



Genetics Pop-Up February 2024

# Instructions

Go to

**[www.menti.com](https://www.menti.com)**

Enter the code

**62 75 39 1**



Or use QR code



# What Rare Disease are you connected to ?

39 responses

mental health  
22q112 deletion syndrome  
brachydactyly  
diastematomyelia  
multiple scoliosis  
myotonic dystrophy  
down syndrome  
fragile x  
pitt hopkins  
cystic fibrosis  
down syndrome  
trisomy 21  
ehlers danlos  
neurofibromatosis  
health condition  
undiagnosed  
cohen syndrome  
creutzfeldt-jakob  
beckwith wederman syndrom  
mitochondrial disorders  
stxbp1  
jra  
mps1  
pku  
otof  
trappc11 mutation  
hnrnph2  
b-thal  
syrinx  
6q2r6





# Have you come to a Genetic Pop-Up before?

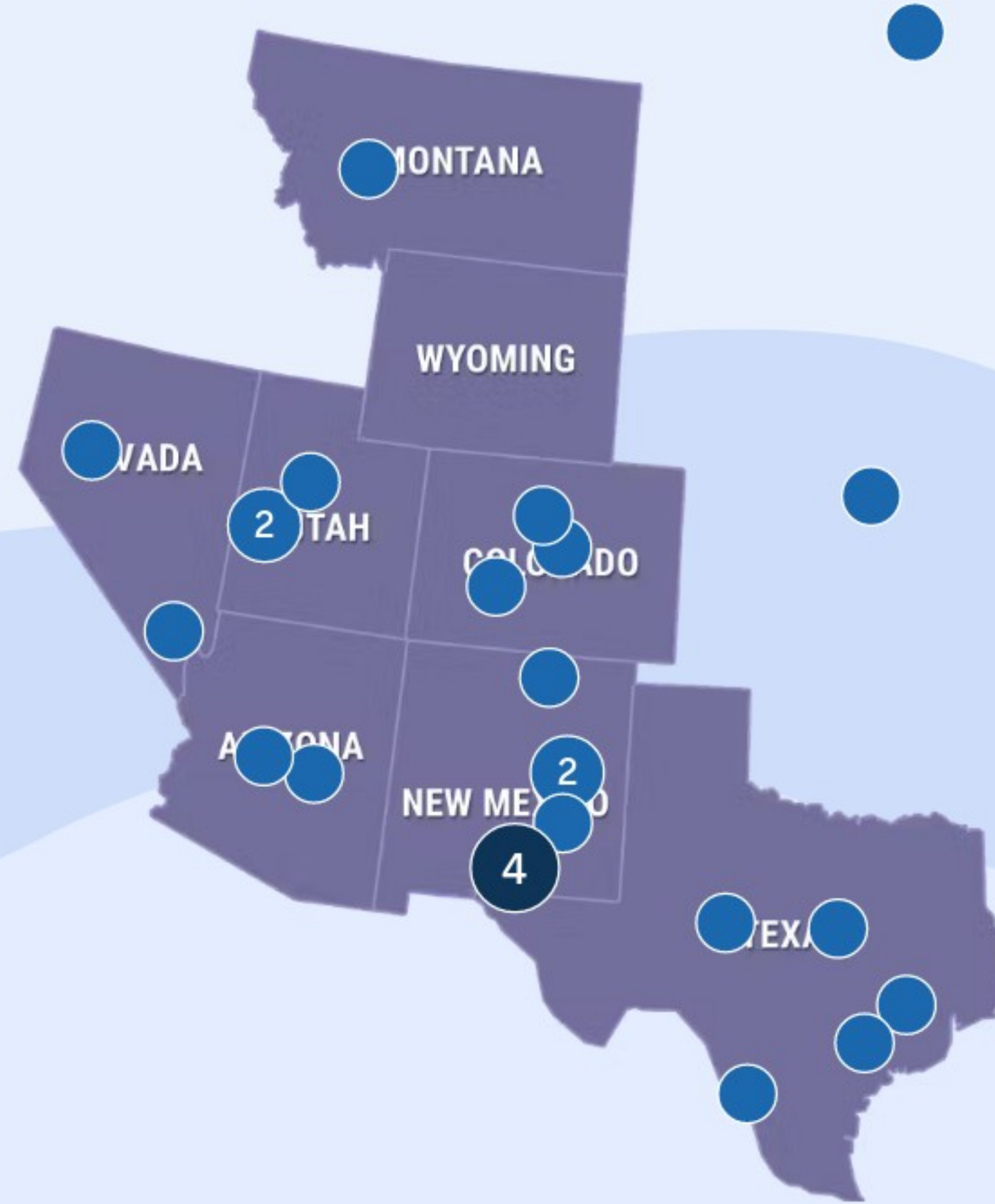


Nope! It is my first time

Hmmm, not sure.

Yes and I am back again!

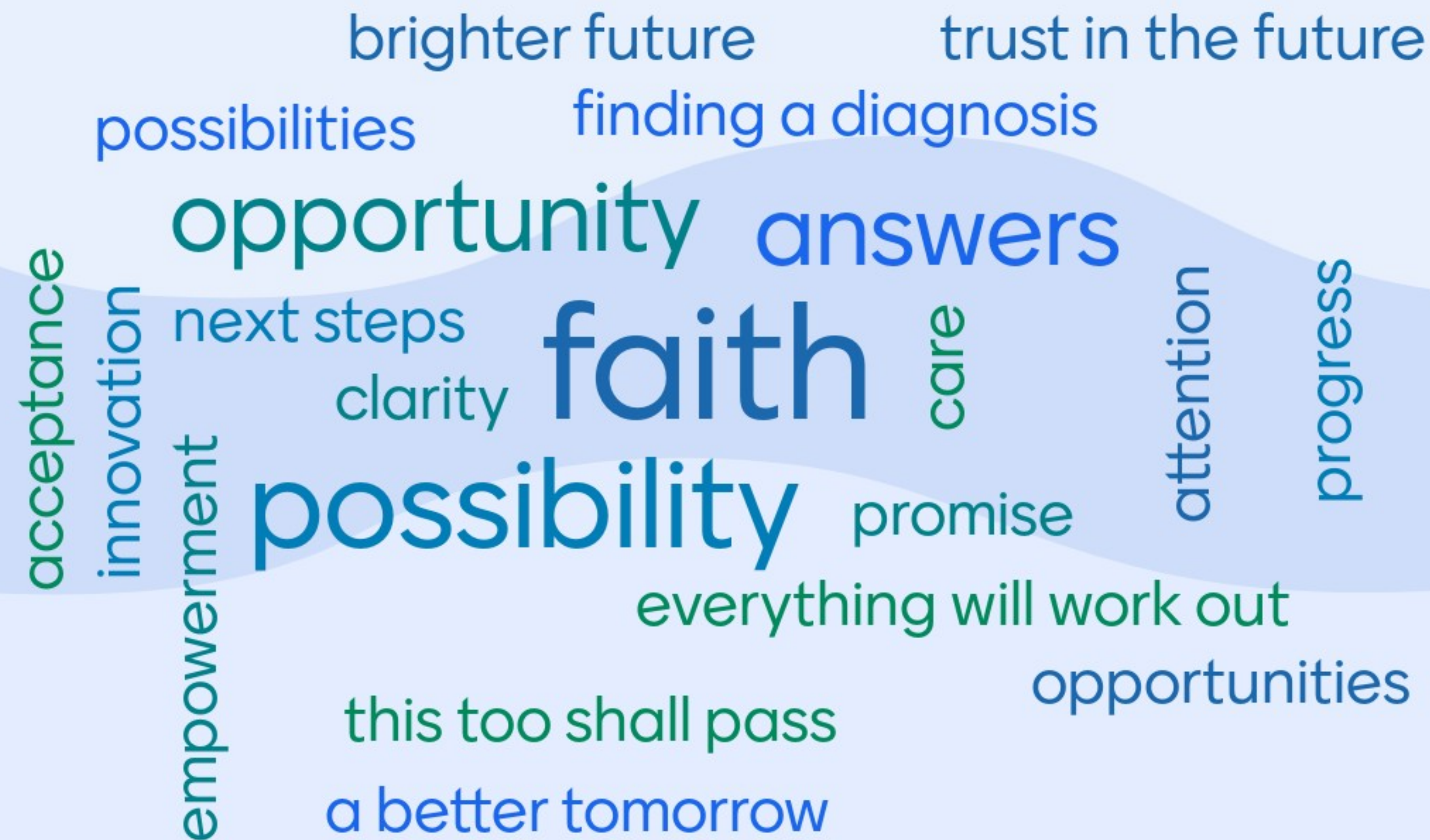
# Drop a pin on where you live!





How do you define HOPE? or What does the word HOPE mean to you and your family?

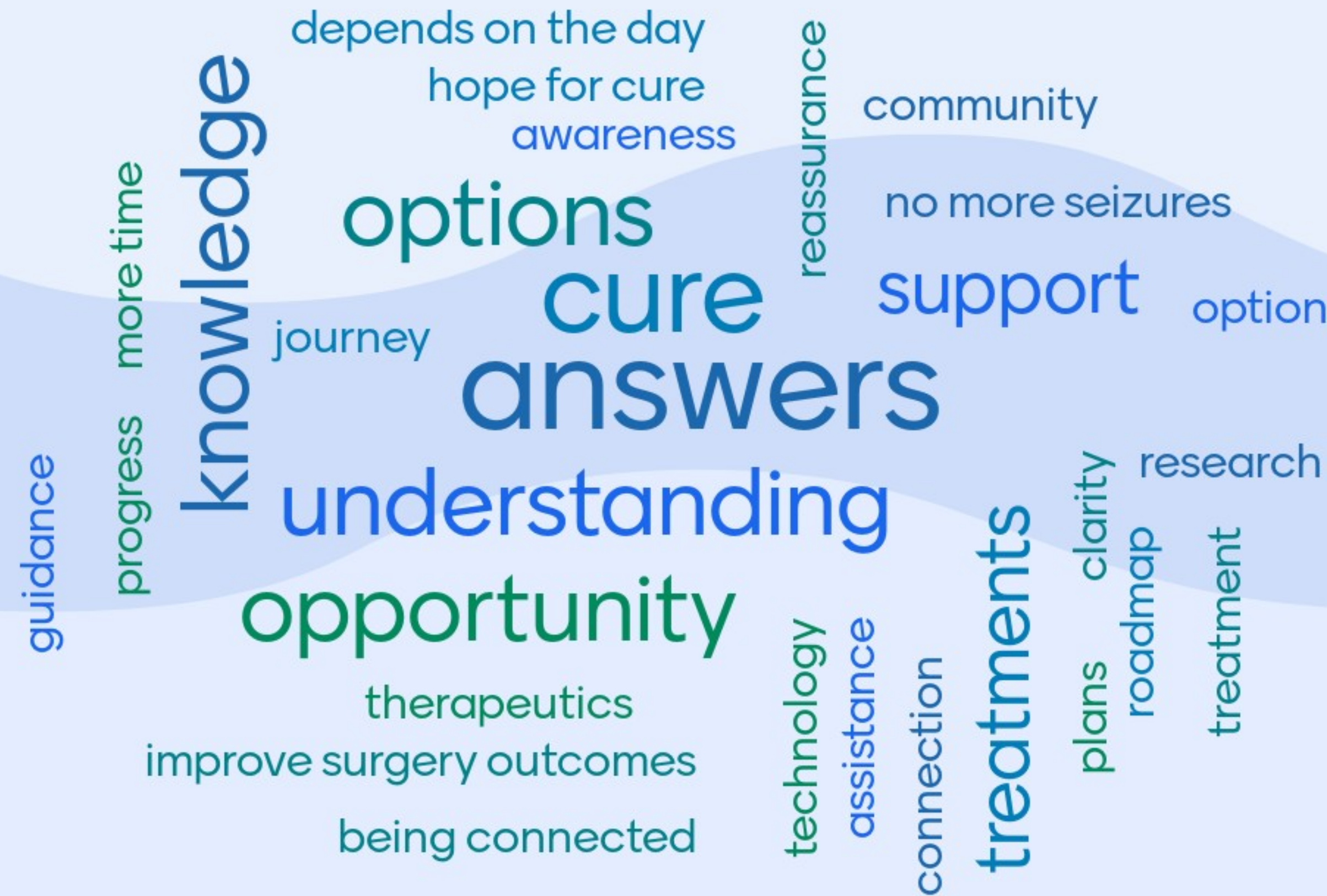
29 responses





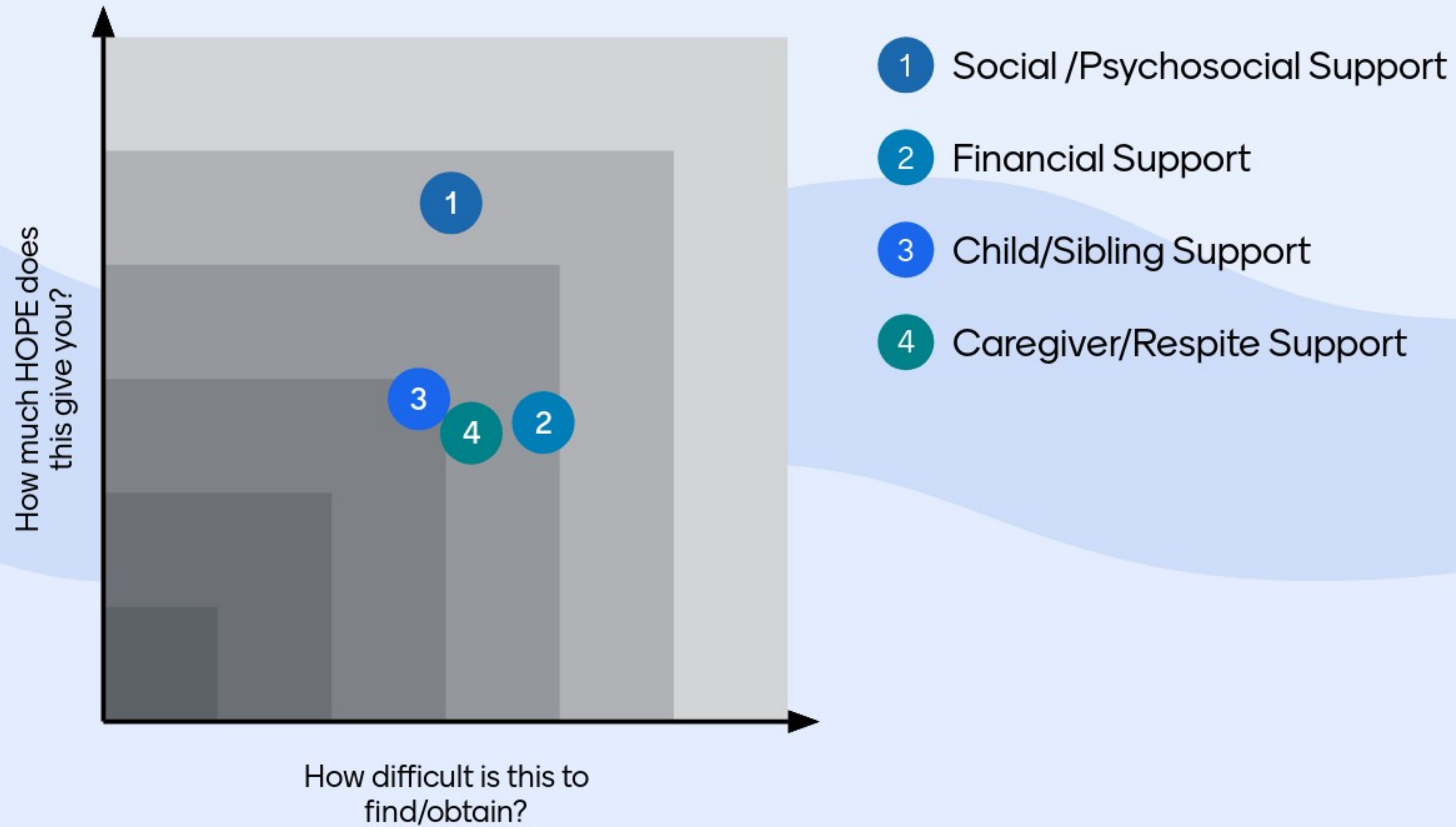
In regards to the topic of Genetic Testing, Diagnosis or Conditions, what does the word HOPE mean to you and your family?

48 responses





# Hope Through Support





# What type of SUPPORT in regards to Genetics are you seeking, today?

Government Support

Resources

support of research

How I can support family's who are just starting their genetic journey.

Support resources for my patients

Knowledge and mentorship

Financial support

Educational



# What type of SUPPORT in regards to Genetics are you seeking, today?

Resources

Shared lived experiences

treatment

Knowledge

Supporting families

Someone with beckwith  
wederman syndrome some  
one with 6q2r syndrome  
treatment

Knowledge of new developments  
in genetic testing and data that  
may help people who are still  
undiagnosed with current testing  
available

references of places where  
they are working on Jacob  
syndrome, I want to participate  
in the studies that are being  
carried out



# What type of SUPPORT in regards to Genetics are you seeking, today?

Educational

"template" care map  
(medical, school,  
community)

Empathy and Financial  
support

New development  
research



# What Genetic Questions do you have today?

More in depth testing for  
beckwith weiderman  
syndrome?

Could there be more genes  
that are responsible for autism  
that have not yet been talked  
about?