

# Myositis Support & Understanding

## 2020 Annual Report



### Our Mission

Our mission is to improve the lives of and empower those fighting myositis through education, support, awareness, advocacy, and access to research.

### MSU Turns Five!

With a mission of improving the lives of and empowering those fighting Myositis, we at MSU were prepared to **celebrate 5 years of phenomenal growth and achievements** but found we had to adapt our outreach to the community in the face of a global pandemic. We were up to the challenge as highlighted below.

### Fundraising

As a small, all-volunteer nonprofit, we provide services and support to our community through our fundraising efforts. Over 72% of our funds come from small donors, supplemented by generous sponsorships from our valued sponsors and partners alike.

Acknowledging the financial burden caused by the pandemic, we delayed our traditional fundraising until September, and we were still able to have a record fundraising year for MSU. Every year our Myositis Awareness month activities drive the message of MSU for the rest of the year. This year was no different. While we didn't use the month to fundraise, we took the opportunity to give back to the community in the form of an anti-fundraiser (giving money away to our members), morale boosting Facebook live videos, and encouragement that our members are not alone; all while educating our members on advocating for themselves in this difficult time. Our signature event, the second annual *Myositis Empower Walk* raised about \$18K, another record. We combined a virtual walk with continuous social media interaction to bring the event directly into the homes of our quarantined community. Giving Tuesday in December raised an additional \$13K.

## Financial Assistance

Our most significant program is the only one of its kind in the myositis community. It was one of only nine organizations listed by Global Genes as providing assistance to the myositis community during the pandemic. Our program stands alone among rare disease organizations.

Started in 2016, we have provided over \$150K in financial assistance to those living with myositis. Fueled by our fundraising and the community need, we awarded almost \$70K in 2020, while increasing the amount per qualified patient from \$1000 to \$1500, to pay for emergency household expenses, assistive devices, medical bills, and medical travel.

Almost 60% of our revenue goes back to the community in the form of direct financial assistance.

## Patient & Caregiver Support

MSU's provides free, 24/7 support to the myositis community by connecting patients and caregivers worldwide. In 2020 we substantially increased our membership, and saw a huge increase in both online and video support, currently hosting four popular *Patient Video Support* sessions, which doubled in attendance in 2020. These sessions were a lifeline for many patients in isolation.

Knowing that support is fluid and each person's needs are different, we decided to host game nights giving patients a way out of isolation to have fun with others who understand. We held our first two game night sessions during special holiday support sessions we hosted this year.

We plan to continue expanding our support platforms and our video support sessions.

## Education

MSU offers a variety of educational and lifestyle webinars. This year we had already decided to focus more on mental health for patients and caregivers, and thankfully so with the global pandemic causing increased isolation in what often feels like an already isolating illness. We would like to highlight two of our biggest educational accomplishments in 2020.

At the start of the pandemic, we were first on the scene together with Dr. Lisa Christopher-Stine and Dr. Christopher Mecoli, both with the Myositis Center at Johns Hopkins. We hosted a live myositis patient FAQ-style webinar about the virus and its potential effects on patients with myositis, many of whom take immune suppressing medications. Later in the year, we were excited to have Dr. Rohit Aggarwal join us to discuss managing patient care during the global health crisis. In addition, we created an FAQ page on our website and a PDF regarding the various COVID-19 vaccines.

Exercise is an important treatment for myositis, and currently the only therapy for those with inclusion body myositis. In an effort to ensure patients can safely continue exercising at home, and that caregivers have the tools they need to prepare and respond, together with Megan McGowan and Lauren Burgess, Occupational Therapists at the Johns Hopkins Myositis Center, we created our popular Exercise in Place webinar series, which we will continue in 2021.

## Advocacy

In the community of rare diseases, we know that when we act with one voice, we can improve the lives of all who are living with a rare disease. To build on the work we accomplished in 2020, in 2021 MSU will be working with other patient advocate groups in the myositis community to better address patient needs.

At a state and national level, through EveryLife Foundations' Community Congress Working Groups, we will be lending our input to legislative and policy working groups in two critical areas, (1) access to approved therapies, and (2) improving the regulatory process and advancing regulatory science for rare disease therapies. As an organization we are committed to having our Diversity, Equity, and Inclusion (DEI) Committee be a driving voice to make sure our policies, and actions are representative of all myositis patients. To this end we will be collaborating with Rare Advocates Movement and participating in the Our Lives Matter DEI assessment program, where MSU will gain insights and strategies to improve our outreach in an inclusive and equitable manner.

## Research

In 2020 we decided that it was time for MSU to be more of an active partner rather than a quiet stakeholder in moving research forward. Below are some highlights of the work we are doing.

- Established a Scientific Advisory Board with Manuel Lubinus, MBA, PhD in Immunology as the MSU Patient-Centric Research Advisor. Manuel will be leading our effort to bring the collaborative network approach to MSU, where myositis patients are a critical stakeholder in research ventures at all stages of the research and clinical development process.
- Working with other rare disease organizations to leverage their experiences. We have had ongoing discussions with Cure JM among others on how to benchmark patient crowdsourcing,
- Collaborating with business, academia and government agencies to influence and support the creation of a patient-centric approach in the myositis community.
- MSU is an initial partner with AllStripes in the IBM disease program, a rare disease bio-informatics startup to accelerate data analysis. Clinical data will be shared with academic groups around the world to promote new treatments and biomarkers for myositis.
- In 2020, we joined IMACS (International Myositis Assessment and Clinical Study Group), sponsored by the National Institute of Health (NIH), to bring the perspective of the patients into this research group in both myositis antibodies and a special working groups within IMACS, including the need for new biomarkers in commercial myositis panels.
- MSU continues to collaborate with medical institutions, helping recruit new patients for clinical studies from NIH and Pharma, and also bringing education from research on new biological and/or clinical results.
- MSU assisted Dr. Salman Bai at UT-Southwestern, a myositis clinician and researcher, gather patient feedback in efforts to develop a multi-disciplinary Myositis Clinic taking into account the long-term and diverse needs of myositis patients.

## Financials

Reports Attached.

## 2020 Board Members

Jerry Williams – Founder and President  
(Delaware)

Lynn Wilson, Vice President  
(Texas)

Penny Bundy, Treasurer  
(Oklahoma)

Jim Doiron, Secretary  
(Virginia)

Caitlin Ray, Board Member  
(Nebraska)

Mary Arnold, Board Member  
(South Dakota)

## 2020 Board Advisors

Emily Filmore, Advisor to the Board, Co-Founding Member  
(Missouri)

Manuel Lubinus, Patient-Centered Research Advisor  
(Texas)

William Tillier, International Research Advisor  
(Canada)

Myositis Support and Understanding Association, Inc.  
Statement of Financial Activities  
for the period of 01/01/2020 to 12/31/2020

Account Number	Account Name	Amount
<b>Income</b>		
4000	Contributions	\$61,352.58
4050	Fundraising/Special Events	\$53,443.15
5400	Other Revenue	\$285.64
Total Income		\$115,081.37
<b>Expense</b>		
7000	Awards, Financial	\$71,762.05
8400	Communication/Education Resources	\$3,561.27
7100	Grants	\$1,100.00
7500	Contract Services	\$218.99
8100	Operating Expenses	\$7,418.67
8300	Travel	\$5,928.86
8500	Other Expenses	\$3,644.34
Total Expense		\$93,634.18
<b>Net Income (Loss)</b>		<b>\$21,447.19</b>