

Brief project report – Mito-run

Project name: Mito-run – Regenerating mitochondria, activating legally blind patients and spreading the word

Project objective and expected results:

- Increased knowledge about mitochondrial diseases among medical personnel and society at large as well as increased knowledge about the patient organisation and group.
- Increased physical activity among persons with mitochondrial diseases and among patients who are often legally blind.
- Increased empowerment among patients and in seeing the possibilities of establishing an association.

Summary of project outcome 2019 – 2020

In spite of the pandemic and restrictions to gather maximum 50 persons, the second Mito-run in September 2020 attracted a total of 50 persons in the Royal National City Park of Haga, Solna. An additional 30 persons took part in the race by registering digitally. “Digital races” with several participants were arranged in other parts of Sweden and in Norway and there were even runners as far away as in Bolivia in Latin America. The first Mito-run in 2019 should be seen as a pilot, but nevertheless it attracted a total of 30 participants and the word was spread in social media, a podcast, a local newspaper and also at a conference prior to the race.

The project objectives and expected results were achieved to a large extent, especially when looking at the results of both events during the first two years, 2019 – 2020. Below is a summary of the results and more detailed information from the activities the first two years.

The first Mito-run 2019 – a Pilot Race to Raise Awareness

The first Mito-run – probably the world’s first Mito-run – was held in Stockholm on 18 September 2019 at hrs. 19.00. A total of 30 persons were involved and the 24 participants who took part in the race included medical personnel, researchers, members of LHON Eye Society (patients, careers and relatives) and representatives from “society at large”.

Apart from the 24 participants several persons were engaged as volunteers, supporting with e.g. distribution of water bottles, jackets, arranging warmup, timing and music to keep up the spirit in the cold weather. Volunteers were also placed at the start/end point and at two pedestrian crossings on the way to/from the Royal National City Park, to support the visually impaired persons running.

Start and finish line of the run was outside the Karolinska University Hospital and the race was 5,5 km long in the nearby City Park. In figure 1 below is a map of the stretch of the first Mito-run in Haga Park, close to Karolinska University Hospital. [Click here for a link to the website for registration and more information on the race 2019](#)).

Spreading the word about the first Mito-run

Before the race, the association’s chairperson 2019 and co-initiator of the race, Fredrik Lindemark Guzmán, held a speech about living with LHON and including the advantages of physical activities, at the Mitochondria Day conference (see figure 1, below). There was an article in two local newspapers about the Mito-run and Félícia Adlersfeld Castillo, co-initiator of the race.

The word about the first Mito-run was also spread in a [podcast on Soundcloud](#), on the website of LHON Eye Society and in internal media of the Karolinska University Hospital. Here is also [a short video clip on Facebook from the first Mito-run](#).

The first Mito-run was arranged in conjunction with the Mitochondria Day for researchers and medical personnel, held in Stockholm the same day. The Mito-run was arranged in collaboration with and close to the Centre for Inherited Metabolic Diseases (CMMS), Karolinska University Hospital, and CMMS's provided access to dressing rooms and showers for the participants.

The aim to contribute to increased knowledge about the fact that physical activity is important for the function of mitochondria as well as for physical and psychological wellbeing was achieved through the conference before the race, during the race itself and in media/social media after the event. Also, the inclusion of the race at the digital platform race.se contributed to spreading the word about mitochondrial diseases.

Below are a few photos from the conference and the first Mito-run that gathered 24 runners and a total of approx. 30 persons.



Figure 1. The Chairperson 2019 and co-initiator of the Mito-run, Fredrik Lindemark Guzmán, in a presentation before the race

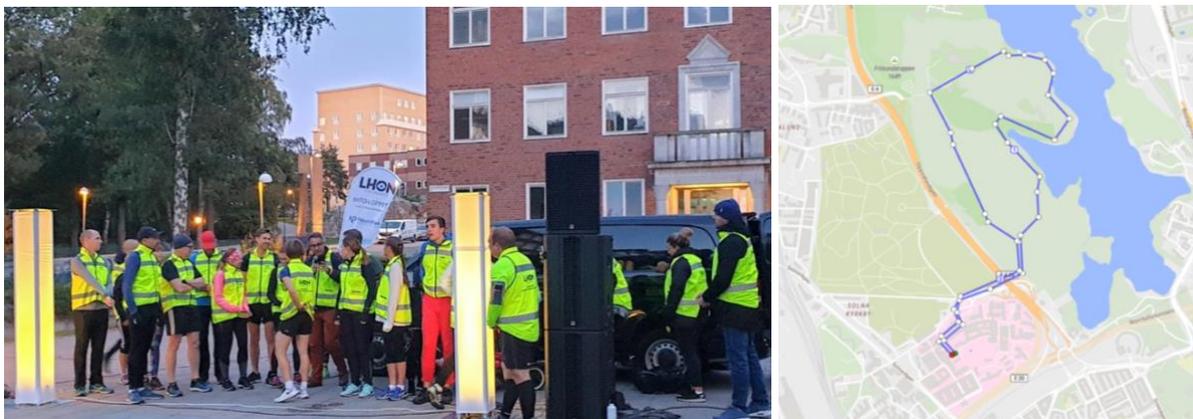


Figure 2. Preparing for the Mito-run 2019 and map over the area of the Mito-run 2019 ([link to online map](#))



Figure 3. The Race is on



Figure 4. Going through the results



Félicia Adlersfeld Castillo vill bidra till forskningen kring LHON inte minst för sina döttrars skull. Här tillsammans med dottern Pátricia. Foto: LäsaBild Privat bild + Mostphotos

Félicia ordnar lopp för att uppmärksamma ovanlig ögonsjukdom

Figure 5. From article in a local newspaper about the first Mito-run and co-initiator, Félicia Adlersfeld Castillo

Follow-up of indicators and results of the Mito-run in 2019

Expected result/indicator	Result	Comment
• 50 participants in the first Mito-run	30 participants in total (in 2020: 80 participants)	Cold weather, short preparation period
• Podcast about the activity	Podcast on Soundcloud	Felicia Adlersfeld Castillo & Oskar Lundell
• Spread of information in social media	Spread on e.g. Facebook and Instagram	Apart from LHON Eye Society participants shared information
• Article about the activities in local media	Articles in local papers in Solna and Sundbyberg and also in Kungsängen, Upplands-Bro.	
• Increased knowledge about LHON and other mitochondrial diseases	Through the conference, information before and after the Mito-run and the race itself, already the first Mito-run in 2019 contributed to increased knowledge (see also below on 2020).	

The Mito-run 2020 – a complete success in spite of the pandemic

The second Mito-run was held in Stockholm on 16 September 2020 at hrs. 17.00. Due to the pandemic the maximum number of persons that could participate was limited to maximum 50 and the physical race in Stockholm reached the maximum number. In addition, 30 persons joined the race in other parts of Sweden, in Norway and even as far away as in Bolivia.

The Mito-run 2020 in Stockholm was held inside the Haga Park, with start and endpoints at Radison Blu Royal Park Hotel. This made the area much safer for visually impaired persons and the park is also a beautiful area for running.

Spreading the word about the Mito-run 2020

Like in 2019, the Mito-run of 2020 was also held after a conference on mitochondrial diseases in Stockholm. The conference included researchers, medical experts, patients and careers, giving their perspective on mitochondrial diseases. At the conference participants were also invited to the physical or digital Mito-run. Here is a link to a video from the conference on YouTube: <https://youtu.be/IAQhbWZhUic>.

Reflective vests and water bottles were distributed to all participants in Sweden and Norway, which contributes to increasing the awareness not only during the race, but also later when the vests and bottles are used by the participants.

Below are some links to articles and YouTube clips from the Mito-run 2020 and photos from Sweden and Bolivia:

- [Short article with photo of the winner 2020](#)
- [Short video clip with high lights from the Mito-run 2020](#)
- [Short video with co-initiator, Félicia Adlersfeld Castillo](#), about the reasons behind the idea (in Swedish)
- [Dr. Martin Engvall, about the medical aspects and a short summary of the Mito-run](#) (in Swedish)

Mito-loppet – kan bli en tradition

I september arrangerade LHON Eye Society Mito-loppet i Hagaparken i Stockholm. En fem kilometer lång slinga med personer med LHON-diagnos och personal från CMMS som utvecklar LHON-registret och ett kompetenscenter för sjukdomen. Mito är en förkortning av mitokondriella sjukdomar, som är en särskild form av ärftlighet på modernet. Loppet genomfördes för andra gången och självklart deltog Lars Kinnunen som är ny ordförande för LHON Eye Society.

– Om man tränar så får man mer energi både mentalt och fysiskt, säger han. Vilket också innebär att antalet friska mitokondrier ökar och det är en stor fördel vid Lebers hereditära optikusneuropati. ©



Figure 6. Article in newspaper with photo of the winner



Figure 7. Warming up before the Mito-run 2020



Figure 8. Start of the Mito-run 2020



Figure 9. Water bottle and reflective vest - A Race to Raise Awareness



Figure 10. Happy participants in the Mito-run 2020



Figure 11. Team Karolinska at the Mito-run 2020



Figure 12. Co-initiator, Fredrik Lindemark Guzmán, running the Mito-run 2020 in La Paz, Bolivia, at 3 600 meters above sea level

Follow-up of indicators and results of the Mito-run in 2020

Expected result/indicator	Result	Comment
<ul style="list-style-type: none"> • 50 participants (in the first Mito-run) 	80 participants (50 in Stockholm & 30 around the world)	Due to the pandemic 50 was the maximum number of persons
<ul style="list-style-type: none"> • Podcast about the activity 	Podcast in 2019 and YouTube clips in 2020	
<ul style="list-style-type: none"> • Spread of information in social media 	Spread on e.g. Facebook , Instagram and YouTube	Apart from LHON Eye Society, participants shared information
<ul style="list-style-type: none"> • Article about the activities in local media 	In 2020 information was mainly spread in digital form (see above).	
<ul style="list-style-type: none"> • Increased knowledge about LHON and other mitochondrial diseases 	Through the conference, information before and after the Mito-run and the race itself, already the first Mito-run in 2020 contributed to increased knowledge not only in Sweden, but in other Nordic countries and there was even a participant running in Bolivia.	

Summary of conclusions and continued work

The Mito-run is here to stay. In only two years' time it has become a tradition. It is planned to be arranged again in September 2021 and through digital races it will be possible to increase the number of participants, independently of the situation in relation to the pandemic.

The race has already during the first two years contributed to increased knowledge about mitochondrial diseases and to increased awareness of rare diseases both among medical personnel and society at large in all countries and places where the race was arranged by one or more participants.

The Mito-run contributed to increased knowledge about the patient organisation and group in all countries/places. Since the race attracted several participants in Norway in 2020 it also contributed to some extent to LHON Eye Society's expansion in the Nordic countries.

The first Mito-run was possible to arrange thanks to financial support from the [Society for the Study of Inborn Errors of Metabolism](#) (SSIEM). Without that support, the race would most probably not have been possible to arrange. In particular, we would not have been able to include water bottles and reflective vests for participants. The vests and water bottles are very much appreciated by the participants and contribute to making race more attractive.

Most probably, many of the participants will use the reflective vests and water bottles throughout the year. Both items include the Mito-run's motto "A Race to Raise Awareness" and will hence contribute to increasing the awareness about mitochondrial diseases not only during the race itself.

The Mito-run, the conferences before the run and also the vests and water bottles contribute to raising the awareness about the importance of physical activities for the functioning of the mitochondria and for wellbeing in general.

Based on discussions with participants in the race and patients that are members in the LHON Eye Society, we can see clear signs that the project has contributed to increased empowerment among patients with mitochondrial diseases. The Mito-run has also contributed to increased physical activity, at least during the race, among persons with mitochondrial diseases and among patients who are often legally blind. Hopefully the event, together with the reflective vests and water bottles, will contribute to making physical activity a habit for many of the participants.

Within the LHON Eye Society we look forward to arranging the next Mito-run in September 2021 and we have the intention to make the event grow in number of participants and outreach year by year.