## To Whom It May Concern:

I am writing as someone diagnosed with myalgic encephalomyelitis/ chronic fatigue syndrome. Prior to my diagnosis I was an active member of the anchorage community. I was the Chief Learning and Access Officer of the Anchorage Museum Education Department where I managed numerous staff, a significant budget, curated shows, developed programs, ran artist and community professional development, and quite frankly, lived for and loved my job. In addition, I taught art history at University of Alaska, Anchorage, and medical professional development at WWAMI. I was also a practicing artist outside of my employment, loved to ski, bike, hike, forage, and lived fully —drinking in the Alaskan experience.

When my first symptoms began, I was dismissed despite crippling fatigue, thick brain fog, wide-ranging neurological and cardiac symptoms, discolored limbs, incontinence, intense full-body pain, and complete dysfunction of all my bodily systems, including my ability to digest food. I am now entirely housebound and largely bedbound, completely unable to work. When I was struck with ME/CFS my entire life was taken from me. For multiple years, I have been entirely housebound, and mostly bedbound. I am unable to function, read, or write without assistive technology. I cannot sit up or stand for any duration despite an array of medicines. I am unable to do basic tasks to care for myself. I cannot even tolerate conversations or visits with loved ones.

Medical professionals continue to be largely uneducated about this complex multisystem disease. In fact, a study in the United States showed only 5.6% of medical schools were judged to deliver sufficient clinical, curricula and research on ME/CFS. Indeed, my partner is an MD practicing here in Anchorage and he was largely unfamiliar with my symptoms and with my condition. He had to educate himself in order to be my caregiver and support my medical appointments. It took over a year for my diagnosis — which is quite fast. A study in 2022 revealed that the average time to diagnosis was 14.9 years. Most of the physicians that I have seen both here in Anchorage and specialists out of state outright acknowledge that they know little or nothing about the condition. Patients like me are left without effective medication or treatment options. Indeed, due to little awareness and research there are no FDA approved treatments for ME/CFS. With so little awareness, how concurrent and future patients with this disease receive appropriate care and early interventions to avoid progression?

A first step to making change is to build awareness. By officially recognizing May 12 as ME/CFS Awareness Day Alaska can help bring attention to this condition which impacts an estimated 3.3 million people in the United States. With recognition of this disease, the state of Alaska can help support increased federal funding, research and treatments, encourage medical education, and support the lives of those enduring this life-stealing disease.

Truly,

S. Hollis Mickey Anchorage 99503 Dan M. Rediske 64893 Da Mar Loop Homer, AK 99603

January 21, 2025

Dear Alaska State Representatives:

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), formerly called Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution is essential to increasing awareness, education, and action in Alaska for a disease impacting approximately 10,000 Alaskans but remains under-recognized and poorly understood.

I have known my wife for over thirty years. She was already sick with ME/CFS when I met her. We did not understand what was wrong, although we knew she was sick. Over a decade later, she got her first ME/CFS diagnosis, but there was virtually no benefit from having this label. Most physicians continued to ignore the diagnosis or discredit it as a "fake" disease, telling her she needed to exercise more or get mental health counseling (both of which she had tried in desperation). She was eventually forced into disability, losing her career that she loved, and this has greatly impacted how and what we do. I am her primary care provider, and we have a helper who lives with us due to the level of her disability. We have sought specialists throughout the United States. She relies on medical care "outside" as no physician in Alaska is educated adequately on ME/CFS to care for this population. Few are interested in learning about ME/CFS and specialist care, nor will they use these organizations/providers' resources. Social Security disability and the International Classification of Diseases-10 (ICD-10) recognize ME/CFS.

We have met many people sick with the same disease who are not taken seriously about it because there is currently no clinical blood test. ME/CFS is often overlooked as a possible diagnosis, so proper management is delayed. If it is considered, it is frequently misunderstood by the provider, and the patient is told they have a mental health or motivational disorder rather than a disease caused by biological processes. Diagnostic reluctance may occur because it is currently incurable. Because of these and other factors, misdiagnosis is rampant.

This resolution will bring much-needed attention to this long-overlooked disease and the suffering patient population in Alaska. It will lend credibility to advocacy efforts made on behalf of people with ME/CFS and improve patient care.

Sincerely,

Dan M. Rediske Homer. AK Subject: Letter in Support of ME/CFS Day of Recognition Resolution

Dear Legislature,

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains underrecognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Alaska is particularly severely impacted by this disease process. As a family medicine physician, I have several patients who are faced with traveling out of state or using their own resources to purchase healthcare at major academic centers because emerging treatments and education are not available here. Our state highlights the devastating destabilization ME/CFS has on economies and families.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Robin Holmes, MD Dear Alaska State Legislature,

I am pleased to support the introduction of the attached final version of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Day of Recognition bill. I strongly believe in bringing about change; the first step is talking about it. To talk about ME/CFS people need to know about it. I am excited about the potential this bill holds to raise awareness and support for those living with ME/CFS and their caregivers/loved ones.

Thank you for your consideration and dedication to this important issue.

Best regards, Toby Currin, DO Family Physician in Anchorage, AK Maxine Fekete 440 w 89th ave Anchorage AK 99515

1/17/25

### Dear Nick Begich,

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

Sincerely,

Maxine Fekete

## 12/22/24

# Dear Rep. Josephson,

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

As a family physician here in Alaska, I know many patients affected by ME or similar conditions. Not only does the medical community still have much to learn about diagnosis and treatment, but the greater social community also has room to grow in understanding and empathy for the very real struggle these patients experience.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help raise funding for research; encourage inclusion of ME in medical curricula; and provide recognition and support to those living with this life-altering illness, as well as to their families whose lives are also affected.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this issue.

Sincerely,

Peek Ehlinger MD Anchorage, AK Susan J. Share 3037 Widgeon Lane Anchorage, AK 99508

12/21/2024

# Dear Representative,

I wholeheartedly support the introduction of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Day of Recognition bill. I am convinced of the potential it holds to raise awareness and support for those living with ME/CFS. I have a dear friend whose life has dramatically changed due to this illness. She and others deserve to benefit from focused research and solutions so they can live vibrant full lives.

Thank you for your consideration and dedication to this important issue.

Best regards, Susan J. Share Mercedes Harness PO Box 1096 Homer, Alaska 99603

11/16/2025

Dear Representative Tobin,

I'm writing as a parent of a child diagnosed with Long-COVID, manifesting as ME/CFS. My child was chronically ill for over two years, and we were routinely told by Alaska-based medical providers that "kids get sick a lot." While this is certainly true, it is also true that my daughter was experiencing a complex medical condition and not receiving appropriate and timely interventions. We saw specialists across the state who minimized her experience, and in both subtle and direct ways, gave us the message that there were no organic causes for her symptoms—which was another way of suggesting her chronic illness was psychosomatic.

My 9-year-old daughter would say things to me like, "It feels like all the energy is leaving my body." She went through periods of breaking out inexplicable body rashes. Her sleep was disrupted and disorganized. Her face was gray and purple under her eyes. Her body was in so much pain she could barely be hugged. If she played in the snow, it took her days to recover. She would say, "My legs feel like they have bricks," and then she would be unable to walk for weeks. My previously active child required a wheelchair. She would wake in the morning and say, "I'm so tired of being tired." These are all classic symptoms of ME/CFS. At the time, I didn't have the language and I waited for her to get better, like the doctors suggested would happen. Finally we took her to the Mayo Clinic where they confirmed that she was experiencing autonomic dysfunction, and then we found a doctor based in Seattle who now oversees her ongoing care.

My daughter still does not have the energy reservoir to attend a brick and mortar school. As I write, she is currently experiencing a flare and is in bed. It took nearly two years and accelerating symptoms before she received medicine and other interventions, and I can't help but wonder what her prognosis may have been if she received help earlier.

I strongly support the ME/CFS Day of Recognition bill. Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. This bill is an important step in building recognition of ME, empowering doctors to trust in the clinical presentations of their patients, and, most importantly, brings light and possibly community to those impacted by ME/CFS, Long-COVID and related conditions.

Best, Mercedes Harness Subject: Strong Support for the ME/CFS Day of Recognition Resolution

To Whom It May Concern:

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

I am an occupational therapist that has been working with this population for over 10 years. Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Currently i am the only provider in the town of Homer that has specific training to assist with one of the few techniques that helps with ME/CFS. With knowledge more people will improve and help to contribute to the positive changes in our future.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Jacquelyn Forster, OTR/L, CLT Owner and occupational therapist

Turn Again Wellness, OT in Homer, Alaska

#### Dear Representative,

I am a family medicine physician in Anchorage and I am writing to you in support of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Day of Recognition bill.

ME is an energy-limiting neuroimmune disease that is frequently disabling but is mostly unknown to people, including health care professionals. It occurs most commonly following an infection, particularly a viral infection, but this is not the sole cause. Despite the pervasive lack of awareness, this disease is distressingly more common than is appreciated. It is estimated to affect as many as 9 million people (including children) in the United States alone.

Many persons with ME have significant disability, with 75% unable to work or attend school and 25% becoming housebound or bedbound. Following the COVID-19 pandemic, the urgency to recognize this disease is compounded as most with Long Covid in fact also meet the criteria for ME. In a paper published as recently as 1/13/2025 in the Journal of General Internal Medicine, data from the NIH's RECOVER initiative found that adults infected with SARS-CoV-2 developed ME five times as often as did uninfected adults. It also found that new incidence cases of ME were 15 times higher than pre-pandemic levels.

The lack of knowledge of this disease within the medical community means that the diagnosis is often missed. The lack of knowledge amongst the general public means that people can't recognize the signs of it, even despite distressing symptoms. This lack of knowledge is particularly harmful as despite no FDA approved treatment, the key to management of ME is awareness. One must identify the disease as early as possible and modify one's usual routine to limit exertion in order to prevent further worsening. This can only be accomplished if people know that this disease exists. Therefore this day of recognition is vital for protecting our community and limiting the degree of disability that our neighbors, friends, and family may otherwise experience.

This issue is of particular resonance to me as my own partner is now disabled and housebound from this disease. I myself did not learn about ME in medical school or residency and was therefore unable to identify its appearance in my own household when the person to whom I am most close became ill with it. My partner had been a particularly high-functioning individual, a professional in our community that contributed to our community through her work in a multitude of ways. This illness has tragically forced her to end her multifaceted and successful career many decades early. Unfortunately she is not alone in this outcome, and I personally know multiple other local medical professionals and other members of our community that are personally affected by this disease as well.

Raising awareness is key. Thank you for your support of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Day of Recognition bill so that we may start to protect our community, our loved ones, and ourselves.

Sincerely,

David Penn, MD Anchorage, AK

### To Whom it May Concern,

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Cody Swanson Susan J. Share 3037 Widgeon Lane Anchorage, AK 99508

12/21/2024

## Dear Representative,

I wholeheartedly support the introduction of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Day of Recognition bill. I am convinced of the potential it holds to raise awareness and support for those living with ME/CFS. I have a dear friend whose life has dramatically changed due to this illness. She and others deserve to benefit from focused research and solutions so they can live vibrant full lives.

Thank you for your consideration and dedication to this important issue.

Best regards, Susan J. Share

#### 1/13/2025

Dear Legislators,

I'm writing to ask you to make May 12 Myalgic Encephalitis (ME) awareness day in the state of Alaska. ME is a disease disabling and killing more and more people, but with very little public awareness or funding for research.

More awareness will lead to more funding and research for treatments, and will also be a way to honor the lives and contributions of the Alaskans impacted by this devastating illness.

Thank you for your consideration.

Sincerely,

Kassi Grunder



Support letter for ME/CFS recognition

Bill Noomah <no.

ckeyes

Tue, Jan 14, 2025 at 6:08 PM

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Wendy Noomah PO Box 384 Homer, AK 99603

January 14, 20∠5

Subject: Strong Support for the ME/CFS Day of Recognition Resolution

Dear Representative Tobin,

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

I grew up in Alaska, commercial fishing, hunting, gardening, working hard, raising children, and when ME/CFS hit me, I resisted as much as I could, until I could barely function. I have been unable to work for the last two decades, and mainly manage my illness. I have found no doctors in my town that know anything about ME/CFS.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage.

Wendy Noomah

1/1

To our legislative representatives,

We are pleased to support the introduction of the attached final version of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Day of Recognition bill. We hope to officially introduce this resolution on January 21, 2025, and are excited about the potential it holds to raise awareness and support for those living with ME/CFS.

Thank you for your consideration and dedication to this important issue.

Best regards,

Kirk Gallardo

Education Interpretation Manager, Anchorage Museum



## Michael Gallagher

6137 Chevigny St Anchorage, AK 99502

January 17, 2025

## Dear Representative Carolyn Hall,

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias. Specifically, I support proclaiming May 12, 2025 as Myalgic Encephalomyelitis (ME) Awareness Day.

ME is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

Without adequate awareness of ME, there is a risk that the stories of those affected will be lost. Instead, those affected should be acknowledged, heard, and most importantly, respected. Something as simple as recognizing their struggle, for one day during the year, can be the beginning of change. Building public awareness of the devasting effects of ME will only help to promote funding for desperately needed research.

In summary, I wholeheartedly support recognizing Myalgic Encephalomyelitis (ME) Awareness Day and believe it is a **necessary** step that must be taken to one day improve the health outcomes of those affected.

Regards, Michael Gallagher

Mu Far

Shina duVall 811 Dogwood St. Anchorage, AK 99501

January 4, 2025

Senator Löki Tobin,

On behalf of all those affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias, I am writing to request that Alaska join the national and international community in proclaiming May 12th as ME/CFS Awareness Day.

Our shared goal is to raise awareness among not only the medical community where considerable misdiagnoses continue to occur, but among the general public in order to gain support for research and, ultimately, a cure.

It is estimated by the CDC that at least 3.3 million Americans suffer from ME/CFS. There are likely more but misdiagnosis clouds the estimate. As a widely misunderstood disease, patients find themselves struggling to find effective treatment and support, often feeling isolated and fearful of what lies ahead as the disease progresses.

This awareness initiative allows for a collaboration of organizations and individuals to come together to bring further national and international attention to the needs of the ME/CFS community.

In recognition of the profound medical support needs of those impacted by ME/CFS, I respectfully request that Alaska support this effort to battle ME/CFS by proclaiming May 12th as ME/CFS Awareness Day.

Thank you for your consideration.

Jania E. Vall

Respectfully,

Dorothy Shearn 2545 Loussac Drive Anchorage, AK 99517

January 12, 2025

Dear Representatives,

I am writing to convey my support for legislation aimed toward bringing awareness and support to the vital needs for individuals affected by Infection-Associated Conditions and Illnesses (IACCI), including Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS), Long COVID, POTS, and other dysautonomias which are poorly understood and yet affect millions of Americans.

ME is a complicated and disabling disease that impacts neurological, immune and metabolic systems. As a result, affected individuals experience significant limitations often affecting their ability to work, attend school, or other activities outside the home. The emergence of Long COVID has amplified this public health challenge as studies have revealed that nearly half Long COVID patients meet diagnostic criteria for ME.

Unfortunately ME is thus far under recognized and underfunded. Medical education on ME is likewise deficient resulting in many healthcare providers being unprepared to diagnose and treat ME.

Declaring May 12, 2025 as Myalgic Encephalomyelitis (ME) Awareness Day is an important way to enhance more recognition, understanding, and funding for research into this disease which will ultimately bring positive change for the ME/CFS community.

Thank you for your leadership and your consideration of this important issue.

Sincerely,

**Dorothy Shearn** 



Support for the ME/CFS Day of Recognition Resolution

Jamie Newsom Eator <a...ews@ymail.com To: S.hellismickey@gmail.com Thu, Dec 19, 2024 at 7:51 AM

Hollis Mickey eta. \*\*\* and ayer generation\*

Dear Senator Tobin and staff,

I am writing to express my sincere support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

I am a licensed massage therapist and I specialize in an area of treatment that supports patients experiencing ME/CFS and Long Covid. I have seen the serious effects that these conditions have on quality of life for clients.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden.

Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely,

Jamie Newsom Eaton, LMT, MLD-C, CLT (she/her) www.LymphaticAK.com 4050 Lake Otis Pkwy Ste 101 Anchorage. AK 99507 Sara Tabbert 1570 Johnathan Way Fairbanks, AK 99709

December 17, 2024

## **Dear Representative Cronk,**

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

My interest in advocating for this issue stems from the experiences of two friends who are affected by ME/CFS. Both have experienced profound changes to their lives and livelihoods and have found limited or no success (and even harm) seeking treatment within the medical system. This is largely because the condition lacks adequate research and funding. To me, one of the cruelest parts of this disease, of which there are many, is that those experiencing it simply do not have the physical energy to advocate for better funding and political action, let alone often for their own care. It is a terrible, frightening, lonely disease.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action.

Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

Sincerely,

Sara Tabbert

Megan Young, DO 1511 Marten St Anchorage, AK 99504

January 7th, 2025

#### Dear Representative Peltola,

As a practicing physician in Alaska, I am reminded daily that our modern understanding of disease is tarnished by centuries of misunderstanding. In particular, the complex interplay between chronic neurologic illness and infectious diseases has been historically underassessed, poorly researched, and mismanaged. From the forced extraction of teeth from the mentally ill in the late 1800s due to a misguided belief, to more recent dismissals of patients with acute onset psychosis who were subsequently found to have an inflammatory condition of the brain caused by viral infections in the mid-2010s.

Honoring my profession means confronting its missteps and being accountable to the patients harmed by our still limited understanding of these complex and life-altering diseases. In recognition of this truth, I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

Sincerely,

Megan Marie Young, DO

Subject: Strong Support for the ME/CFS Day of Recognition Resolution

Dear Sen. Click Bishop,

Witnessing a dear friend and a community of young people's life being robbed by this condition, I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Maite Agopian Email address: Rep.Alyse.Galvin@akleg.gov

**Subject:** Strong Support for the ME/CFS Day of Recognition Resolution

Dear Representative Galvin,

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

In our community, I have seen the impacts through the diagnosis of my colleague and friend, as well as my niece. As with all debilitating diseases, the numbers of affected

people are much larger than those diagnosed. Parents, siblings, the entire support system for each individual is impacted. This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Monica Shah Shane Castle 3124 Linden Drive Anchorage, AK, 99502

January 5th, 2025

Dear Rep. Jennie Armstrong,

I am writing to voice my strong support for advancing legislation that addresses the pressing needs of individuals living with Infection-Associated Chronic Conditions and Illnesses (IACCI), such as ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that are set to be introduced during the upcoming legislative session in January in Anchorage, Alaska. Although brief, these drafts signify an important move forward. I was particularly glad to see that revisions now explicitly include "ME" alongside "Chronic Fatigue Syndrome," as accurate terminology is crucial for raising awareness and tackling the diverse challenges these conditions present.

Incorporating the comprehensive language initially developed by Whitney Fox as a foundational framework is key to giving these bills the necessary context. This foundation underscores the urgency of addressing these issues. Additionally, established resources from organizations like MEAction and Solve M.E. provide critical research, advocacy tools, and personal stories that can further strengthen the case for these policies.

I encourage you to continue enhancing the legislation to reflect the full scope of these conditions and their far-reaching impact on patients and their communities. Placing an emphasis on patient experiences and evidence-based approaches will help create a compelling argument for action.

Thank you for your dedication to supporting individuals affected by ME/CFS and related conditions.

Sincerely, Shane Castle

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Honorable Lisa Murkowski,

Please support the resolution recognizing Myalgic Encephalomyelitis (ME/CFS). This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

ME/CFS is a complex, debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME/CFS face severe limitations. 75% are unable to work or attend school, and 25% become housebound or bedbound.

Long COVID has magnified this public health challenge: approximately half of Long COVID patients meet the diagnostic criteria for ME/CFS. This has led to an exponential increase in both its prevalence and the need for research, funding, and comprehensive care.

Despite its profound impact on individuals and families, ME/CFS remains underfunded and under prioritized. Medical education on ME/CFS is critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME/CFS, further compounding the challenges faced by patients.

Proclaiming May 12, 2025 as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Michael Dickerson Kayo Bogdan 2827 Lore Road Anchorage AK 99507

December 20, 2024

### Dear Representative Schrage,

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

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Sincerely.

Kayo Bogdan

Subject: Strong Support for the ME/CFS Day of Recognition Resolution

Dear Rep. Ashley Carrick,

Witnessing a dear friend and a community of young people's life being robbed by this condition, I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Maite Agopian

Simonetta Mignano 3124 Linden Drive Anchorage, AK, 99502

January 5th, 2025

Dear Rep. Jennie Armstrong,

I am writing to express my strong support for advancing legislation that addresses the urgent needs of individuals living with Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I had the opportunity to review draft bills scheduled for discussion in the upcoming legislative session this January in Anchorage, Alaska. While concise, these drafts represent a significant step in the right direction. I was especially encouraged to see revisions ensuring that "ME" is explicitly mentioned alongside "Chronic Fatigue Syndrome" in the language, as precise terminology is critical for raising awareness and addressing the complex challenges these conditions entail.

It is essential to incorporate the previously drafted comprehensive language, originally developed by Whitney Fox, as a foundational framework for these bills. This material provides valuable context that highlights the necessity of legislative action. Additionally, leveraging established resources from organizations like MEAction and Solve M.E. can offer a wealth of research, advocacy tools, and personal testimonials to support these efforts.

I urge you to continue refining the legislation to fully capture the complexity of these conditions and their profound impact on patients and their communities. By centering patient voices and grounding the bills in evidence-based research, we can build a stronger case for meaningful change.

Thank you for your dedication to improving the lives of those affected by ME/CFS and related conditions.

Sincerely, Simonetta Mignano

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Molissa Udevitz 7351 Huntsmen Circle, APT D Anchorage, AK 99518

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December 26, 2024

Subject: Strong Support for the ME/CFS Day of Recognition Resolution

Dear Representative Josephson and Senator Gray-Jackson,

As your constituent, I first want to thank you for your work in the Legislature. Today, I'm writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. ME is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children.

My good friend, mentor, and fellow Anchorage resident has lived with a ME diagnosis since 2021. She is one of the most brilliant and creative people I know, and she used to be incredibly involved in making Anchorage a better place through her work at a local nonprofit and with our local art community. Her unfortunate diagnosis now prevents her from participating in the workforce and community as she once did. She can no longer do simple daily tasks most of us take for granted: reading books, preparing food, or leaving home. Despite these incredible challenges, she continues to give back by dedicating her severely limited energy to raise awareness about and support research for ME.

I strongly urge this ME/CFS Day of Recognition Resolution's introduction and passage. The resolution is an important step towards ensuring people like my dear Anchorage friend are not forgotten through increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Thank you for your leadership and consideration of this critical issue.

Sincerely, Molissa Udevitz

Simonetta Mignano 3124 Linden Drive Anchorage, AK, 99502

January 5th, 2025

Dear Rep. Jennie Armstrong,

I am writing to express my strong support for advancing legislation that addresses the urgent needs of individuals living with Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I had the opportunity to review draft bills scheduled for discussion in the upcoming legislative session this January in Anchorage, Alaska. While concise, these drafts represent a significant step in the right direction. I was especially encouraged to see revisions ensuring that "ME" is explicitly mentioned alongside "Chronic Fatigue Syndrome" in the language, as precise terminology is critical for raising awareness and addressing the complex challenges these conditions entail.

It is essential to incorporate the previously drafted comprehensive language, originally developed by Whitney Fox, as a foundational framework for these bills. This material provides valuable context that highlights the necessity of legislative action. Additionally, leveraging established resources from organizations like MEAction and Solve M.E. can offer a wealth of research, advocacy tools, and personal testimonials to support these efforts.

I urge you to continue refining the legislation to fully capture the complexity of these conditions and their profound impact on patients and their communities. By centering patient voices and grounding the bills in evidence-based research, we can build a stronger case for meaningful change.

Thank you for your dedication to improving the lives of those affected by ME/CFS and related conditions.

Sincerely, Simonetta Mignano

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Maxine Fekete 440 w 89th ave Anchorage AK 93515

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1/17/25

### Dear Nick Begich,

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

Sincerely,

Maxine Fekete

Maria Williams 910 East 17<sup>th</sup> Avenue Anchorage, AK 99501

January 12, 2025

Dear Representative Zach Fields:

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI) including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions.

Sincerely,

Maria P Williams



#### Subject: Strong Support for the ME/CFS Day of Recognition Resolution

Sat, Dec 14, 2024 at 11:18 AM

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Dear Senator Claman.

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains under-recognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed. My dear friend Hollis Mickey suffers ME debilitations here in Anchorage.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

Drive more federal and private funding for research into the disease.

Foster the development of diagnostic tools and effective treatments.

Encourage the inclusion of ME in medical education curricula,

Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely, Rebecca Pottebaum

Constituent of Senate District H

#### Francesca Du Brock

2000 Hillcrest Dr.

Anchorage, AK 99517

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12/13/2024

#### Dear Mr. Fields,

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action.

Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. ME/CFS has greatly affected a close friend and former colleague of mine, as well as other writers and creatives whose work I follow. The lack of public awareness of these devastating diseases is truly shocking, and there is much work to be done. This is a good first step.

Sincerely,

Francesca Du Brock

Whey Bowerson 440 W 89th Ave Anchorage, AK 99515

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01/17/25

## Dear Nick Begich,

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

Sincerely,

Whey Bowerson

From: Steven Godfrey

4840 Kent Street Anchorage AK 99503

To: Alise Galvin

Date: 12.31.24

RE: ME Awareness Day

#### Dear Ms. Galvin

I am writing to express my strong support for the resolution recognizing Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and to urge its introduction and adoption. This resolution serves as a vital step toward increasing awareness, education, and action for a disease that affects millions of Americans but remains underrecognized and poorly understood.

Myalgic Encephalomyelitis (ME) is a complex and debilitating disease that impacts neurological, immune, and metabolic systems. It affects as many as 9 million people in the United States, including children. Many individuals with ME face severe limitations, with 75% unable to work or attend school and 25% becoming housebound or bedbound. The lack of understanding and acknowledgment surrounding ME has left an alarming 90% of cases undiagnosed.

The emergence of Long COVID has further magnified this public health challenge, with studies showing that approximately half of Long COVID patients meet the diagnostic criteria for ME. This has led to an exponential increase in ME prevalence, highlighting the urgency for research, funding, and comprehensive care for those affected.

Despite its profound impact on individuals and families, ME remains underfunded and under prioritized, receiving significantly less funding relative to its burden. Medical education on ME is also critically deficient, with only one-third of medical schools addressing the disease in their curricula. This gap in education leaves many healthcare providers unprepared to diagnose or treat ME, further compounding the challenges faced by patients.

Proclaiming May 12, 2025, as Myalgic Encephalomyelitis (ME) Awareness Day is an important step toward addressing these gaps. Increased awareness will help:

- 1. Drive more federal and private funding for research into the disease.
- 2. Foster the development of diagnostic tools and effective treatments.
- 3. Encourage the inclusion of ME in medical education curricula.
- 4. Provide recognition and support to those living with this life-altering illness.

This resolution has the potential to ignite significant change for the ME/CFS community, and I strongly urge its introduction and passage. Thank you for your leadership and consideration of this critical issue.

Sincerely,

Steven Godfrey (he/him) Professor of Art Andrea Huyck 38645 Fritz Creek Valley Dr Homer, AK 99603

1/4/2024

#### Dear

I am writing to express my support for advancing legislation that addresses the critical needs of individuals affected by Infection-Associated Chronic Conditions and Illnesses (IACCI), including ME/CFS, Long COVID, POTS, and other dysautonomias.

Recently, I reviewed draft bills that will be presented during the upcoming legislative session in January in Anchorage, Alaska. While brief, these bills mark an important step forward. I was pleased to see that revisions were made to ensure "ME" is explicitly included alongside "Chronic Fatigue Syndrome" in relevant language, as accurate representation is vital for increasing awareness and addressing the multifaceted challenges these conditions present.

The inclusion of previous comprehensive language, initially drafted by Whitney Fox, as foundational background is essential for framing these bills. These robust resources will help underscore the urgent need for legislative action. In this context, I have also emphasized the importance of utilizing established materials from MEAction and Solve M.E., which offer substantial research, advocacy strategies, and real-world testimonials to support the case for these policies.

I encourage you to continue refining this legislation to reflect the full complexity of these conditions and their profound impact on individuals and communities. Centering patient experiences and evidence-based research will strengthen the argument for decisive action. Thank you for your commitment to addressing the needs of those affected by ME/CFS and other related conditions. Please let me know how I can assist in further advancing these efforts.

Sincerely,

Andrea Lynn Huyck