



**END EPILEPSY**



# Access to Care Survey

Input from the Community  
Affected by the Epilepsies

# IMPROVING THE LIVES OF PEOPLE WITH EPILEPSY AND THEIR FAMILIES, TO A LARGE EXTENT, BEGINS WITH ACCESS TO HIGH-QUALITY, PATIENT-CENTERED HEALTH CARE THAT FACILITATES ACCURATE DIAGNOSIS AND EFFECTIVE TREATMENTS AND MANAGEMENT.

- INSTITUTE OF MEDICINE REPORT,  
EPILEPSY ACROSS THE SPECTRUM,  
2012 REPORT

## INTRODUCTION

Access to affordable, quality, provider-directed and patient-centered health care is critical for people with the epilepsies.

From October 4 to October 25, 2019, a survey went out to our community asking them about their experiences and challenges accessing needed health care. Please note that the participants for the survey were not recruited through random selection and therefore any results should not be generalized to a broader population. Participants were recruited through convenience sampling; the survey was distributed through the Foundation's and partner organizations' communications channels. The Foundation is committed to doing representative samples in the future, but with this data, we can start to better understand the experiences of people with the epilepsies, improve systems that connect people to epilepsy health care and advocate for improved access to care. This report provides a snapshot of how individuals responded.

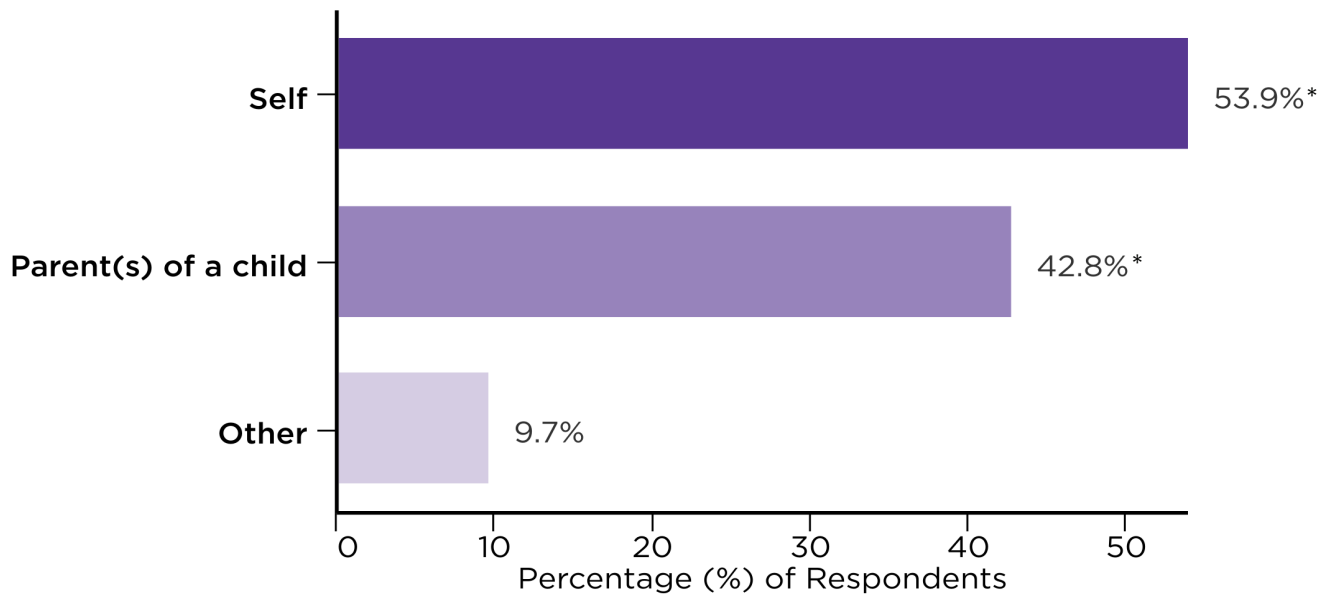
The Epilepsy Foundation thanks our partners who helped disseminate the survey. We also thank everyone who took the time to respond.

Visit [Epilepsy.com](https://www.epilepsy.com) for more information  
Epilepsy & Seizures 24/7 Helpline  
1-800-332-1000 [contactus@efa.org](mailto:contactus@efa.org)

# WHO RESPONDED

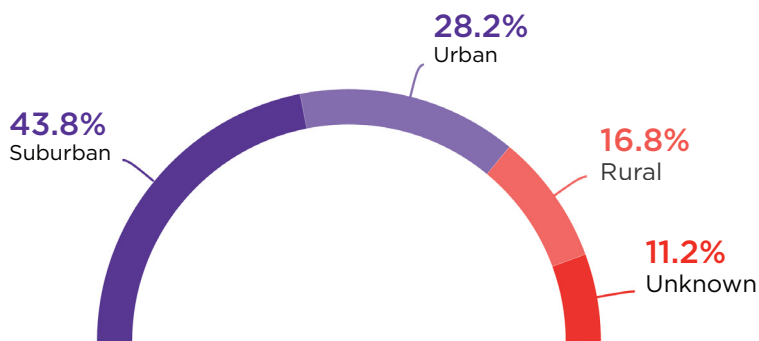
 **1,564**  
Individuals responded

## Relationship to Epilepsy

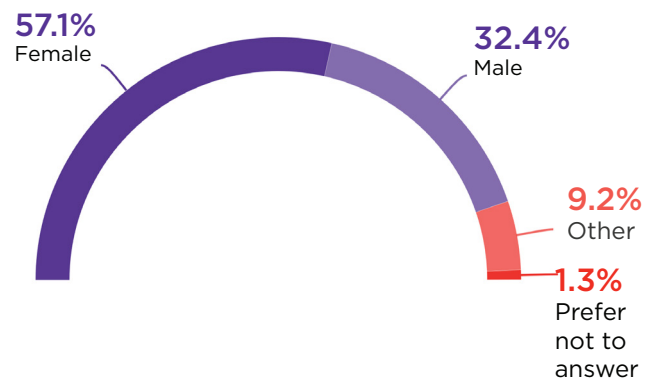


\* Some identified as both a person with epilepsy and a parent of someone with epilepsy

## Geographic Area

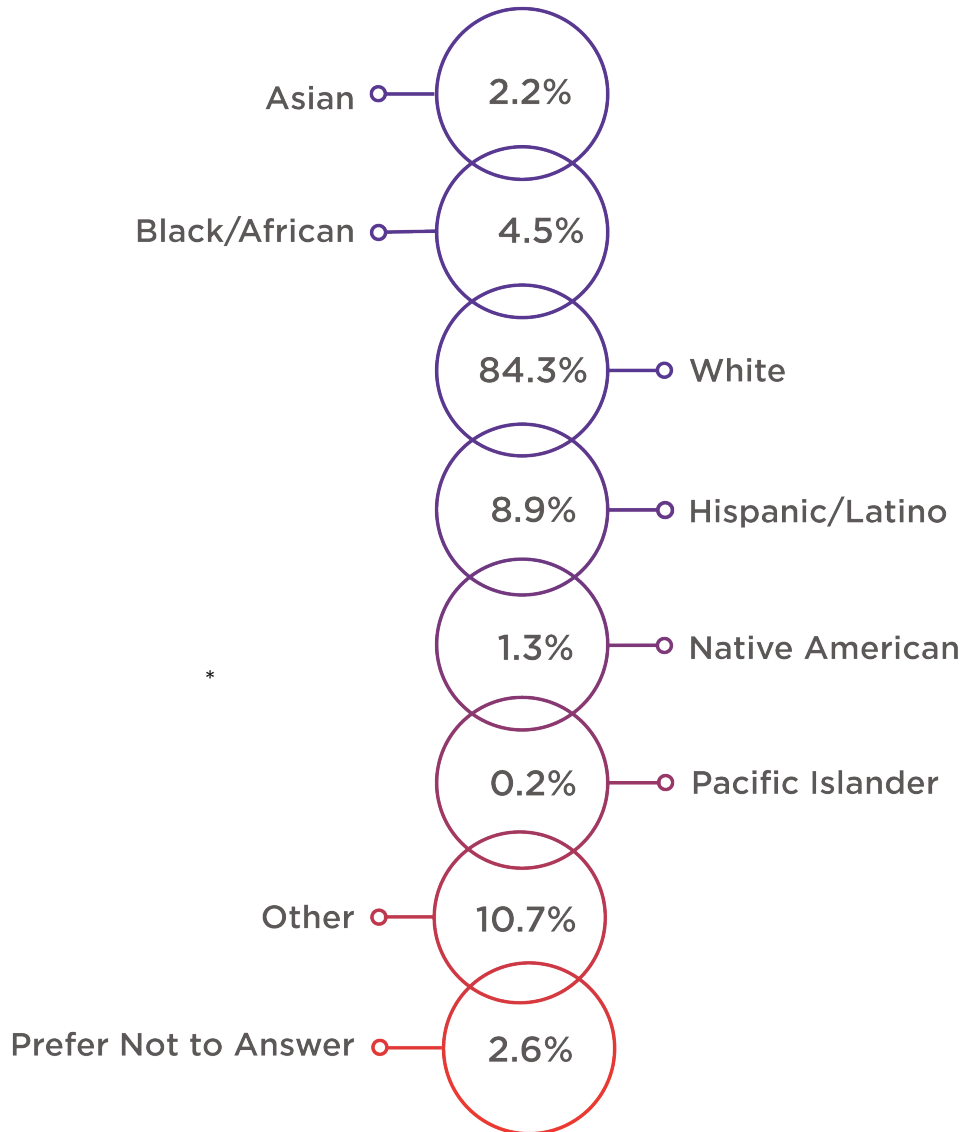


## Gender




# ETHNICITY OF RESPONDENTS

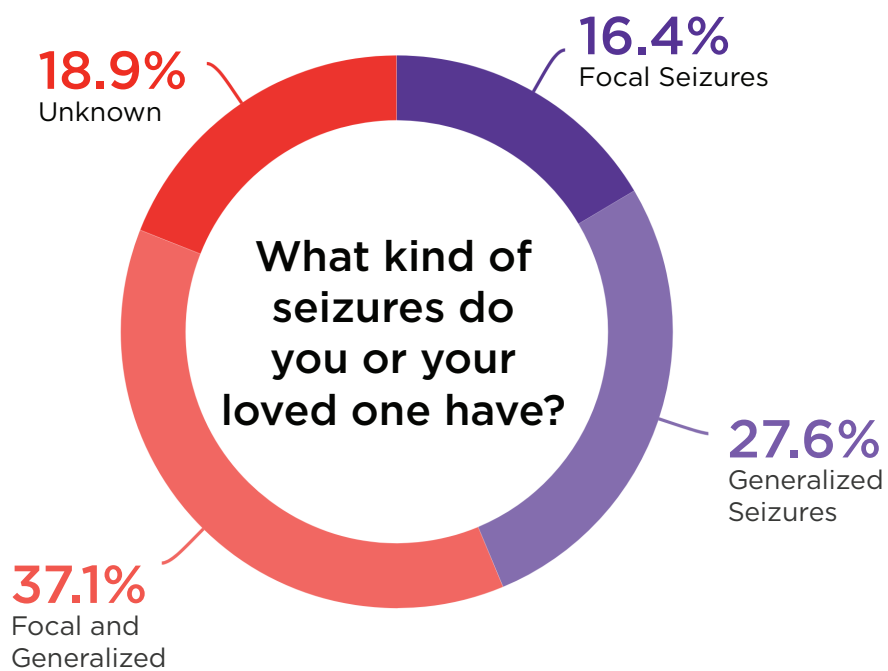
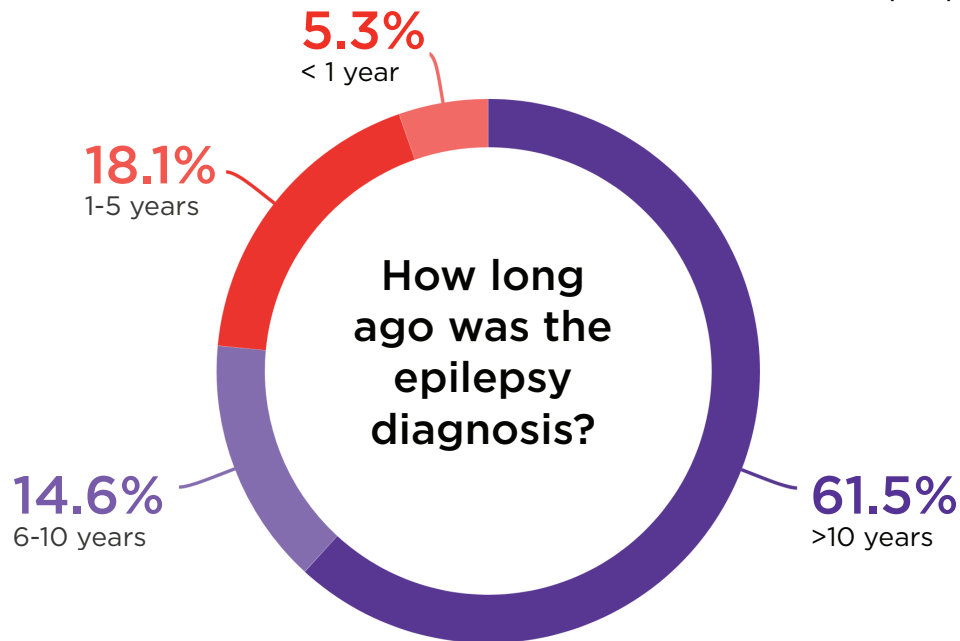
 **1,551**  
Individuals shared



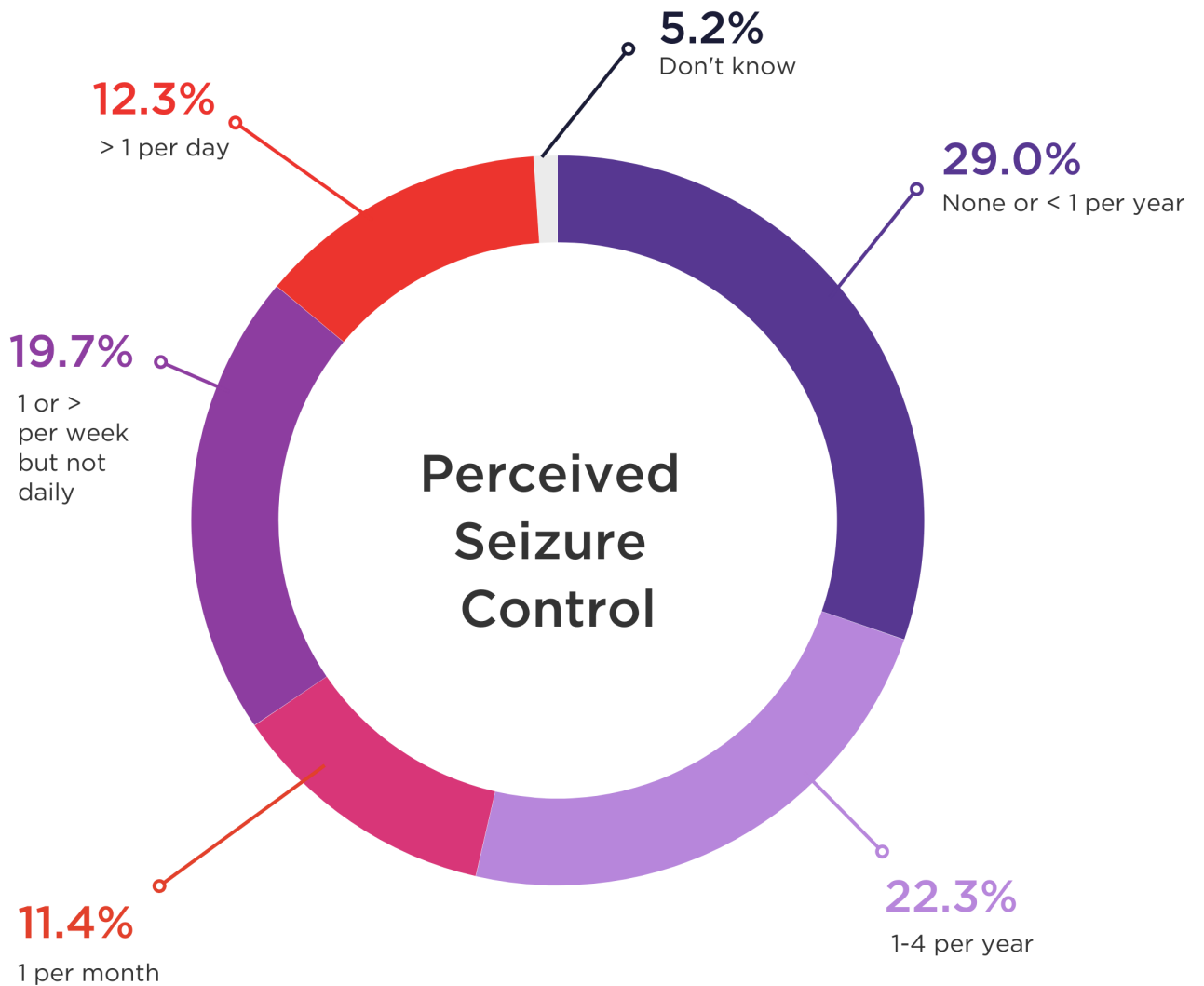
\*able to selected multiple categories

## SEIZURE HISTORY

 **8.6%**  
of respondents  
indicate a rare  
epilepsy condition



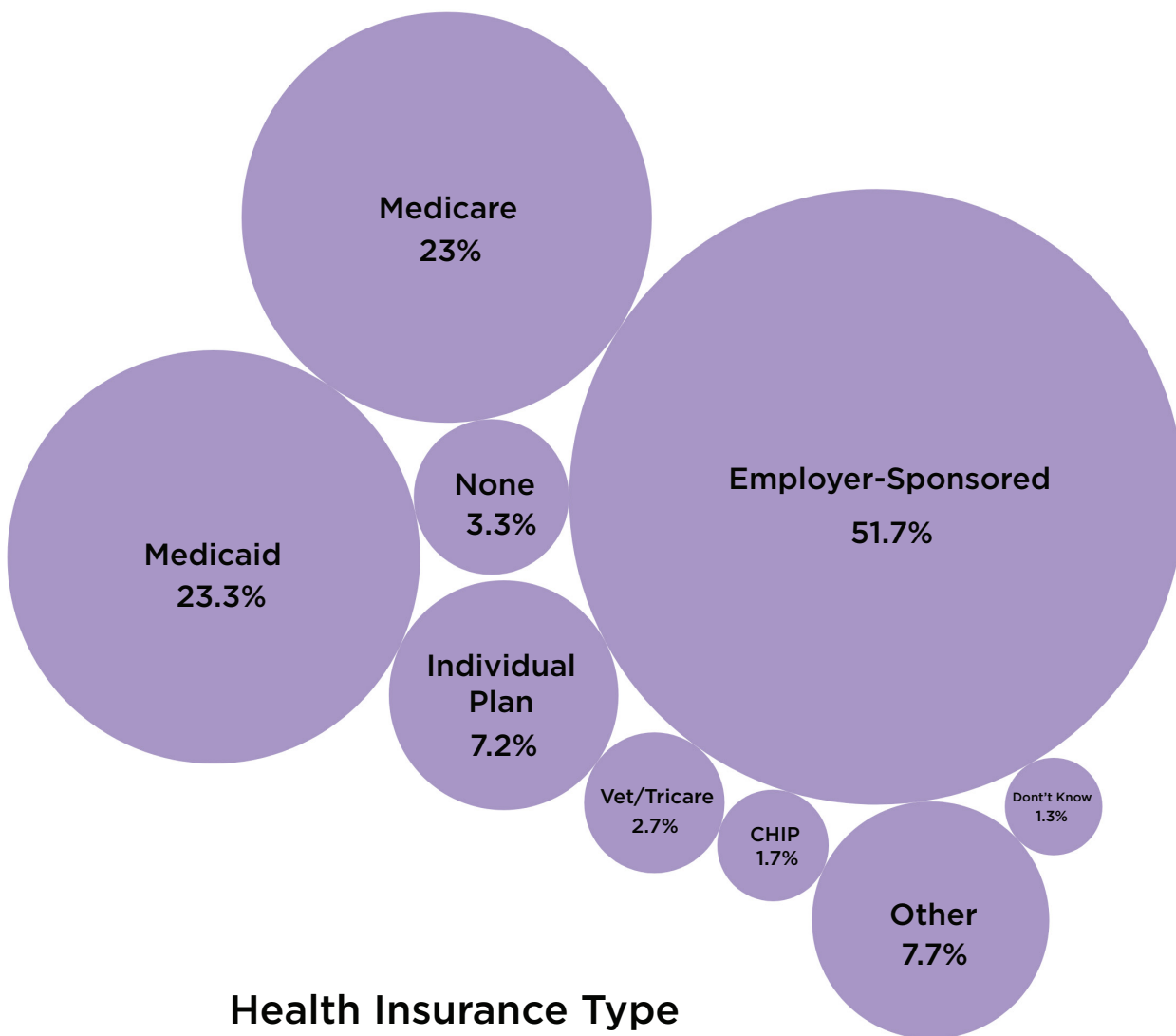
## SEIZURE HISTORY



**65%**

of respondents had at least one seizure in the last year

# EXPERIENCE WITH HEALTH INSURANCE



Note: Individuals could have more than one type of insurance coverage.

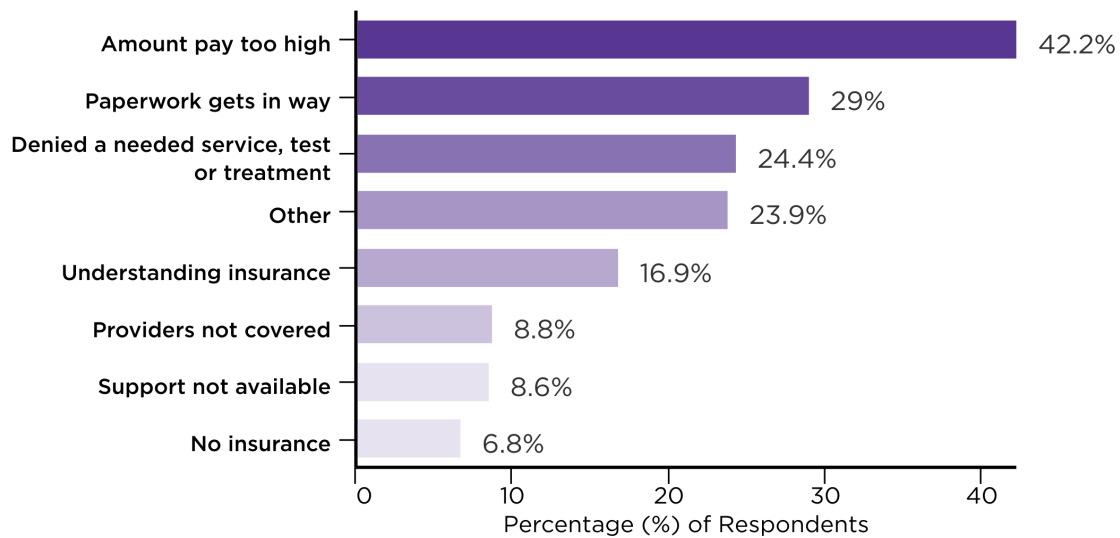
## EXPERIENCE WITH HEALTH INSURANCE



**59%**

of respondents reported health insurance challenges. Of the 59% who reported challenges, these were the issues:

### Health Insurance Challenges



### Top 20 words shared about barriers to health insurance



Note that about 10% also indicated that insurance barriers were why they had not tried other treatment options



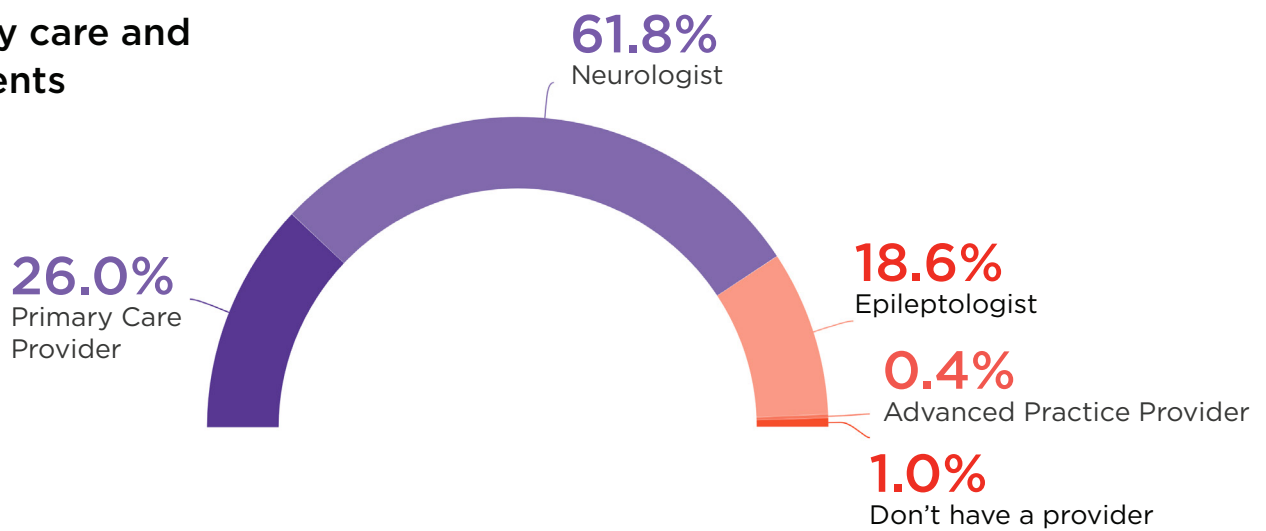
### Other challenges shared

- “ Copay and medicine and deductible are all extremely expensive.
- “ Dealing with formularies, and being sure drugs are in the plan, drug costs are high even with good insurance.
- “ It’s very difficult to even find insurance that’s affordable when you’re self-employed.
- “ My son takes 3 AED as he has had poor seizure control in the past and has tried many medications and one of them is very expensive and I am frequently battling with insurance to have it covered.
- “ Trouble getting doctor prescribed medicine approved.



## EXPERIENCE WITH PROVIDERS

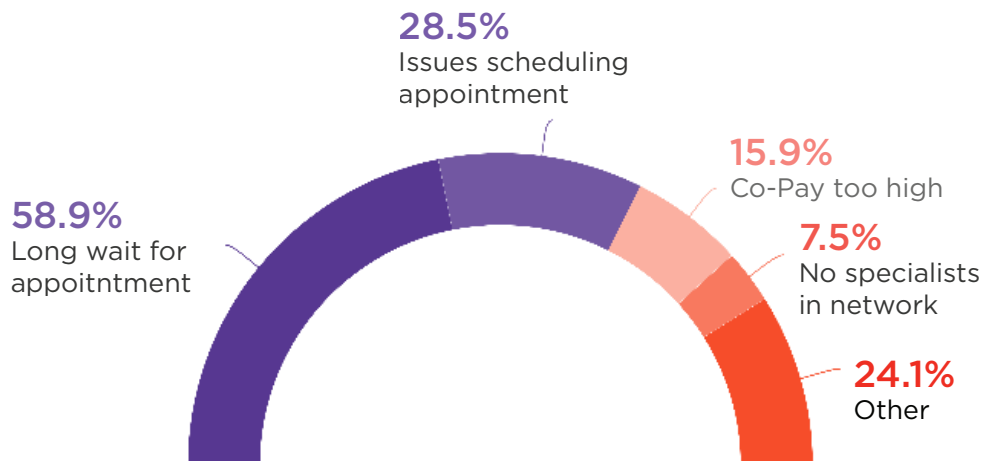
### Providers seen for epilepsy care and treatments



**45%**

of respondents reported challenges to seeing a neurologist/epilepsy specialist.

Of the 45%, these were the top barriers reported:



## EXPERIENCE WITH PROVIDERS



**59%**

of respondents had not been to an epilepsy center for treatment. Of those, 96% had never been referred to a center.



Top 20 words shared about barriers to seeing a specialist



Other challenges shared

- “ The specialists are at least 6 to 7 hours away.
- “ Hard time finding an epileptologist, there is only one in my city.
- “ I can no longer drive. My neurologist is 2 hours away and I have to get a ride each time.
- “ I didn't even know specialists existed or were available until I'd already had a diagnosis for 12 years. By then I'd already been taking various meds picked randomly for years.
- “ It took over 3 years to get a proper diagnosis and epileptologist referral.

## EXPERIENCE WITH MEDICATIONS

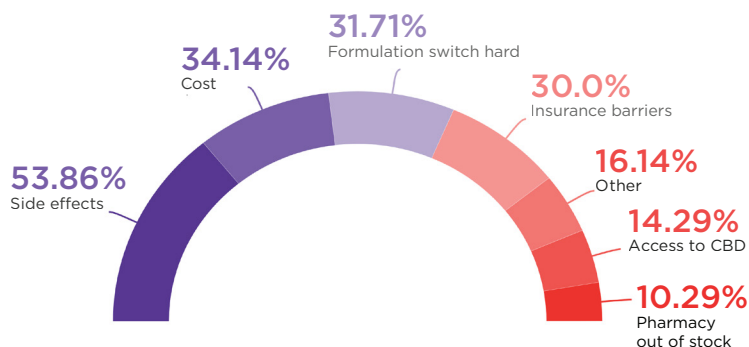
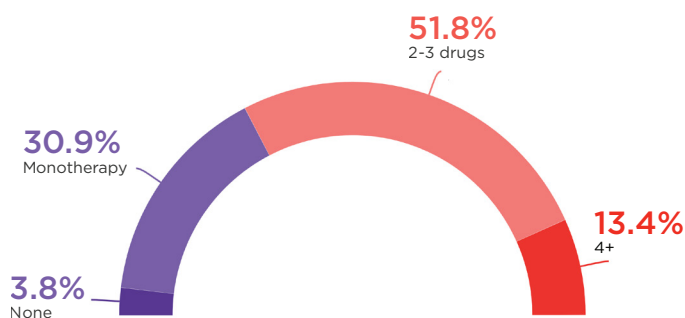


**70%**

of respondents reported challenges with anti-seizure medications.

Of those 70%, these were the top challenges reported:

### Number of anti-seizure medications taken



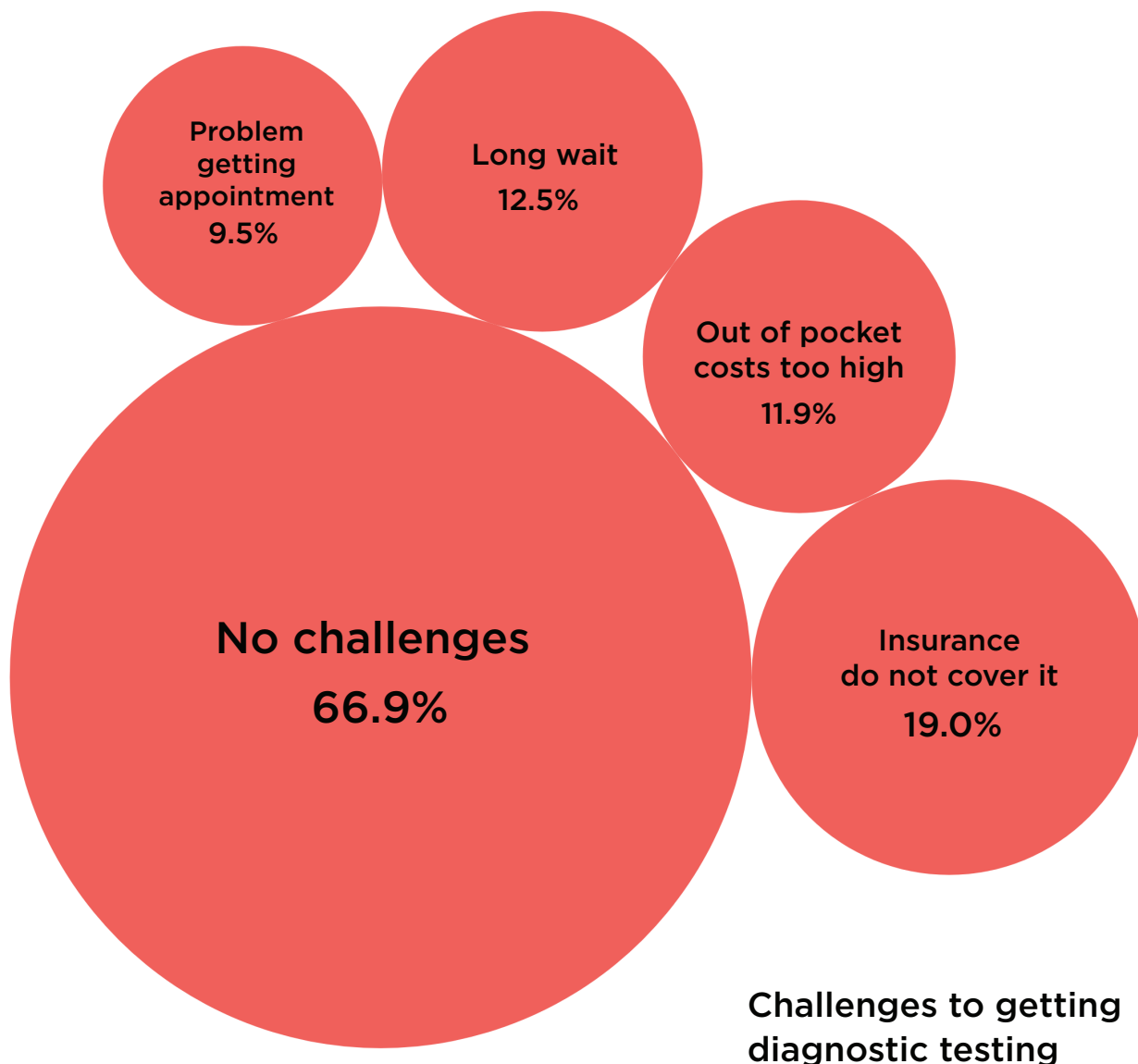
### Top 20 words shared about challenges with anti-seizure medications



### Other challenges shared

- “ Had to “fail” at various meds, before getting the one he needed.
- “ Insurance requires waiting 27 days to refill. If I don’t get to pharmacy in those 3 days (if it’s closed for a holiday, or I’m away, don’t get there before closing, forget, am sick, etc), I’m stuck. One Thanksgiving they were closed citywide so I spent the evening in an ER just to get the day’s pills, to not die. Also, some are controlled substances, so if I fill part of it at one location, I can’t at another, even the same pharmacy chain. And if they run out, they can’t even tell me which locations have it in stock.
- “ We had to appeal to get name brand medication and we did get it but only for 1 year. We desperately hope it is extended as the generics aren’t effective and cause side effects.

## EXPERIENCE WITH DIAGNOSTIC TESTING



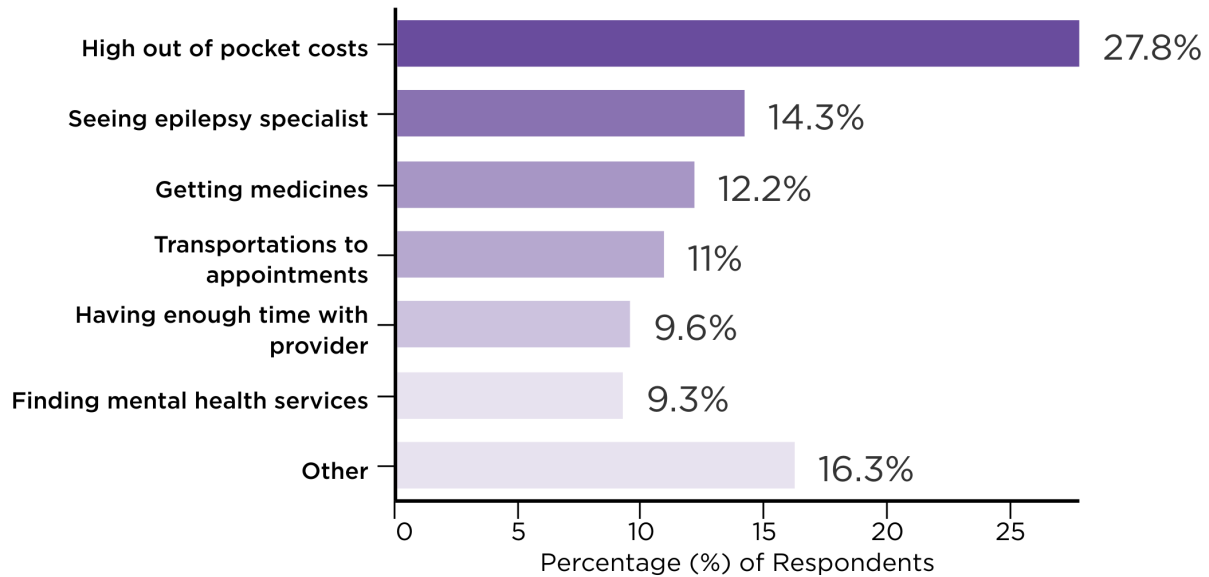


**68%**

reported that there were barriers to getting needed healthcare.

Of those 68%, the biggest barriers to getting needed healthcare were:

## THE BIGGEST BARRIER TO GETTING NEEDED HEALTHCARE



Top 20 words shared about biggest barriers to getting needed healthcare



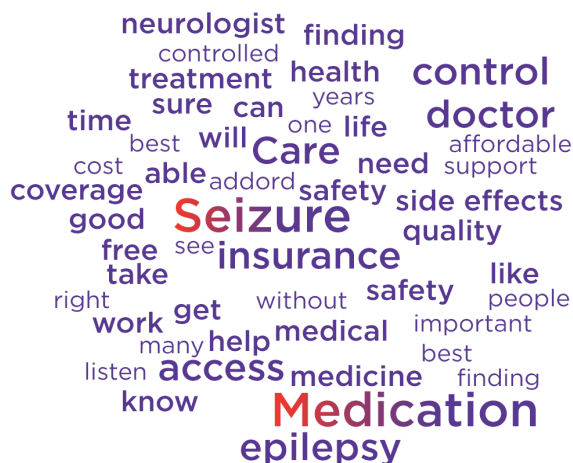
Other challenges shared

- “ The red tape...everything is a fight.
- “ Discrimination from those around me.
- “ Fighting with insurance over my medicines and the very high copay, I can only spend \$10 a week on food.
- “ Having the right to use medical cannabis.
- “ Seeing a doctor who cares and listens to me.

# WHAT IS MOST IMPORTANT TO YOU OR YOUR LOVED ONE WHEN IT COMES TO EPILEPSY CARE?



## Top 50 words shared by respondents



- “ Maintaining control of my seizures and trying to fill the roles as wife and parent to my expectations. Memory, word finding and stress/ anxiety are my worst enemies.
- “ Making sure he is safe, especially with the risk of SUDEP, and also allowing us comfort that while he sleeps we can monitor from our bedroom.
- “ Epilepsy is hard to live with and we just want to live a life knowing that if something happens it will be ok.
- “ Understanding that seizures don't make me different. I have been treated nearly my entire 55 years - life like I am a freak. Because of this, my social skills are non-existent. I live by myself dealing with the effects of epilepsy without support. The family does not understand my epilepsy has caused too much of an effort on their part.
- “ Having ER staff/Drs understanding her rare type of epilepsy and actually respecting my knowledge and listening to what works for her treatment.
- “ That someone actually understands what epilepsy is and how to treat it. Recognizing that epilepsy is not a “one size fits all” diagnosis. Help to identify a treatment plan based on the patient's preference of how they still want to live and enjoy life even with this disability.
- “ His monthly maintenance medications are over \$3,000/month. I am terrified of losing his medicaid. My job's insurance is so ridiculously high I can't afford it. My husband's job does not offer insurance. So making sure he has what he needs to safely live his life without fear of epilepsy taking it is THE most important thing. The only way that is possible is by him having access to quality care which has been made possible through the help of Medicaid.
- “ In a word, freedom. This means access to specialists and regular EEG testing and the freedom to try the drugs his doctor thinks will work best.