

Florida Specific Data- FI Rep/ Senate Request
COVID-19 Longhailer Advocacy Project & Florida COVID-19 Longhailers Chapter

- 1) 52% of Long Haulers have been sick for over a year due to their COVID-19 infection. Another 31% have been sick for over 6 months, which qualifies them under the criteria for chronic illnesses such as POTS and ME/CFS.
- 2) The majority of Longhailers at 60% reported having up to 20 symptoms. 13% up to 40 symptoms, 9% up to 50 symptoms, 7% up to 70 symptoms, 6% up to 90 symptoms and 5% over 100 symptoms. To note, there have been over 200 symptoms associated with COVID-19 and Long COVID.
- 3) When asked how they would compare their Longhaul symptom severity to their acute-infection symptoms, 16% of Longhailers said their symptoms are less severe, 32% said their symptoms are about the same and 52% said they are more severe.
- 4) Longhailers were asked about the conditions they have developed post-COVID-19 infection only. We specifically only asked about what we call the “big 6”, being a very common diagnosis post-COVID-19 infection in Longhailers.
 - A. POTS (Postural Orthostatic Tachycardia Syndrome): 23% have been diagnosed, and 50% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis.
 - B. ME/CFS (Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome): 22% have been diagnosed, 46% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis.
 - C. Autoimmune Disease: 24% have been diagnosed, 49% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis. To Note: The most common autoimmune diseases being diagnosed in Longhailers are Lupus, Sjogren's Syndrome, Rheumatoid Arthritis, Sarcoidosis, Amyloidosis and Anti-phospholipid Syndrome.
 - D. MCAS (Mast Cell Activation Syndrome): 13% have been diagnosed and 52% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis.
 - E. SFN (Small Fiber Neuropathy): 17% have been diagnosed and 35% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis.
 - F. Fibromyalgia or another chronic pain condition: 24% have been diagnosed and 37% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis.
 - G. Organ damage: 29% have been diagnosed and 33% responded they have not been diagnosed but it is suspected and they are pending testing and diagnosis.
- 5) Longhailers were asked if their quality of life before COVID-19 infection was 100%, how would they now rank their quality of life. 34% rated their quality of life under 30%, 34% rated their quality of life between 40-50%, 27% rated their quality of life between 60-70% and 5% rated their quality of life over 80%. Not one person reported maintaining 100% quality of life and over 64% reported losing over 50% of their quality of life.

- 6) When asked how much time they are stuck in bed due to their illness, 28% said over 70% of the time, 27% said between 50-70% of the time, 26% said between 30-50% of the time and 19% said under 30% of the time. 55% of Long Haulers are confined to their beds over 50% of the time.
- 7) When asked to determine how disabled they would rate themselves with 10/10 being the most disabled, Longhaulers responded as follows: 31% said an 8/10 or higher, 31% said a 6-7/10, 24% said a 4-5/10, and 14% said below a 3/10. 62% are above a 6/10 level of disability.
- 8) When asked how being a Longhauler has affected their employment, 43% reported that they have already been fired or had to quit because of their health issues, 20% said they are still working, but suffering greatly and are on the verge of being fired or having to quit, 29% said they are still working but have had to reduce their work hours and are no longer making the living they need to be to make ends meet. 8% said their employment has not been affected and they can keep up without consequence.
- 9) When asked if they were out of work because of their illness and how long they have been out of work, Longhaulers responded as follows: 19% said they have been out of work for over a year, 10% said they have been out of work for 9-12 months, 5% said they have been out of work for 6-9 months, 12% said they have been out of work for 3-6 months and 4% said they have been out of work under 3 months.
- 10) For those who have had to reduce their work hours due to their illness, 13% said they have had to do this over a year, 9% for 9-12 months, 8% for 6-9 months, 13% for 3-6 months and 2% under 3 months,
- 11) For those that have been completely out of work, we asked if they saw themselves being able to return to work. 20% said they do not think they will ever be able to return to work, 10% said they think they might be able to return to work but believe it will take years and do not know how many years, 7% said they think they might be able to return to work but will need *significant* accommodations and 14% said they will need to find a new line of work if they are able to go back to work, as they would be unable to perform the same job they had prior to COVID-19 infection.
- 12) For those who had been working reduced hours/ capacity we asked if they saw themselves returning to full capacity. 30% said they do not ever see themselves returning to work at full capacity/ full time hours, 9% said they think they can return to work in years but do not know how many years, 9% said they may be able to return to full capacity but with *significant* accommodations and 9% said they believe they will need to find a new line of work if able to return full time/ full capacity.
- 13) We asked Longhaulers what they have applied for and the decision/ status. Workers Compensation- 13% denied, 3% approved, 2% pending. Short Term Disability- 12% denied, 14% accepted, 1% pending. Long Term Disability 15% denied, 3% accepted, 6% pending. SSDI- 1% denied, 0% accepted, 11% pending. 62% said they have not applied for any of these.
- 14) Longhaulers were asked about the level of accessibility to quality medical care. 5% said it has been easy to obtain, 22% said it has been moderate, 42% said it has been hard and 31% said it has been impossible. Medical gaslighting is an extreme issue and lack of

provider education surrounding Long COVID and its associated conditions is significantly lacking.

- 15) When asked how often they have dealt with gaslighting, patient blaming and being told their issues are psychosomatic or due to anxiety, 5% said not at all, 27% said rarely, 52% said most of the time and 16% said all the time. That is 68% of Long Haulers who are not being listened to, believed, heard or offered help.
- 16) Longhaulers were asked if they have a child who contracted COVID-19 and if they became a Longhauler. 38% said they do not have a child. Of those who did have children, 25% reported that their child had COVID-19 and became a Longhauler. 16% said their child got COVID-19 but did not become a Longhauler, and 21% said they have a child, but they did not get COVID-19.
- 17) For those that did have a child who became a Longhauler, they were asked how being a Longhauler has affected their ability to go to school and participate in normal childhood activities. 1% said not at all, 5% said mildly, 8% said moderately and 11% said severely.
- 18) Longhaulers were asked if they were able to get tested for COVID-19. 55% said yes and it was positive, 9% said yes but their test was a false negative based on having all the symptoms and or being positive for antibodies, 14% said yes but it was negative because by the time they were able to access the test it was out of the testing window/ too long after infection, 2% said no, they were asymptomatic and did not get tested but they are now a Longhauler, 12% said no because tests were not available in their area, 6% said no they were not able to access a test in time so never went, and 2% said their provider would not test them and advised them to just quarantine. That is a total of 43% of Longhaulers who have no documentation of a positive test due to lack of access to testing period, or lack of access to testing in a timely manner. This is only a glimpse into the drastic undercounting of COVID-19 cases and Longhaulers. Additionally, those with antibodies are not counted as a COVID-19 case and they should be.
- 19) When asked if they developed antibodies, 24% said no, 37% said yes and 39% said they do not know. To Note: Many infected with COVID-19 never developed antibodies, others have but only had them 3 months, others 9 months and some over a year. There is no answer as to why this happens. Additionally, there is a T-cell test out. Many Longhaulers were excited about this as they felt it was their chance to prove they had COVID-19. Unfortunately of hundreds who have taken this test in the groups, only 1 I know of came back positive. There are also Long Haulers who got the vaccine and did NOT develop antibodies from the vaccine either. This needs to be studied. We also had Long Haulers reinfected who were still positive for antibodies and it is not known whether they were exposed to a high viral load, they had a low level of antibodies or it was a variant that evaded their current antibodies.
- 20) When asked how long their antibodies lasted, 61% said they do not know, 15% said they never developed antibodies, 4% said less than 3 months, 8% said 3-6 months, 4% said 6-9 months, 7% said 9-12 months and 1% said over a year.
- 21) When asked if they have been reinfected with COVID-19 7% said yes with natural antibodies present, 5% said yes without natural antibodies present, 1% said yes after receiving one shot of vaccination (pfizer, moderna), and 5% said yes after being fully vaccinated with 2 shots (pfizer, moderna) or 1 shot of J&J.

- 22) We asked Longhaulers if they got vaccinated, how they felt now. 0% reported being completely cured, 18% said they have seen improvements in their symptoms but they are not cured, 20% said they saw improvements in their symptoms but in a week or two returned to their normal longhaul hell, 22% said they have gotten worse and 40% have not gotten the vaccine. To note: what we are seeing is that the newer Long Haulers are the ones typically seeing the improvements that last. The Long Haulers who are at or over the year mark, are the ones getting worse after the vaccination. Additionally, Long Haulers are experiencing a highly overactive immune system and many have been advised that a challenge to the immune system at this time is not a good idea, hence many Longhaulers not getting vaccinated.
- 23) 20% of respondents were male, 77% female, and 3% non binary.
- 24) 0% of respondents were under 17 (though parents did answer about children in another question) and 0% of respondents were older than 86. 4% were between 18-25, 14% were between 26-35, 26% are between 36-45, 22% were between 46-55, 26% were between 56-66, 7% between 66-75 and 1% between 76-85. 62% of respondents are in the prime of their lives. They are of childbearing and child raising age, in an age critical to career development and creating life savings and the foundation of their futures. They have not become disabled, unable to work, unable to care for and provide for their children. It is not just the Longhaulers being affected by their illness, it is their families and their entire futures.
- 25) Long Haulers were asked what daily activities they have difficulty with. 61% said driving, 45% said bathing, 58% said cooking, 62% said laundry, 75% said sweeping and mopping, 48% said dishes, 37% said helping care for the children, 28% said dressing, 39% said caring for a pet, 58% said reading/ writing, 56% said food shopping, 87% said remembering, 43% said making appointments, 37% said talking on the phone, 65% said communicating, and 3% said none of the above apply. To Note: When people have difficulty with normal everyday tasks, they cannot work, or be expected to work.
- 26) When asked what they have had difficulty paying due to the illness and employment status, Longhaulers responded as follows: 37% paying their rent or mortgage, 39% paying utilities, 28% paying their car lease/ finance/ insurance, 48% said paying medical bills, co-pays, deductibles, premiums, insurance, 26% paying for food, 36% paying credit cards or loans, 8% paying their businesses bills, 16% paying for their child's activities, 19% paying for school/ training, 17% paying for their pets food/ needs. 41% said none of the above apply.
- 27) When asked what Longhaulers wanted their Florida members of Congress to do, they responded as follows:
- A. 89%- Add Long COVID to the list of accepted disabilities and provide ADA.
 - B. 88%- Admit that COVID-19 is a real problem taking lives and ruining lives through the development of chronic illness
 - C. 86%- Fund education and awareness campaigns to educate the public, other Longhauler, and medical providers about Long COVID.
 - D. 80%- Hold a round table meeting with Longhaulers and experts to learn face to face and listen to the science and real life experiences.

- E. 80%- Work with Longhaulers to form COMPREHENSIVE Post-Covid Care Centers (not the PCCC's that exist now)
- F. 69%- Provide supplemental income to Longhaulers
- G. 66%- Keep and enforce mask mandates, social distancing guidelines, capacity limitations, and travel restrictions
- H. 66%- Provide funding that can help Longhauler maintain their bills/ offer forgiveness programs
- I. 64%- Provide Long Haulers with free medical care
- J. 56%- Reform the healthcare system