

STATEMENT FOR THE RECORD

HEARING BEFORE THE SUBCOMMITTEE ON HEALTH
COMMITTEE ON ENERGY AND COMMERCE

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“Survivor Corps PASC Research Brief”

Submitted by Survivor Corps

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Chairwoman Eshoo, Ranking Member Guthrie, Chairman Pallone, Ranking Member McMorris-Rodgers, and distinguished members of the Subcommittee:

Thank you for the opportunity to submit testimony today. In this brief we summarize the research findings of Survivor Corps and our research collaborators regarding patients' experiences with Post-Acute Sequelae of SARS-CoV-2 infection (PASC).

Key research findings about PASC:

- People suffering from PASC experience a wide range of long-lasting COVID-19 symptoms (over 100 symptoms identified by our research)¹
- In our study of COVID-19 patients' electronic health records, 27% of COVID-19 positive patients reported symptoms after 60 days. Being asymptomatic at onset of COVID-19 was the strongest predictor of developing PASC², which indicates that large numbers of people who did not know they had COVID-19 are likely to develop PASC
- While the impact of COVID-19 on the lungs and vascular system is becoming well known, our research found that brain, whole body, eye, skin, and dental symptoms are also frequently occurring health problems for people suffering from PASC
- On average, our research participants with PASC reported 21.4 symptoms and the number of symptoms ranged from 1 to 93³
- The most commonly reported long-lasting COVID-19 symptoms found by our research are: fatigue (79.0%), headache (55.3%), shortness of breath (55.3%), difficulty concentrating (53.57%), inability to exercise or be active (49.6%), cough (49.0%), changed sense of taste (44.9%), diarrhea (43.9%), muscle or body aches (43.5%), difficulty sleeping (41.8%), and memory problems (40.1%)
- The PASC symptoms that survivors reported most impacted their ability to work included the relapsing/remitting nature of illness (described by survivors as "changing symptoms"), inability to concentrate, fatigue, and memory problems, among others
- Patients reports suggest that PASC symptoms occur in waves, from neurological and cardiovascular manifestations with some indicators of a strong immune response, followed by microvascular consequences, and then impact on endocrine (thyroid) function

¹ <https://www.survivorcorps.com/s/2020-Survivor-Corps-COVID-19-Long-Hauler-Symptoms-Survey-Report-revised-July-254.pdf>

² <https://www.medrxiv.org/content/10.1101/2021.03.03.21252086v1>

³ <https://www.medrxiv.org/content/10.1101/2021.03.22.21254026v2>

FIGURE 1. PERCENTAGE OF RESPONDENTS REPORTING EACH PASC SYMPTOM (OUT OF 5,163)

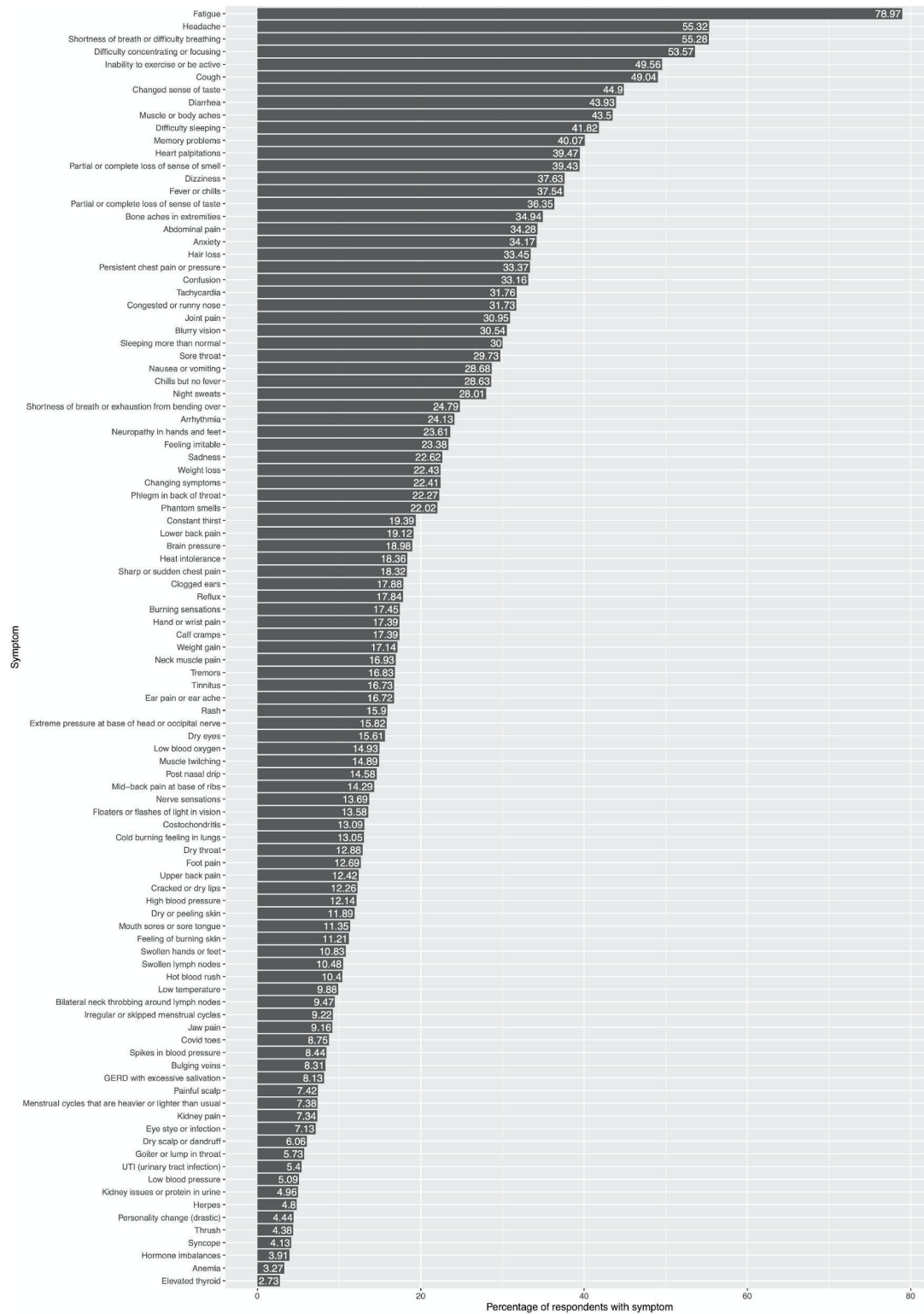


FIGURE 2. NUMBER OF COVID-19 SYMPTOMS EXPERIENCED BY PASC SURVIVORS

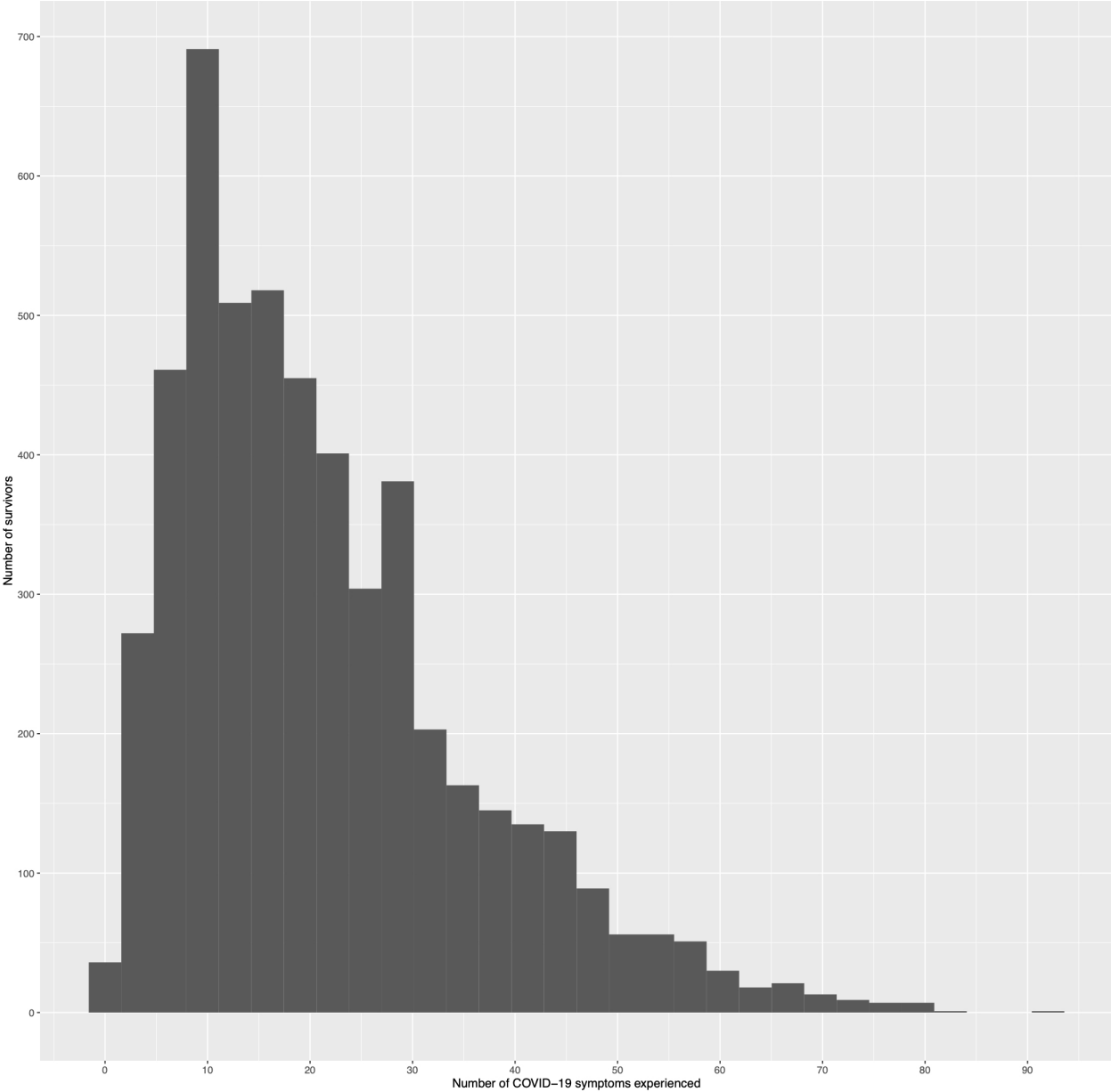


FIGURE 3. THE SYMPTOMS OF PASC AND THEIR IMPACT ON SURVIVORS' ABILITY TO WORK

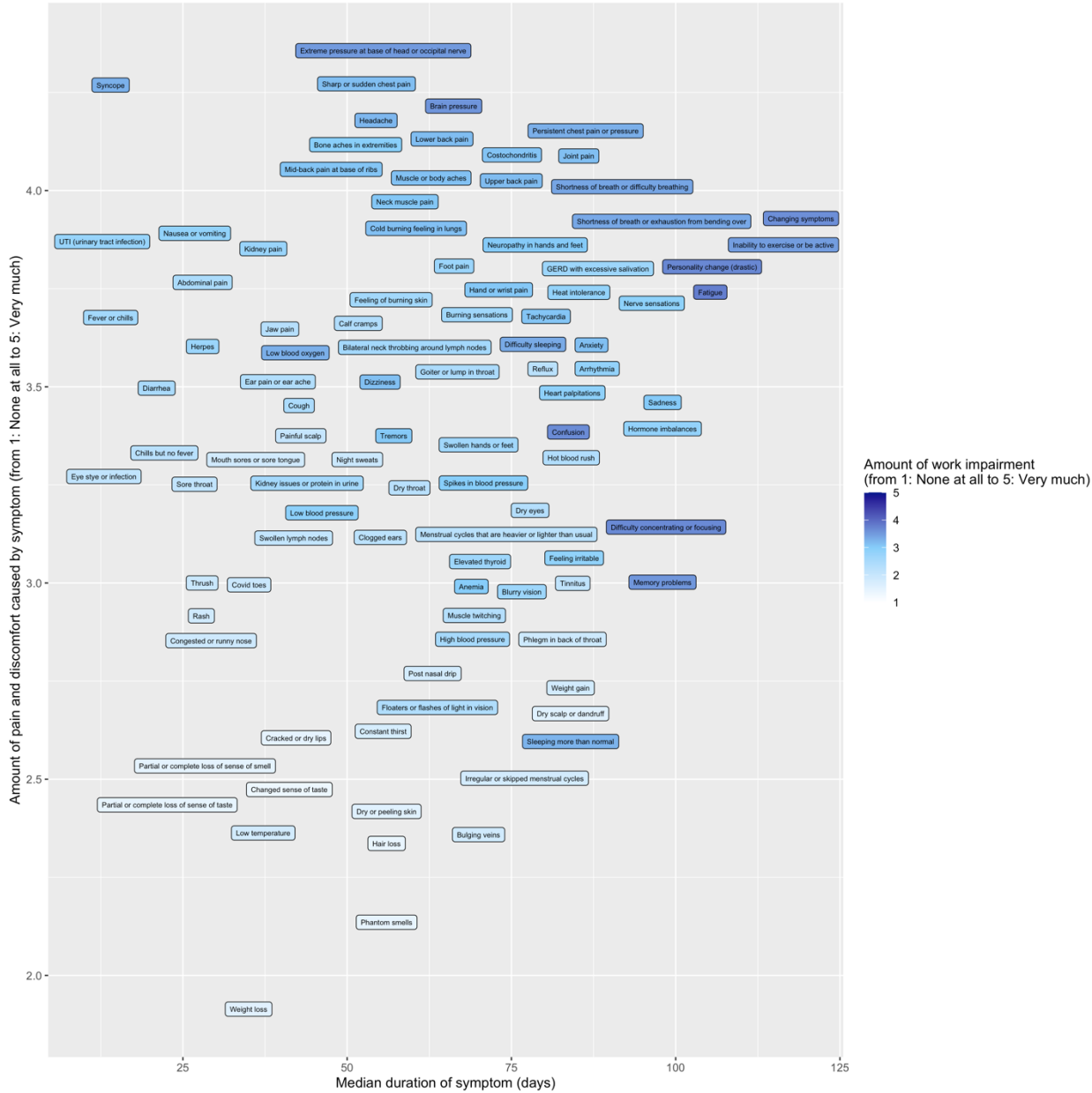


FIGURE 4. PASC INDICATING WAVES OF SEQUELAE IN PLOT OF MEDIAN SYMPTOM ONSET AND DURATION



TABLE 1. PASC SYMPTOMS AND THEIR HEALTH IMPACTS

Symptom	Number of patients reporting symptom	Percentage of patients reporting symptom (%)	Median start date (days)	Median duration (days)	Average pain/discomfort of symptom (1-5)	Average work impairment of symptom (1-5)	Average social impairment of symptom (1-5)	Percentage afflicted reporting symptom as ongoing (%)	Percentage afflicted reporting symptom as intermittent (%)
Fatigue	4077	78.97	1	105	3.77	3.79	3.68	83.25	53.74
Headache	2856	55.32	1	56	4.15	3.22	3.07	65.90	76.68
Shortness of breath or difficulty breathing	2854	55.28	5	84	4.04	3.40	3.26	72.04	66.40
Difficulty concentrating or focusing	2766	53.57	7	105	3.14	3.66	3.18	83.41	69.99
Inability to exercise or be active	2559	49.56	1	112	3.84	3.48	3.60	84.25	32.00
Cough	2532	49.04	2	42	3.48	2.46	2.39	52.41	57.23
Changed sense of taste	2318	44.90	5	35	2.50	1.32	1.63	53.71	31.58
Diarrhea	2268	43.93	5	21	3.50	2.49	2.39	44.22	63.62
Muscle or body aches	2246	43.50	2	63	4.05	3.12	2.98	64.07	61.62
Difficulty sleeping	2159	41.82	7	84	3.59	3.35	3.16	80.45	50.58
Memory problems	2069	40.07	14	98	3.00	3.55	3.10	86.52	63.80
Heart palpitations	2038	39.47	14	84	3.51	2.90	2.74	76.55	84.69
Partial or complete loss of sense of smell	2036	39.43	5	32.25	2.50	1.47	1.71	48.33	22.94

Dizziness	1943	37.63	7	56	3.53	3.14	2.92	68.76	82.86
Fever or chills	1938	37.54	1	14	3.68	2.60	2.47	27.19	57.28
Partial or complete loss of sense of taste	1877	36.35	4	28	2.46	1.44	1.71	45.07	24.08
Bone aches in extremities	1804	34.94	5	62.5	4.12	2.97	2.88	73.61	69.90
Abdominal pain	1770	34.28	7	28	3.77	2.47	2.56	61.07	80.51
Anxiety	1764	34.17	8	84	3.60	3.15	3.39	88.72	83.84
Hair loss	1727	33.45	56	56	2.34	1.40	1.74	76.03	15.98
Persistent chest pain or pressure	1723	33.37	7	84	4.12	3.30	3.15	66.69	67.38
Confusion	1712	33.16	7	84	3.38	3.65	3.33	78.62	77.10
Tachycardia	1640	31.76	14	84	3.62	3.09	2.94	70.49	76.77
Congested or runny nose	1638	31.73	2	31	2.86	1.89	1.83	57.39	53.79
Joint pain	1598	30.95	7	84	4.06	3.15	3.04	76.47	62.08
Blurry vision	1577	30.54	15	77	2.98	2.69	2.21	79.71	71.85
Sleeping more than normal	1549	30.00	1	84	2.63	3.25	3.16	68.82	38.80
Sore throat	1535	29.73	1	28	3.28	2.09	2.02	43.06	52.44
Nausea or vomiting	1481	28.68	5	28	3.88	2.84	2.77	45.78	70.02
Chills but no fever	1478	28.63	4	28	3.30	2.24	2.19	42.69	77.13
Night sweats	1446	28.01	6	49	3.29	1.93	1.88	49.03	69.16
Shortness of breath or exhaustion from	1280	24.79	7	91	3.80	3.37	3.15	76.17	55.55

bending over									
Arrhythmia	1246	24.13	14	84	3.53	2.84	2.77	79.86	87.72
Neuropathy in hands and feet	1219	23.61	21	84	3.71	3.04	2.86	79.66	68.33
Feeling irritable	1207	23.38	14	84	3.06	2.85	3.36	79.45	77.96
Sadness	1168	22.62	14	98	3.44	3.04	3.48	79.54	69.26
Weight loss	1158	22.43	7	35	1.91	1.55	1.53	36.01	18.05
Changing symptoms	1157	22.41	7	119	3.93	3.61	3.61	83.49	82.45
Phlegm in back of throat	1150	22.27	7	84	2.86	1.90	1.85	71.83	54.87
Phantom smells	1137	22.02	28	56	2.14	1.43	1.54	64.82	81.71
Constant thirst	1001	19.39	7	56	2.63	1.74	1.66	67.43	43.96
Lower back pain	987	19.12	7	63	4.10	3.17	2.99	65.96	63.32
Brain pressure	980	18.98	7	63	4.22	3.56	3.42	73.16	78.27
Heat intolerance	948	18.36	21	84	3.70	2.83	3.03	83.23	51.58
Sharp or sudden chest pain	946	18.32	14	56	4.25	3.15	2.95	59.83	79.49
Clogged ears	923	17.88	12	56	3.12	2.19	2.17	70.21	63.06
Reflux	921	17.84	14	84	3.56	2.23	2.23	73.07	72.42
Burning sensations	901	17.45	14	70	3.71	2.64	2.58	70.26	81.69
Calf cramps	898	17.39	17.25	56	3.69	2.37	2.28	71.38	84.97
Hand or wrist pain	898	17.39	28	77	3.78	3.05	2.47	77.17	67.37
Weight gain	885	17.14	28	84	2.72	1.81	2.11	82.94	15.14
Neck muscle pain	874	16.93	7	58	4.00	3.07	2.85	66.48	58.81

Tremors	869	16.83	14	56	3.35	3.05	2.75	66.28	76.18
Tinnitus	864	16.73	17	84	3.01	2.13	2.08	75.35	60.19
Ear pain or ear ache	863	16.72	8	42	3.51	2.35	2.23	58.98	69.06
Rash	821	15.90	21	28	2.91	1.84	1.87	46.41	46.04
Extreme pressure at base of head or occipital nerve	817	15.82	7	56	4.36	3.51	3.32	66.10	71.73
Dry eyes	806	15.61	14	84	3.16	2.32	1.99	74.81	54.59
Low blood oxygen	771	14.93	7	49	3.61	3.30	3.18	54.22	58.75
Muscle twitching	769	14.89	21	70	2.92	2.32	2.21	68.14	79.32
Post nasal drip	753	14.58	3	63	2.77	1.80	1.75	67.60	53.25
Mid-back pain at base of ribs	738	14.29	14	56	4.05	3.09	2.91	63.01	63.96
Nerve sensations	707	13.69	21	98	3.72	2.89	2.81	76.38	74.82
Floaters or flashes of light in vision	701	13.58	21	67	2.67	2.38	2.06	74.04	72.18
Costochondritis	676	13.09	14	70	4.11	3.10	2.93	67.01	60.06
Cold burning feeling in lungs	674	13.05	7	62	3.93	3.13	3.07	64.39	70.62
Dry throat	665	12.88	3	58.5	3.26	2.24	2.14	68.42	58.80
Foot pain	655	12.69	28	70	3.80	2.72	2.62	80.61	68.09
Upper back pain	641	12.42	7	77	4.03	3.17	3.02	69.11	62.25
Cracked or dry lips	633	12.26	7	42	2.60	1.46	1.46	60.98	36.02

High blood pressure	627	12.14	14	70	2.89	2.55	2.41	68.58	55.34
Dry or peeling skin	614	11.89	21	56	2.42	1.56	1.55	66.61	29.97
Mouth sores or sore tongue	586	11.35	21	28	3.30	1.84	1.85	46.93	47.10
Feeling of burning skin	579	11.21	16	56	3.69	2.59	2.49	60.28	72.54
Swollen hands or feet	559	10.83	21	70	3.35	2.62	2.40	73.35	63.69
Swollen lymph nodes	541	10.48	7	42	3.12	2.07	1.98	52.87	43.81
Hot blood rush	537	10.40	14	84	3.34	2.38	2.36	70.02	80.63
Low temperature	510	9.88	7	35	2.39	1.82	1.87	53.33	68.63
Bilateral neck throbbing around lymph nodes	489	9.47	14	56	3.66	2.58	2.54	68.92	74.03
Irregular or skipped menstrual cycles	476	9.22	21	77	2.50	1.79	1.84	66.39	42.44
Jaw pain	473	9.16	21	42	3.63	2.30	2.20	58.14	67.23
Covid toes	452	8.75	21	35	3.00	1.96	1.85	50.00	44.91
Spikes in blood pressure	436	8.44	14	77	3.25	2.98	2.76	63.53	74.77
Bulging veins	429	8.31	42	70	2.36	1.84	1.75	73.43	62.00
GERD with excessive salivation	420	8.13	21	84	3.80	2.68	2.70	77.38	65.48
Painful scalp	383	7.42	21	42	3.35	2.04	2.02	54.57	57.96

Menstrual cycles that are heavier or lighter than usual	381	7.38	21	84	3.09	2.22	2.24	69.55	44.88
Kidney pain	379	7.34	21	35	3.86	2.74	2.60	49.34	67.28
Eye stye or infection	368	7.13	21	14	3.28	2.12	1.93	33.70	32.61
Dry scalp or dandruff	313	6.06	24	84	2.64	1.56	1.71	79.23	28.75
Goiter or lump in throat	296	5.73	21	63.5	3.57	2.45	2.37	65.54	50.68
UTI (urinary tract infection)	279	5.40	28	14	3.87	2.75	2.74	31.54	38.71
Low blood pressure	263	5.09	14	45	3.21	2.92	2.77	61.22	59.70
Kidney issues or protein in urine	256	4.96	21	42	3.28	2.58	2.51	58.59	37.89
Herpes	248	4.80	28	28	3.60	2.71	2.68	52.82	50.40
Personality change (drastic)	229	4.44	21	102	3.78	3.69	3.98	68.12	48.91
Thrush	226	4.38	28	28	3.00	1.95	2.05	33.63	30.09
Syncope	213	4.13	14	14	4.27	3.29	3.15	38.03	62.44
Hormone imbalances	202	3.91	26.25	98	3.42	2.82	2.88	68.32	45.54
Anemia	169	3.27	21	70	3.00	3.01	2.90	73.96	23.67
Elevated thyroid	141	2.73	42	70	3.02	2.67	2.52	68.79	17.73

Thank you, Madame Chair and members of the Subcommittee. We appreciate the opportunity to present what we have learned about PASC from those suffering from the disease.

Thank you for the opportunity to submit this testimony today.