

Negative Reaction, Positive Action

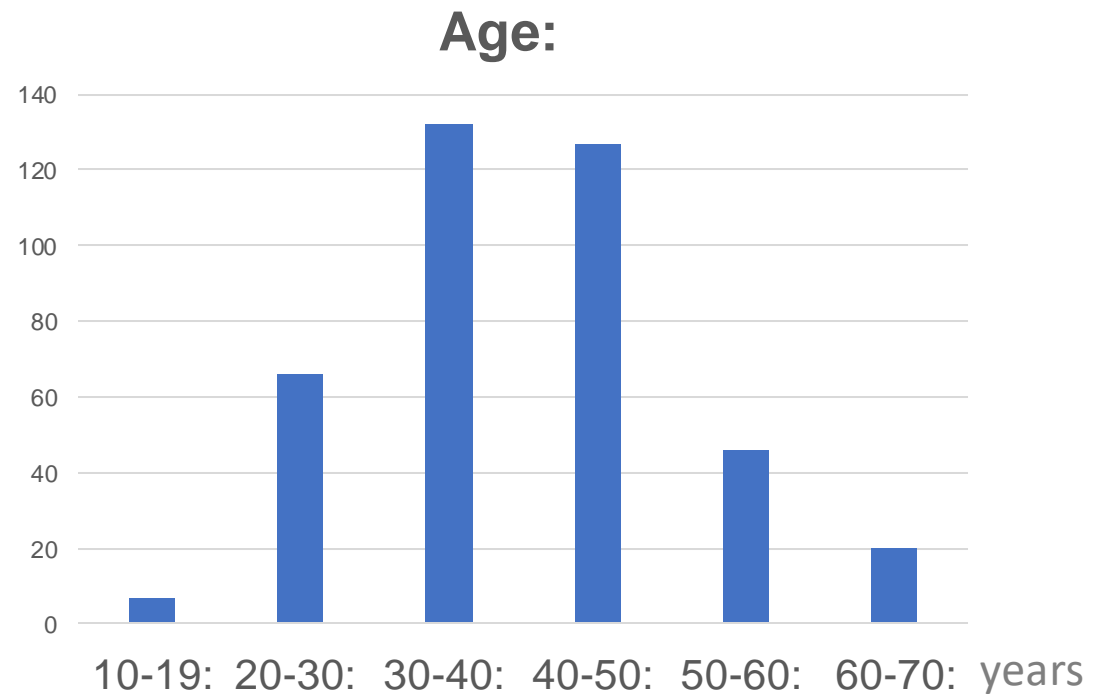
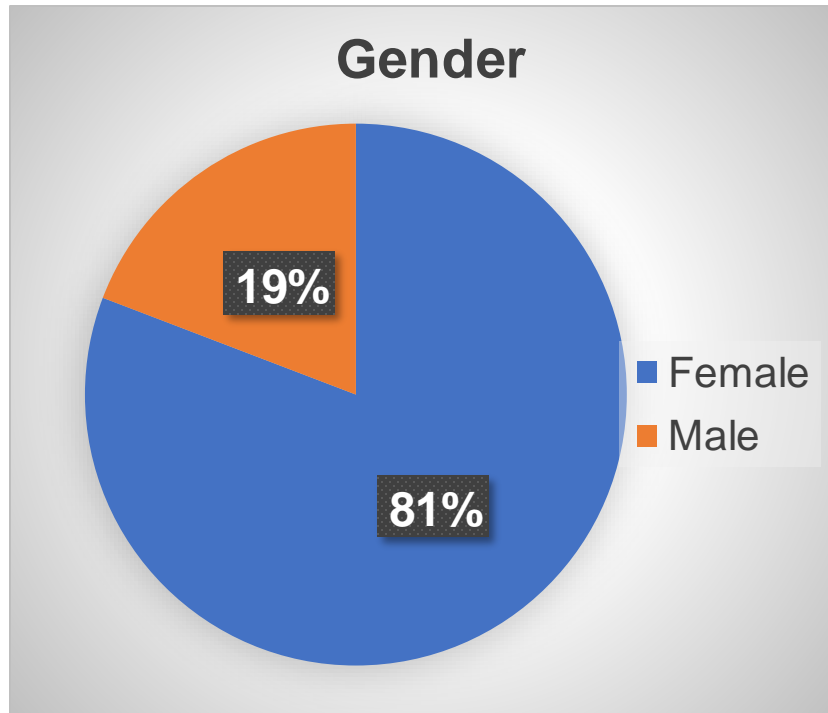
Our Mission:

- To **conduct patient-led research** and collaborate and participate in research through institutions and clinics.
- To **connect patients to compassionate practitioners.**
- To **increase awareness** and understanding of the nature of these syndromes, and hopefully pave the way for symptomatic improvement or a cure. Reduce the stigma.
- To raise funding to provide financial medical assistance to the injured to help them heal.

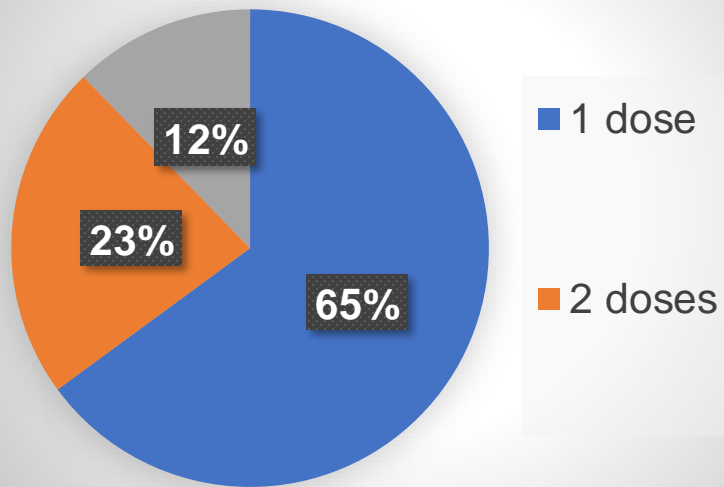
Survey Intro

- Survey gathered from 508 participants
- All participants suffering a wide range of persistent symptoms after receiving the Sars-Cov-2 Vaccine
- Participants based in the United States
- Covid Vaccine Persistent Symptoms Review, Theoretical Mechanisms of Action, Diagnostic Tools, and Possible Solutions

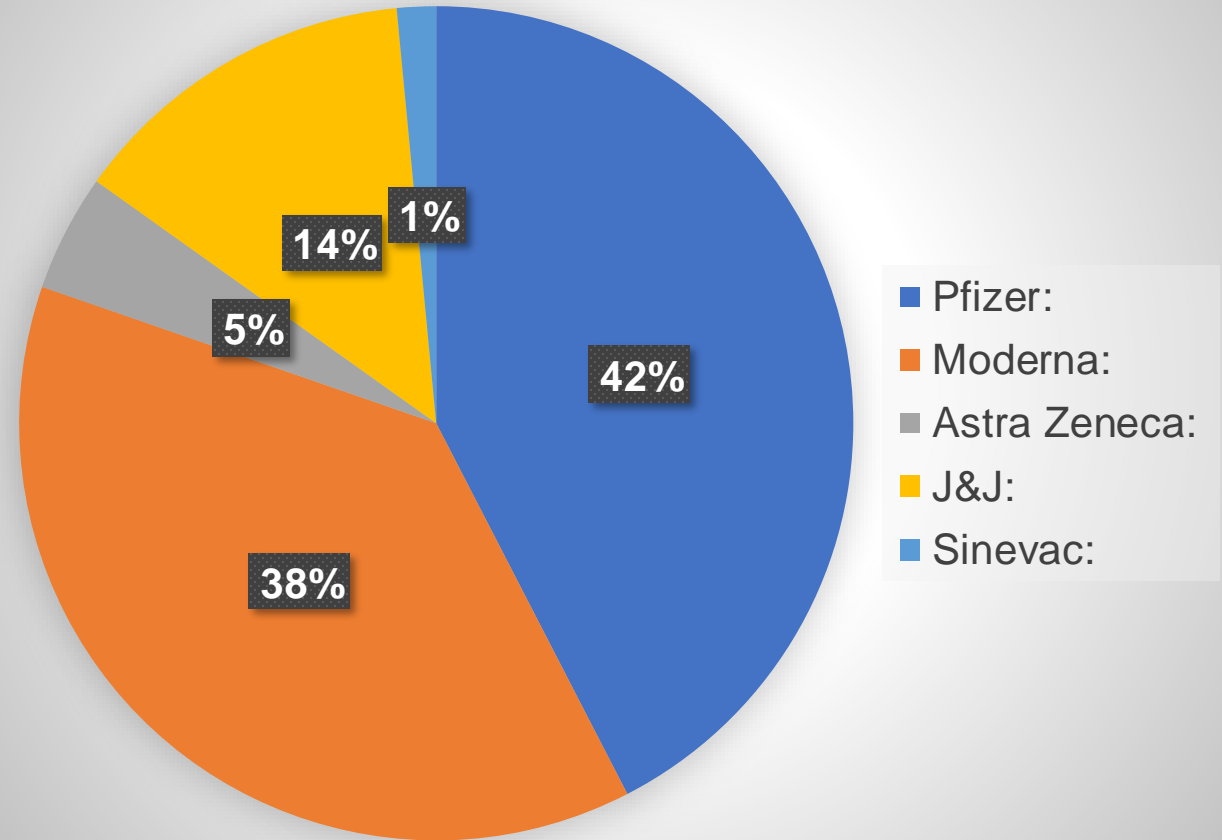
Gender & Age Breakdown



of Doses Received



Brand of Covid Vaccine



Medical History

Have you ever had a positive Covid infection?

No:	85%
Yes:	4%
Don't know:	11%

PRE-EXISTING HEALTH CONDITION:

NO:	71%
Yes:	29%

Prior to Covid vaccination, have you ever reacted to any previous vaccine you had received?

NO:	94%
YES:	6%

Are you the only one in your family to have a persistent adverse reaction to the vaccine?

Yes:	92%
No:	8%

Have you had EBV in the past:

Yes:	38%
No:	30%
Don't know:	32%

High Cholesterol pre vax:

No:	61%
Yes:	16%
Don't know:	23%

Optional - Do you have any known mutations to the mthfr gene?

Never been tested:	93
Yes:	19
No:	13

Top Reported Symptoms

Constitutional

Fatigue:	411
Exercise Intolerance:	178
Insomnia:	150
Chills:	53
Night Sweats:	66
Excessive Sleep:	60
Weight Loss:	40

Neurologic

Paresthesia (burning, tingling):	343
Brain Fog:	346
Dizziness:	277
Persisting Headaches:	209
Nerve Pain:	211
Memory Loss:	125
Difficulty with Speech:	34
Paralysis:	14

HEENT

Tinnitus:	180
Visual disturbance / loss:	141
Sound Sensitivity:	83
Dry eyes:	72
Light Sensitivity:	62
Sore Throat:	41
Jaw Pain:	55

Respiratory:

Shortness of Breath:	154
Cough:	30

Cardiovascular:

Palpitations:	275
Tachycardia:	182
Chest Pain:	160
High Blood Pressure:	74
Low Blood Pressure:	50
Arrhythmia:	17

Gastrointestinal

Nausea:	146
Diarrhea:	76
Abdominal Pain:	102
Dysphagia:	12
Heartburn/Indigestion:	74
Bloody Stool:	4

Genitourinary/ Reproductive

Frequent Urination:	65
Irregular Menstrual Periods:	81

Endocrinologic

Heat Intolerance:	143
Adrenaline Surges:	118
Increased Thirst:	83
Hair Loss:	41
Disturbance in glucose levels:	29

Allergy/Immunology

Lymphadenopathy:	96
New Food Allergies:	44

Musculoskeletal

Muscle Twitching:	254
Joint Pain:	226
Muscle Aches:	204
Heaviness in Lower Extremities:	194
Muscle Atrophy:	82
Swelling in Extremities:	40

Dermatologic

Skin Redness or Swelling:	35
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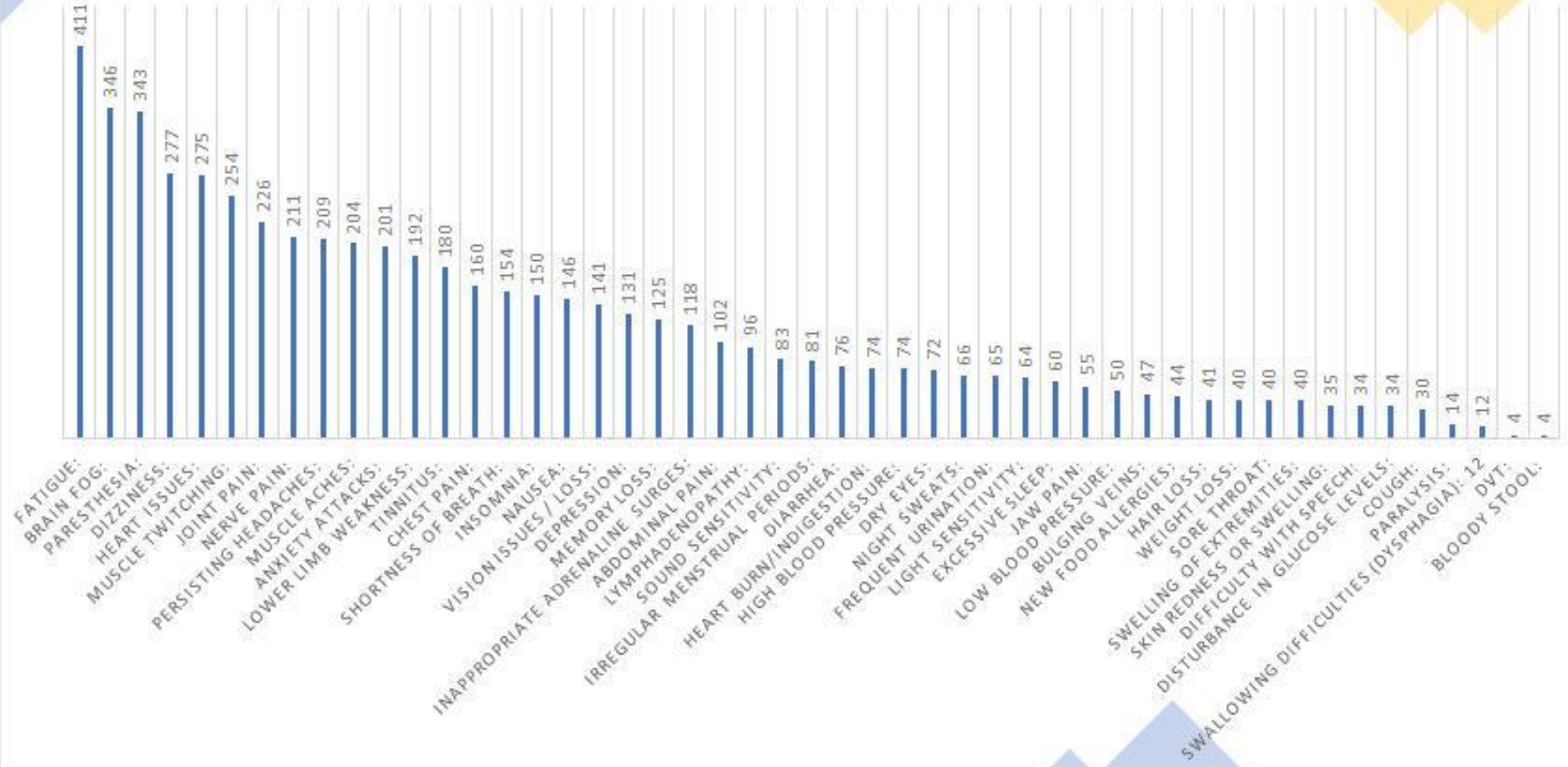
Psychiatric

Depression:	131
Anxiety Attacks:	201

Hematologic

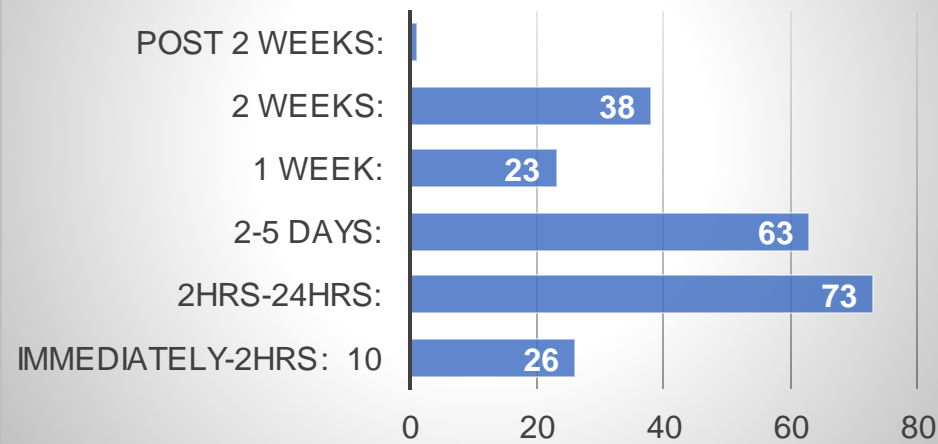
DVT:	4
Bulging Veins:	47

SYMPTOMS

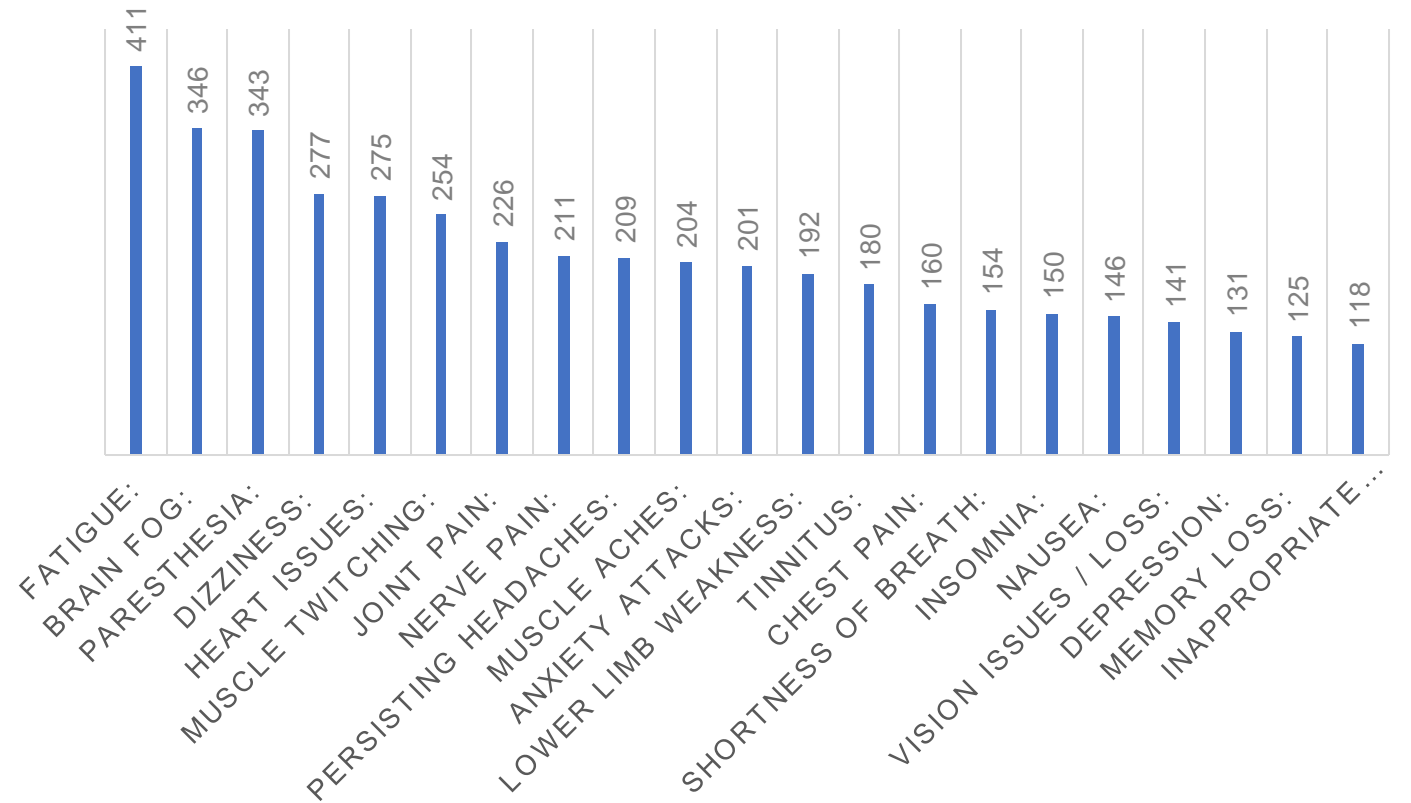


SYMPTOMS TIMELINE AND OVERVIEW

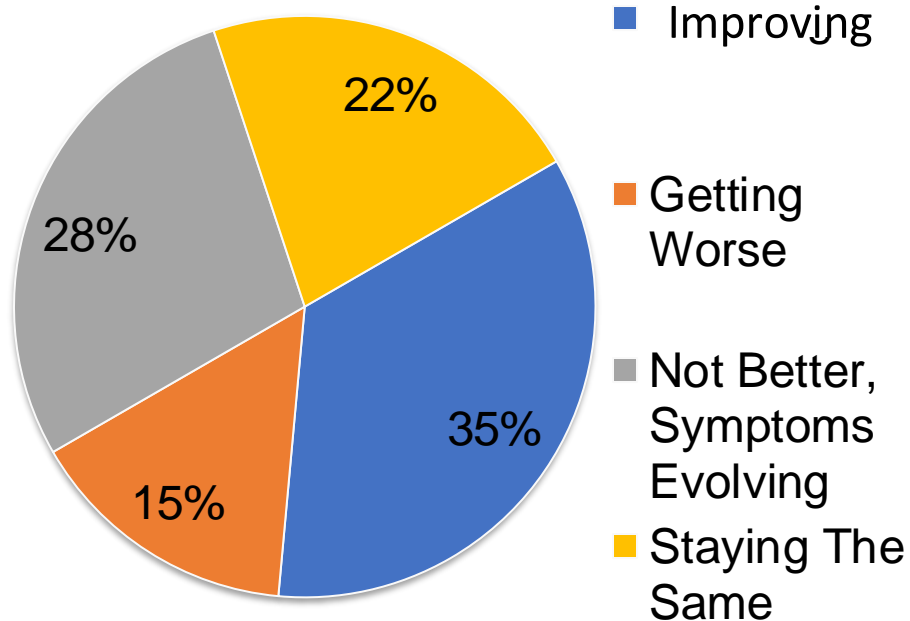
When did symptoms begin?



TOP 20 REPORTED SYMPTOMS



Over the last 6-8 months, are you improving, not better, getting worse, staying the same?

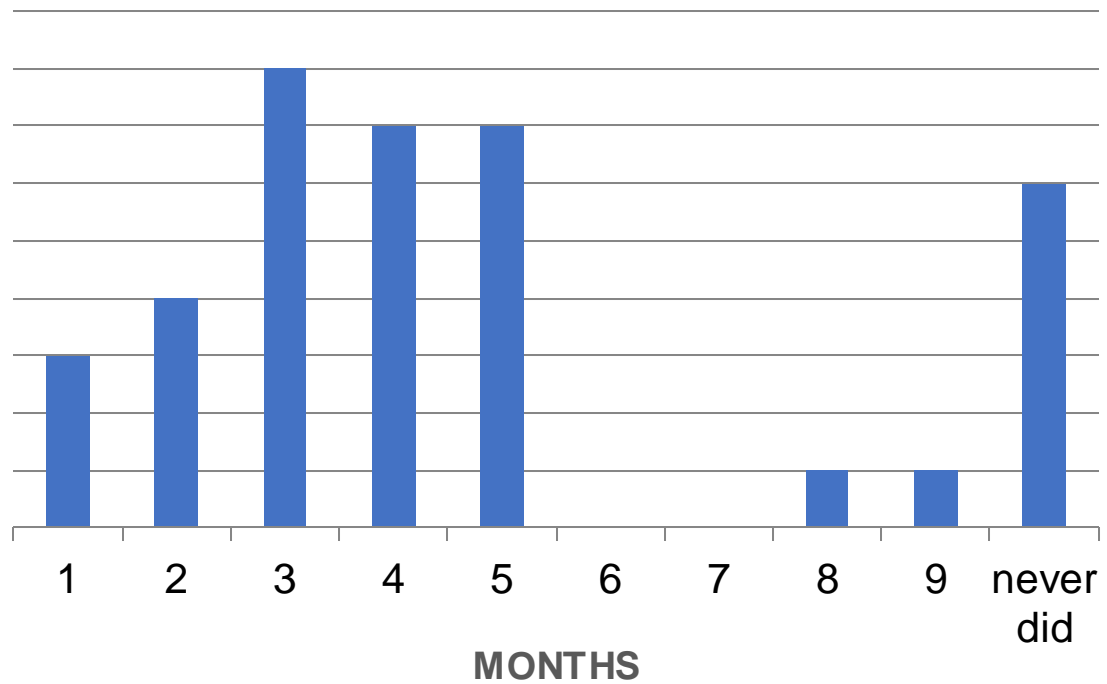


HELPING WITH SYMPTOMS:	
Time	110
Rest	80
Supplements	59
Gentle Exercise	36
Anti-inflammatory Diet	28
Positive Outlook	25
Antihistamines	28
Meditation, vague nerve exercise	6
Acupuncture	4
Distraction	12
Fasting	11
Ivermectin	7
Steroids	10
Red Light therapy	2
Miraviroc	2
Gabapentin	8
Antidepressants fluvox / doxepin	4
IVIG	3

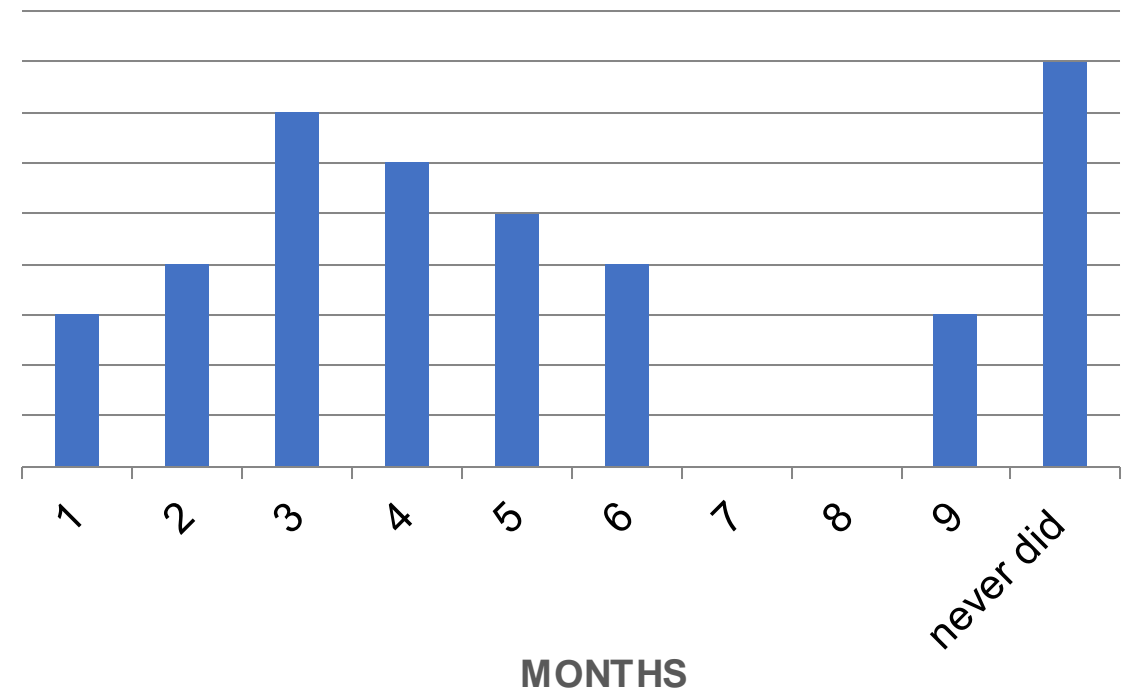
CAUSES SYMPTOMS TO WORSEN:	
Lack of Sleep	93
Stress:	92
Overdoing:	67
Heat:	55
Menstrual Cycle:	36
Sunlight:	23
Humidity:	19
Heavy Endurance Training:	19
Unhealthy food:	13
Dairy:	12
Walking:	11
Gluten	10
Too much screen time:	10
Those with Neuropathy warm water:	9
Those with Neuropathy cold water:	4
Caffeine:	9
Greasy foods:	3

SYMPTOMS TIMELINE

IN WHAT MONTH DID SYMPTOMS BEGIN TO LEVEL OFF?

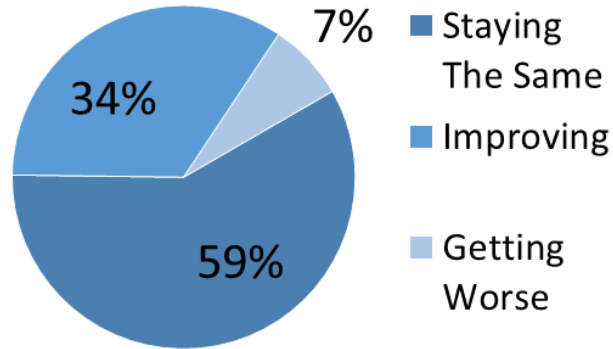


IN WHAT MONTH DID SYMPTOMS BEGIN TO IMPROVE?

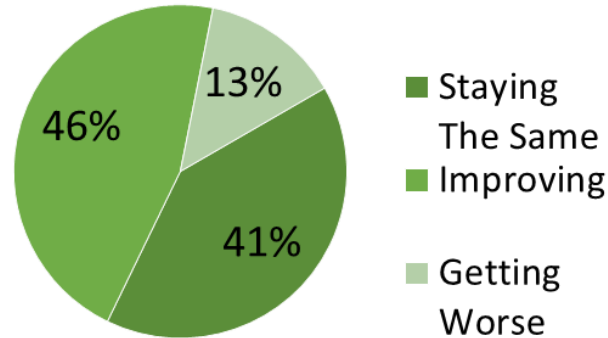


SYMPTOMS PROGRESSION / REGRESSION - (1)

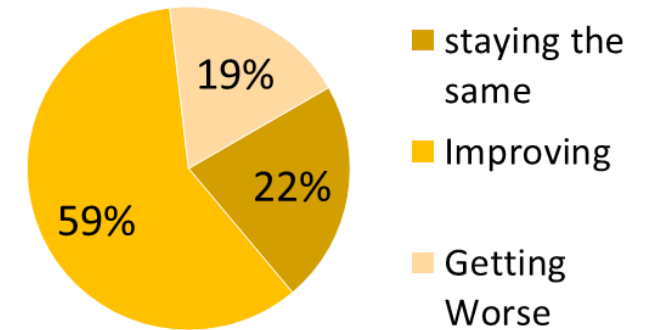
Fatigue



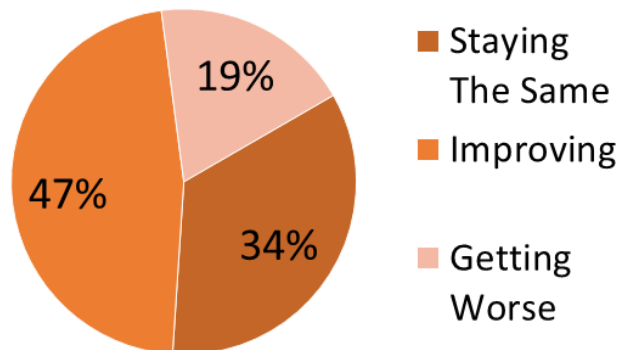
Brain Fog



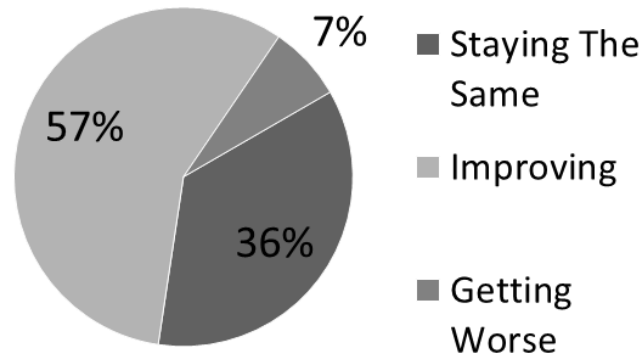
Burning Sensation



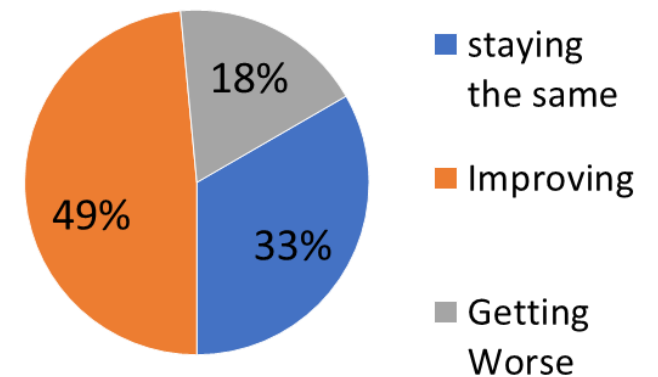
Tingling / Numbness



Dizziness

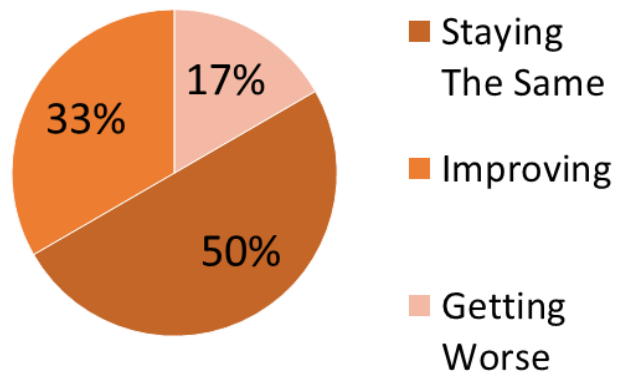


Muscle Twitching

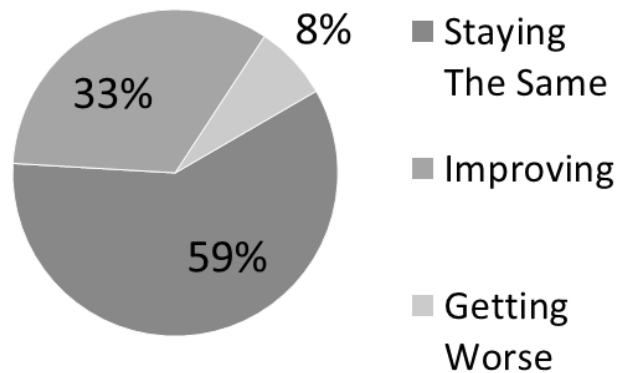


SYMPTOMS PROGRESSION / REGRESSION (2)

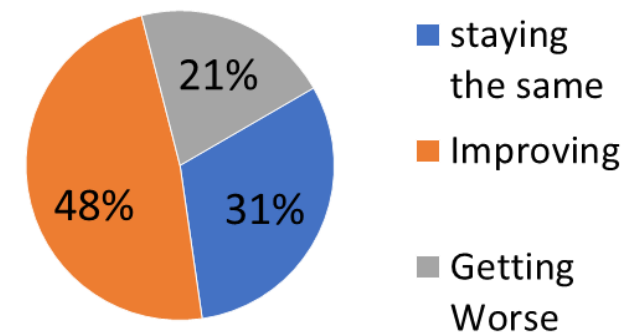
Heaviness In Legs



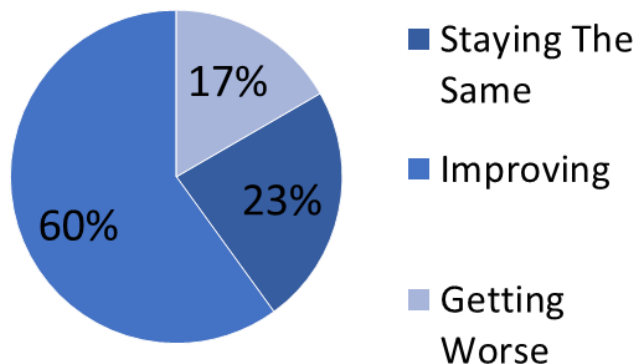
Internal Vibrations



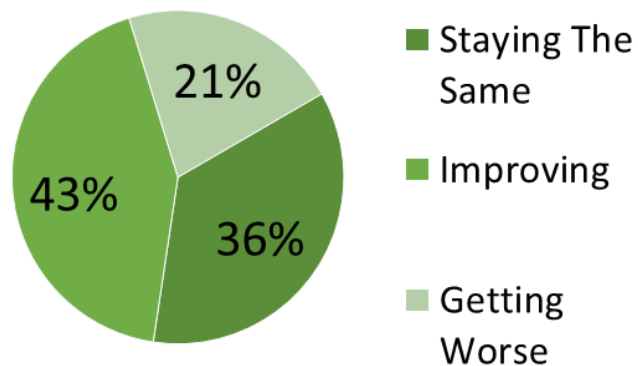
Tinnitus



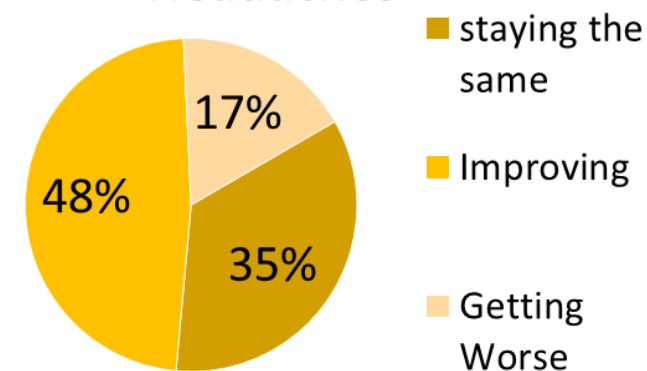
Heart Palpitations



Nerve Pain

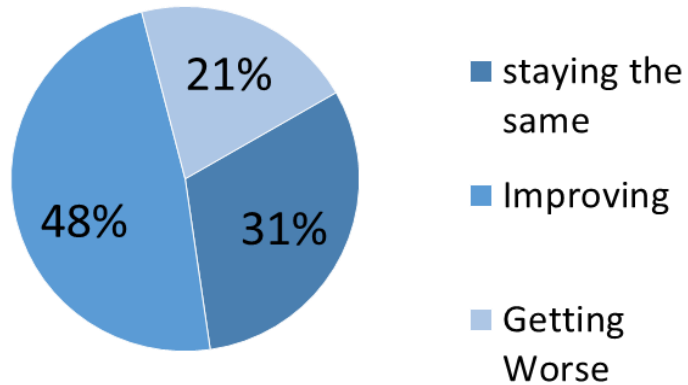


New Persistent Headaches

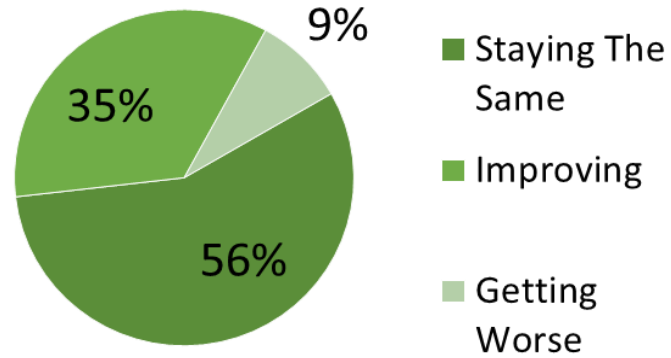


SYMPTOMS PROGRESSION / REGRESSION (3)

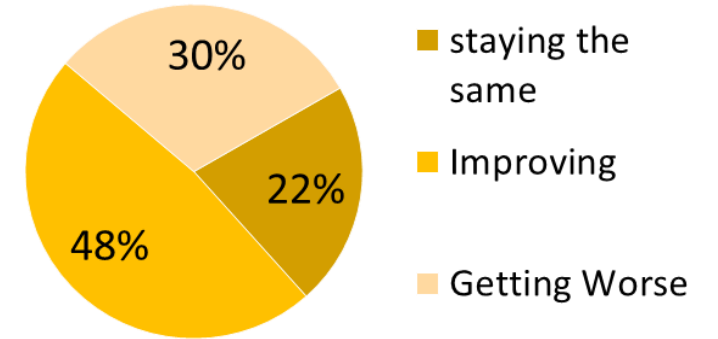
Insomnia



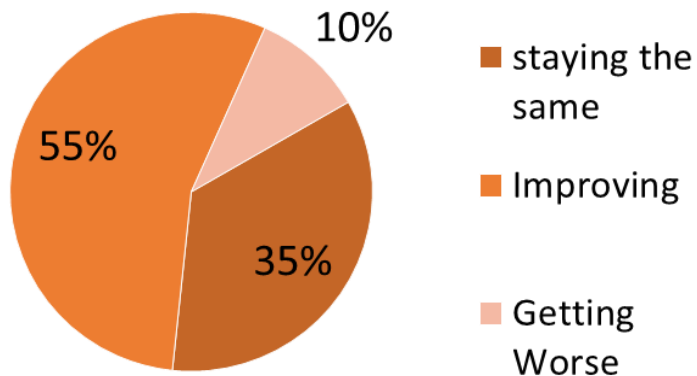
Visual Disturbances



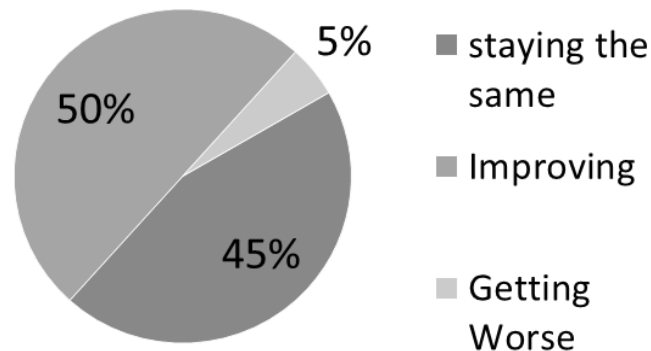
Anxiety



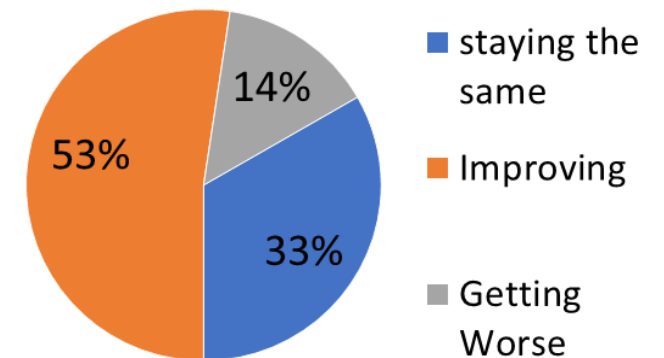
Lymphadenopathy



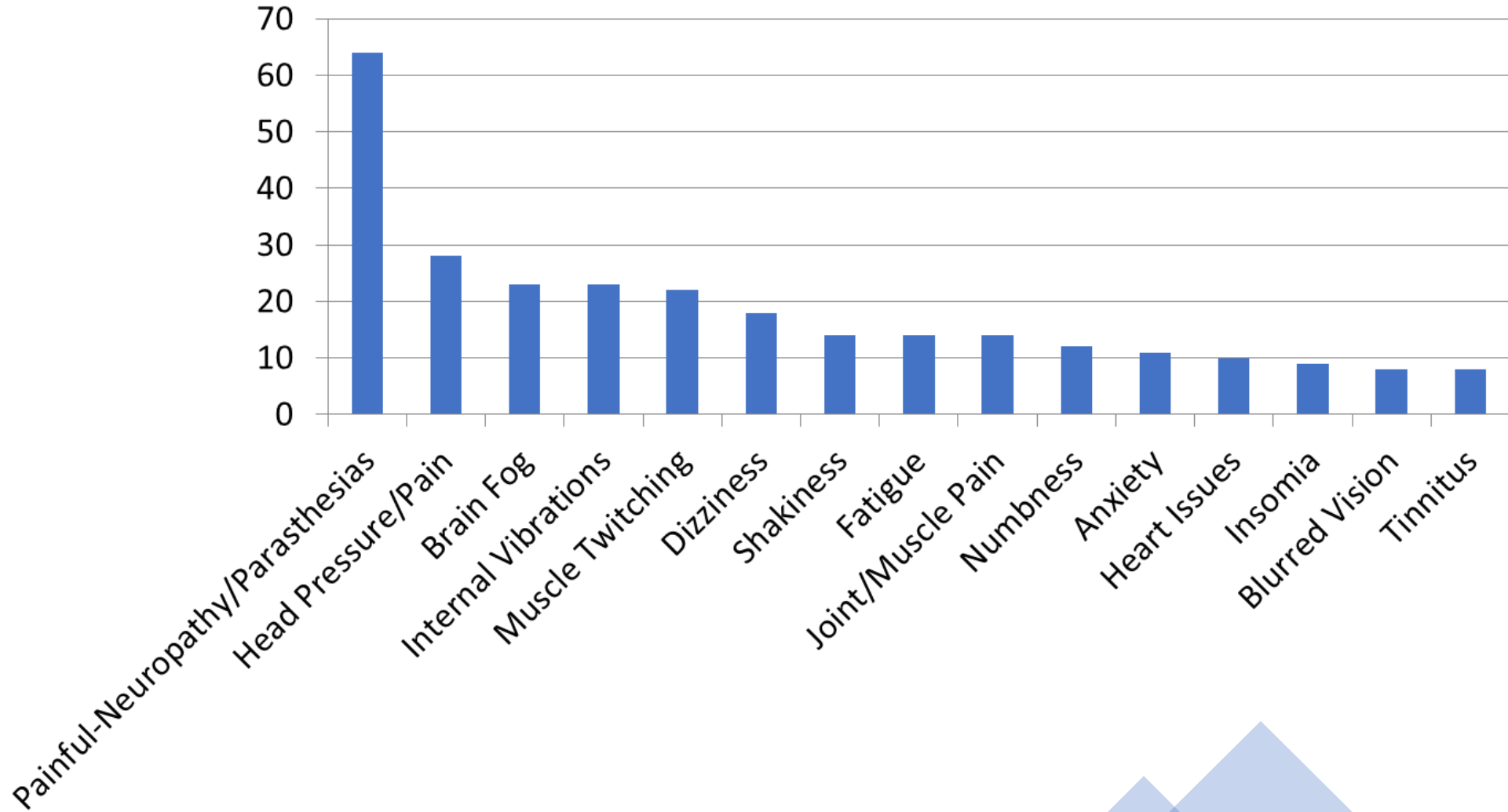
Irregular Menstrual Cycle



Tremors



IF YOU COULD PERMANENTLY ELIMINATE ANY SINGLE SYMPTOM,
WHICH ONE WOULD IT BE?



ETIOLOGY - POSSIBLE MECHANISMS OF ACTION

An immune mediated response in both the innate immune system and the adaptive immune system, that leads to a cascade of dysfunction in systems throughout the body, including neurological, musculoskeletal, dermatological, digestive, metabolic, cardiovascular, etc. These mechanisms can be generally classified into three subgroups:



Allergic

Allergic: Mast cells secrete histamine, tryptase, cytokines, prostaglandin, heparin, chromogranin A,, leukotriene E4, and other factors that are part of immune and neuroimmune systems. To a varying degree patients are exhibiting signs of a prolonged allergic reaction, and some are obtaining primary clonal or secondary non-clonal Mast Cell Activation Syndrome (MCAS) diagnoses.



Autoimmune

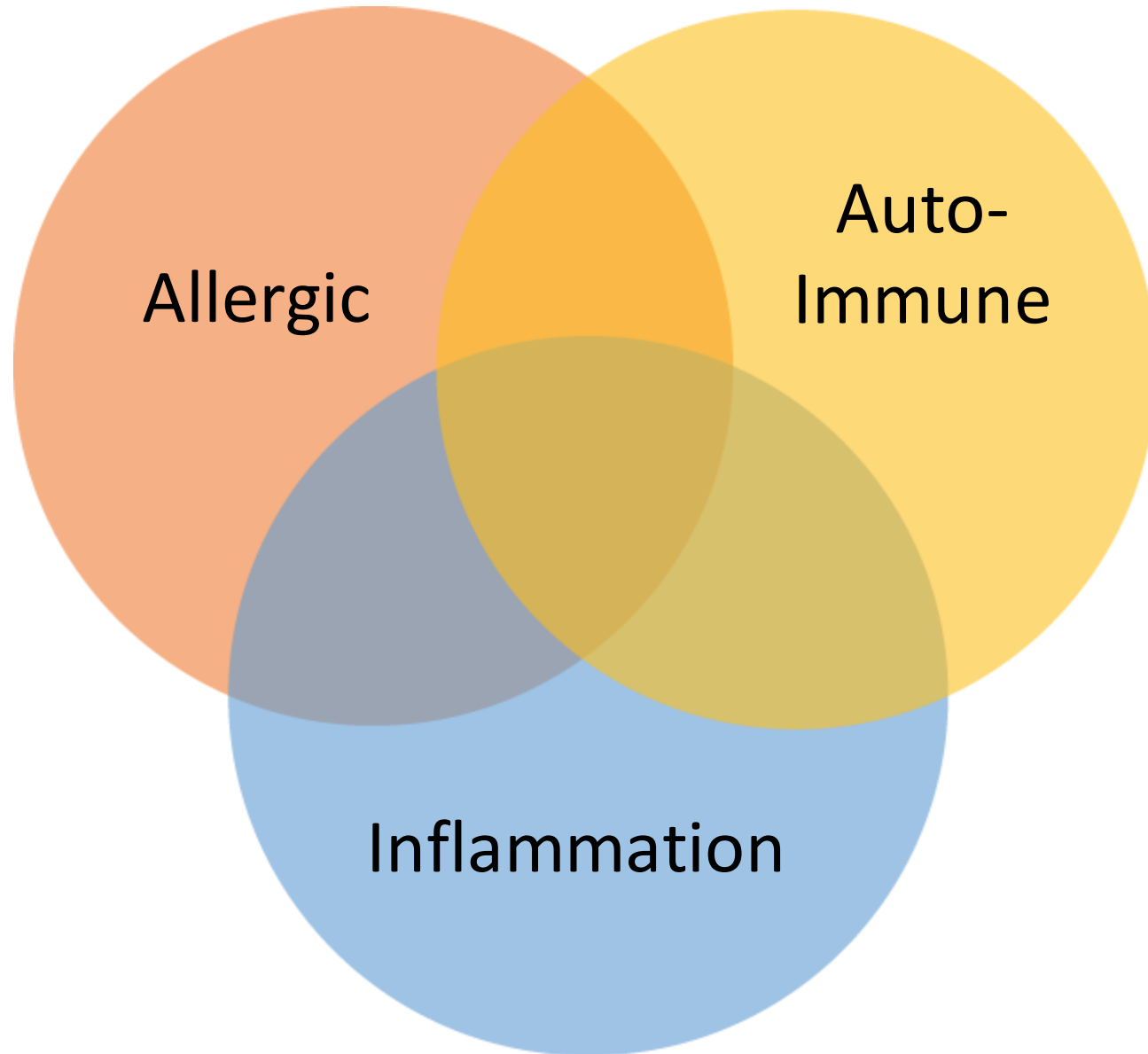
Autoimmune: It is possible that a formation of autoantibodies is involved in our pathogenesis. Some people are finding high ANA (antinuclear antibodies) levels, a non-specific readout for autoimmunity, as well as many different special tests that are strong indicators for autoantibody issues.



Inflammation

Inflammatory: CNS inflammation can be identified on MRIs as well as in clinical presentation. Also found at systemic and cellular levels. Patients are finding increased markers for inflammation: cytokines, CRP, and copper. It is not known yet how the spike protein acts in the body and it is possible that as a pro-inflammatory and vasoactive mediator, it could lead to inflammation and/or vascular damage, especially in the brain.

ETIOLOGY - POSSIBLE MECHANISMS OF ACTION



As the lingering post-vaccination symptoms are diverse, a multitude of independent and **often overlapping** mechanisms could be at play.

These same mechanisms are at play with **Long-Covid**. We can *learn a lot from research already done in this area.*

<https://fluidsbarrierscns.biomedcentral.com/articles/10.1186/s12987-020-00216-1>

Post-Covid Vaccine Syndrome - vs - Post Acute Sequelae of Covid

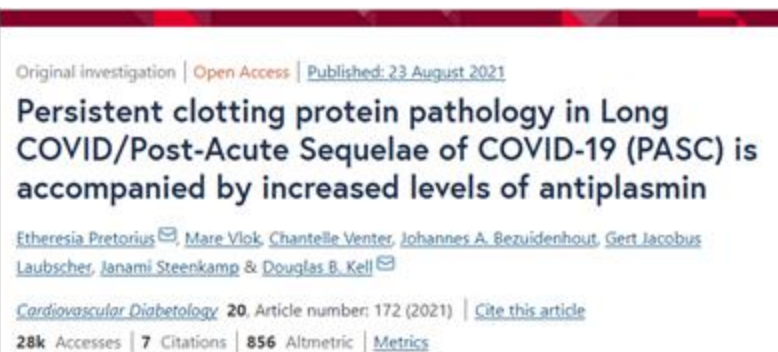


Many similarities between Long-Covid and Vaccine injury exist.

<https://www.science.org/content/article/rare-cases-coronavirus-vaccines-may-cause-long-covid-symptoms>

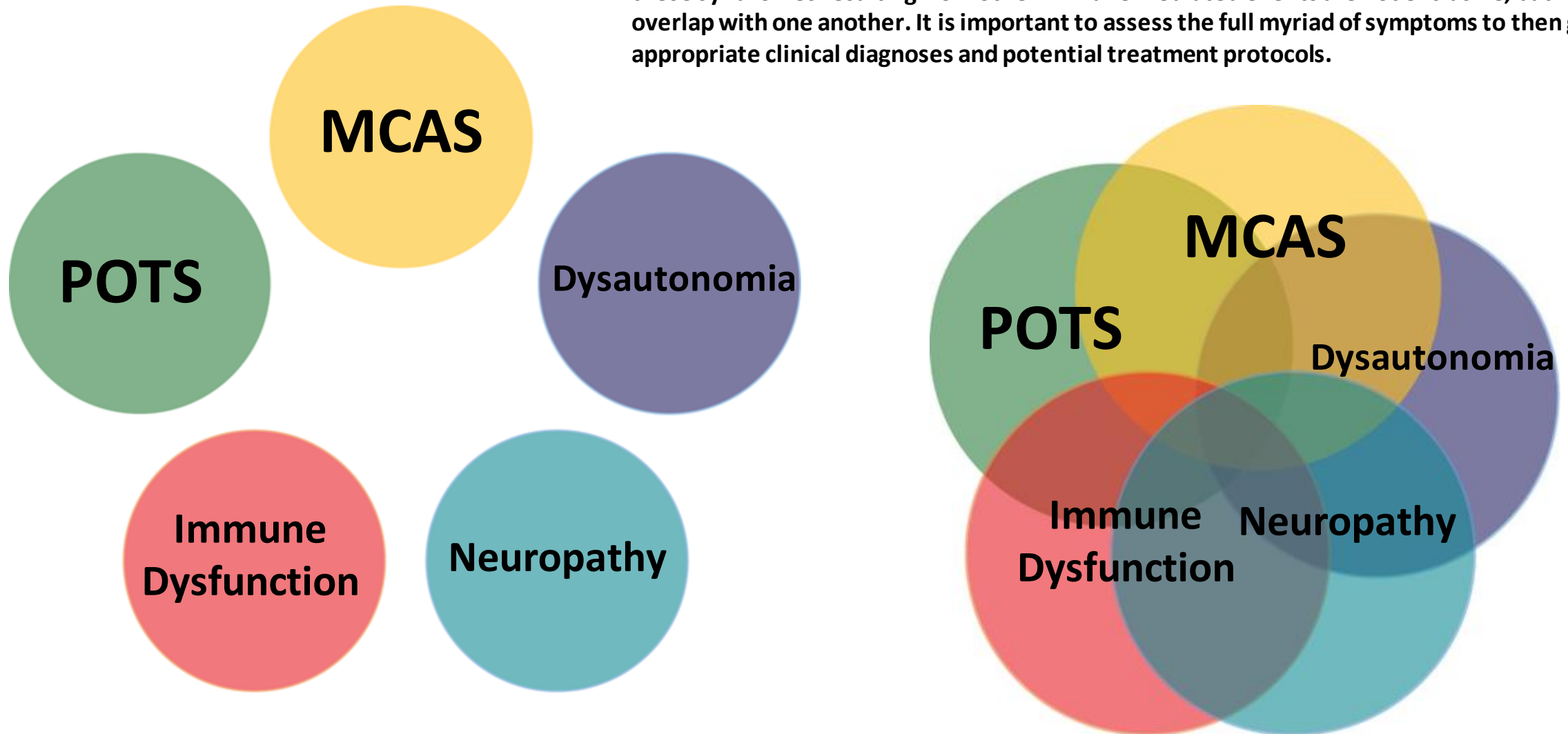


Several **Long-Covid** researchers are now investigating the vaccine injured with striking similarities. Research in each area may inform the other. The Vaccine injuries may hold the key to Long-Covid



SYMPTOMOLOGY – CLINICAL PRESENTATION

Clinical care with specialties often result in a myopic examination and treatment. Historically these syndromes resulting from other immune mediated events are not exclusive, but rather overlap with one another. It is important to assess the full myriad of symptoms to then guide appropriate clinical diagnoses and potential treatment protocols.



Allergic-1

MCAS Anaphylaxis IGE

(See the next page
for resources on
MCAS, Anaphylaxis,
and IGE)

A well-recognized reaction is **anaphylaxis**, where a near immediate response is noted in the patient and can be life threatening. A longer-term reaction that can persist for months, potentially years, can involve **Mast Cells** or via a persistent reaction presenting with elevated **IGE**. To a varying degree patients are exhibiting signs of a prolonged allergic reaction, and some are obtaining primary clonal or secondary non-clonal **Mast Cell Activation Syndrome (MCAS)** diagnoses. Often a clear MCAS diagnosis is challenging to achieve given that its difficult to capture the mediator rise in the blood due to timing, or in the urine due to the required temperature and specialized labs. Some physicians have found it effective to clinically assess patients' response to MCAS protocols, without definitive labs.

Symptomatology: Mast cell mediator release may cause or exacerbate: brain fog, headaches, feelings of anxiety - neurologic, flushing, rashes, hives – skin, throat itching or swelling - ear nose & throat, nausea, bloating, constipation, diarrhea - gastrointestinal and can escalate to anaphylaxis.

Diagnostic Tests: Obtaining a **MCAS diagnosis** can be challenging

1. **Blood Tests:** Tryptase (typically only high in a flair. 1 in 5 MCASers return elevated Tryptase), Chromogranin A, Histamine, and Immunoglobulin Type E, Copper
2. **24-Hour Urine Tests:** Elevated histamine, prostaglandin D2, n-methylhistamine (temperature sensitive, degrades quickly)
3. **Clinical Assessment:** responsiveness to antihistamines and/or mast cell stabilizers, symptoms in 2 or more organ systems, exhaustive patient work-up, and subsequent follow-up
4. **Skin Prick Test, Food Allergy Tests:** they do not assess mast cell mediator release but may help assess triggers

Treatment: Some vaccine injured patients experience a reduction of symptoms with

- **Daily Antihistamines:** H1 and H2 blockers (such as Allegra and Pepcid 2x/day)
- **Mast Cell Stabilizers:** Cromolyn, Ketotifen, Montelukast (blocks leukotriene, be cognizant of black box warning), or Xolair (anti IGE MAB)
- **Supplements:** natural flavonoids (quercetin, luteolin), DAO Enzyme (1 before each meal, breaks down histamines in the digestive system), vitamin C, and vitamin D
- **Diet Modification:** Low-histamine diet, or low-inflammatory diet

Allergic-2

Additional Resources:

Beginner's General Review of MCAS:

<https://www.legalnomads.com/mast-cells?fbclid=IwAR30JlvhhBZh5DmbFhyWUsgEgCQAS-mhXbCAVaUgrhygrzB1BoNdfXHETJg>

MCAS Diet:

https://www.mastzellaktivierung.info/downloads/foodlist/21_FoodList_EN_alphabetic_withCateg.pdf

Dr Tina Peers:

<https://static1.squarespace.com/static/5a4269f28c56a85fe95206ea/t/5fa6d3044f8f02449aaacea3/1604768517153/Dr+Tina+Peers+-+Histamine+Intolerance+Factsheet+-+Nov+2020.pdf>

MCAS and Brain Disorders:

https://www.courtneysnydermd.com/blog/mast-cell-activation-inflammation-in-brain-disorders-how-to-calm-things-down?fbclid=IwAR3dieAPAYfVdqZnXighWh2eUn6tUO7s7LDUaAYbH7oo_DlrBjvT1f0VIDA

Hoffman Centre, Natural Options:

<https://hoffmancentre.com/natural-treatments-for-mcas/?fbclid=IwAR1tpVdDaSe5cpqXukMRKocAl-2YweaP7d-HMz9Mzet0pJSzmEjmeo9FaWc>

Published Literature:

Long Covid and Mast Cells-
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8250989/>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7267424/>
<https://pubmed.ncbi.nlm.nih.gov/33023287/>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7644430/>
<https://pubmed.ncbi.nlm.nih.gov/32920235/>

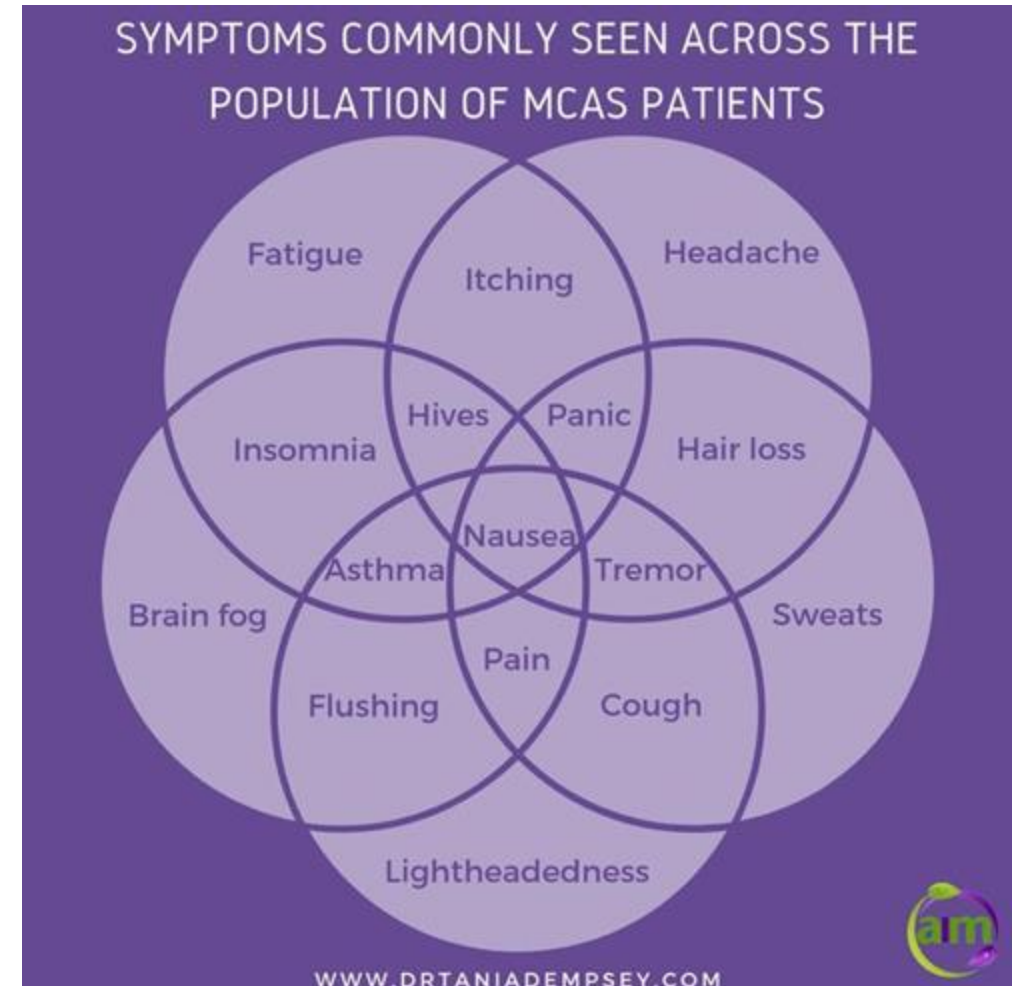
Mast Cells and Neuroinflammation-

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4282993/?fbclid=IwAR2qSfV8WmUrKUDNY-w1SbvlaDi94BzBhKMufGJ6nsR8zD2bQn_aHcbIB9w

Educational Videos:

<https://youtu.be/MQN8cS-di4U>
Dr Been explains MCAS in Long-Covid

<https://youtu.be/eS9TuruvJLU>
(At 6 minutes Dr Syed explains the medications for MCAS)



Autoimmune-1

Autoimmune

Persistent Immune

Dysfunction

(See the next page for more resources)

Worsening or new emergence of autoimmunity has been noted in several case reports. It is also possible that a formation of **autoantibodies** is involved in our pathogenesis. Some people are finding high ANA (antinuclear antibodies) levels, a non-specific readout for autoimmunity. A group out of Germany identified the existence of functional autoantibodies against G-protein coupled receptors (GPCRs) in long covid, which could very well be playing a role in neurological/ neuropathic symptoms. They identified targets against adrenoreceptors, angiotensin II receptors (AT-1), nociceptin-like opioid receptor, muscarinic receptor, MAS receptor, and ETA receptor.

Some patients in the adverse vaccine reaction groups have sent their blood to groups in the US and Germany testing and have received positive results. Related to both inflammation and autoimmunity, some patients have received small fiber neuropathy (SFN) diagnoses or damage to peripheral nerves. These symptoms can be autonomic and somatic in nature. Some patients have had IVIG (intravenous immunoglobulin) as a treatment. Some patients have had positive results for TS-HDS and/ or FGF3 autoantibodies- often found in patients with neuropathic pain and/or SFN.

Therapies for autoimmunity can be challenging.

Symptomatology Paresthesias, neuropathic pain, tingling, numbness, demyelination, denervation, POTS, Dysautonomia, gait disturbances, heart and blood pressure dysregulation, autoimmune encephalitis, PANS, PANDAS, etc.

Diagnostic Labs – These tests have been found to be relevant to ruling out underlying etiology with these patients' symptoms. These labs are not standard. However, these specific labs have been a critical tool to guide treatment protocols. (links to labs are found on the next page)

Specific autoantibody testing panels:

1. ANA
2. G-protein coupled receptor
3. FGF3
4. Mayo Clinic POTS panel
5. Washington U panel (TS-HDS)
6. Cell-Trend Auto-Antibody Panel
7. Sjogrens, Lupus, and others
8. PANS/PANDAS

9. IGG3

Autonomic Testing:

8. Tilt-Table Test (neuro lab tilt table, different than cardio tilt-table)
9. Catecholamines
10. QSART/Q-Sweat
11. SFN – Small Fiber Neuropathy Test – Skin Biopsy
12. EMG – Large nerve fibers

Treatment Some vaccine injured patients are responding to a reduction of symptoms with select immunomodulatory and/or immunosuppressive therapies, often in conjunction with many other trialed therapies from other areas of focus:

- Immunomodulatory therapy
- IVIG
- High dose IV Steroids
- Low Dose Naltrexone
- Immunosuppressants
- Neuropathic pain medication
- MAB drugs – Rituximab, Leronlimab

Autoimmune-2

Anti-Idiotypic Antibodies

Molecular Mimicry

Recent publication postulates that an immune process produces Anti-Idiotypic Antibodies.

[A Possible Role for Anti-idiotype Antibodies in SARS-CoV-2 Infection and Vaccination | NEJM](#)

COVID infection and the vaccines elicit antibodies to the spike protein. Spike binds to (ACE2) receptor on target cells. The receptor is widely expressed. These antibodies are called Ab1. The idiotype portions of Ab1 that bind and neutralize the spike protein have distinctive sequences and those antibody-binding regions can themselves elicit antibody responses called anti-idiotype (Ab2) antibodies

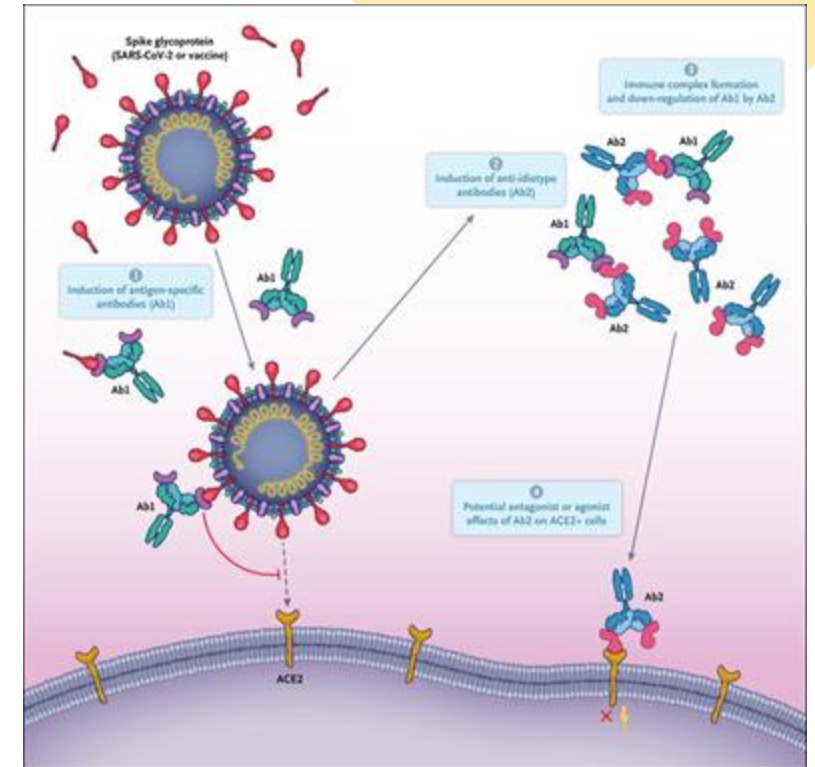
May bind to the protective neutralizing Ab1 antibody, resulting in immune-complex formation and clearance, thus impairing Ab1 efficacy.

May also mirror the spike protein itself and bind to the same target as the spike protein, the ACE2 receptor.

May suppress, stimulate or even cause immune attack against ACE 2 expressing cells.

These are Anti-ACE2 antibodies. The binding region looks like the spike and acts like it. Monoclonal antibodies to the spike protein would likely bind to the Ab2

CellTrend and BerlinCures are finding the Anti-ACE2 antibodies in a large portion of Long-Haulers and now the Vaccine Injured.



Molecular Mimicry, another possibility

[https://www.thelancet.com/journals/lanmic/article/PIIS2666-5247\(21\)00033-1/fulltext](https://www.thelancet.com/journals/lanmic/article/PIIS2666-5247(21)00033-1/fulltext)

Antibodies produced bind to spike-similar glycoproteins within the body, causing immune attack and autoimmune phenomenon, neurological problems, etc.

Autoimmune-3

Additional Resources:

NIH briefly discusses

Covid vaccine reactions: (Spring '21)
<https://youtu.be/YpfHoz22ePk>

Long-Covid Auto-Antibody
POTS Research with Dr. Grubb
https://fb.watch/a8_9peQIK6/

Auto-Immune Encephalopathies
<https://youtu.be/3ula0hZ2rQs>

POTS may be an autoimmune disorder
Dr. Grubb
<https://medicalxpress.com/news/2021-03-evidence-pots-autoimmune-disorder.html>

Covid Care Group.org - POTS
https://www.covidcaregroup.org/blog/postural-orthostatic-tachycardia-syndrome?fbclid=IwAR19NzsZ_ZKcWEFrA-GX7Cx858U9XGGmCiCyHixjOBunQ8YTHulp-X4nPg

Autoimmune Basis for Postural Tachycardia Syndrome
<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC3959717/>

Autoimmune markers and autoimmune disorders in patients with postural tachycardia syndrome (POTS)
<https://pubmed.ncbi.nlm.nih.gov/26038344/>

Neuro Auto-immune
<https://onlinelibrary.wiley.com/doi/10.1002/ana.26065>

Auto-Antibodies
https://www.nejm.org/doi/full/10.1056/NEJMcibr2113694?fbclid=IwAR0hKDnMpi8uJlkoWP4XlZ9I26jiZ-arMI08bFD6a_uqtzoKgBdYEmOBxA
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8049853/>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7264560/>
<https://www.sciencedirect.com/science/article/pii/S0140673620326611>

Auto-Antibody Blood Panels:
CellTrend – German Lab:
[GPCR-Antibodies - CellTrend Luckenwalde](https://www.celltrend.de/wp-content/uploads/2021/06/Patient-Instructions.pdf)

<https://www.celltrend.de/wp-content/uploads/2021/06/Patient-Instructions.pdf>
<https://www.celltrend.de/wp-content/uploads/2021/10/Request-form.pdf>

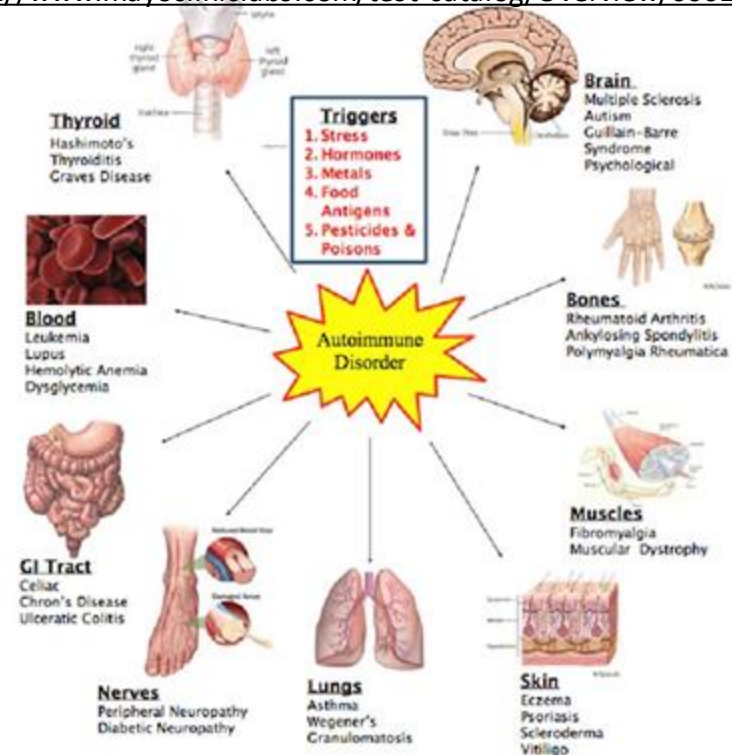
Washington University Neuromuscular Clinical Laboratory (THSDS)

<https://neuromuscular.wustl.edu/over/labdis.html>

Mayo Labs 1 - <https://www.mayocliniclabs.com/test-catalog/Overview/92121>

Mayo Labs 2 – Movement Disorders

<https://www.mayocliniclabs.com/test-catalog/Overview/606192>



Inflammation-1

Neuro- Inflammation Generalized Inflammation MIS-V

Inflammatory. On both **systemic and cellular levels**, inflammation is another mechanism at play. Patients are finding **increased markers for inflammation** which include elevated cytokines, CRP, and copper. It is not known yet the etiology of the proinflammatory response, but this systemic persistent inflammation has potential to disrupt function in many systems in the body. This can lead to vascular damage, including in the brain. Previous Covid studies have reported that the spike protein can disrupt the BBB (blood brain barrier) in vitro and it can cross the BBB in mice. If the spike protein enters the brain or is expressed in neurons and/or glial cells, microglial mediated inflammation could also be at play. **Multiple forms of inflammation have the potential to be present in the same patient...** Systemic Inflammation, Neuro-Inflammation, as well as forms of cardiovascular inflammation

Symptomatology Chest pain, deep muscle pain, swelling, MCAS like sensitivities and intolerance, paresthesia, Increased intracranial pressure, headaches, sensitivity to light or sound or touch, neuropathic pain, tingling, numbness, demyelination, denervation, POTS, Dysautonomia, gait disturbances, sleep disturbances, brain fog, memory loss, tinnitus, confusion, etc..

Diagnostic Tests

Testing panels:

1. Cytokines (including SCD40-L, VEGF)
2. ESR
3. CRP
4. D-Dimer
5. Troponin
6. Copper

7. MCAS tests (as seen on previous pages)
8. Prostaglandin (PG D2)

CNS Inflammation

Imagery – MRI/CT Scans

- Full Brain and Spine

Lumbar Puncture – CSF fluid proteins

Neuropathy Testing (found on next pages)

Treatment Options include immunosuppression, MCAS protocols with antihistamines. The SSRI, Fluvoxamine has been studied repeatedly in acute and long-covid and has consistently presented positive outcomes. Patients need to be cognizant of serotonin syndrome. Physical and emotional stress can also cause inflammation to persist or worsen, so rest, and effective stress management is important as well. Inflammation studies in general show that TCAs (amitriptyline, nortriptyline, doxepin) also function to reduce inflammation particularly in the nervous system and the brain, however have not yet been studied in Covid or Long-Covid.

- Steroids - low dose or IV
 - short duration or long taper
- Low-Histamine Diet
- Low Dose Naltrexone
- Aspirin (lowers prostaglandin synthesis.
Increases NOx in the Blood. Thins the blood)

- Neuropathic pain medication
- Mab drugs – Leronlimab
- Immunosuppressants
- Natural Anti-Inflammatories like Turmeric Oil
- Stress Management. Regular sleep schedule

Inflammation-2

Cardiovascular Inflammation

Microvascular Inflammation

Inflammatory. On both systemic and cellular levels, inflammation. Cardiovascular inflammation can appear in the form of myocarditis, pericarditis. Covid studies point to potential micro-clotting, as well as microvascular inflammation in which the endothelium becomes inflamed, promoting platelet adhesion, and thus potentially restricting flow in the capillary veins. This inflammation can begin immediately, or a week or two after the shot.

Symptomatology Chest pain, deep muscle pain, swelling, MCAS like sensitivities and intolerance, shortness of breath, headaches, neuropathic pain, tingling, neuropathy due to decreased blood flow, numbness, POTS, etc..

Diagnostic Tests

Testing panels:

1. Cytokines
2. ESR
3. CRP
4. D-Dimer
5. Troponin
6. MCAS tests (as seen on previous slide)
8. Prostaglandin (PG D2)

(including SCD40-L, VEGF) Neuropathy Testing (found in Neuropathy section)

Cardiovascular Inflammation

Imagery – Cardiac MRI, CT angiogram, cardiac xray
- EKG
- ECG
- Troponin

Treatment Options include immunosuppressive drugs. MCAS and low-inflammatory diet also are crucial. Stress Management and regular sleep schedule also play a role in persistent or worsening inflammation. Many times, improvement may take weeks or months.

- steroids, low dose or IV
-short duration or long taper
- Low-Histamine Diet
- Turmeric Oil
- Low Dose Naltrexone
- Aspirin (lowers prostaglandin synthesis.
Increases NOx in the Blood. Thins the blood)
- Immunosuppressants
- Neuropathic pain medication
- Mab drugs – Leronlimab
- Stress Management
- Regular sleep schedule

Inflammation-3

Additional Resources:

OVERVIEW for Inflammation in Long-covid:

<https://www.covidcaregroup.org/blog/understanding-inflammation-and-long-covid?fbclid=IwAR1OP1RRsQsdg3r4rrbE9AA9qUijTzj832IAonbiWtOAdYGzyjjcJAj6zIU>

Dr Been Explains Inflammation in Covid:
<https://www.youtube.com/watch?v=HiVoMHQkL4o>

Dr Been Discusses 5-11 Year Olds Myocarditis

<https://youtu.be/8GjRVhyezV8>

Dr Been Discusses Heart Issues with Vaccines

<https://youtu.be/WbXjx7dsLY4>

Dr Been Discusses Spike Protein Behavior

<https://youtu.be/JwjJs5ZHKJI>

Neuro Autoimmune:

<https://youtu.be/WbXjx7dsLY4>

Auto-Antibodies:

<https://www.sciencedirect.com/science/article/pii/S0140673620326611>

MIS-V:

https://wwwnc.cdc.gov/eid/article/28/2/21-1938_article

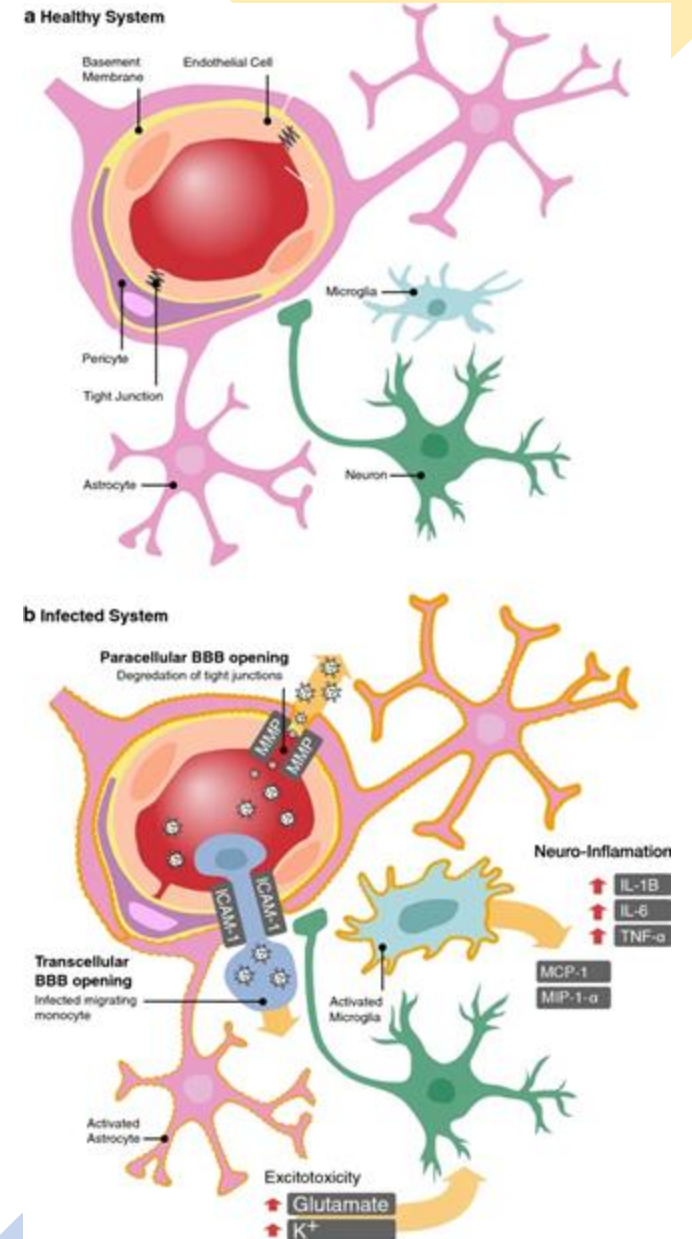
<https://casereports.bmj.com/content/14/7/e243888>

<https://www.sciencedirect.com/science/article/pii/S0264410X21000931>

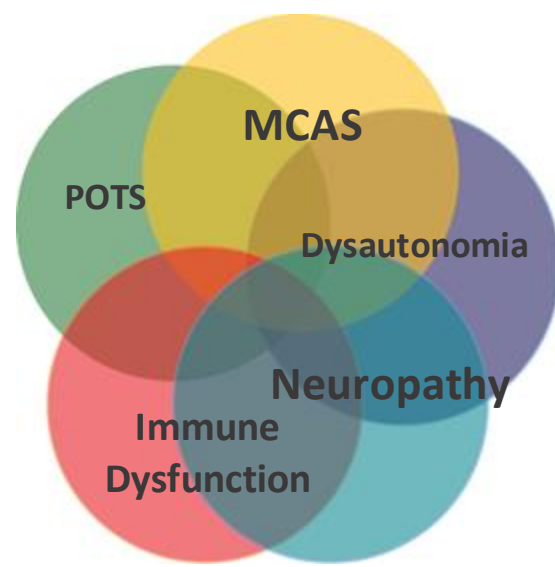
<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC8544993/?fbclid=IwAR13buXwx3zEL6bHVzZkhWjO0z5iGxxh56J-U4h802agCRvJNOqt7qQm8N0>

<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC8237872/>

<https://www.mdpi.com/2076-393X/9/11/1353/pdf>



Neuropathy- 1



Neuropathy can impede the lives of those suffering persistent symptoms post Covid vaccine. Neuropathy can result from the central and peripheral nervous systems falling prey to microvascular inflammation (clotting micro small fiber neuropathy), auto-immunity. Central nervous system neuropathy can sometimes be identified through imaging, or other testing, but sometimes may only be found through clinical presentation or bio. In addition to MCAS, Autoimmune, and inflammation testing, neuropathy testing can be a smoking gun needed to provide evidence necessary for insurance approval and a pathway to possible treatments.

Symptomatology can be vast but can include: POTS, dysautonomia, GBS-like weakness, fatigue, paralysis, central or peripheral nerve pain, paresthesia, sensory disturbances, etc.

Central NS
Neuropathy

Diagnostic Tests

1. Small Fiber Neuropathy
- skin punch biopsy
2. EMG
3. Neuro Tilt-Table Test
4. Q-Sweat/QSART
5. Autoimmune panels

Peripheral NS
Neuropathy

Treatment It can be challenging to treat and further testing may be necessary to determine the underlying cause:

- Immunomodulatory agents
- Steroids
- IVIG
- Plasmapheresis/Plasma Exchange
- Apheresis
- Low Dose Naltrexone
- Low Inflammation protocols (including diet)

- Alternative – Red Light Therapy
- Alternative – Hyperbaric Oxygen Therapy

Nerve Pain / Symptom management

- Alpha Lipoic Acid
- Cymbalta/Lamotrigine/Nortriptyline

Small Fiber/
Polyneuropathy

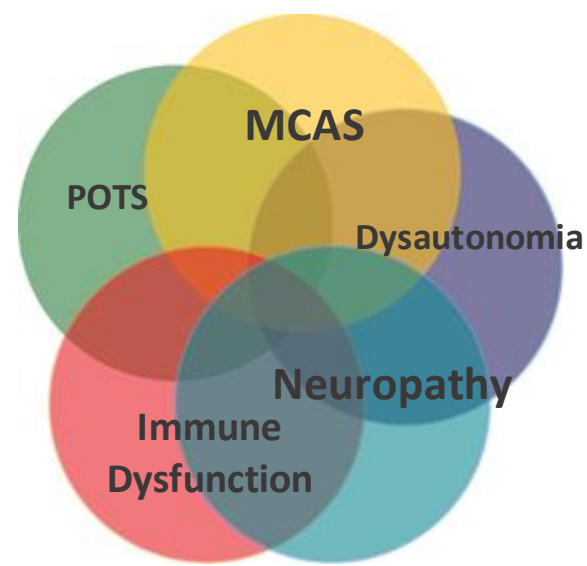
Neuropathy- 2

Additional Resources:

Neuropathy Testing:
<https://youtu.be/yL7mQhOtg3o>

Peripheral Neuropathy Basics:
<https://www.webmd.com/brain/understanding-peripheral-neuropathy-basics>

Neuropathy Basics, Mayo:
<https://www.mayoclinic.org/diseases-conditions/peripheral-neuropathy/symptoms-causes/syc-20352061>



Vaccine tied to small fiber neuropathy:
https://onlinelibrary.wiley.com/doi/10.1002/mus.27251?fbclid=IwAR02TKBTYjfQK1UKyq5z8BYuZym1tIOPaABLpuliJOD-kzg1Y0R-zU_LrRE

IVIg for Auto-Immune Polyneuropathy
<https://pubmed.ncbi.nlm.nih.gov/29403541/>

How We Treat Autoimmune Small Fiber Polyneuropathy with IVIG
<https://www.karger.com/Article/Fulltext/498858>

Treatment of inflammatory polyneuropathy with Plasma Exchange
<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC1083155/>

SYMPTOMS OF SMALL FIBER NEUROPATHY

PAIN AND BURNING IN THE LOWER AND UPPER EXTREMITIES
"PINS AND NEEDLES"
LOSS OF FEELING IN THE HANDS AND FEET
FEET AND HANDS ARE TENDER OR SORE
CRAMPING IN FEET, ANKLES, CALVES, AND HANDS
NUMBNESS
FATIGUE
INABILITY TO SWEAT
DRY EYES
SKIN DISCOLORATION
DIZZINESS, LIGHTEADED
DIFFICULTY BREATHING
INCREASED HEART RATE
DIFFICULTY WITH BOWEL AND BLADDER FUNCTIONS



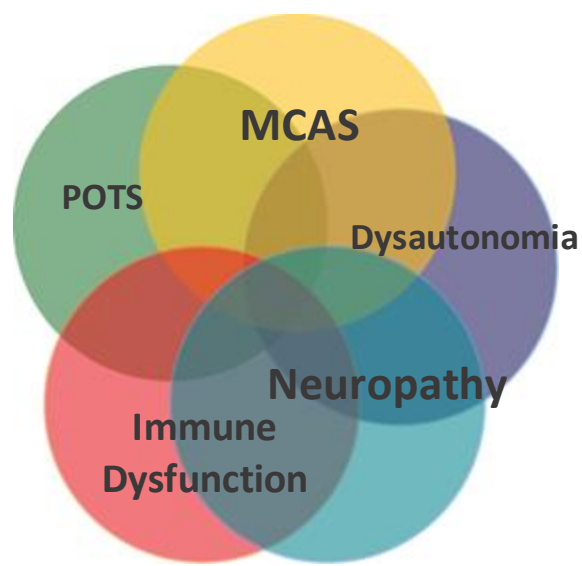
WWW.FACEBOOK.COM/CFMNETWORK



Immunotherapy for Neuropathy/MCAS/POTS Publications:
<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC5778345/?fbclid=IwAR3ikEVxIUJmnyHtlvwu1LeoAdONGMMLqpid9F-taq8sxdc1kEtFFjC-DiE>
<https://pubmed.ncbi.nlm.nih.gov/30889595/>

Neuropathic Pain, A clinician's Guide:
<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC1513412/>

Summary of Labs/ Testing:



Specific autoantibody testing panels:

Specific autoantibody testing panels:

1. ANA (negative result does not rule out further autoimmune workup)
2. G-protein coupled receptor
3. FGF3
4. [Mayo Clinic POTS panel](#) (optional)
5. [Washington U panel \(TS-HDS\)](#)
6. [Cell-Trend Auto-Antibody Panel](#)
7. Sjogrens, Lupus, and others
8. PANS/PANDAS
9. IGG3 (low, immunodeficiency)
10. IGE (high, allergic)

Specific Inflammation testing panels:

1. Cytokines (including SCD40-L, VEGF)
2. ESR
3. CRP
4. D-Dimer
5. Troponin
6. MCAS tests (as seen above)
8. Prostaglandin (PG D2)

CNS Inflammation

- Imagery – MRI/CT Scans
 - Full Brain and Spine
 Lumbar Puncture – CSF fluid proteins

Autonomic Testing:

6. Tilt-Table Test (neuro lab tilt table, different than cardio tilt-table)
7. Catecholamines test (hyper POTS)
8. Q-Sart/Q-Sweat
9. SFN – Small Fiber Neuropathy
 – Skin Punch Biopsy
10. EMG – Large nerve fibers

Rule Out:

Other Infectious Diseases

- Acute Covid
- Previous Covid Infection (opens doors to more clinicians)
- Reactivation of previous infections:
- EBV/Mono - Lyme - Shingles

Syndromes:

- Autoimmunity
- POTS/Dysautonomia
- Neuropathy
- Cardiovascular Inflammation
- Clotting/Micro Clotting

Transverse Myelitis/GBS
 MCAS

Movement Disorders

Vestibular Neuritis
 Ocular Issues

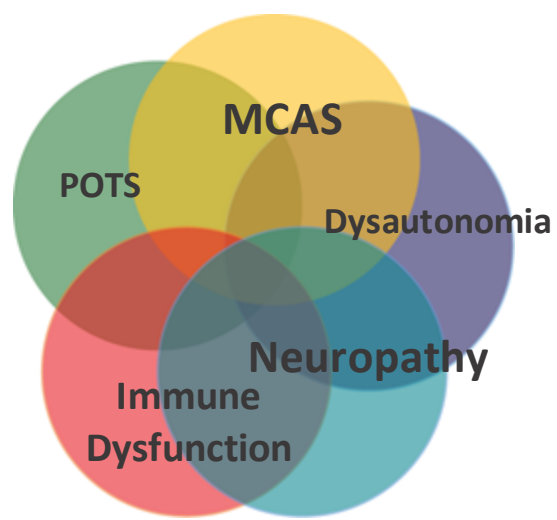
MCAS/Allergy:

1. Elevated tryptase (which is typically only high in the midst of a flair. 1 in 5 MCASers return positive Tryptase)
2. Elevated histamine (requires a 24 hour urine sample, temperature sensitive, degrades quickly)
3. Improvement of symptoms to antihistamines and/or mast cell stabilizers.
4. Elevated IGE – Immunoglobulin Type E
5. Prostaglandin (PG D2)
6. Skin Prick Test, Food Allergy Tests
7. Copper (tied to Zinc deficiency)

Neuropathy:

1. Small Fiber Neuropathy – skin punch biopsy
2. EMG
3. Autonomic Testing
4. Auto-Antibody Testing

Alternative Therapies



Other Remedies: List of options that others have been trialing. Some have had great benefits, others have not as much.

DIZZINESS:
Addressing the POTS can help as well

PT: Check with our physician if you are experiencing vertigo to rule out other possible issues - <https://www.stronglifep.com/vertigo.html> (2nd video)

OTHER THERAPIES:

HYPERBARIC CHAMBER
RED LIGHT THERAPY

Naturopathic

1. Glutathione – (oral)
2. DAO Enzyme before each meal
3. NAD stack [link] mixed results
4. Turmeric
5. Ginger tea/vit b6 for nausea
- 6.. Low Histamine or Low Inflammatory Diet
- 7.. Natural flavonoids (quercetin, luteolin)
- 8.. Ashwagandha

Alternative Options It can be challenging to treat and further testing may be necessary to determine the underlying cause:

- Lymphatic Massage
- Breathing Exercises (balance the sympathetic and parasympathetic NS)
- Alternative – Red Light Therapy to
- Alternative – Hyperbaric Oxygen Therapy

9. PEA supplement
10. Cordyceps mushroom (may aggravate MCAS), Lion's mane (may aggravate MCAS)

IV therapies

1. Glutathione – mixed results
2. IV Ozone – mixed results
3. Vit B or C infusions – mixed results
4. Peptides – mixed results

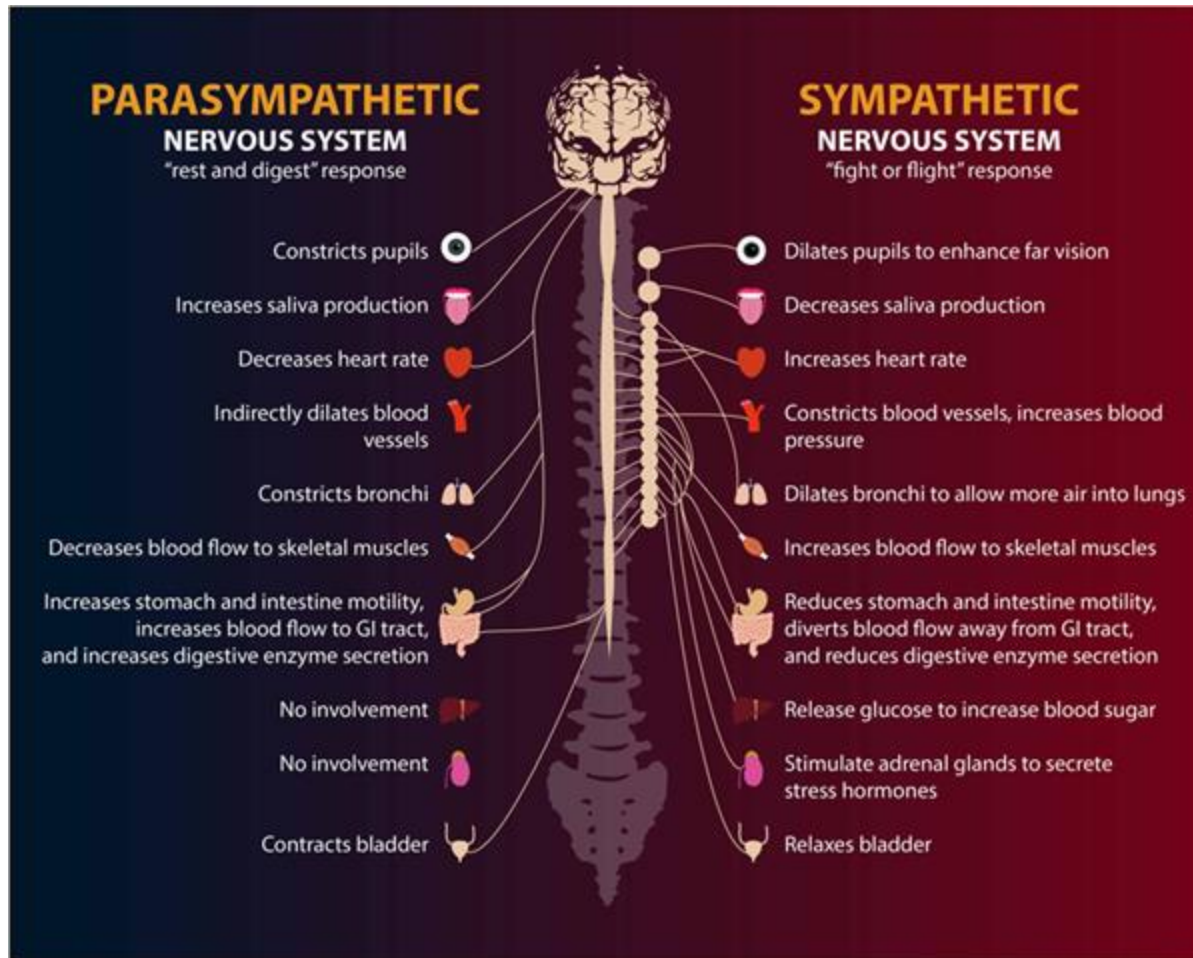
- Acupuncture – mixed results, possible severe adverse effects
- Acupressure – mixed results
- Wim Hof method – after acute phase, nervous system needs to be calm for this one

Nerve Pain / Symptom management
- Alpha Lipoic Acid

Alternative Therapies

Nervous System Balance, 1

Hyperadrenergic Pots
Dysautonomia



This dysregulation of the autonomic system also causes an **imbalance of the sympathetic and parasympathetic nervous systems.**

Our sympathetic (fight or flight) nervous system can become engaged and stay in the ON position, while the sympathetic nervous system (rest & digest) doesn't engage like it used to... so those suffering an acute reaction that lasts days, weeks, or even months, can easily be flipped into fight or flight, or get stuck there altogether.

When the **sympathetic nervous system is stuck ON**, our body dumps chemicals like adrenaline and norepinephrine into our system. Increasing blood pressure, heart rate, sweat, sensitivity to light & sound, tightness in the chest, enhanced startle reflex, and what can feel like an anxiety attack.

This same phenomena happens with Long-Covid patients. Physical therapists at Cedar Sinai have been treating these patients for over a year, and the main rule for them is to not push these patients, be **extremely gentle with yourself mentally and physically**, to get the sympathetic system regulated again.

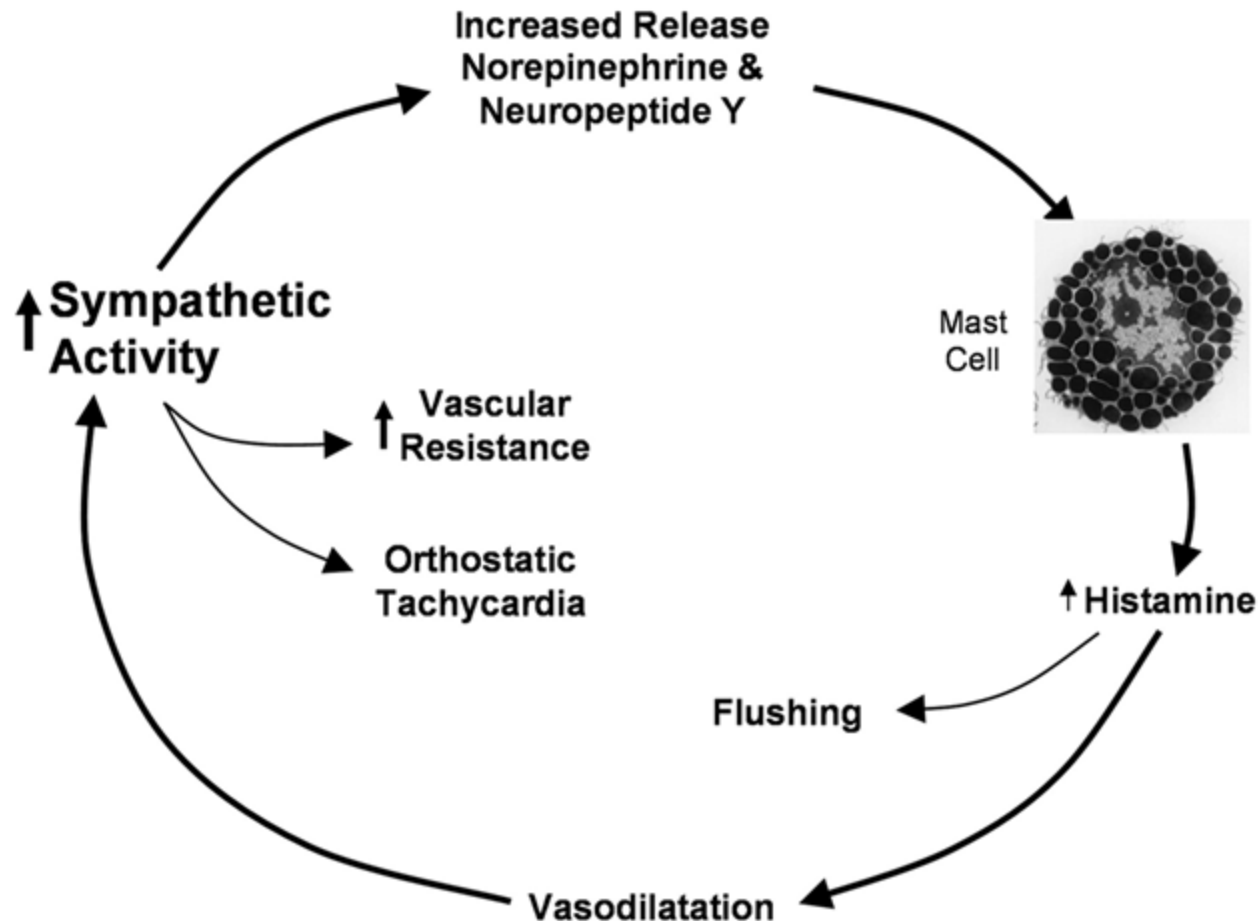
Fortunately, there are medications to help chemically, and once it is calmed down enough, with the help of therapists or individually, patients can routinely practice engaging our sympathetic nervous system, to retrain our brain to know when to dis-engage the sympathetic nervous system, and activate the parasympathetic nervous system.

This takes time, and patience and very regular practice. But it has really helped long-haulers.

Alternative Therapies

Nervous System Balance, 2

Hyperadrenergic POTS, ACE2 Imbalance
Dysautonomia



<https://www.ahajournals.org/doi/10.1161/01.hyp.0000158259.68614.40>

[https://www.healthrising.org/blog/2018/08/17/hyperadrenergic-pots-dsyaonomie-international-conference-v/](https://www.healthrising.org/blog/2018/08/17/hyperadrenergic-pots-dsyaautonomie-international-conference-v/)

<https://youtu.be/i1Vylm5CMMY>

In addition to medications, exercises can help. Simple breathing exercises have been studied a lot in long-covid and just the simple practice of breathing is helping get the nervous system regulated and the brain firing more appropriately. (The exercises won't help if you are stuck in fight or flight. If this is the case, medications (MCAS protocol can play a role in this as well) can help bring those chemicals back to balance. THEN these practices have a potential to be useful, when done regularly. In addition, reaching out and finding a **compassionate therapist** who can validate your experiences has been found to be key for many patients.

Daily breathing APS:
Stasis breathing program
Calm
Headspace

Grounding practice:
<https://youtu.be/1ao4xdDK9iE>

Breathing practice:
https://youtu.be/t4aupp_YO9c

(Sample meditation) Acceptance
Meditation:
<https://youtu.be/eLOOJQxb2Qg>

Polyvagal theory and the nervous
system balance:
<https://youtu.be/OeokFxnHGQo>

<https://youtu.be/L1HCG3BGK8I>

Other Psychology Help:
EMDR – for PTSD

POTS

POTS – Postural Orthostatic Tachycardia Syndrome, Hyperadrenergic POTS, CNS POTS

Symptomatology can be vast but can include, POTS, dysautonomia, GBS-like weakness, fatigue, paralysis, lesions, paresthesias, etc.

Diagnostic Tests

1. Small Fiber Neuropathy –
skin punch biopsy
2. EMG
3. Neuro Tilt-Table Test
4. Q-Sweat/QSart
5. autoimmune panels
(previous slides)

Treatment It can be challenging to treat and further testing may be necessary to determine the underlying cause:

- Salt Intake
- Really increase blood volume
- Rest Horizontal
- IVIG
- Plasmapheresis/Plasma Exchange
- Low Dose Naltrexone
- Intensive Physical Therapy
- Alternative – Red Light Therapy
- Alternative – Hyperbaric Oxygen Therapy

Covid Care
Group.org - POTS
https://www.covidcaregroup.org/blog/postural-orthostatic-tachycardia-syndrome?fbclid=IwAR19NzsZ_ZKcWEFrA-GX7Cx858U9XGGmCiCyHixjOBunQ8YTHulp-X4nPg



POTS: A Look Beneath The Surface

She looks fine, but here's what she could be experiencing if she has postural orthostatic tachycardia syndrome (POTS).

- reduced brain blood flow
- trouble concentrating
- lightheadedness
- fainting
- migraines
- altered sleep phases
- abnormally dilated pupils
- sensitivity to light
- esophageal dysmotility
- nausea/bloating
- diarrhea/constipation
- peripheral neuropathy
- blood pooling in the limbs

- vertigo (dizziness)
- sensitivity to noise
- tachycardia (fast heart rate)
- chest pain
- shortness of breath
- profound fatigue
- iron storage deficiency
- low blood volume
- muscle weakness
- bladder problems
- reduced ability to sweat
- heat/cold sensitivity
- and more...

www.dysautonomiainternational.org/POTS

DysAUTONOMIA INTERNATIONAL
AWARENESS ADVOCACY ADVANCEMENT



POTS

ME-CFS - Dysautonomia/POTS:

Dr. Lucinda Bateman - Bateman Horne Center

- [Chronic Illness Patterns.pdf](#)
- [Top Resources Page](#) [all of the links below can be found on the Top Resources page]
- [ME/CFS Crash Survival Guidebook](#)
- 10 Minute NASA Lean Test ([patient instructions](#), [provider instructions](#))
- [Orthostatic Intolerance Educational Handout](#) (great resource)

Dysautonomia

Symptomology can be vast but can include, POTS, dysautonomia, GBS-like weakness, fatigue, paralysis, lesions, paresthesia, etc.

Diagnostic Tests

1. Small Fiber Neuropathy –skin punch biopsy
2. EMG
3. Neuro Tilt-Table Test
4. Q-Sweat/QSART
5. auto-immune panels (previous slides)s)

Treatment It can be challenging to treat and further testing may be necessary to determine the underlying cause:

- Salt Intake
- Really increase blood volume
- Rest Horizontal
- IVIG
- Plasmapheresis/Plasma Exchange
- Low Dose Naltrexone
- Alternative – Red Light Therapy
- Alternative – Hyperbaric Oxygen Therapy

DYSAUTONOMIA CAN IMPACT THE WHOLE BODY

BRAIN

fatigue
brain fog
migraines
vertigo
fainting
lightheadedness



HEART

tachycardia
bradycardia
palpitations
chest pain



STOMACH

bloating
nausea
vomiting
pain



MOUTH

dry mouth
tooth decay
difficulty swallowing



BLOOD VESSELS

hypotension
hypertension
poor perfusion



INTESTINES

impaired motility
constipation
diarrhea
pain



EYES

dryness
sluggish pupils
sensitivity to light
greyed out vision



IMMUNE CELLS

increased allergies
inflammation



GALLBLADDER

reduced motility
inflammation
pain



SKIN

dryness
reduced sweating
increased sweating



BLADDER

frequent urination
retention
nocturia
pain



DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

...and MUCH more!

WWW.DYSAUTONOMIAINTERNATIONAL.ORG

Patient Advocacy Resources:

#ME Action

http://me-pedia.org/wiki/Welcome_to_MEpedia

Solve M.E.

<https://solvecfs.org/>

Vestibular.org

[VEDA support forum](#)

Dysautonomia International

<http://dysautonomiainternational.org/>

Long Covid Alliance

<https://longcovidalliance.org/>

The Spoon Theory



The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.



The Spoon Theory was written by Christine Miserando, which you can check out on her website www.butyoudontlooksick.com.

Tinnitus

Tinnitus is **when you experience ringing or other noises in one or both of your ears**. The noise you hear when you have tinnitus isn't caused by an external sound, and other people usually can't hear it.

Tinnitus is a common problem. It affects about 15% to 20% of people and is especially common in older adults.

- Source Mayo Clinic



Tinnitus

- The background rate for tinnitus is ~15% / life expectancy.
- So, ~0.2% of the population develops persistent tinnitus per year, or ~660,000 per year, or ~55,000 per month.

- However, tinnitus in many cases is not bothersome, and has never historically been reported at these amounts.
- For the last ten years on average a little over 40 reports from flu vaccines have mentioned tinnitus in VAERS. For Covid vaccines there are over 13,000 reports of tinnitus in VAERS post vaccination.
- In this survey 180 out of 508 reported tinnitus which is ~35%.
- Under reporting is possible as individuals may not associate with vaccination, not know how or where to log information, and may not have sought medical care.



Tinnitus

Diagnose of tinnitus is usually based on symptoms alone.

Imaging often done if unilateral presentation.

Audiological testing - usually only tests up to 8,000 hz which does not capture high frequency loss.



Most often described as “ringing in the ears” but can be described as

Buzzing

Roaring

Clicking

Hissing

Humming

Tinnitus Possible C19 Vaccine Etiologies

- Covid vaccines, which are variants of the spike protein, directly interact with weaknesses in the high-risk population.
- COVID-19 vaccines possibly disrupt ACE2 function, causing inflammation of the blood vessels and breaking down blood brain barrier, leading to cluster symptoms including tinnitus.
- COVID-19 vaccines are highly immunogenic and they may trigger an off-target inflammatory responses that include tinnitus.

Tinnitus/Sensorineural Hearing Loss

- **Causes:**
 - low/high frequency hearing loss, medications including vaccinations, loud noise exposure, ear wax/blockages, injuries.
- **Treatments:**
 - Depends on the underlying cause. In most cases, there are no medical interventions for tinnitus.
 - Administering steroids within 72 hours of onset of tinnitus increased likelihood of resolution.
 - Immediate use of steroids for SNHL is evidence-based practice.
 - **In the case of post-vaccine onset:** a small study has shown that **initiating high dose steroids** immediately upon onset may reverse tinnitus. (Italian Study):
 - <https://www.tandfonline.com/doi/full/10.1080/14992027.2021.1931969>
 - Other treatments include: HBOT, acupuncture, Gingko biloba, bioflavanods, and other herbal and vitamin supplements.

Tinnitus

Trial Data Example (Need to Edit):

- With COV3001, the original analysis had a 6v0 imbalance. It was only after further follow up, did the imbalance become 15v4.
- The placebo rate is close to what you would expect from the background for persistent tinnitus development, but this included those with temporary tinnitus development as well.
- However, it does show, that follow up and reanalysis can identify and strengthen the confidence. 15v4 actually has a smaller p-value than 6v0.

Peer-Reviewed Publications to Mention

[Full List of Peer Reviewed Publications – react19.org](#)

Resources for Neuropathy -

IVIG for Auto-Immune Polyneuropathy

<https://pubmed.ncbi.nlm.nih.gov/29403541/>

How We Treat Autoimmune Small Fiber Polyneuropathy with

IVIG <https://www.karger.com/Article/Fulltext/498858>

Treatment of inflammatory polyneuropathy with Plasma Exchange

<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC1083155/>

Small Fiber Neuropathy after Vaccination:

https://onlinelibrary.wiley.com/doi/10.1002/mus.27251?fbclid=IwAR02TKBTYjfQK1UKYq5z8BYuZym1tI0PaABLpuliJOD-kzg1Y0R-zU_LrRE

COVID-19 mRNA vaccination leading to CNS Inflammation: a case series

https://link.springer.com/article/10.1007/s00415-021-10780-7?fbclid=IwAR1WlozzELtGyD_DttkLNZFMcl3yW6iBW9C0v8uRyiYtTulzRvKVPE_xYko

Mast Cells -

Long Covid and Mast Cells-

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8250989/>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7267424/>
<https://pubmed.ncbi.nlm.nih.gov/33023287/>

Mast Cells and Neuroinflammation-

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4282993/?fbclid=IwAR2qSfV8WmUrKUDNY-w1SbvIaDi94BzBhKMufGJ6nsR8zD2bQn_aHcbIB9w

Auto-Immunity -

Anti-Idiotypic Antibodies from Spike

[A Possible Role for Anti-idiotypic Antibodies in SARS-CoV-2 Infection and Vaccination | NEJM](#)

Autoimmune Basis for Postural Tachycardia Syndrome

<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC3959717/>

Autoimmune markers and autoimmune disorders in patients with postural tachycardia syndrome (POTS)

<https://pubmed.ncbi.nlm.nih.gov/26038344/>

Neuro Auto-immune

<https://onlinelibrary.wiley.com/doi/10.1002/ana.26065>

Auto-Antibodies:

<https://www.sciencedirect.com/science/article/pii/S0140673620326611>

MIS-V (Multisystem Inflammatory Syndrome):

https://wwwnc.cdc.gov/eid/article/28/2/21-1938_article

<https://casereports.bmj.com/content/14/7/e243888>

<https://www.sciencedirect.com/science/article/pii/S0264410X21000931>

<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC8544993/?fbclid=IwAR13buXwx3zEL6bHVzZkhWjO0z5iGxxh56J-U4h802agCRvJNOqt7qQm8N0>

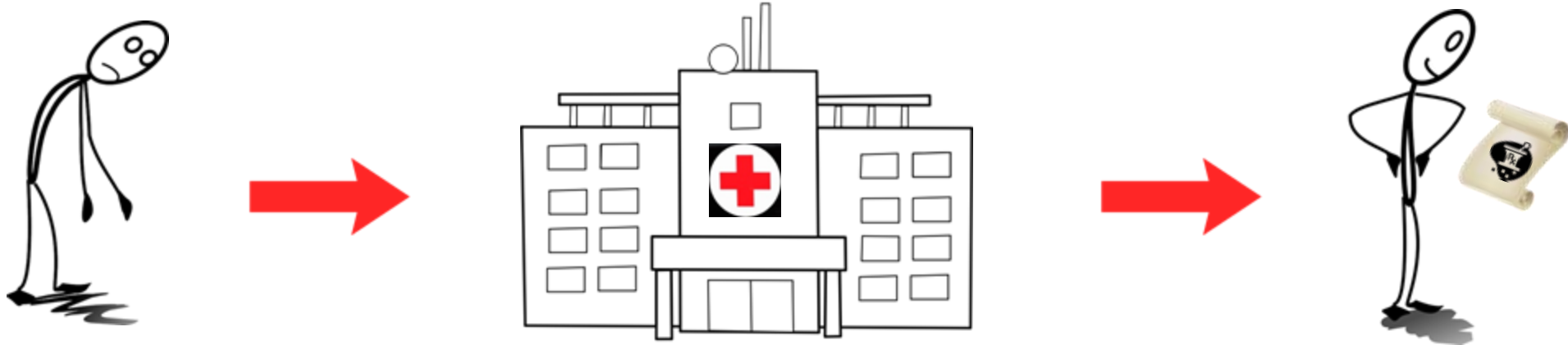
<https://www.ncbi.nlm.nih.gov/labs/pmc/articles/PMC8237872/>

<https://www.mdpi.com/2076-393X/9/11/1353/pdf>

POTS following Pfizer:

<https://www.cureus.com/articles/56242-a-case-of-postural-orthostatic-tachycardia-syndrome-secondary-to-the-messenger-rna-covid-19-vaccine>

Typical Access to Medical Care



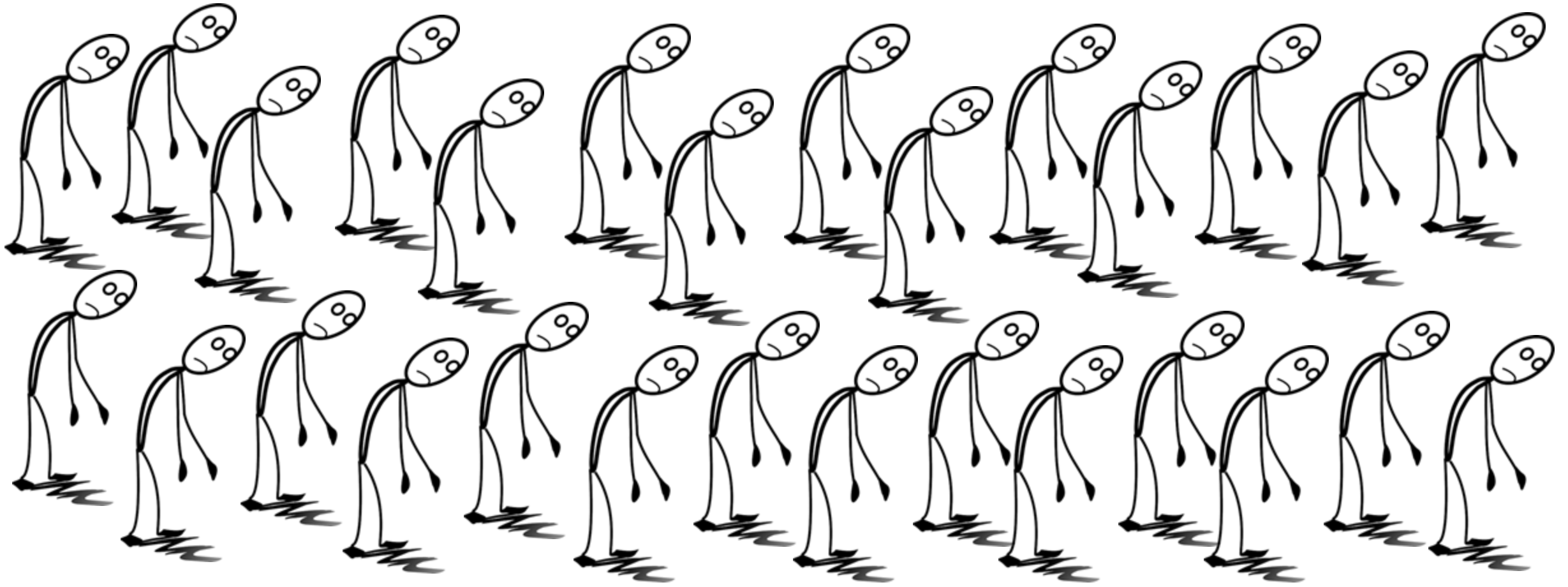
Vax Injured Have No Access to Medical Care



Vaccine injuries are denied by Regulatory Agencies and the media.
Doctors do not believe they occur.
No treatment information or symptoms to look for...
No funded research to look into why or risk factors and treatments.

Vax Injured Have No Access to Medical Care

Inability to access medical care has created a backlog of patients in need.



Vax Injured Have No Access to Medical Care

 **WE NEED HELP** 

- **Medical Care** – Network of caring practitioners willing to work through these complex syndromes with the patient
- **Research** – Connect with researchers with institutions who are able to **start IRBs**.
- **Counselors** – Network of caring therapist and mental health professionals willing to work through the complex mental component these suffering injured are living through.
- **Possible Payment Plans** for the injured in need.

Mental Health

Mental Health Resources:

"How To Find a Mental Health Counselor"

How to find mental health support, emergency intervention resources, and substance abuse resources

The neuropsychiatric impact of the vaccine is very real.

Your Life Matters.



- Crisis? Need help now? **Text “TALK” to 741741** American Foundation for Suicide
- If you are experiencing any thoughts of self-harm, disassociation, depression, suicide, please reach out for help from local mental health facilities or **the national suicide hotline: 1-800-273-8255.**
- This line is more than just for those who are in a moment of crisis. It is for anyone who is feeling like they need someone to talk to.