ME International was formed in November 2019 as a nonprofit corporation to support Myalgic Encephalomyelitis (ME) patients, caregivers, and organizations around the world. In January 2020, the organization approved six board of directors, officers, bylaws, conflict of interest policy, and established a bank account. It is important to note that board members, members, and others involved in the organization are volunteers; no salaries or compensation is provided for their services. We purchased liability insurance in April 2020. During the first quarter, the board developed the mission or purpose statement, tagline, logo, website banner and various cosmetic items. At mid-year, we added two more board members for a total of eight. The board had four board meetings during the year; only three are required in our bylaws.

We sent a monthly e-newsletter containing useful information for myalgic encephalomyelitis (ME) patients, caregivers, and advocates to all members. Social media has been a constant and important marketing and communication tool throughout the year. Direct advocacy activities included a submission to the UK NICE draft guideline. The year ended with 238 members of ME International worldwide.

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. Since the formation of ME International's website, we have added 12 separate country pages that list known support/information organizations for ME-ICC patients and those using other criteria. Our blog page includes ways COVID-19 affects the ME community. Guest blogs were done by Joan McParland (Northern Ireland) and John Duncan (US).

Future work will expand these organization pages, as well as our patient resources, medical/research information, and blogs.
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.

**MISSION / PURPOSE STATEMENT**

**GOALS AND OBJECTIVES**

The board identified goals and objectives for 2020 and beyond. The primary goal was to educate medical providers to create awareness about ME. Objectives and strategies were identified to achieve the goal. By May 2020, we produced two videos (long and short) about ME as defined by the International Consensus Criteria (ICC). An informational sheet was in final draft that is intended to educate medical practitioners about ME based on the International Consensus Primer (IC Primer). The website and social media efforts included information about ME that medical providers as well as ME patients can use. Materials in multiple languages are included as translations become available. We are coordinating with Marjorie van de Sande (one of the IC Primer editors) to post translated versions of the ME IC Primer, many which can now be found at: [www.ME-International.org/primercheat-sheets.html](http://www.ME-International.org/primercheat-sheets.html).

Another primary goal was to assist needy ME patients and to support ME patients, caregivers, advocates, family, and friends. Our website, social media, and monthly newsletters provided valuable information to help accomplish this goal. ME International recognized a need to help ME patients track their heart rate and oxygen levels to minimize post-exertional neuroimmune exhaustion (PENE also known as “crashes”). We solicited donations to purchase and mail pulse oximeters to members who requested one. Response from our membership has been very positive to the point where we will continue doing so as long as funds are available.

**COMMITTEES**

Functioning committees of board members, and in some cases other volunteers, include website, newsletter, marketing, fundraising, brochure, and global leadership. We formed a Global Leadership Committee (GLC) 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, UK, and United States. We identified other potential committees that will hopefully become functional in the future.
Much has been written and discussed about diagnosing myalgic encephalomyelitis (ME), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), chronic fatigue syndrome (CFS) and systemic exertion intolerance disease (SEID aka ME/CFS). ME International supports the International Consensus Criteria as defined in the IC Primer. Some other organizations and governmental entities support other diagnostic criteria. Therefore, ME International developed a Position Paper to clarify its position on diagnostic criteria. The Position Paper is on our website and has been distributed to our members and various other organizations.

ME International’s position, as stated in the Position Paper, is that myalgic encephalomyelitis is a complex, acquired multi-systemic disease apart from CFS and ME/CFS, that all patients need to be screened for ME in accordance with the IC Primer, and all research labeled “ME” use the ICC.

FINANCES

In 2020, the only fixed expenses were for liability insurance and the annual website fee. Again, all board members and volunteers are not compensated for their services. Donations covered these overhead costs as well as the pulse oximeter project with $768 remaining at the end of the year. Our fundraising paid for 50 pulse oximeters that are being provided free to our members worldwide that need one.