

Experiences with Electrical Muscle Stimulation

February 2024

Background

The Pompe community has many individuals who have worked with physiotherapists and undergone their own experimentation to discover exercises or other manipulation strategies that may improve muscle function, strength, and endurance. As a community we are also aware that there may be neurological involvement as was shown when diaphragmatic pacing clearly showed that breathing without ventilation was possible for some children and adults¹.

We developed the hypothesis that improving and maintaining the neural connectivity between CNS and muscle through Electrical Muscle Stimulation may provide significant benefit to Pompe patients.

To test our hypothesis, we organised assessments for five individuals after which we hired one example of EMS, the Mollii² suit from Remotion Ltd, for a short pilot study.

Sensory-level stimulation, not muscle contraction

This type of EMS gives a sub-threshold, sensory electrical type of stimulation. There are many other types of EMS available, some will cause a muscle contraction. However, the type used for our study avoids this and, instead, provides a sensory-level input to have its effect via multiple selected muscle receptors.

The pilot study was extended to six months due to several problems we encountered, one of which was that our technical support from the EMS suit distributor became difficult as enquiries soared after the suit was discussed on BBC media.

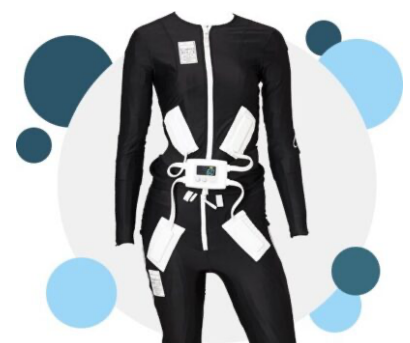
Initial assessment days

Pompe Support Network organised assessment days of the Mollii Suit for five Late Onset Pompe adults to assess the benefits of wearing the suit for just one hour.

The assessment was facilitated by Remotion Ltd and monitored by Nicola Condon, a physiotherapist at Queen Elizabeth Hospital, Birmingham and Andrew Oldham, a neuromuscular physiotherapist from the Mark Holland Metabolic Unit, Salford Royal.

Each individual assessment took a few hours overall and had several stages:

- Initial assessment of the patient needs and baseline function.
- Programming the suit electrical stimulation pads.
- Wearing the suit for about 60 minutes.
- Assessment to determine any immediate benefits.



¹ www.frontiersin.org/articles/10.3389/fresc.2023.1184031

² www.remotion.co.uk/what-is-mollii/

Assessment day results

Three of five Pompe adults reported significant benefit. The three later said that they would like an opportunity to continue using the suit. The price is too expensive for most people and is unlikely to be funded by our National Health Service.

- Patient 1 felt much improved “muscle recruitment.”
 - Felt “more solid.”
 - When walking, feet felt more in-line when changing direction.
 - More in control of forward lean and rise when sitting – more natural.
 - Driving home felt more comfortable – using arms, not body to steer.
 - Felt the effects afterwards for 4 days or more.
- Patient 2 experienced:
 - Greater core stability in standing from a seated position.
 - Improved walking in a straight line – less wandering.
 - Whole body tremors disappeared when pushing hard against physiotherapist resistance.
 - Less fatigued at the end of the assessment day.
 - Slept that night for 5 - 6 hours – usually only 2 hours, due to discomfort.
- Patient 3 also showed greater core stability:
 - in standing from a seated position.
 - and walking in a straight line – less wandering.
- Patient 4 was very mildly affected by Pompe disease and gained little benefit.
 - Main symptom before EMS was muscle pain.
 - Had previously stopped ERT as was feeling little benefit.
- Patient 5 was also mildly affected by Pompe disease.
 - Felt little benefit.
 - Interested in buying a suit.

If you are interested in collaborating with Pompe Support Network to develop a more rigorous study of EMS for Pompe disease, please contact us to discuss:

Email hello@pompe.uk

Website: www.pompe.uk

Short Pilot Study:

Experiences reported by Kevin Annesley

After my assessment with a Mollii suit for just one hour I was quite impressed with the results. I therefore volunteered to be the guinea pig for a three-month pilot study. The EMS system was programmed to stimulate the muscles that I was not effectively recruiting. I was advised by the company to wear the suit for one hour every day for two weeks, followed by one hour every two to three days, for a further two weeks.

The first week was good as I felt more solid in my posture and noticed that I was more secure - even when standing on a ladder!

Painful muscle spasms

Halfway through the second week, however, I started to suffer from painful muscle spasms at the top of my right shoulder blade, and also in my lower back. I stopped using the suit and booked a couple sessions with my chiropractic to release the spasms. Also, I started to feel very fatigued.

Due to communication problems, it took three weeks to relay my problems back to the company, I returned the EMS controller to be reprogrammed to reduce the stimulation intensity in the areas experiencing spasms.

EMS Suit reprogramming

I resumed testing but extended the time between sessions to five days. The spasms returned and I stopped using the suit.

I then asked if the suit could be reprogrammed to only stimulate muscles I was already using. With the remaining four weeks of study, the spasms ceased and there was no fatigue. I felt slightly more solid, and my thighs seemed to be performing better.

Leg muscle tightness.

The last session I had was at the end of August and I returned the suit. Since then, my right leg suffered some kind of light spasm where all the muscles in the calf and thigh became very tight. It was very hard bear weight on that foot, especially after sitting down for any length of time. My GP thought it was a damaged knee. I was dubious as exercise seemed to ease the muscles. An Xray confirmed that there was no damage to the knee. I used a TENS machine on the affected area, which helped with the muscle tightness. After about two months it started to ease and is now almost back to normal.

My right leg has always been the most affected by Pompe, and when I underwent an EMG nearly 20 years ago, before receiving the correct diagnosis, it was thought I had SMA due to the lack of electrical activity in the right thigh. I do wonder if the suit re-energized the nerves in my legs, and that the muscles adjusted to being activated correctly after years of neglect.

Reduced Creatine PhosphoKinase (CK) level

I had my regular six-monthly check-up two months after wearing the suit for the last time. I had a blood test after completing a six-minute walk test (6MWT). Usually, my CK level would be slightly elevated due to exercise before testing. It has never been below 245 units/L, and I was astonished that my CK value was only 154 U/L, which is well within normal range (55-170). If the suit was in some way correcting the electrical circuitry in the muscles, is it possible that muscles perform more efficiently after EMS, reducing muscle damage and the elevated CK?

Conclusion

There do seem to be real benefits to using the Mollii suit, but every Pompe patient would need their own personalised EMS program. I think that programming the EMS to enhance the least-affected muscles, would be most efficacious. I don't know if a slightly different electrical stimulus could be programmed to enhance this.

For future studies I would recommend much closer involvement with the suit's supplier and a neuromuscular physiotherapist, preferably one familiar with Pompe patients.

My thanks go to Pompe Support Network for giving me the opportunity and financial support to carry out this study, and I hope that it can be a steppingstone to a better understanding of the benefits of Electrical Muscle Stimulation (EMS) for the whole Pompe patient community.



For anyone interested in trying EMS for themselves, we would strongly recommend doing so with medical supervision, preferably by a healthcare professional with a broad understanding of Pompe disease.