

Shortening the Diagnostic Odyssey

2020 Assessment

Survey Summary

Thank you to our partners



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What does the diagnostic journey really look like in child neurology?

CNF conducted two surveys to learn more about the diagnostic journey from the professional and family perspectives.

We received 334 responses from the CNS membership

With the support of 37 advocate organization partners, the family Survey received 1,155 responses.



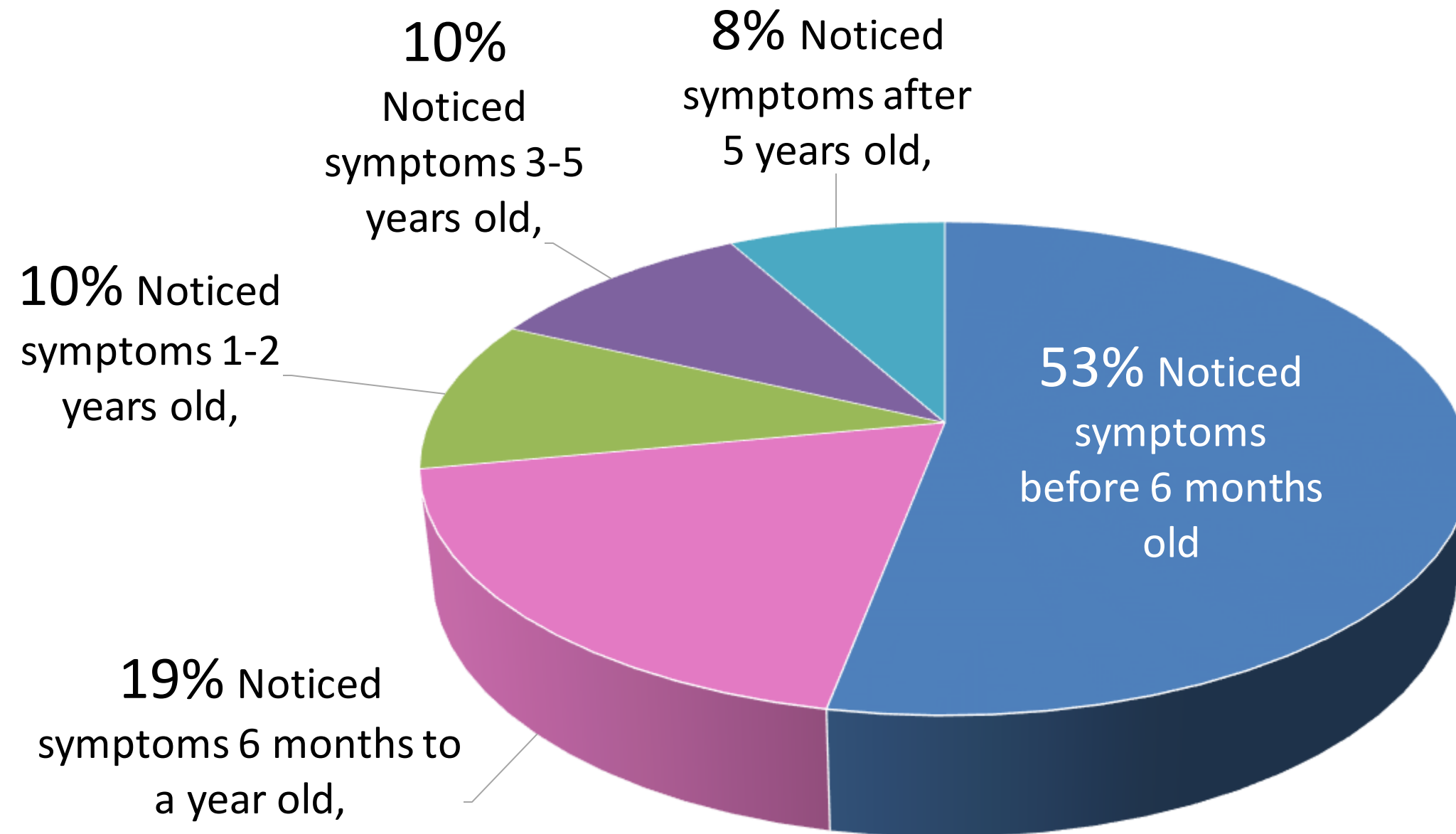
About the Survey

We conducted two online surveys from July 20-August 19, 2020 to gather the professional and family perspective on the diagnostic journey. These are assessment surveys and not IRB approved studies.

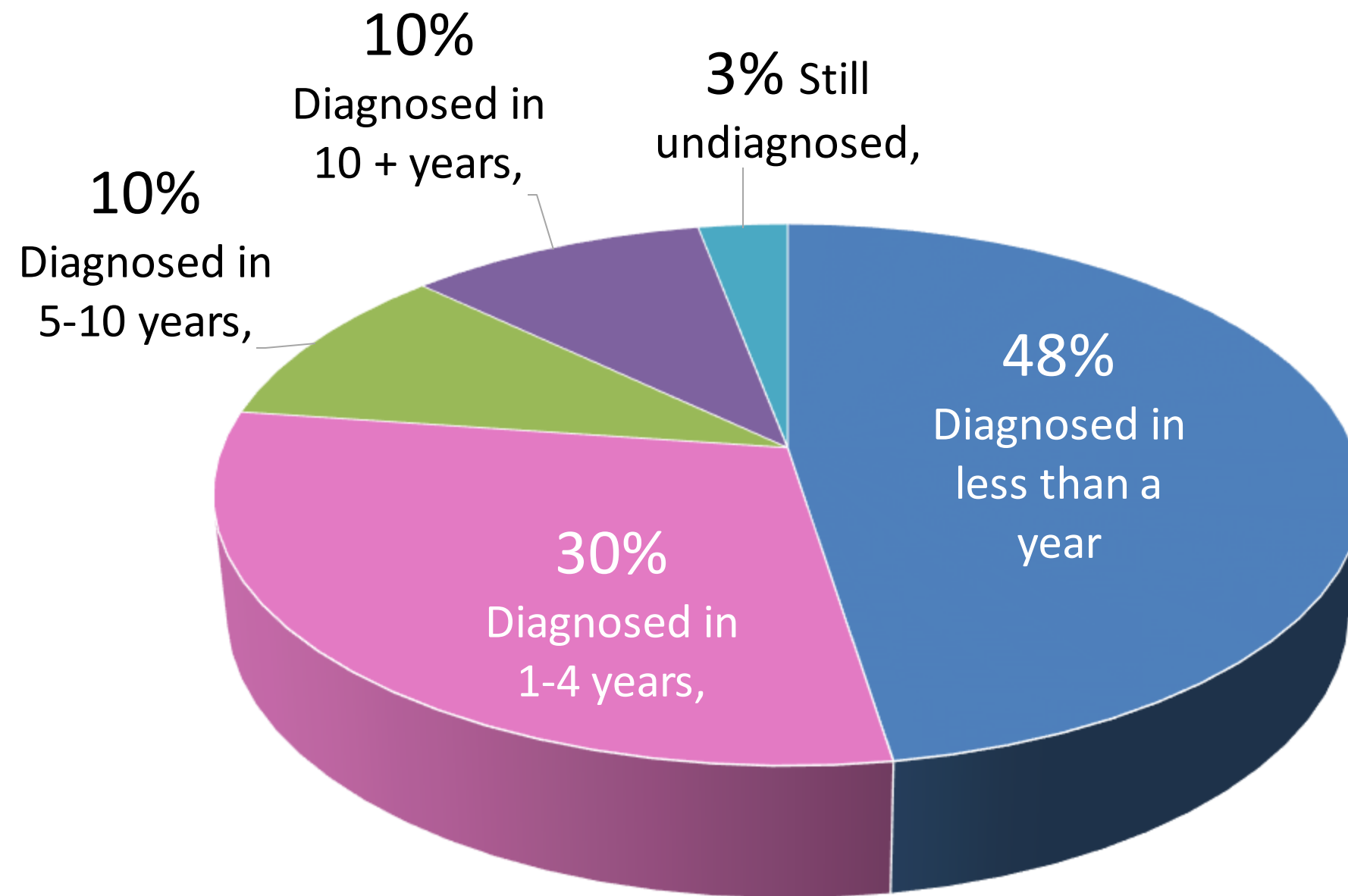
Please note that we believe this data under-states the magnitude of the problem because we were more successful in reaching families with financial and educational means, and less able to reach underprivileged families who might lack insurance or access to health care. We infer that if we were able to reach a larger population that better represents the country as a whole, our data would reveal an ever more serious set of challenges.

Families notice symptoms early

Nearly 75% of families notice symptoms in the first year

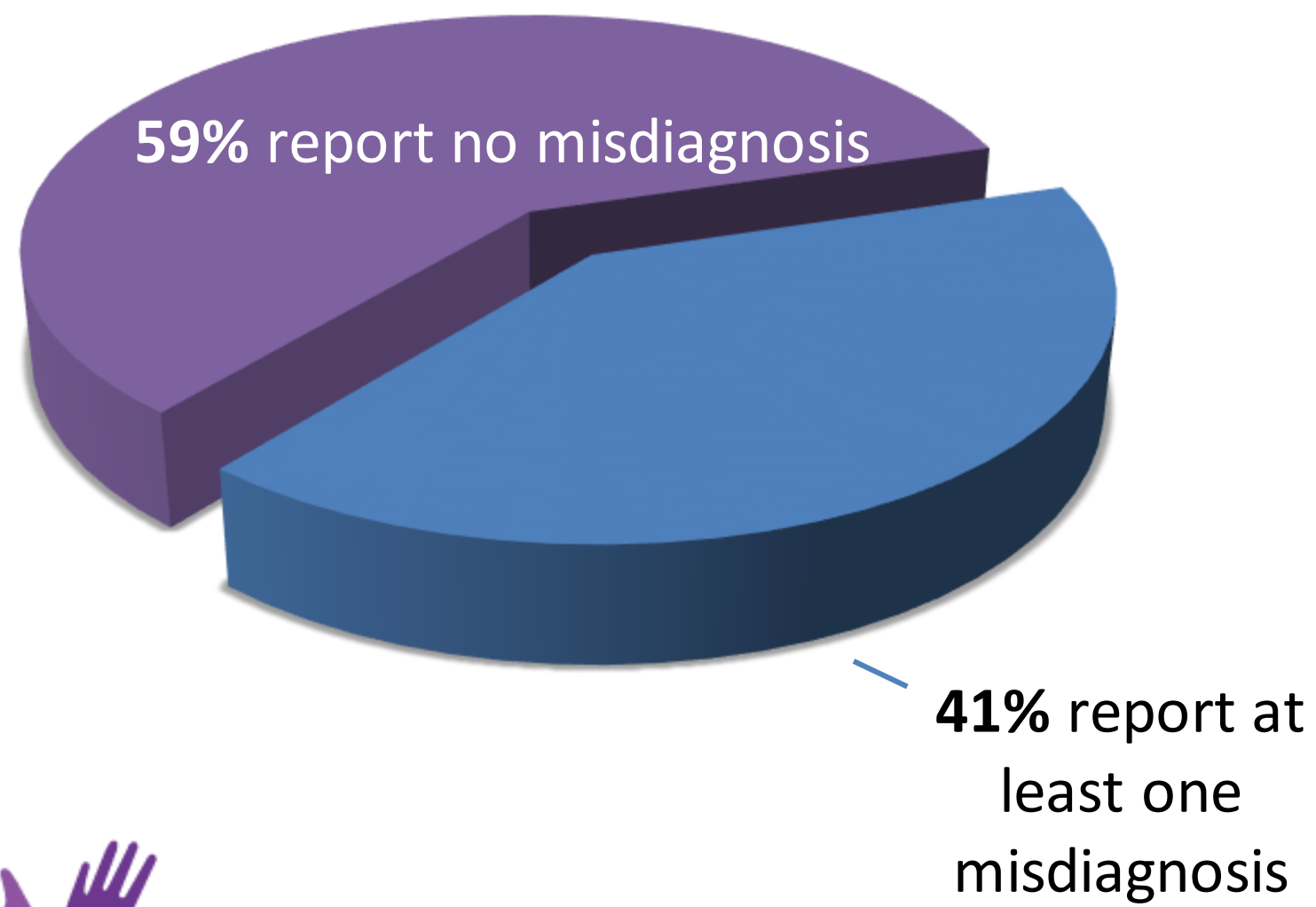


The diagnostic odyssey may last for years

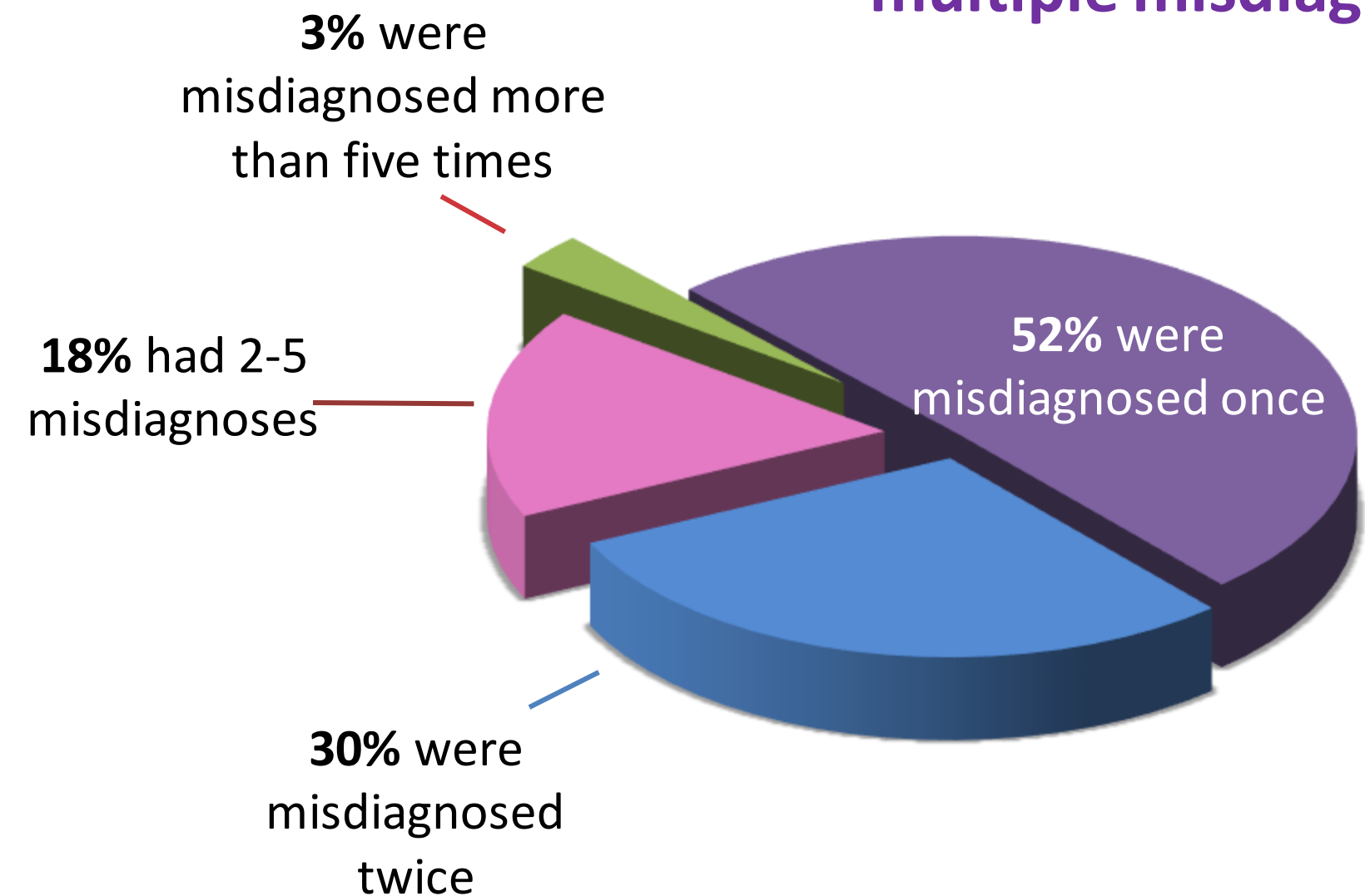


- A quarter of children are without a diagnosis for five years or more.
- Ten percent wait more than ten years without a diagnosis.

Misdiagnosis occurs too frequently



Of those with a misdiagnosis, almost half received multiple misdiagnoses.

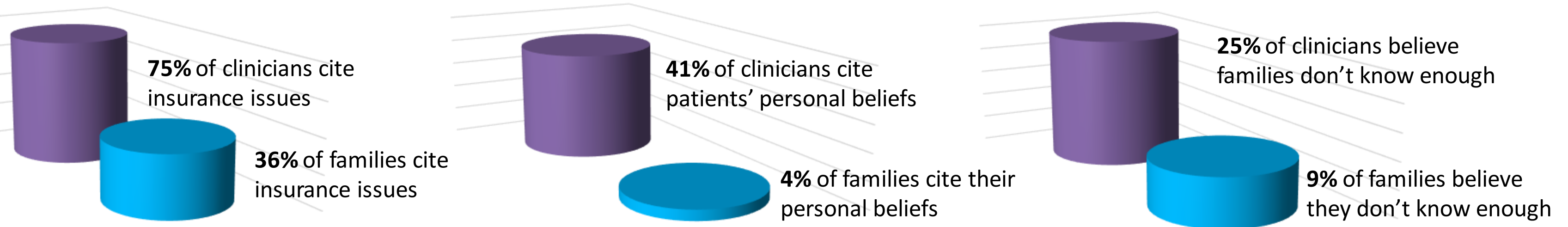


Families rarely decline diagnostic tests*



Only **25%** of families report declining diagnostic tests.

When they do decline, it's for different reasons than clinicians expect.



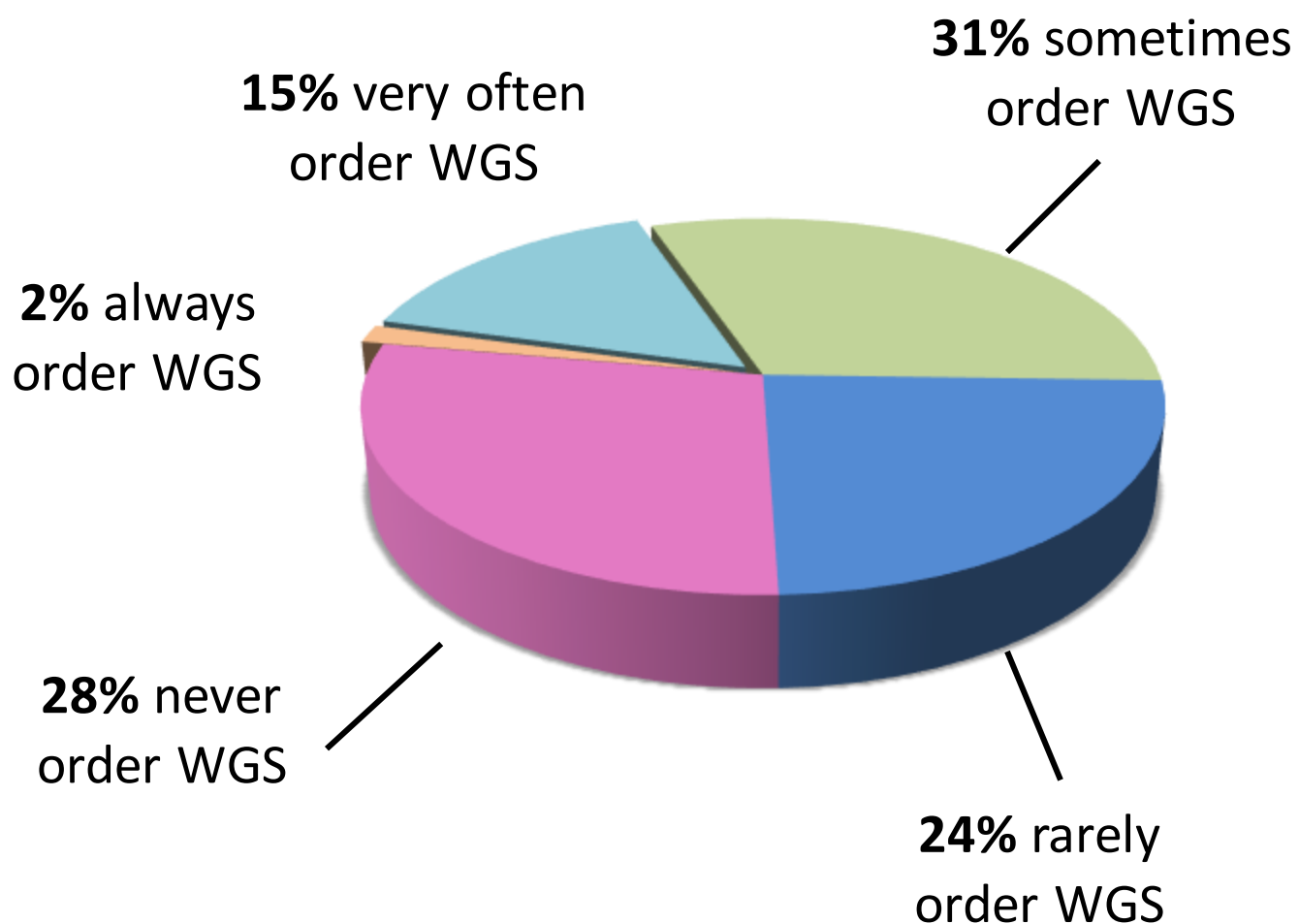
The top reasons families cite for declining diagnostic tests is that they are **too invasive**.

*Diagnostic tests include tissue or fluid samples, imaging or scans, genetic tests, etc.

Clinicians face challenges ordering Whole Genome Sequencing

Top reasons given for *NOT* ordering WGS

- ✓ Believe insurance won't cover the cost
- ✓ Refer patient to geneticist to order testing



“Our institution only has a part-time geneticist, so child neurologists are forced to try to obtain genetic testing.”

“Insurance is still a barrier to genetic testing.”

“We have a shortage of genetic counselors.”

“Getting insurance approval for genetic testing is prohibitive.”



Getting a diagnosis is not the end of the journey

Families were asked how many hours spent on certain activities, over the past 3 months



Average Number of Hours



During the odyssey, collaboration and connection are essential

“Why are we not on the same team? I urge parents to trust their instincts and never give up. I beg docs to start really listening to parents.”

“I wish neurologists could guide us on what should be our next step, and to help us connect with support groups or other families with same diagnoses.”

“It’s really hard to communicate what we see EVERY DAY in the space of 30 minutes...with a wild child in tow.”

“Recently found a doctor that asks a lot of questions and isn't afraid to hear my concerns...we have a mutual respect and a sense we are working as a team. THAT is worth its weight in gold! ”

“What made my journey better is that my neurologist took the time to listen to my concerns and what I learned from my [parent advocate] group.”

“When doctors don't listen, it makes parents second guess themselves and the care they are desperately trying to find for their child.”



For more info

If you have questions or would like to share results from these survey assessments, please contact info@childneurologyfoundation.org