



World Mitochondrial Awareness Week 2023 Report for the Board

12 January 2024



BACKGROUND

Executive Summary

World Mitochondrial Disease Week (WMDW) raises awareness of mitochondrial disease (mito) on a global scale through educational, fundraising and advocacy activities. On behalf of IMP, Mito Foundation (MF) managed the WMDW website and the majority of organic social media campaign across WMDW platforms. Platform, a creative agency, managed the paid for social media content.

The goals for the week were to **increase general awareness** of mito, to **increase membership participation** in our events.

Highlights:

- This year we reached more people than ever - we estimate around half a million people in 2023.
- Our paid for ads on Facebook and Instagram reached 469,039 people
- Light Up for Mito increased its number of lit-up monuments by 51, bringing it to a global total of 383
- Social media reach across all platforms outperformed 2022's reach. This is largely due to the Meta ads, run across Facebook and Instagram, run by the Platformcan agency.
- Traffic to the [Mitochondrial Disease Week website](#) was disappointing. The most popular page was Light up for Mito

RESULTS OF WMDW AWARENESS DAY 2023

Website Reach

During September 2023 the WMDW website received 4,227 unique users. Overall website traffic was low and indicates that either IMP members aren't promoting the website or that people aren't clicking through. Aside from the homepage, Light Up For Mito pages were the most popular.

Results of Social Media Campaign

This year we posted our social media assets on Facebook, Instagram and X and then boosted some of the posts. This was managed for us by Platform. The agency spent €978.25 on 28 ads across Facebook and Instagram. This helped us reach a fantastic number of people, engaging with 195,152 people on Facebook and 273,887 on Instagram (bringing us to just under half a million people in total).

[This was our most popular Facebook post](#)

[This was our best performing Instagram post](#)

LHON Awareness Day

On LHON Awareness Day (19 Sept 2023) we held an honest engaging interactive webinar with over 50 people, as we discussed the realities of living with mito. [A recording of the webinar is available on our You Tube channel](#)

Light Up for Mito

This year, there were 383 monuments across 17 countries. This was 51 more monuments than 2022 and continues the upwards trend.

Faces of Mito

In 2023, 4 stories were showcased on the WMDW website (the Faces of Mito webpage received 104 unique users in September), 6 stories were shared on Facebook, 5 on Instagram.

POST EVENT RESPONSE FROM MEMBERS

Following the events of WMDW, we sent a survey to our members to find out how they participated and what was useful to them.

Participation: The majority of respondents (89%) both created and re-shared social media content. 67% held their own events and 78% raised awareness through their local media channels.

Toolkits and social media assets: Feedback indicated the toolkits were very useful to reducing the resources required by members to create content, with the overwhelming majority finding them useful. Most used them exactly as they are, whilst some made edits to suit their local audiences, suggesting that providing them in Canva was a practical support to members. It was noted that it would be useful if the toolkits were provided sooner. An important note to consider is the return of investment of the assets, given the low click-throughs they created (eg they did not drive much website traffic). Members would like to be part of the discussion about whether it will be better to fund more staff resources than investing in social media assets during WMDW.

Paid for social media boosts: Most members did not invest in boosting social media content. The majority responded that this was due to a lack of financial and human resources.

Theme: Responses to the introduction of a theme (fatigue) this year were mixed. Some found it helpful as a focus, while others felt there was already so much content to the week and the sub-events. Feedback also suggested that the theme could be useful if confirmed earlier in the year so it could be integrated into other social media strategies. Suggestions for future themes include muscle weakness and POLG disorders.

LEARNINGS & CONCLUSIONS

In reviewing this year's awareness week, it seems clear that it would be worthwhile to spend some time agreeing the goals for future events, determining what the indicators of success might be and how they will be measured.

This year was the first that we have sought funding for Awareness Week. This allowed us to create the Tool Kit, assets and boost social media. The investment paid off and we will look to do it again next year. It will also be advantageous to be able to share the toolkits, theme and goals of the event(s) earlier in the year so that members have more time to prepare their own activities.

The low WMDW website views indicate that it drives limited engagement. Following a conversation with the Mito Foundation it has been agreed that the WMDW information will move to the new IMP website which will be created in early 2024. The MF team will continue to support IMP with the WMDW pages on the new site.

It would be good to explore more involvement from other IMP members and develop a strategy to reach out to mito organisations who are not part of IMP.

In conclusion, as ever, there is a lot to learn and adjustments to be made. However for an organisation with a very small team, we are thrilled with the reach we were able to achieve this year and look forward to building on that success with next year's World Mitochondrial Disease Week.

RECOMMENDATIONS FOR WMDW 2024

- IMP will invite members to join the WMDW Working Group, expanding it's expertise, geographical split and organisational size and age
- IMP will seek funding from our industry partners to support the campaign and boost social media
- Campaign development will begin in January, including the development of a Tool Kit and editable social media assets
- WMDW webpages will move to the new IMP website
- IMP will hold a webinar for members in Q1 showcase the assets and campaign and answer questions