


Long Covid Action Project










[@LongCovidAP](https://www.instagram.com/LongCovidAP)

Email: longcovidactionproject@gmail.com

Completed & Ready for Action:

- A. LCAP [NIH 12 s/sx Retraction Letter](#)
- B. LCAP [End The Long Covid Crisis Letter to Government - Sign & Share!](#)
- C. LCAD [Long Covid International Awareness Day Press Release - Share w/ press!](#)
- D. LCAP [UK End The Long Covid Crisis Letter to Parliament - Sign & Share!](#)
- E. LCAP UK LCAD  UK Press Release: Long COVID Awareness Day Campaign
- F. [Gaslighting Letter](#)

Working Documents:

- G.  LCAP: Patient Led Protocol
- H. [Volunteer for Long Covid Awareness Days](#) »  ILCA/LCAD Debrief
- I. LCAP  LCAP "End The Long Covid Crisis" Responses
- J. LCAP UK  LCAP UK "End The Long Covid Crisis" Letter Campaign
- K.  LCAP Political Action: Government Committee Petition & More (Public)
- L.  LCAP Political Action: Stakeholders Info
- M.  Market Analysis: LC Political Advocacy Groups
- N.  LCAP Brands
- O.  LCAP Scorecard

Working Commercials: click on videos to add comments

- A. [Tinnitus Ad Spot 1](#)
- B. [Covid-Nineteens](#) (original non-LC version)
- C. Covid-Nineteens (LC new version)
- D. [Covnesia](#) (music, shots, script, effects still being worked out)
- E. Myth vs Fact #1
- F. Insomnia

LCAP Twitter Space

Weekly Agenda:

(previous agendas/spaces at bottom of doc)

VISION

End the Long COVID crisis

MISSION

LCAP is a united, diverse force of non-partisan individuals taking action to end the Long COVID crisis. We demand urgent treatment and support for the Long COVID community by mobilizing public awareness and driving government accountability.

LCAP Action Consensus

We invite all people who align themselves with this agreement to participate in the Long Covid Action Project.

Long Covid Action Projects 2023

In 2023, we will engage in campaigns to address the growing Long Covid [demands](#) facing the worldwide community.

Forms of Action

We say what we do and do what we say. Through action, we stand up against infrastructure that fuels the Long COVID crisis and the lack of support for complex chronic conditions. Our goal is to push forward the cause of Long COVID health and disability justice. We intend to put forth a variety of actions and initiatives, including and not limited to: Petitions, direct mailings, political lobbying, protest actions, online communications, and media creatives.

Through possibilities of obtaining information in the run-up to each action, each person will make a conscious decision about their role in the forms of action.

We will not let ourselves be stopped by structural obstacles; we will flow through and around institutional or academic barriers. We act thoughtfully and do not harm people. Our actions are not directed against people, but against health and disability injustice.

Our diverse forms of protest and action reflect our values of diversity, creativity and openness. We strive to break down barriers to allow all people to participate.

Capacities

We pay attention to one another. Everyone should decide for themselves how to take action. We make space for each others' symptoms and help when a member needs to rest. We support each other, we process the experience together and bear repercussions collectively.

Cooperation with Related Long Covid Groups

We invite related groups to enrich our mission with their forms of action. Should groups express a wish for support, it is for LCAP and support structures to decide, based on their capacities and in close exchange with the groups, whether and how they can support them.

Self-Understanding

We come from different social movements and political spectra and see ourselves as part of the Long Covid health justice movement. We are in solidarity with all those who resist for a just society. We resist petty divisions and infighting in order to make the greatest positive collective impact. We focus on the work to be done.

In our actions we envision the world we want to see. We make our decisions in a grassroots democratic way and by consensus; we try to reduce hierarchies as much as possible.

No Room For Gaslighting & Discrimination

Our struggle for a health justice world is inclusive, diverse, and anti-oppressive.

We are committed to being aware of and taking action against everyday and structural discrimination among ourselves and by society. We will provide space and solidarity to the people and groups among us who are affected by discrimination.

Scripts

Script for public outreach:

1. Long covid definition
 - a. Script:
 - i. Government & Big media are telling you long Covid is lingering symptoms
 - ii. But really it's...
 - iii. Why are they hiding from the truth?
 - iv. Longcovidfacts.com
2. Heard about Long Covid e.g. of the older script we did at PHS (change script to LC):
 - a. Script: <https://www.youtube.com/watch?v=Ou4-PgNpCRg>
3. When you can't get the truth from hospitals or doctors e.g. to reframe for LC:
 - a. Script: <https://www.youtube.com/watch?v=lotEV7iyjS8>
4. Viral persistence visual - showing how it covers our bodies:
 - a. Script:
5. Tinnitus
 - a. Script:
 - i. Have your ears started ringing? Has it been going on for weeks or months? Have you heard about Long Covid? Did you know Long COVID can cause ear issues like tinnitus, hearing loss & vertigo? Studies are finding ear ringing is a common symptom of Long Covid. Find out more at longcovidfacts.com, hear stories from more people like you
 1. What we know: resources
 2. Demand more NIH funding for research: facts on funding being depleted
 - a. Petition
 - b. Petition for debunked therapies
 - c. Don't see your issue here, suggest ideas
longcovidactionproject@gmail.com
 3. More resources:
 - b. Script:

- i. My ears have been ringing for months but my doctor keeps saying it's nothing to worry about. Are you trying to tell your doctor something is wrong, but they won't listen? [Ghostbusters vibe: "We're ready to believe you!"] Hear stories from people whose ears won't stop ringing longcovidfacts.com
 - c. Script:
 - i. Someone trying to navigate life but noise prevents them; can't hear bank teller, telephone, child asking for help, horn in traffic
 - d. Script:
 - i. Are you one of the millions of people who are still struggling with the effects of COVID-19 long after your initial infection? Long COVID is a real and serious condition that can affect anyone who has had COVID-19. Symptoms can include ear ringing, known as tinnitus. If you're experiencing these symptoms, don't suffer in silence. Hear stories from people whose ears won't stop ringing longcovidfacts.com
- 6. Insomnia
 - a. Script:
 - i. Are you waking up a lot more at night, are you trying to sleep but just can't anymore? Sleepless nights happen to all of us, but doctors are learning that people are struggling with insomnia after covid.
 - ii. "Without restful sleep, it's so tough getting through the day like i used to do"
 - iii. "It's hard to think clearly when i toss and turn all night"
 - iv. "I thought I left night sweats behind in menopause. now i have them every night"
 - v. "I can't take time off - I have to work for my family. But I feel worse every day. I'm worried about taking care of them in the future."
Living with Long Covid can mean sleep interruptions that don't ever go away. Get the facts about living with Long Covid at longcovidfacts.com
- 7. General info
 - a. Script:
 - i. When covid started we thought you just had to survive. but in 2023, there's more to covid than whether you die or not. Living with Long Covid can mean living with health problems that may not ever go away. Get the facts about living with Long Covid at longcovidfacts.com
 - b. Script:

- i. Beans: [@BoundedEnergy](#)

8. Testicular health

a. Script:

- i. Reinfection of covid killing sperm count and people's fertility
 - Covid can cause unexplained testicular injury
 - Trying to have a baby? did you know that each infection w covid can xyz your sperm? Doctors are learning that covid could make it harder for you to start a family - today, or twenty years from now. Get the facts about living with Long Covid at longcovidfacts.com

9. Menstrual health

a. Script:

- i. Have you had unexplained changes in your period since you had covid? Doctors are learning that Long Covid can affect your reproductive system. Get the facts about living with Long Covid at longcovidfacts.com

10. Diabetes

a. Script:

- i. People are developing diabetes from COVID – insulin is expensive, diabetes may be permanent?, diabetes can shorten your life

11. Solidarity/Activism - Bring out the activist, script to inflame action/advocacy

a. Script:

- i. Caring about your community means thinking outside yourself. Working together to lift up the invisible ones so they don't get left behind. Solidarity is the way out of this pandemic.
- ii. People in your community – your neighbors – are developing Long Covid after Covid infections. Are they disappearing? Learn how to help Get the facts about living with Long Covid at longcovidfacts.com

b. Script:

- i. Living through the pandemic has been confusing – and now they say it's over? You, your loved ones, or your neighbors could be left with Long Covid symptoms or even new post-viral conditions while the government moves on. Don't get left behind. Get the facts about living with Long Covid, and demand our leaders take responsibility, at longcovidfacts.com

12. Dysautonomia

a. Script:

- i. Systems of the body not working together as they should. Everything's out of balance; your body temperature might be off, you might be dizzy, you might be unable to regulate your sleep patterns or use energy properly. Dysautonomia is the body being thrown into chaos.
- ii. Some people are developing dysautonomia after Covid infections. It's one of the many conditions that are described as Long COVID. Get the facts about living with Long Covid at longcovidfacts.com

13. Long Covid Nerves

a. Script:

- i. Being separated from reality from the body visual:
- ii. Long covid can feel like your world is disappearing
- iii. Long covid can feel like you're out of step...symphony going off pace, symptoms don't work together gracefully

b. Script:

- i. Sudden terror like alarms going off for no reason - unexplained adrenaline rushes - fear jolting. Visual of car instrument panel warning lights?

14. Reinfection – Every Covid-19 infection places you at risk for Long Covid

- i. [insert statement "Long Covid stole my life away" "I live in torture from this disease"]
- ii. There are no cures for Long Covid, no treatments for Long Covid.
- iii. Now millions are unable to work, to live, to pursue their happiness.
- iv. We cannot allow this to continue.
- v. The NIH has 1.6 billion in funds for Long COVID, what are they waiting for?
- vi. Demand our government take action today.
- vii. Send them a message.
- viii. Go to LCAP.org

15. Coming out about Long Covid

a. Script: Inspired out of LCAP #5 talk: "I didn't tell anybody I had Long Covid for one full year"

- i. Two people building the foundation for a bond
- ii. One starts to slow down
- iii. The other notices & asks if something's wrong

- iv. "I wanted to tell you that I have Long Covid"
- v. The healthy person helps the one w/ LC
- vi. Endscreen: It's ok to talk about Long Covid, we're here to help
longcovidactionproject.com

Script for AMA & CDC (establishing protocols/biomarker testing/registry/etc.):

1. Script needs to address: Drug companies provide a lot of information to doctors – why can't patients create the same kind of influence on Doctors' recommendations?
 - a. Script: Providing educational models to doctors
 - b. Script: Create print & digital educational models that are on hand for patients in doctors' offices and hospitals
 - i. Digital example of education (change subject to Long Covid):
<https://www.youtube.com/watch?v=lotEV7iyjS8>
 - c. Script to inform patients:
 - i. A 2023 study found 1 in 10 people infected by COVID-19 are at risk of Long COVID
 - ii. Every reinfection creates the same risk - whether vaxxed or not
 - iii. Long COVID is [define]
 - iv. Long COVID looks like [symptoms/conditions]
 - v. Talk to your doctor about your symptoms and how they impact your life, and get the facts at longcovidfacts.com
2. Do we need a script to call on doctors to sign a letter to AMA/CDC asking for XYZ long COVID action? If yes, we can draft something here:
3. Letter drive: Government has been ignoring chronic illnesses for decades:
 - a. Script:
 - i. Visual of every chronic illness in the US growing together w/out a cure
 - ii. Call-to-action: will Long COVID be the straw that breaks the camel's back?
 - iii. It's time to change this story, call on the CDC/AMA to establish new protocols for long COVID, got to longcovidfacts.com & sign our letter

Script for supporting R&D:

1. "Nothing about us without us" - involve active LC patients!
 - a. Script:

2. Long COVID sufferers are standing by waiting to share their experience and learnings with the medical and research communities
 - a. Script:
3. Patient-Led Research - partner with them? Spotlight existing research and trials? Use as example of modern cooperative research done right
 - a. Script:

Script for protection and prevention:

1. Seatbelt and masking analogy (comedy):
 - a. Script:
 - i. you're going to wear a seatbelt, what a sellout,
 - ii. you're wearing a mask, what a sellout,
 - iii. Wait, have you heard of reverse psychology?
 - iv. gov wanted us to mask, now they don't want us to mask,
 - v. Is the government watching us? I don't want the government watching my family?
 - vi. Kids get the masks on, why dad?
 - vii. Cause screw the government?
 - viii. N95 Masks help prevent longcovid and government surveillance
2. Script to target people who can rebuild engines and replace every part but won't wear a mask to protect their parts
3. T cells / immune system getting crushed
 - a. Script:
 - i. Immune gauntlet
 - ii. Build the metaphor for t cells
4. Covid Infection
 - a. Script:
 - i. Covid Smoke in the air as a metaphor for covid spread
 1. Fake council meeting of someone lighting a cigarette
 - a. We decided as a society that wouldn't smoke in a room anymore for health issues, now we allow a virus capable of producing Long COVID to xyz
 - b. Restaurant? Show that smoke is gross - virus in air is gross
 - b. Script:
 - i. Covid-Nineteens ad created by Long Covid Battle Rabbit (AUS)

Script for Adversaries:

1. Response to TNR
 - a. Script:
 - i.
2. Response to the Hill
 - a. Script:
 - i.
3. Response to Israel Study
 - a. Script:
 - i.
4. Response to NYTIMES
 - a. Script:
 - i.

Scripts for **Myths vs Facts:**

1. Diet/exercise prevent Long Covid
2. I probably won't catch Long COVID if I already caught it.
3. I can't get Long COVID if I'm vaccinated
4. I can't infect somebody if I'm vaccinated
5. I'm young and healthy so Long COVID won't impact me
6. I caught it once and it didn't hit me hard, so it probably won't hit me hard the next time
7. Everybody can just protect themselves at whatever level they're comfortable with
8. Masks don't work
9. Eye protection isn't necessary
10. We have the tools to address Long COVID
11. If COVID doesn't kill me it makes me stronger
12. I can afford to get Long COVID
13. Long COVID is not a serious risk for healthy people/young people
14. Long COVID is just anxiety
15. Long COVID is always/only vax injury
16. Long Covid can be cured by nicotine gum
17. Long Covid is created by vaccine shedding
18. You can just go to the doctor

Script Health/Wealth/Dreams:

1. Young people who are suffering w/ LC explain how their dreams are lost because their health is crashed:
 - a. Anyone below 30, are you willing to share your story for a commercial? If so, add your info here or DM the team on twitter @LongCovidAP
2. Professionals who are suffering w/ LC explain how their wealth & financial security is now at risk due to this illness.
 - a. Are there LC patients willing to do this? If so, add your info here or DM the team on twitter @LongCovidAP
3. How to script to fallacy about long COVID being a bunch of freeloaders or lazy workers
 - a. Long COVID is a Get Poor Quick scheme
 - i. Anyone out there willing to say how much they've spent or lost in a quick 15 second video? If so, add your info here or DM the team on twitter @LongCovidAP
 - ii. There's nothing to gain with Long COVID

Volunteer work needed for pre-production, production, post, distribution

anyone willing to volunteer add your info here or DM the team on twitter @LongCovidAP

- Need help with:
 - Creative Director
 - Brand design
 - Website design
 - Copy editor
 - Music for commercials
 - Music sourced partly from Shutterstock PHS license
 - Volunteer work secured: Support: <https://linktr.ee/cupajoe99>

- Research license free music, sounds for commercials
- Recreate & rebrand any CDC or NIH advertising about LC to our own message
- ~~Graphic design~~
- TikTok Producer / strategist
- ~~Twitter comms~~
- Who are the influencers in the Long COVID space? Start with 25 people who are on board with us who can spread the word when a new creative goes out:
- Editors for commercials
 - PHS
- Film crews for commercials
- ~~Social Media Coordinator~~
- Political outreach
- Airdrop crew: people willing to send out messages/etc.
- Direct action campaign work (DM to remain anonymous):
 - Put out messages over projectors
 - Wheat paste posters
 - Etc.
- Voice narration
- Press Releases: write
- ~~Possible Advisory panel~~
- Comms/Hype
 - Send press releases
 - Work with influencers
 - [add your level of advocacy]
- Contentious Action – go after gov orgs for more research
- Political team to bird dog Democrats
- Science advisory panel
- Resources for Website (check bottom of this doc to add more)
- TikTok researcher to find long COVID videos
- Grant writer
- Spanish translator
- Petition Research – Current, Historical - Bri looking into NIH after 2/6/23

More call-to-action ideas to explore

- A. Congressional seats every two yrs
- B. Autopsy reports demonstrate viral persistence to respond to
- C. Remind everyone to pace
- D. Emotion is greatest trigger of crashes
- E. Adversary:
 - a. MSNBC - study on Long COVID going away after a yr - Israel study that says they
 - i. Penn Clinic
 - b. BuzzFeed - Long COVID history
- F. Advocate for Ultrasensitive PCR
- G. Long Covid data is nonexistent - covid data is getting taken offline - check link in twitter space for 01/11/23
- H. Post acute care collaborative, (check Michael's reference)
- I. Wiki for patient experiences - Personal profiles where people can fill out bio information, symptoms, treatments tried, location. Researchers could slice and dice data to pull sets eg. "All people under 50 who developed diabetes" or "All women with POTS who tried guanfacine" etc. Also a way for researchers to reach LC patients, solicit study participants, learn from lived experiences, and read anecdotal data.
 - a. Could be possible to create a video network for this, but would be reliant on videos rather than text
- J. Business media - scared impact, economy could be compromised
- K. Let's learn from history - HIV, repeating history, we need open discussion about, learning from the past - dragging your feet gets us deeper in the hole, kicking the can
- L. Vaccines can't solve Long COVID
- M. Treatment as prevention message - can vaccines do this etc.
- N. Family values getting infected
- O. What is our government walking us into - juxtaposition of the past and present
- P. Drawing parallels - we've all had chicken pox
- Q. The message to the moms - showing how the layers of this can destroy your life with your child and maybe leave them parentless

- R. The before and after visual – covid is not selective and doesn't matter what your political ideology is, everyone's lives regardless of profession are being impacted
- S. Similar to shocking smoking ads with the people with throat conditions talking through microphones to get their voice out
- T. Brain fog visual & word to display
- U. Fatigue visual to display
- V. Cartoon battery reference – it's in the twitter comments
- W. What we don't know layered in scenes, and that we need to know this
- X. Heard of Long COVID, but don't know the severity
- Y. Healthcare workers and gaslighting – a lot of viruses do that
- Z. Showing a person tired is not enough
- AA. For support, to let people know to “hang in there, and the science will validate us” / “You're not wrong, you're just early”
- BB. Creating a level of severity for LC, stage 5 etc.
- CC. Ideas for what to target: NIH funding,
- DD. “Just Say Long Covid” campaign or “Just say mask”
- EE. Definition:
 - a. Gambling script - there is no cure
 - b. Potentially include scale in definition, functional language
 - c. End the silence – Long Covid damages our bodies, our health, our society, our economy
 - d. We don't know where this story ends
 - e. Word that describes Long COVID / “They say it's lingering symptoms? Do these sound like no big deal”
- FF. ADA Resources
 - a. Employees:
 - <https://askjan.org/blogs/jan/2021/03/Long-COVID-and-the-Americans-with-Disabilities-Act.cfm>
 - b. Employers:
 - <https://www.dol.gov/sites/dolgov/files/ODEP/topics/pdf/long-covid-report-v2-accessibilized.pdf>
 - c. Advocacy for accommodations (remote work, flexible schedules, etc.)
 - i. pandemicpatients.org

Potential Advocates to try & connect w/ who have a platform

- [Curated master list of celebrities w/ LC](#)
- Tim Kaine
- Mark Ruffalo
- Vandana Shiva
- Dave Navarro
- Justin Bieber
- Jon Stewart
- Lady Gaga (fibro)
- Sharon Stone
- Dr. Drew
- Not Dead Yet
- Mark Cuban (Pittsburgh Connection)
- Vitalik Buterin - Fund gone
 - Cryptokings interested in Long COVID
 - Explain the pitch process, the steps we're taking
- Chris Cuomo (<https://twitter.com/ChrisCuomo/status/1597299478939471873>)
- Eric Topol
- Sam Reich (Collegehumor)
 - (<https://twitter.com/samreich/status/1585337079528988672>)
- UK - Jamie Oliver (wife has Long COVID)
- UK - Piers Morgan (had Long COVID)
 - (<https://twitter.com/piersmorgan/status/1501131835312676865?>)
- Imani Barbarin (on Tiktok, 500k+ followers)
 - <https://www.tiktok.com/t/ZTRsnGsYA/>
- Shania Twain
 - (<https://www.skynews.com.au/lifestyle/celebrity-life/shania-twain-breaks-silence-on-very-scary-pneumonia-and-covid-battle-after-being-airlifted-to-hospital-unable-to-breathe/news-story/49e0edabd2c2e3fb35d225e6e22c364d>)
- Colin Farrell
 - (<https://www.independent.co.uk/tv/culture/colin-farrell-long-covid-golden-globes-b2272011.html>)
-

Resources list for website

Long Covid Patient Resources:

- CDC: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>
- CDC (checklist): <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-covid-appointment/appointment-checklist.pdf>
- CDC before appointment: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-covid-appointment/index.html>
- Patient & Physician guide from Covid-19 Longhailer Advocacy Project: <https://docs.google.com/document/d/1VfENjAiOBKryT-dlOFyU8CyEAAKVR5xk9WYvIZF-u4M/edit?pli=1>
- Information for doctors: <https://longcovidfamilies.org/healthcare/for-doctors/>
- ME/CFS testing recommendations: https://drive.google.com/file/d/1Yu79EYxQlwNVER5tErp7LH7KY8pl8S_e/view
- World Physiotherapy Pacing Resources:
 - <https://world.physio/covid-19-information-hub/long-covid>
 - <https://longcovid.physio/resources>

Long Covid Trial research resources:

- <https://t.co/OJ7OCMiF43>

Long Covid Viral Persistence References:

- <https://lc19.org/viral-persistence/>
- <https://www.nature.com/articles/s41586-022-05542-y>

Long Covid Biomarkers research:

- Elevated vascular blood biomarkers: <https://pubmed.ncbi.nlm.nih.gov/36217108/>
- Changes to white matter in brain two years after Covid: <https://www.thno.org/v13p0724.htm>

- Apparent Risks of POTS After Covid – Vaccine and Virus:
<https://www.nature.com/articles/s44161-022-00177-8>
- Possible mechanism of Autonomic Dysfunction Post-Covid:
<https://www.sciencedirect.com/science/article/pii/S1566070222001308>
- Circulating Anti-Nuclear Antibodies in Covid Survivors Predict Long Covid Symptoms <https://erj.ersjournals.com/content/61/1/2200970>
-

Long Covid Science/Studies:

- r/longhaulresearch:<https://reddit.com/r/longhaulresearch>
- Highlighted studies:
 - <https://www.nature.com/articles/s41579-022-00846-2>

Long Covid News/articles:

- [is there an aggregate?]

Long Covid General Resources:

- <https://www.boundedenergy.co.uk/resources>
- <https://longcoviddoctors.org>

Long Covid MCAS Resources:

- <https://mastcell360.com>

Long Covid Gaslighting References:

- <https://publicherald.org/the-new-republic-has-long-covid-all-wrong/>

Long Covid Petitions:

- **LCAP** [End The Long Crisis Letter to Government - Sign & Share!](#)
- <https://actionnetwork.org/petitions/tell-nih>
-

Describe Long Covid w/ One Word

- A. Agonizing
- B. Hell
- C. Paralyzing

- D. Damage
- E. Lost
- F. Useless
- G. Living hell
- H. Living death
- I. Ghosted from my own life
- J. Zombified
- K. Cruel
- L. Elusive
- M. Pervasive
- N. Persistent
- O. Varying
- P. Unsettling
- Q. Whack-a-mole
- R. Unpredictable
- S. Unknown
- T. Uncertain
- U. Variable
- V. Disabling
- W. Widespread
- X. Terrifying
- Y. Frustrating
- Z. Progressive
- AA. Chronic
- BB. Radiating
- CC. Lethal
- DD. Hellish
- EE. Misery
- FF. Swimming through molasses
- GG. Exhausted
- HH. All hell breaks loose
- II. Quicksand
- JJ. Brutal
- KK. Destructive
- LL. Dehumanizing
- MM. Diabolical
- NN. Heartbreaking

- OO. Limiting
- PP. Lonely
- QQ. Isolating
- RR. Internal 20-car crash
- SS. Torturous
- TT. Life-threatening

Long COVID definition

CDC working Long covid definition for thought:

“Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing- remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.”

[More Long COVID glossary terms from CDC »](#)

DONATE TO LCAP

[CLICK TO DONATE »](#)

[LCAP FINANCIAL DASHBOARD »](#)

Previous Spaces & Agendas

LCAP Twitter Space

Weekly Agenda: 04/06/23 7pm EST

(previous agendas/spaces at bottom of doc)

- P. Who is LCAP? LCAP vision & mission
- Q. Where is LCAP with actions: AGENDA UPDATES
 - a. LCAP website complete
 - b. All actions listed on website
- R. [LCAP Political Action Group: debrief](#)
- S. **Co-hosts take**
- T. Volunteers
 - a. Volunteer DM open: Political Discussion & Research, Social Media, Design, Communications, Op Ed writers - DM [@LongCovidAP](#)
 - b. [Volunteers for International Long Covid Awareness Day needed](#)
- U. Hot new & old action items!**
 - a. **All action items [now available on LCAP's website](#)**
 - b. LCAP Letter to Healthcare Providers
- V. Latest News
- W. Public Discussion
 - a.

Weekly Agenda: 03/30/23 7pm EST

(previous agendas/spaces at bottom of doc)

- X. Who is LCAP? LCAP vision & mission
- Y. Where is LCAP with actions: AGENDA UPDATES
 - a. FDA Long Covid Drug Trials
 - b.

LCAP Twitter Space

Weekly Agenda: 03/15/23 7pm EST

(previous agendas/spaces at bottom of doc)

Z. Special agenda: Long Covid Awareness Day Actions

LCAP Twitter Space

Weekly Agenda: 03/08/23 7pm EST

(previous agendas/spaces at bottom of doc)

AA. Who is LCAP? LCAP vision & mission

BB. Where is LCAP with actions: AGENDA UPDATES on 02/22/23

- a. LCAP End the Long Covid Crisis Letter results
- b. #LongCovidAwarenessDay press release
- c. Tinnitus Final Cut Commercial spot is ready! Will begin this week

CC. LCAP Political Action Group: debrief

DD. **Jammers take**

EE. Volunteers

- a. Volunteer DM open: Political Discussion & Research, Social Media, Design, Communications, Op Ed writers - DM [@LongCovidAP](#)

FF. Hot action items!

- a. **March = Long Covid Awareness**
- b. **International LC Awareness Day** – Press Release is live! What to do?
 - i. Create PDF of Press release or use public Google Doc link & send to your local papers, or any press contacts
- c. LCAP **“End the Long Covid Crisis Letter”** to Government is live! What to do?
 - i. **Sign, resign & sign again x1000**
 - ii. Blast this out on your social media platforms
 - iii. Copy suggested email sharing options and send out on email listservs
 - iv. Use letter link to ask politicians on twitter when they will respond to the letter?

GG. Latest News

- a. LCAP UK - international chapters
- b. Response from Senator Bob Casey to Public Herald about LCAP letter campaign:

- c. Dr. Jha's
- HH. Speakers
 - a. JD Davids
- II. Public Discussion
 - a. How do we honor those who've died because of Covid & Long Covid?

Weekly Agenda: 03/08/23 7pm EST

(previous agendas/spaces at bottom of doc)

- JJ. Who is LCAP? LCAP vision & mission
- KK. Where is LCAP with actions: AGENDA UPDATES on 02/22/23
 - a. LCAP End the Long Covid Crisis Letter results
 - b. #LongCovidAwarenessDay press release
 - c. Tinnitus Final Cut Commercial spot is ready! Will begin this week
- LL. [LCAP Political Action Group: debrief](#)
- MM. [Jammers take](#)
- NN. Volunteers
 - a. Volunteer DM open: Political Discussion & Research, Social Media, Design, Communications, Op Ed writers - DM [@LongCovidAP](#)
- OO. **Hot action items!**
 - a. **March = Long Covid Awareness**
 - b. **International LC Awareness Day** – Press Release is live! What to do?
 - i. Create PDF of Press release or use public Google Doc link & send to your local papers, or any press contacts
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LCAP Twitter Space

Weekly Agenda: 02/22/23 7pm EST

(previous agendas/spaces at bottom of doc)

PP. Who is LCAP? LCAP vision & mission

QQ. Where is LCAP with actions: AGENDA UPDATES on 02/22/23

- a. LCAP End the Long Covid Crisis Letter is live!
- b. #LongCovidAwarenessDay press release is out!
- c. Latest Commercial spots are linked for review in LCAP public doc

RR. [LCAP Political Action Group: debrief](#)

SS. MythsFact Ad Review, Covnesia Ad Review both available in working commercials for notes

TT. Latest News

UU. Volunteers

- a. Volunteer DM open: Political Discussion & Research, Social Media, Design, Communications, Op Ed writers - DM [@LongCovidAP](#)

VV. **International LC Awareness Day** – Press Release is live! What to do?

- a. Create PDF of Press release or use public Google Doc link & send to your local papers, or any press contacts

WW. LCAP **“End the Long Covid Crisis Letter”** to Government is live! What to do?

- a. Sign letter & send to all of the elected officials that show up in your zip code & those at the federal level
- b. Blast this out on your social media platforms
- c. Copy suggested email sharing options and send out on email listservs
- d. Use letter link to ask politicians on twitter when they will respond to the letter?

XX. Public Discussion

- a. Misinformation circulating:
 - i. Emily Oster [tweet](#)

LCAP Twitter Space

Weekly Agenda: 02/15/23 7pm EST

(previous agendas/spaces at bottom of doc)

YY. Where we are: AGENDA UPDATES on 02/15/23

- a. #LongCovidAwarenessDay press release update
- ZZ. LCAP Strategy Group: debrief, mission and vision statements
- AAA. Tinnitus Ad Spot review, Covid Nineteens talk
- BBB. Latest News
- CCC. Production updates
- DDD. Volunteers
 - a. Assembling Social Media action team - DM Claudia
 - b. Communications volunteers – Op Ed writers - DM Joshua
 - c. Political Research volunteers – DM Joshua
- EEE. One month from **International LC Awareness Day** – open forum for ideas?
 - a. LadyWLongCovid / @TheExtraFiles releasing press release next week – morning Space at 9am PST, Not Recovered online protest, online art show
 - b. Lady will be requesting photos of LC sufferers from each year of pandemic to make online mosaic – will include online form in press release
 - c. Jammer / @AcrossTheMersey's idea – Series of themed Spaces that day hosted by different LC people, like a sequential bar crawl
 - d. @MamaSitaa's idea – viral LC challenge/activity similar to Ice Bucket Challenge
 - e. @BillyBob547 – light up buildings, etc. w/ LC colors
- FFF. Twitter Space Agenda: 02/08/23 7pm EST
- GGG. Ongoing items of interest:
 - a. DEBRIEF: [Political Action: LC Government Committee Draft Letter](#)
 - b. [Petition to extend COVID-19 Emergency](#)
 - c. Music update
 - i. Support: <https://linktr.ee/cupajoe99>
 - d. Video work
 - e. Tinnitus commercial draft
 - f. Cigarette commercial draft
 - g. Volunteer work
 - h. Myth vs. Facts
 - i. I probably won't catch COVID if I already caught it.
 - ii. I can't get COVID if I'm vaccinated
 - iii. I can't infect somebody if I'm vaccinated
 - iv. I'm young and healthy so COVID won't impact me
 - v. If I catch it once and it doesn't hit me hard, it probably won't hit me hard the next time

- vi. Everybody can just protect themselves at whatever level they're comfortable with
- vii. Masks don't work
- viii. Eye protection isn't necessary.
- ix. We have the tools to address COVID
- x. If COVID doesn't kill me it makes me stronger
- xi. I can afford to get COVID
- xii. Long COVID is not a serious risk for healthy people/young people
- xiii. Long COVID is just anxiety
- xiv. What's the point of trying to eradicate COVID? It'll never happen, so why try?
- xv. The choice is either "always mask forever" or "never mask ever"

Twitter Space Agenda: 02/01/23 7pm EST

- i. Tinnitus campaign
- j. Action Consensus (at bottom of doc)
- k. Patient resources added
- l. Opportunity for volunteer work (see down below in doc)
- m. [Draft LC Government Committee Petition](#)
- n. Open Discussion on Long Covid Advocacy
 - i. Biden decision to end COVID emergency
 - 1. How's this going down?
 - 2. How does this impact us? Social safety nets?
 - 3. What do we want to say?
 - 4. Is the Coronavirus committee contingent on the COVID Emergency? If virus is now 'endemic,' shouldn't permanent funding be allocated for LC?

Twitter Space Agenda: 01/25/23 7pm EST

- HHH. Where we are:
 - a. Opportunity for volunteer work (see down below in doc)
 - i. Music work
 - ii. Reddit volunteer
 - b. Open Discussion on Long Covid Advocacy

- i. What's next: We're moving forward with a tinnitus ad campaign. What other ad campaigns do people want to see at the top of the table based on the scripts below?
- c. Go over demands
 - i. RECOVER didn't get requested funding - let's build a petition
 - ii. Establishment of an institute for Complex Chronic Conditions (need permanent structure in NIH to incentivize career paths, funding)
 - iii. Private & public education campaign (go after providers to stop harming patients) - pushing Nature study on website

1/18/23

III. Long Covid Definition

- a. How it's poorly defined: lingering symptoms, fatigue, resolved over time
- b. How it's defined in latest highlighted study:
- c. How to define it for taking action
 - i. Percentage (would you take these odds) vs. reframing language to make the threat more clear
 - ii. Definition that looks at stages of function
 - iii. Definition issues
 - iv. End screen "There is no cure"
 - v. "We don't know how this story ends"

III. Anonymous LC action team: e.g. Yes men team, The Good Liars:

- a. Who wants to stay anonymous and perform actions?
 - i. Create Signal group, Discord, create OBSninja space for protection to organize (sign-up via DM or email longcovidactionproject@gmail.com)