**Respondents quotes explaining why they would prefer to only carry a genetic diagnosis (7/195, 4%)**

1. The genetic disorder fits her problems more than a true CP diagnosis.
2. Because she was [an adult] when she was diagnosed with [genetic condition] we always said she had severe developmental delay which cerebral palsy was also included in this.
3. Not sure I accept the diagnosis of cerebral palsy. At the time it seemed to be thrown out as a diagnosis when there were no other obvious conclusions to explain the developmental delays.
4. The genetic diagnosis give a full meaning as to why my daughter is the way she is where the cerebral palsy is an "umbrella" term and has such a wide range. Doesn't give a good idea of life expectancy.
5. For clarity about the cause of motor struggles and the combination of symptoms

**Respondents quotes explaining why they would prefer to only carry a CP diagnosis (30/195, 15%)**

1. more resources,treatment, services
2. In my country the diagnosis gives certain rights. As free medical and physiotherapy treatment.
3. If it's genetic it's more likely to be passed down to other generations Or in same generation
4. A genetic origins would be a burden for my child
5. Knowing it's not genetic means that it will be less likely that my offspring will have Cerebral Palsy.
6. While a genetic diagnosis \*may\* give a clear prognosis, it is also probable that a genetic diagnosis would impact future children. A non-genetic diagnosis offers better option for potential future children.
7. A genetic disorder means that future generations may have it.
8. I chose this because the CP was a fluke. A genetic disorder is more likdly to affect more of my family members.
9. Too much change is stressful
10. Genetic diagnosis could include other issues separate from the CP and would be an additional stressor to have to think about
11. i simply have never been given any family history or research to indicate a genetic cause.
12. good to never have to worry about genetics for the disability issues
13. I have never been genetically tested
14. As A twin it was a breech birth and complications.
15. A brain injury during birth changed my baby's life. It is not genetic.
16. CP isn't progressive and some genetic disorders are progressive.
17. We know mine was not genetic and was caused due to traumatic birth.
18. I have CP and too busy learning to live with it on a daily basis
19. Checked family history without this feature

**Respondents quotes explaining why they would prefer to carry both a cerebral palsy diagnosis and an etiologically-specific genetic diagnosis (78/195, 40%)**

1. I think the more you know, the more you can help your child get access to the proper medical equipment, treatment options and therapy needed.
2. can research each, resources, knowledge
3. Not all genetic conditions are well known especially as science continues to evolve. So for my daughter's rare gene of [gene name], insurance companies have no idea what it is or what it causes. Having a diagnosis of CP was broad enough for them to understand she has a change in muscle tone, global delays and seizures. CP was a generic way to get my daughter the services she needed covered by insurance.
4. We like having the genetic diagnosis because it connects us to a small group of caregivers who also have children with this same rare genetic diagnosis. I also very much appreciated having the cerebral palsy diagnosis as it was the reason our daughter immediately qualified for physical and occupational therapies as a baby.
5. [Genetic disorder] is very rare and alone cannot be used to justify medical equipment and other needs. Cerebral palsy is just a generic diagnosis that has helped us receive help with many different areas of need. But I personally needed to know what caused it so the real diagnosis was important to me.
6. Certain diagnoses make it easier to obtain therapies and interventions for a child who needs help.
7. Having multiple diagnoses has helped us access more services and resources for my daughter. However, we view the CP diagnosis as a formality and don't view her as having CP in the traditional sense.
8. The genetic diagnosis is what caused the cerebral palsy, which is important information, but it does not describe the person's condition. Not everyone with the same genetic diagnosis have the same symptoms. Also, the genetic diagnosis is rare and not many people, even medical professionals, may be familiar with it, so cerebral palsy is a general term that most people understand. Also a cerebral palsy will allow the patient to get more resources such as funding for equipment and therapy.
9. We need the cerebral palsy diagnosis to get services and supports. It is a funding phrase.
10. It provides wider range of possible treatments that could enhance life
11. I want as much info as possible to the degree that DX informs life course, research possibilities and treatment options. Support too.
12. I feel both diagnoses may be helpful in better understanding and explaining the challenges and needs. Both diagnoses may also be helpful in accessing interventions, treatment, care, coverage and support.
13. I'd like to know the source of my son's CP but would still want the CP diagnosis since his symptoms align with that. Having CP diagnosis opens opportunities for insurance coverage, resources, research, specialists, etc
14. The CP diagnosis will help with the physical issues, therapy & treatment that meets the physical needs. If there is also a genetic cause of the CP it will probably help with the understanding of other accompanying diagnosis and possible treatments or issues that arise from that.
15. Cerebral palsy is more widely recognized by medical professionals and schools for services like therapy etc. a genetic disorder though pin points exactly what is going on with your child. It's explains the child's behaviors and issues much better whereas cp is an umbrella term.
16. I think it's important to have both. Mostly the label is important when receiving resources and treatment.
17. CP is just a description of the symptoms my daughter has because of her brain injury. We use it because it opens doors to services and it connects her with other people with similar issues.
18. It is easier to get/request services when a diagnosis is standard - when there's a box you can check and say so the powers that be can say "Yup, people with CP typically need these services." We have a doctor who thinks our daughter DOES NOT have ADHD, but presents like she does, and thinks it's better to say she has it just so we can get necessary accomodations.
19. The genetic diagnosis was nice because it was nice to know what the actual cause of the problem is - it made me feel less guilty to know that it was a genetic cause and not something I did. Also, it made it easier to make decisions about what the chances were of this happening again if we had another baby. It is also nice to have the cerebral palsy diagnosis because it is sometimes easier to explain to people and also sometimes when you are applying for things (such as Medicaid waivers, etc.), "cerebral palsy" is considered to be an official diagnosis that makes your kid eligible, whereas "point mutation in STXBP1 gene" is not an officially recognized diagnosis.
20. Our neurologist diagnosed cerebral palsy as an umbrella term to describe [person's] condition so other health professionals would have a clear picture about jack. There was a lot of blame coming from me thinking it could have been prevented or did something happen in pregnancy that could have been prevented. Once we got the genetic diagnosis as a causative factor, the weight suddenly lifted and I knew it was nothing that we could have prevented
21. Knowing the origin was the deletion is comforting, that there isn't some other factor behind the diagnosis.
22. For some parents, especially mothers, it would be comforting to know that there wasn't any blame on their part - living with any guilt is, or can be extremely difficult.
23. Knowing the cause of CP is important for understanding what treatments may be helpful. Also, any genetic diagnosis allows for future plans for the child and the parent for having more children.
24. The more information I had the better informed I would be and the more information I had it would influence future Healthcare and child bearing choices (genitic vs non genetic) I already have a grown daughter with no health issues and both her parents have 2 different types and causes of CP
25. Since it is cerebral palsy, it needs to be treated medically as such, but if it were genetic, I would also like to have that diagnosis for understanding; & so that future generations can be aware/take preventive measures if possible.
26. Genetic information is helpful to know to share with my children.
27. I would like to know if genetic factors caused CP, especially for future family planning.
28. Even if the cause is genetic you still have cerebral palsy and should be treated by medical professionals as such, therefore you should always have that diagnosis. For me the genetic component is important because you could possibly pass that on and you should be aware that the cause was genetic and not due to hypoxia or other common causes.
29. More knowledge about my daughter's condition is better.
30. Because the type of cerebral palsy diagnosis is defined related genetically
31. Knowing the reasons for the diagnosis of my CP will be easier to explain to doctors, specialists and others. It would also give me peace of mind.
32. I want all info.
33. To be able to gather as much information as possible
34. would like to know more what caused the CP which is really just a catch all type of diagnosis based on particular movement, communication, functional abilities, developmental milestones, etc.
35. I feel it would be good to understand all the factors that could have caused CP in my son.
36. It might provide more specific insight and understanding about my particular case
37. If some of the features of CP have a genetic link, it would be nice to know.
38. I would love to know what caused my CP since my mother has no idea what happened. I was born at full term but only weighed 6 pounds 3 ounces.
39. Because CP can be such a generic umbrella that I feel a genetic diagnosis might aid in a treatment plan
40. Information is empowering. By the way, my mother's mother lost 2 boys at birth. My mother lost a boy 4 years before I was born. They all had the umbilical cords around their necks. My younger brother, who was born by cesarian, had his cord around his neck. All girl births were fine.
41. being given both pieces of information would provide different information and insights that would be helpful throughout life.
42. I'd want any diagnosis to be identified
43. It is always best to have the full clear answer when it comes to diagnosis accompanied by all tests that brought to that conclusion.
44. I want to Have as much information as possible. An accurate diagnosis can be valuable when considering therapy or treatment options in the future.
45. More info is better than less.
46. I want to know ALL conditions involved. To me, one is not more important over another.
47. So I would know the cause as well as symptoms of Cerebral Palsy diagnosis
48. The more information the better. However I do not think I have a genetic cause
49. I WOULD LIKE AS MUCH INFORMATION AS POSSIBLE. I DO NOT THINK THE DOCTORS AT [HOSPITAL NAME] EVEN MENTIONED CP OR THE POSSIBILITY OF ANY LIFELONG DISABILITY TO MY PARENTS. MY BELIEF IS THAT INFORMATION WAS WITHHELD FROM MY PARENTS BY THE DOCTORS
50. While a genetic diagnosis wouldn't provide more useful information about symptoms, current treatment options, or quality of life, it may be useful if I decided to participate in genetic research in the future.
51. I don't have a genetic reason for my CP, but if it was genetic I would want to know. I think being aware of it would be. helpful. I chose my answer because I feel like CP is more widely recognized then a genetic diagnosis might be.
52. If the cause of my CP was genetic, I think it would be interesting to know, but I don't think it would affect my life currently.
53. I would want to know as much as possible.
54. Knowing the cause of CP is helpful in understanding and accepting the diagnosis.
55. I want cause and origin information
56. Either diagnosis would be helpful in learning all of the causes of the symptoms of my son's diagnosis of cerebral palsy.
57. It's always good to have as much information as possible
58. Because it accurately names the cause (genetic) and the outcome (CP). Helps people understand where to start with treatments.
59. I believe it is the most accurate and gives the most explanation.
60. I would like to know all aspects involving my CP and/or stroke diagnosis
61. I feel like that would make the picture whole
62. Knowing a cause to my cp might be helpful to know how it will affect me over time as I get older
63. As a mother, I like to know as much as possible as to my son's conditions, regardless of whether it changes his outcome, treatment, etc.
64. Curious if genetics had a part to play in the dignoisis
65. Double diagnosis will be more convincing
66. I still had a brain injury
67. Cp is a hard lonely road at first...and while a second diagnosis could be overwhelming it is nice to be able to find a community with others with that diagnosis. CP is so broad.
68. When my child gets older, I would want him to be able to connect with as many people as possible with a shared identity. I would want to know to access research for both groups, etc.
69. Either way, my symptoms would be the same
70. It wouldnt change symptoms
71. doesn't matter

**Respondents quotes explaining why they are unsure or ambivalent about their diagnostic preferences (80/195, 41%)**

1. I chose that I would be equally comfortable because no matter what diagnosis she has, as long as she gets the help that she can get so she may lead the best life possible, it doesn't matter to me what that diagnosis is.
2. I'm open to finding any diagnosis information available. I am an identical twin(almost identical severity, spastic diplegia), we have always been told our CP is not genetic, but were never given any cause diagnosis. We both have children of our own, none having CP. It would be good to know if there is any genetic concern my children should be aware of when deciding to have their own children.
3. To share with family members
4. This is not hereditary
5. Having answers that make sense. It's been a struggle to find answers for him. It took 7 years to get him diagnosed with Mito and start proper treatment and get his hypoglycemia under control a little bit. Having doctors who understand 16p hasn't happened yet
6. I would be okay either way because I just want to be properly educated regardless of the outcome.
7. My son is [an adult]. Having a diagnosis would not change our lives. There is no treatment or cure so having a diagnosis name would not change anything.
8. Frankly, though I'm fairly sure that my condition is not genetic in nature, the more I could know about my condition the better. But knowing anything more than I now know is better than not knowing.
9. Either option would provide information for proceeding with research of the effects of aging process.
10. I am seeking clarity. There are too many unknowns or assumptions.
11. More information means more informed chocies even if that information means my chocies are more limited.
12. A cause is helpful regardless
13. I am not concerned with the reason from an emotional standpoint, only from the standpoint of being able to find a treatment or cure.
14. Since CP is such a broad spectrum, having more specific terminology to describe it (such as spastic diplegia, PVL, or a specific genetic mutation) would be helpful, but diagnosis is really just a word to describe how something affects someone, so either CP or a genetic term is fine.
15. currently you can't cure It But knowing may heIP Lader for others and not havinga fuming historyknowing my geniitcs will help
16. I think it is extremely important to fully understand all aspects of my child's diagnosis and treatment outcomes.
17. I want to understand the full picture.
18. for treatment, my physiatrist says it doesn't matter,but i'd like to know
19. I would like to know one way or another if CP has any genetic predisposition.
20. I know I have cerebral palsy, I just would like to have a somewhat better understanding of it.
21. I'm interested to know as much as possible about my disability (causes, prognosis over time)--more information is better!
22. I would be comfortable with both since it would give me a broader picture regarding my medical history and health.
23. I'm comfortable with either diagnosis, whichever is most accurate.
24. To me, a diagnosis is just the starting point of the journey; not the end point...So, the diagnosis may help define the milestones. but ultimately it is just a label, Dont focus on the label, but on the person
25. Makes no difference, the outcome is still the same.
26. More important to me than the diagnosis is treatment.
27. It doesn't really matter as long as it explains why I have the symptoms that I have.
28. I have a healthy attitude toward CP. It's part of who I am. As far as I am concerned, what does it really matter which diagnoses option it is?
29. The diagnosis itself isn't as important to me as understanding symptoms and how to manage them.
30. There was nothing that could be done in either case. Genetic or medical wise. His early birth could not be changed, nor could any genetic abnormalities.
31. I was unaware that genetics play a role with Cerebral Palsy.
32. I'm not so concerned with the diagnose.
33. I would work through either
34. I'm unclear on the ask here.
35. More concerned about treating/caring for my son than the why or how he got CP. The why /how is best left up to the experts and hopefully information we provide can help in that endeavor.
36. Because the paralysis was caused by trauma at birth
37. I don't know that it would change anything
38. I am highly educated and do not have a preference on the diagnoses.
39. I have never thought about there being a genetic component to my diagnosis. While what happened to me could have been avoided, it is what it is.
40. I'm willing be comfortable with any diagnosis
41. To me the cause is not important; treatment is.
42. It doesnt matter
43. He has had whole exonerated sequencing and no genetic cause was found
44. I have always believed CP IS due to an accident, a preemie birt, lack of oxygen or an infection. I tend to believe if a genetic label is attached, it may be for financial reasons in the medical research field?
45. We are just fine with the diagnosis, this helps us get all the services needed.
46. Not sure how would feel about receiving genetic information.
47. I'm so sure my son has CP because he lacked oxygen during birth that I don't know how I would feel if I learned that he also has a genetic condition
48. My son's CP was caused by a forceps induced skull fracture resulting in a massive intracranial bleed. I have never considered a genetic cause.
49. I'm unclear on the ask here.
50. Doesn't change who he is today
51. Not relevant to my situation
52. is there actually a genetic component? i guess i don't know much about that.