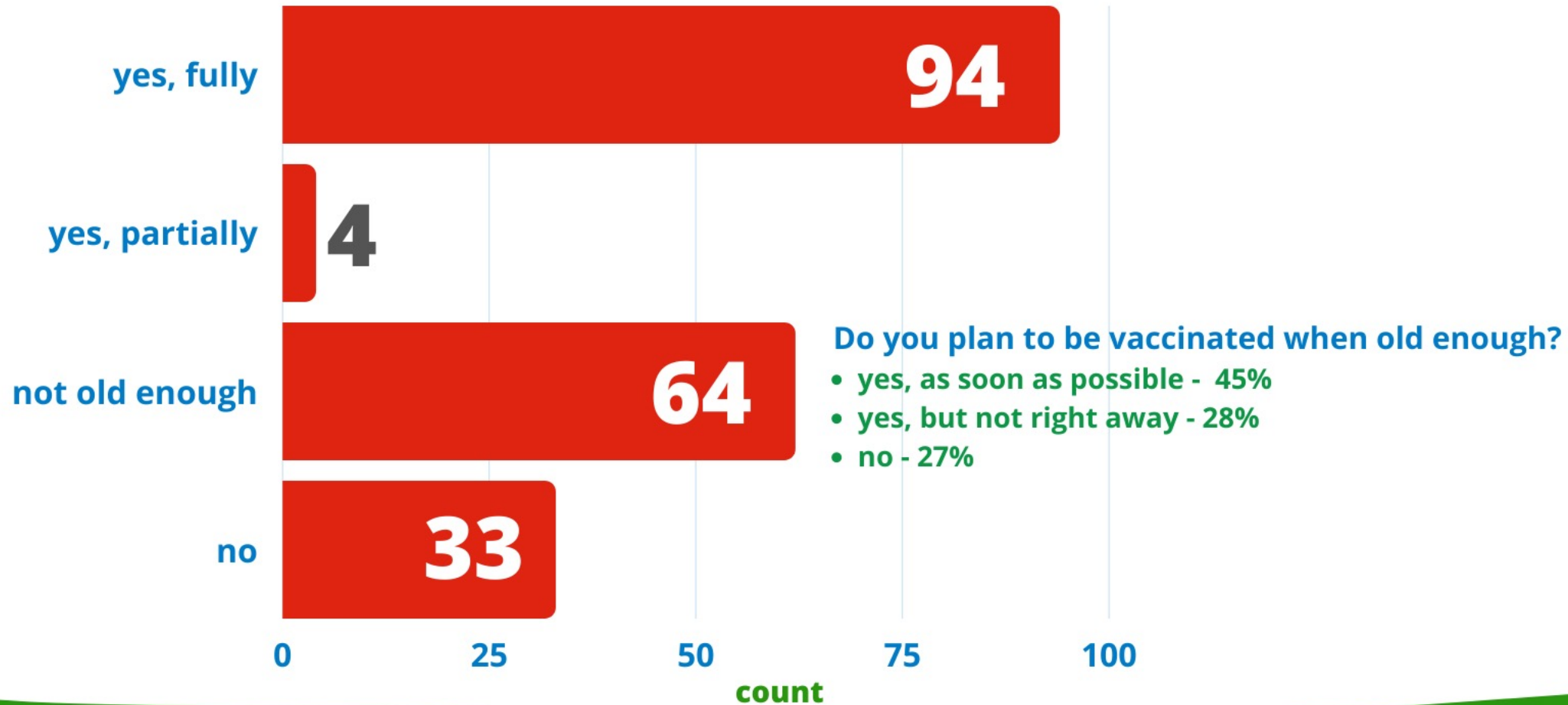
# Patient Results

## symptoms



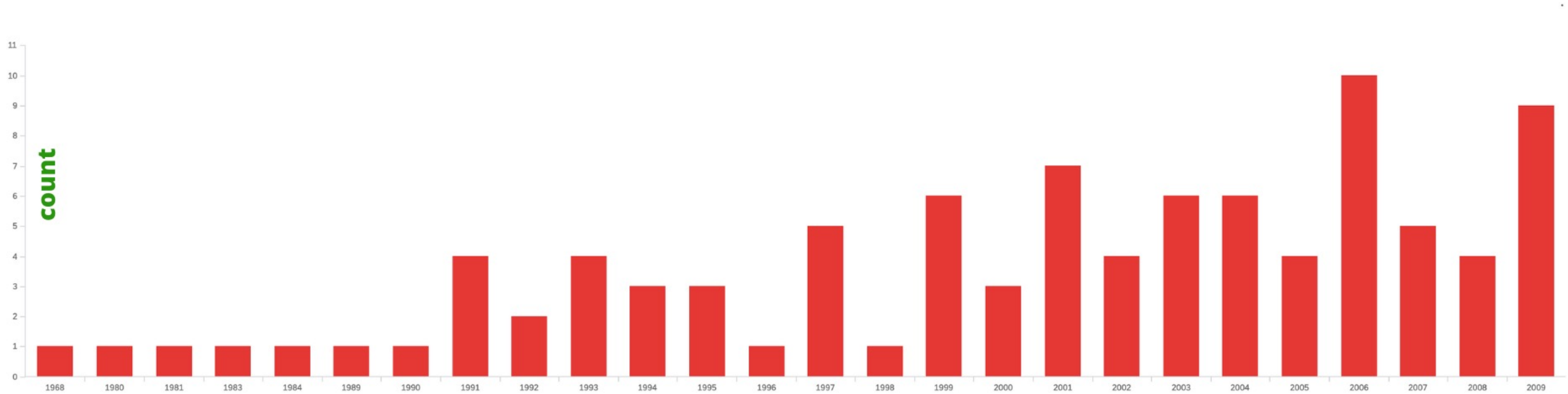
# Patient Results

## Have you been vaccinated?



# Patient Results

ages of patients receiving COVID-19 vaccine



year of birth

oldest - 53 years

youngest - 12 years

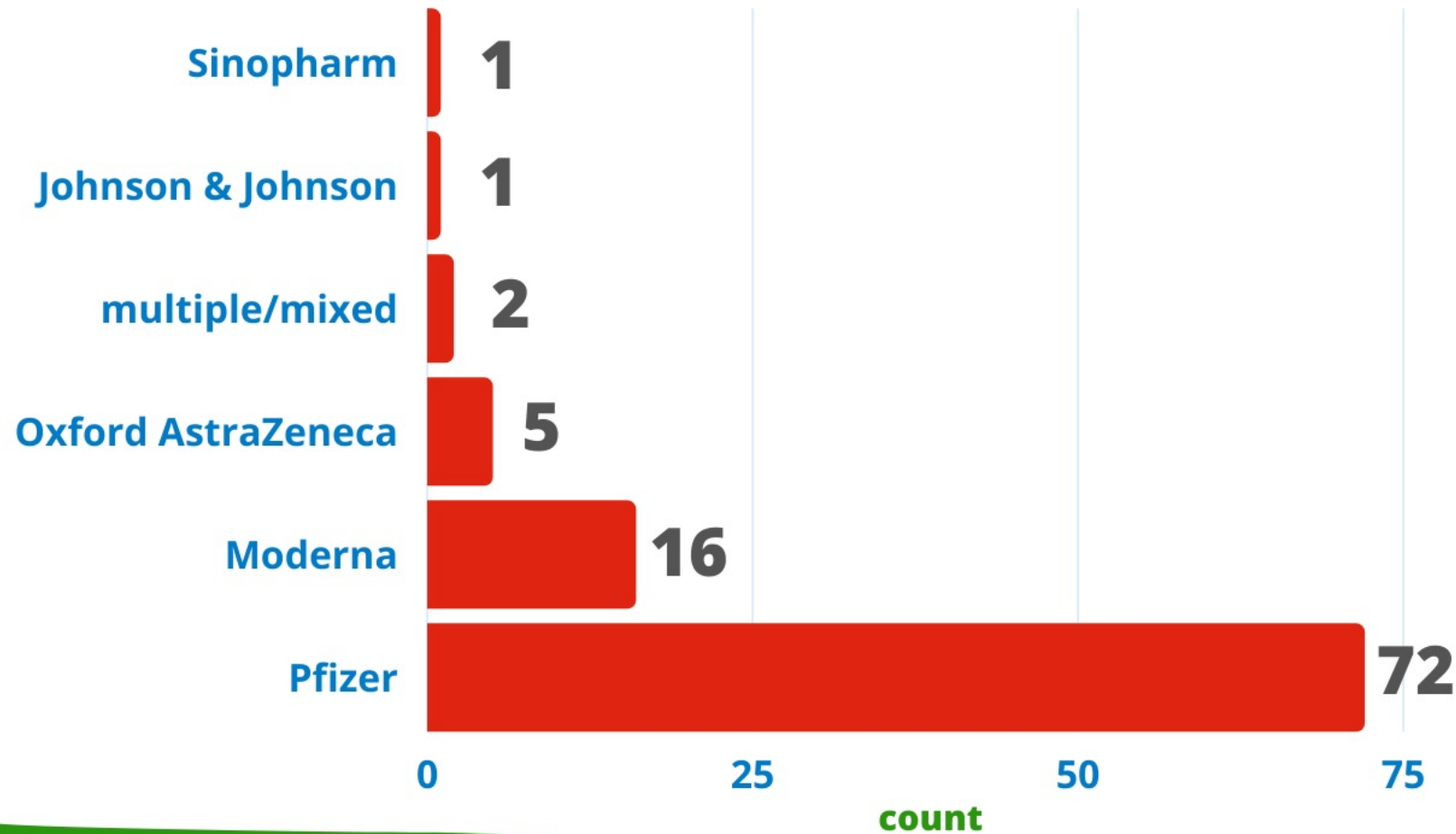


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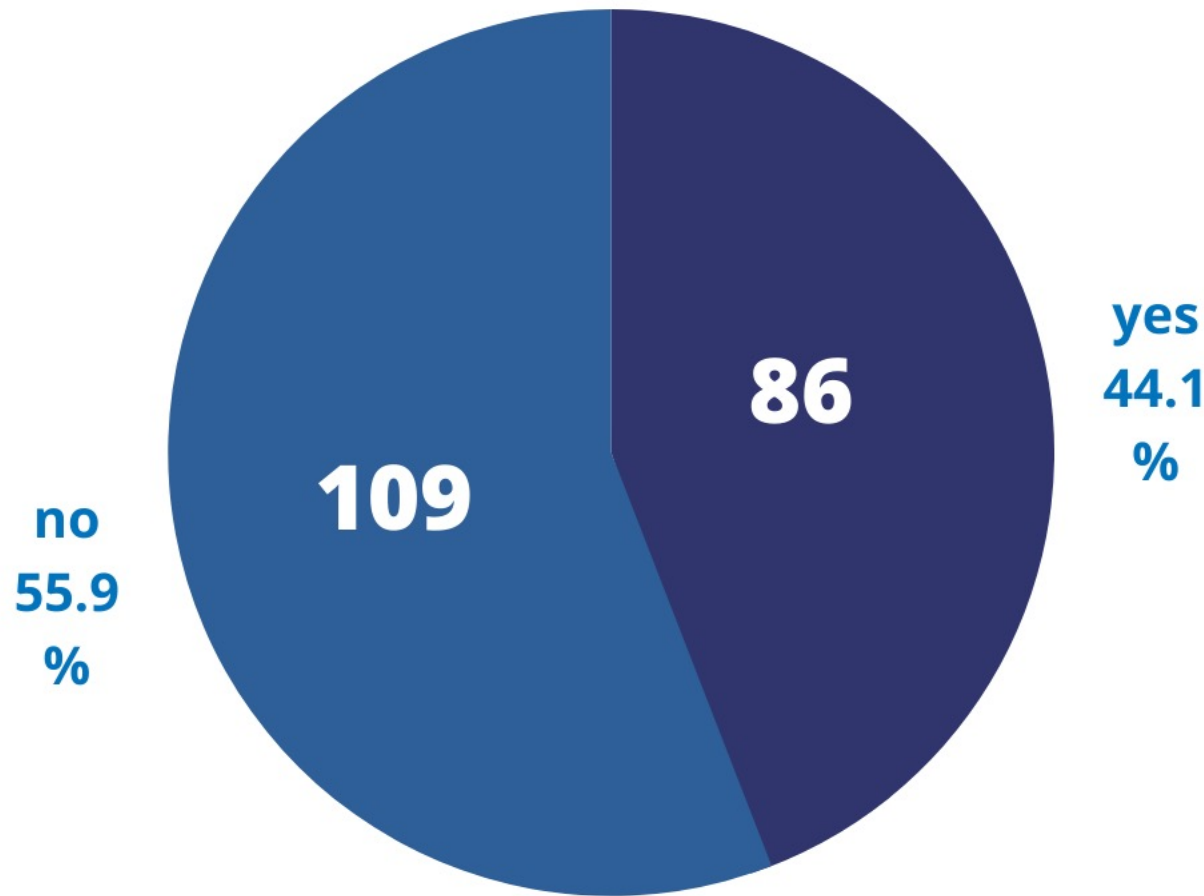
# Patient Results

## Brands of Vaccines Received



# Patient Results

**Did/do you have concerns about receiving the COVID-19 vaccine?**



## Types of Concerns:

- newness of vaccine
- unknown risks/side effects, including long term
- potentially trigger new Glut1 symptoms
- blood clotting
- previous vaccine reactions
- short testing time frame/fast development
- untested in Glut1 Deficiency

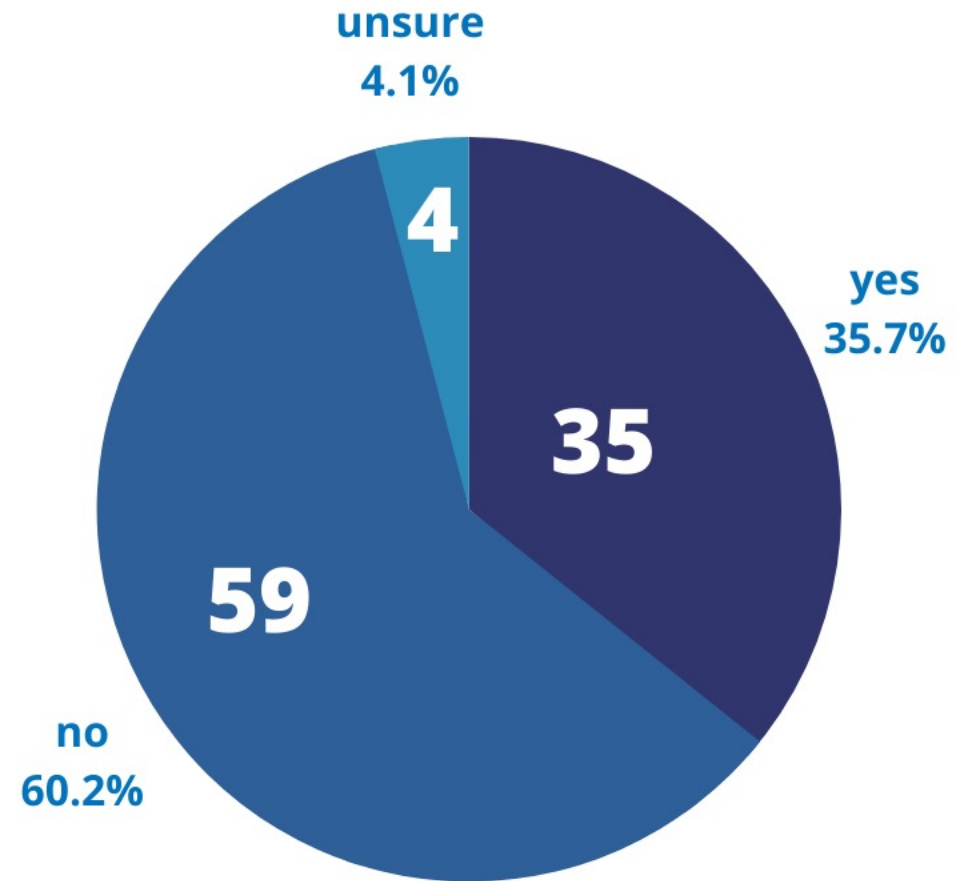
many with concerns still chose to get vaccinated or plan to when available for their age group



# Patient Results

## Did you have vaccine side effects?

- side effects were reported across different brands, 1st/2nd dose, and patient ages
- 14% also had reactions to other vaccines in the past
- 10 reported receiving booster shot and 19 plan to when eligible





# Patient Results

## reported vaccine side effects

myocarditis, pericarditis, blood clots, rash/hives, anaphylaxis

no reports

other

3

hot/cold at same time - 1, neck pain - 1, menstrual cycle irregular -1

increased or worsening Glut1 symptoms

3

chills

4

nausea

4

muscle pain

8

fever

10

headache

15

tiredness/fatigue

23

vaccine site pain/redness/swelling

23

0

5

10

15

20

25

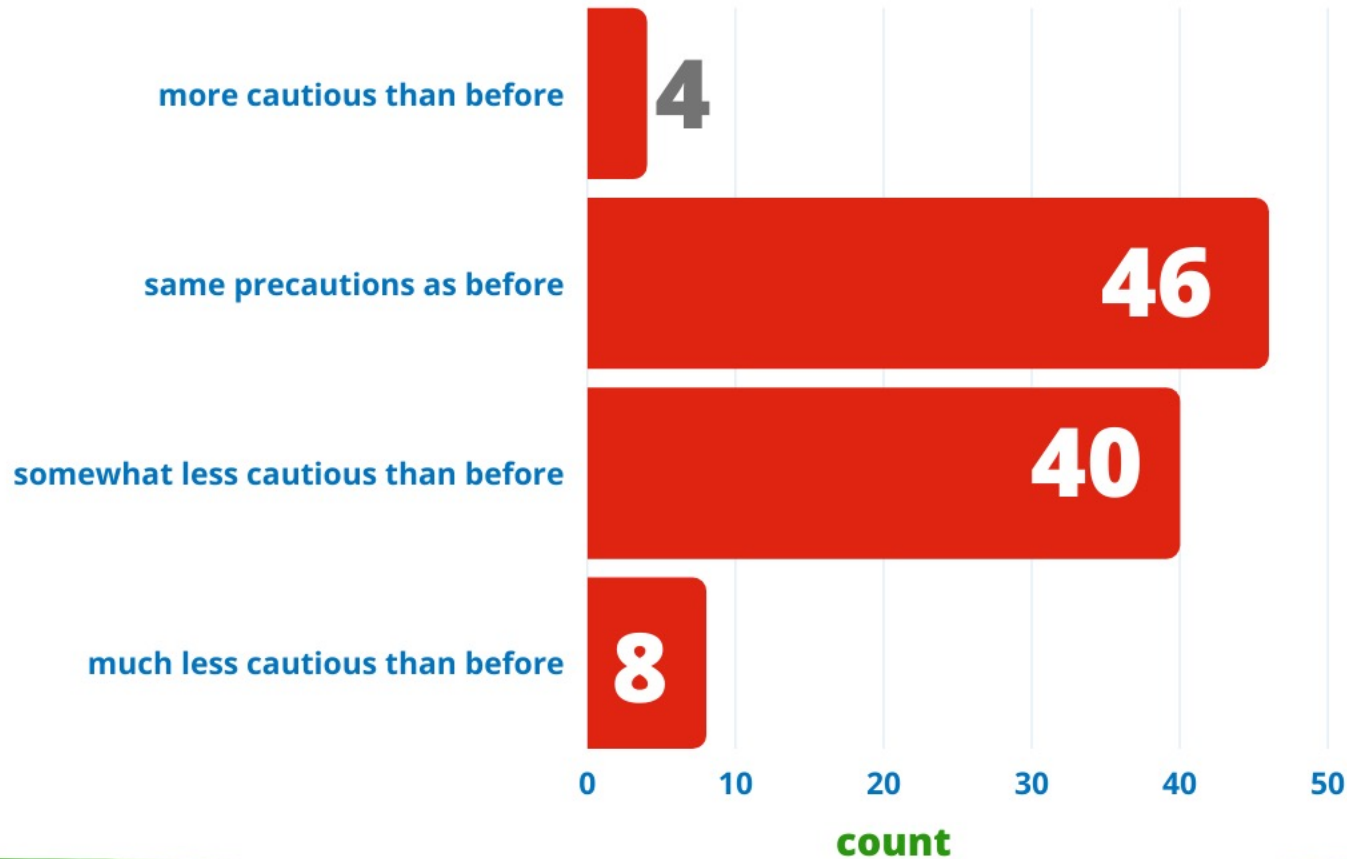
count



# Patient Results

## level of precaution after vaccination

masking, social distancing, hand washing, etc.



# Clinician Results

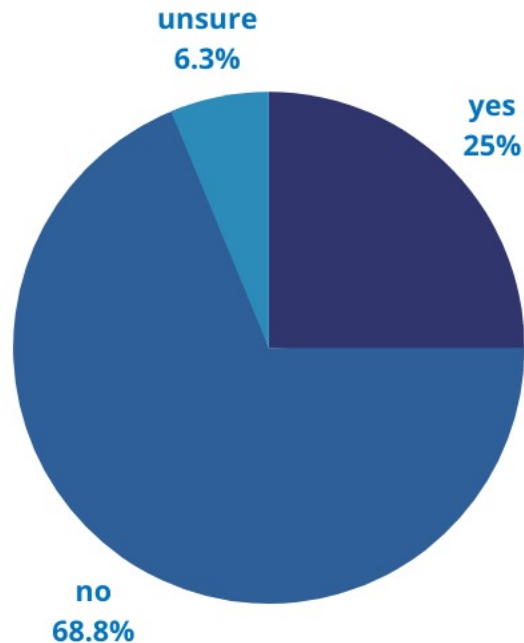
**16 clinicians representing 361 patients**  
**both pediatric and adult**





# Clinician Results

**Are you aware of any Glut1 Deficiency patients testing positive for COVID-19?**



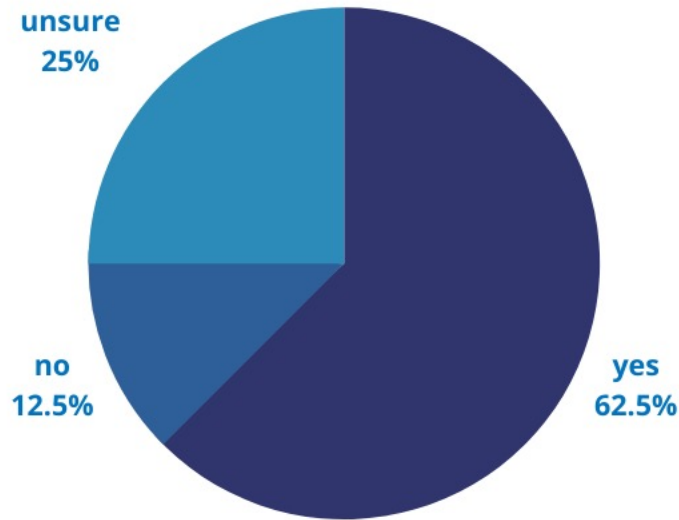
**total number of patients reported COVID-19 positive and severity level**

- 4 asymptomatic
- 4 mild illness
- 4 moderate illness
- 4 severe illness



# Clinician Results

**Have your Glut1 Deficiency patients  
received COVID-19 vaccines?**



**total number of patients reported with  
vaccine side effects**

- **3 moderate**  
(vaccination site pain, fever, irregular menstruation)
- **0 severe**
- **1 increased Glut1 symptoms**  
(dip in ketones and increased ataxia and dystonia)



# **Clinician Results**

## **experiences compared to general population**

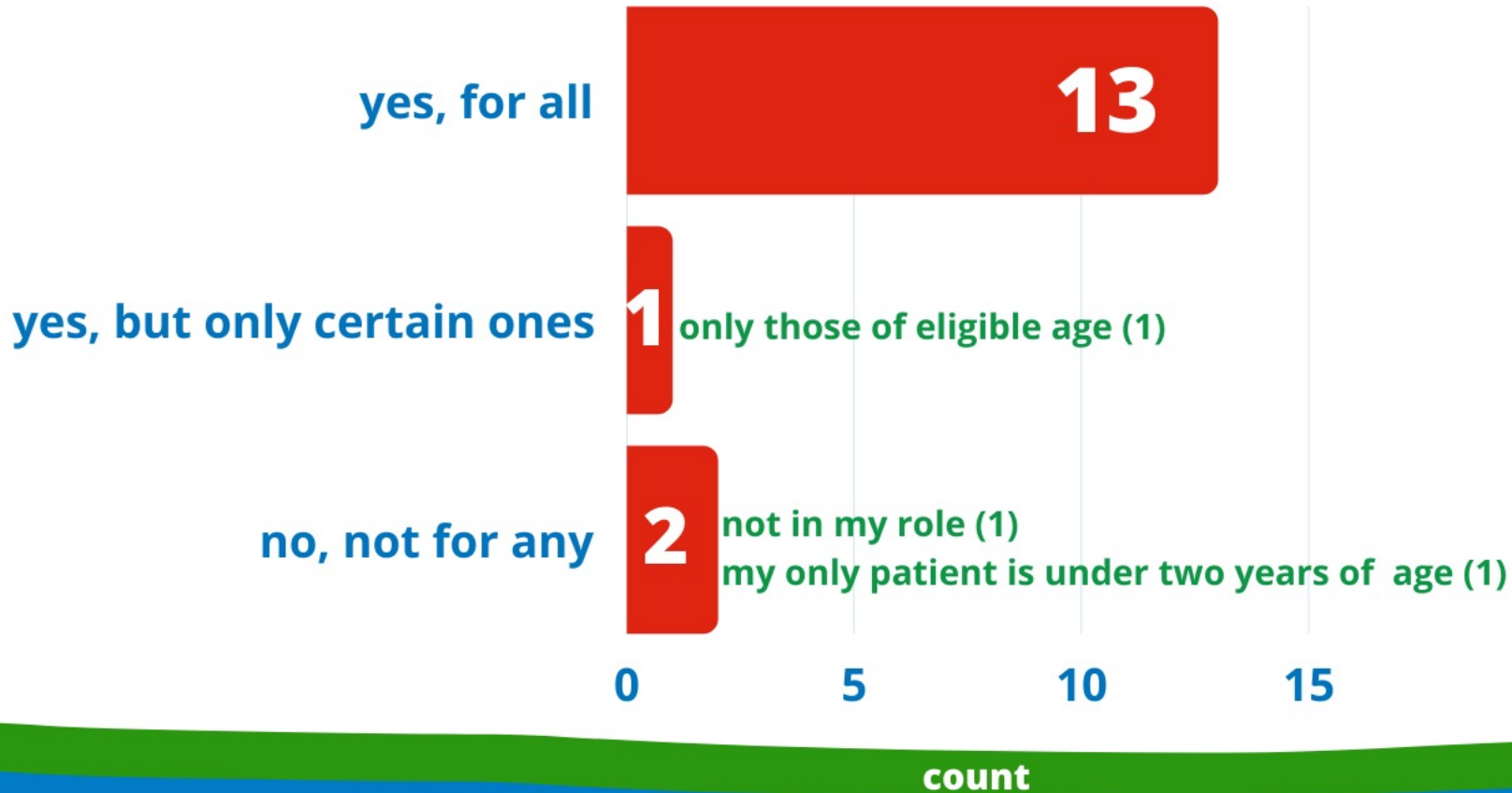
- **none felt that Glut1 Deficiency patient experiences were different**
- **none felt that symptom severity was different**
  - \*1 felt Glut1 patients fared slightly better**
- **none felt that vaccine experiences were different**





# Clinician Results

**Are you recommending COVID-19 vaccines to your Glut1 Deficiency patients?**



**None reported that their vaccine recommendations were different for their Glut1 Deficiency patients than their other patients**



# Limitations and Lingering Questions

- **did not define severity categories:**  
what is mild, moderate, or severe?
- **most clinicians on our mailing list are neurologists:**  
did they only hear about more severe illness or vaccine effects?
- **did not ask about ketogenic diet use:**  
does it play a role somehow?

**PubMed search: ketogenic, cytokine storm, COVID-19, inflammation, prevention**



# COVID-19 Experiences in Glut1 Deficiency

**THANK YOU**  
*for your help!*

