ME International was formed in November 2019 as a nonprofit corporation to support Myalgic Encephalomyelitis (ME) patients, caregivers, and organizations around the world. The organization had seven board members at the end of 2021. All board members and our many active members are volunteers; no salaries or compensation is provided for their services. Board member bios can be seen HERE.
The purpose of ME (Myalgic Encephalomyelitis) International is to educate the general public, medical providers, and governments throughout the world as well as support ME patients, caregivers, advocates, organizations, family and friends.

The board had identified goals and objectives during 2020. However, during 2021, the board specifically identified two primary goals that will be the priority to achieve in 2022 and beyond. These goals are (1) Empower/Educate ME Patients and (2) Assist Needy/Severe ME Patients. So, our highest priorities are helping our ME member patients. Objectives and strategies were identified to achieve these goals in addition to several other important goals that are also being implemented. Other goals are Educate Medical Providers; Support ME Patients, Caregivers, Advocates, Family & Friends; Alleviate Loneliness; Advocate on Behalf of Membership (Outreach); and Support ICC Research. The board is planning to finalize a 3-year plan and budget to implement the goals and objectives.

The website, monthly newsletters, social media, pulse oximeter project, and Facebook chat rooms are the primary current projects to help our ME members.

At the end of 2021, ME International had 473 members in 27 different countries worldwide. Members consist of primarily patients with ME, but also ME supporters and caregivers. Many members are volunteers that help on various committees including Global Leadership, Newsletter, Website, Facebook chat rooms, and advocacy.

We have formed Facebook country groups for those living in Australia, Canada, USA, Europe, UK, and Africa. This gives our members in one location or region a place to talk, get acquainted with others in their country, and learn more about ME and what is offered in each country.

We have also formed Creative Groups on Facebook. These groups don't concentrate on ME or other chronic illnesses, but rather participate in discussions about doing creative things, such as cake baking, crocheting, redoing furniture, making jewelry or other crafts. These Creative Groups help take our minds off our illness and spend some time on a hobby or craft.
Helping our ME patient members, as mentioned previously, is of the highest priority for ME International. In addition to the website, monthly newsletters, and social media, two successful projects in 2021 are noteworthy.

**Pulse Oximeter Project**

During 2021, ME International provided **FREE** pulse oximeters to 91 of our members that needed one. The devices were purchased and individually shipped to members worldwide.

The use of a Pulse Oximeter can be especially useful for people with ME (Myalgic Encephalomyelitis). From the ME IC Primer: "A heart rate monitor can assist in keeping cardiovascular responses below the anaerobic threshold, resting heart rate is elevated in people with ME, and low blood volume can lead to elevated heart rate." It helps to understand how ME affects the heart rate; therefore, we make available a flyer that describes the importance of measuring heart rate for people with ME. We have heard from many of our members that received one and they were very appreciative of the generosity of this program.

**Facebook Chat Rooms**

The ME International chat room is a place for sufferers to engage with others in a video call setting similar to Zoom. We've settled on this format for now as it’s easy and convenient for most people. It has its own Facebook page that utilizes the “rooms” function. People join the page and then can enter when there’s a room open or they’re welcome to create their own room. People have the option to turn their cameras on or off and or mute and just listen along.

It started in March of 2021 and currently has 276 members. That number is expected to increase. There are a little over 15 regular members but we have had 25 people that have participated at least 1 time. We have participants from the USA, UK, South Africa, Canada, Australia, UK, Norway, The Netherlands, New Zealand and India. On average we have about 6 participants but have had days with 12.

The regularly scheduled rooms are as follows:
- **Monday-Sunday 1-3 pm USA EST**
- **Tuesdays 9-11 am EST**
- **Wednesdays 5-7 pm EST**
- **Fridays 7-9 pm EST**

We have received only positive feedback. It has created friendships that people foster outside of the chat group. Many people speak one on one and have developed a support system that they use on their personal Facebook pages.

It is accomplishing our goal of alleviating loneliness, providing support, and getting to know our members.
ME International made significant comments on several major projects and proposals by other organizations and agencies. We also coordinated with such agencies and organizations to develop a relationship and advocate our position on behalf of people with ME. We advocated our position that was developed in our Position Paper in 2020. Following are some of the most important accomplishments:

**NICE (National Institute for Health and Care Excellence)**
ME International provided comments on the proposed NICE Guideline on ME/CFS Diagnosis and Management in early 2021. The final Guideline was to be published in April 2021 and was reset for August 18, 2021. On August 17, NICE paused the publishing of the Guideline. After roundtable discussions among some parties, the final Guideline was published on October 29, 2021. The final Guideline made it clear the graded exercise therapy (GET) should not be offered for treatment for ME/CFS and that cognitive behavioral therapy (CBT) should only be offered to ME/CFS patients with care. The Global Leadership Committee of ME International provided comments that can be seen HERE.

**CDC (Centers for Disease Control and Prevention)**
ME International submitted a detailed response to the CDC’s Federal Register notice of May 16, 2021 on the report titled "Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): An Updated Systematic Evidence Review." Our comments were submitted before the August 16, 2021 deadline. Our 77 page response can be seen HERE.

**Proposed US Diagnosis Code Change**
ME International volunteers created and submitted comments on the diagnosis codes presented at the September 15, 2021 ICD Coordination and Maintenance Committee meeting. ME International rejected some of the proposed code changes. See our full response HERE. A response by the ICD Coordination and Maintenance Committee is expected in March 2022.

**Long COVID Alliance (LCA)**
ME International joined the LCA in February 2021 when it was first formed. The LCA is led by Solve ME and currently has nearly 100 members recognized on the LCA website. Members of ME International board have attended all monthly meetings of the LCA from the first meeting in March through December 2021. We have advocated our position among the members and have been constantly recognized as an international ME organization.

**COMMITTEES**
Functioning committees of board members and other volunteers include website, newsletter, marketing, fundraising, website, membership, and global leadership. The Global Leadership Committee (GLC) is comprised of members of ME International that represent the organization in their home country. Currently there are GLC members in Australia, Canada, Nigeria, South Africa, Spain, UK, and the United States.
The website at www.ME-International.org is the information hub of our organization. Here members and the public can find definitions and history of ME criteria used by the medical community and researchers, along with resources for health, support, and research for ME.

During 2021, much work has been done on the Patient Resource page including Do I Have ME, Symptom Info for Doctors, Managing Symptoms of ME, Communicating With Your Doctor, Severe ME, and Disability Information. Other important website pages were added or updated including 2021 Research Using the International Consensus Criteria (ICC) and Understanding Criteria.

Board member, Colleen Steckel, participated in an audio interview on Myalgic Encephalomyelitis and Chronic Fatigue Syndrome in POTS Patients. The interview of December 2021 can be viewed HERE.

ME International Statement of Financial Position December 31, 2021

The 2021 end of year balance is $12,891 going into 2022.