



WORLD  
MITOCHONDRIAL  
DISEASE WEEK



international mito patients

# PUTTING MITO ON THE MAP



**CAMPAIGN  
TOOLKIT**

# Contents

<b>3</b>	World Mitochondrial Disease Week	<b>21</b>	Get Involved
<b>5</b>	2026 Campaign Theme	<b>22</b>	Logo
<b>7</b>	Key Messages	<b>25</b>	Colour Scheme
<b>15</b>	World Mitochondrial Disease Week Dates	<b>26</b>	Typography
<b>16</b>	TK2d Awareness Day	<b>27</b>	Social Media Assets
<b>17</b>	LHON Awareness Day	<b>29</b>	Social Media Content Calendar
<b>18</b>	Light up for Mito	<b>30</b>	Members
<b>19</b>	The Global Mito Map	<b>31</b>	Contact
<b>20</b>	The Mito Pin		



# About World Mitochondrial Disease Week

## 14 - 20 September 2026

**World Mitochondrial Disease Week** raises awareness about mitochondrial diseases (mito). It aims to improve the lives of people affected by mito and to increase awareness among doctors and the general public.

### What are Mitochondrial Diseases?

Most people have never heard of mitochondrial disease. Once considered rare, it is now thought to affect 1 in 5000 people, making it the second most commonly diagnosed, serious genetic disease after cystic fibrosis. Researchers have discovered links between mitochondrial dysfunction and other conditions including Alzheimer's disease, Parkinson's disease, diabetes, cardiac issues and some cancers.

Scientists believe that by focusing on mitochondrial dysfunction, they may be able to devise effective treatments and potential cures for mito and help the millions of people who suffer from the above-mentioned diseases.



# About World Mitochondrial Disease Week

**Mark your calendars for 14 - 20 September 2026 and take part in World Mitochondrial Disease Week 2026!**

Be creative and share with each other about World Mito Week, spread the word amongst your friends, family and others.

Post your events using the form on our website and use social media to make your personal Mito Week a success, don't forget to use the official hashtags **#WorldMitoWeek2026** and **#PuttingMitoOnTheMap** so everyone can see your contribution!



The theme of World Mitochondrial Disease Week 2026 is:

# PUTTING MITO ON THE MAP



# 2026 Campaign Theme

This year's official World Mitochondrial Disease Week theme is: Putting Mito on the Map

Mitochondrial disease affects people around world, yet awareness, understanding, and recognition of mito remain limited in many communities. This year's theme focuses on making mitochondrial disease more visible globally by amplifying patient voices, strengthening awareness, supporting advocacy, and connecting people across borders.

**"Putting Mito on the Map"** is about ensuring that no person living with mito feels unseen, unheard, or isolated, no matter where they live.

The campaign highlights the importance of global collaboration between patients, families, healthcare professionals, researchers, organisations, and advocates to improve diagnosis, care, support, and research. Through shared stories, awareness activities, education, and community action, World Mitochondrial Disease Week aims to help make mito recognised, understood, and prioritised worldwide.





# Key Messages - short version

## 1. Mitochondrial disease affects people everywhere

- Mitochondrial disease impacts individuals, families, and communities around the world, yet many people still do not know what mito is or how deeply it affects lives.

## 2. Awareness leads to understanding and change

- Greater awareness helps drive earlier diagnosis, better support, more research, and ultimately increases hope for those affected by mitochondrial diseases.

## 3. Every voice helps put mito on the map

- Every story shared, every event organised, and every conversation started helps make mito more visible, more understood, and harder to ignore.



# Key Messages - short version

## 4. Progress comes through collaboration

- Real change happens when patients, families, organisations, researchers, healthcare professionals, and advocates work together across borders and communities

## 5. This is a global movement

- Around the world, patients, families, clinicians, organisations, and advocates are uniting to ensure mitochondrial disease is recognised, understood, and prioritised, no matter where you live.

## 6. The future of mito is being written now

- Scientific research is opening new doors for people living with mitochondrial disease, and the global community plays a vital role in making that progress possible.





# Key Messages - long version



## 1. Mitochondrial disease affects people everywhere

- Mitochondrial disease affects people of all ages, backgrounds, and communities across the globe. There are hundreds of different types of rare mitochondrial diseases, many of which are individually rare or ultra-rare. Collectively, an estimated 1 in 5,000 people live with a mitochondrial disease, equivalent to approximately 1.5 million people worldwide.<sup>[1]</sup> Despite this, awareness and understanding remain limited in many countries, and families often face long diagnostic delays, uncertainty, and a lack of support. Diagnosing mito often takes years - sometimes decades. Patient organisations in countries across the globe are working to change this, offering support, advocacy, and connection to those who need it most. Increasing awareness helps ensure more people affected by mito are recognised, understood, and connected to the care and community they need.



# Key Messages - long version



## 2. Awareness leads to understanding and change

- Awareness is a powerful step towards supporting the lives of people affected by mitochondrial diseases. Many people spend years searching for answers before receiving a diagnosis, often seeing multiple specialists along the way. Greater awareness among healthcare professionals, policymakers, educators, and the public can help improve understanding of mito, encourage earlier diagnosis, strengthen support systems, and increase investment in research.

Mitochondrial disease can affect any organ, at any age, with any symptom, making it one of the most challenging conditions to recognise.<sup>[2]</sup> But when more healthcare professionals recognise the symptoms, the chance of a correct diagnosis increases. Better awareness creates opportunities for meaningful and lasting change.

# Key Messages - long version



## 3. Every voice helps put mito on the map

- Putting mito on the map starts with people. Every patient story, awareness activity, fundraising event, social media post, and conversation helps bring mitochondrial disease into a greater public view. Visibility matters because many people affected by mito feel isolated or misunderstood. Research shows that patients with rare diseases experience significantly higher rates of anxiety and depression, in part due to the difficulty of obtaining a diagnosis and finding others who understand their experience.<sup>[3]</sup> But when communities speak up, things change.

Patient organisations across the globe are working tirelessly to amplify these voices, connect communities, and ensure that mito is recognised in every country, every healthcare system, and in every conversation about rare disease.

Together, we are putting mito on the map one story, one event, and one connection at a time.



# Key Messages - long version



## 4. Progress comes through collaboration

- Progress in awareness, care, support, and research depends on collaboration across the global mito community. Patients, families, healthcare professionals, researchers, advocates, and patient organisations each play a vital role in advancing understanding and improving outcomes for people affected by mitochondrial disease. By sharing knowledge, resources, experiences, and expertise across countries and communities, we can strengthen advocacy efforts and accelerate meaningful progress together. No single country, organisation, or individual can put mito on the map alone. But together, we can.



# Key Messages - long version



## 5. This is a global movement

- The movement to put mito on the map is truly global. Across the world, there are patient organisations, researchers, healthcare professionals, and advocates working together to raise awareness, improve access to diagnosis, and push for better care and research funding. From national campaigns to community fundraisers, from clinical networks to social media advocacy, people across the world are finding ways to make mito more visible. No one should face this disease feeling alone or unseen, and through the collective power of this global community, more and more people are finding connection, support, and hope. World Mitochondrial Disease Week is one moment in that wider movement: a time to come together, amplify our voices, and remind the world that mito matters.



# Key Messages - long version



## 6. The future of mito is being written now

- Advances in research and emerging therapies are bringing new hope to the mito community. Research is accelerating, but progress depends on continued investment, global collaboration, and the participation of patients and families.<sup>[4]</sup> By putting mito on the map, we help ensure that research funding follows, that clinical trials reach more people, and that the next generation living with mito has more options, better care, and a brighter outlook. The future of mito depends on the actions we take today, and every patient, advocate, and researcher is part of writing that story.

## References

The following sources informed the statistics and claims included in this document. Organisations using these key messages are encouraged to verify figures against the most current published data and supplement with locally relevant statistics where available.

**[1]** Gorman GS, et al. Prevalence of nuclear and mitochondrial DNA mutations related to adult mitochondrial disease. *Ann Neurol.* 2015;77(5):753–759. [Estimated 1 in 5,000 prevalence]

**[2]** Mitochondrial Disease Foundation. What is Mitochondrial Disease? Available at: [www.mitoaction.org](http://www.mitoaction.org) [Any organ, any age, any symptom]

**[3]** Bogart KR, Rottenstein A, Loewy M, Supples M. Patients with rare diseases experience higher rates of anxiety, depression and social isolation. *Orphanet J Rare Dis.* 2019. [Mental health impact in rare disease]

**[4]** Parikh S, et al. Patient care standards for primary mitochondrial disease: a consensus statement from the Mitochondrial Medicine Society. *JIMD Rep.* 2017;32:1–97. [Emerging treatments and research priorities]

# World Mitochondrial Disease Week Dates

Join us in raising awareness and support for those affected by mito during World Mitochondrial Disease Week.



**8 September**  
TK2d Awareness Day



**19 September**  
LHON Awareness Day



**19 September**  
Light up for Mito

Find out more on our website [mitopatients.org/mito-week](https://mitopatients.org/mito-week)



# TK2d Awareness Day

## Save the Date for TK2d Awareness Day - Tuesday 8 September

Thymidine kinase 2 deficiency (TK2d) is a debilitating and life-threatening genetic disease that causes progressive and severe muscle weakness. Many patients lose the ability to walk, eat, and breathe independently.

Join us in raising awareness about TK2d!

**Learn more about this condition at [mitopatients.org/mito-week](https://mitopatients.org/mito-week)**





# LHON Awareness Day

## Mark your calendars for LHON Awareness Day - Saturday 19 September!

Leber's Hereditary Optic Neuropathy (LHON) is a rare, inherited condition that causes sudden, painless vision loss often in young adults. It is a type of mitochondrial disease, caused by mutations that impair the function of mitochondria, the tiny powerhouses of our cells.

Because the optic nerve demands high levels of energy and must remain transparent to light, it is especially sensitive to mitochondrial dysfunction. As a result, LHON primarily affects the cells responsible for transmitting visual information from the eye to the brain.

LHON affects approximately 1 in 25,000 to 1 in 50,000 people and occurs more frequently in males.

On September 19, join us in raising awareness about LHON.

Together, we can support those affected, drive research forward, and shine a light on this often-overlooked disease.

**Learn more at: [mitopatients.org/mito-week](https://mitopatients.org/mito-week)**





On **Saturday 19 September**, monuments, landmarks and buildings will light up in green to raise awareness of mito.

- **Get involved!** Invite a local building or monument to participate. We have a template invitation letter that you can personalise and send. Raise more awareness by personalising our press release and sending it to your local news outlet. [Add your location](#) to the global mito map on our website.
- **Light Up Your Home!** Want to raise awareness with your neighbours? Buy a green light bulb (or use your Smart light) and turn your door or windows into a green awareness raiser! Talk to your local community about why your home has gone mito green!
- **Find your nearest participating site [here](#).**
- **Share your Light Up photos!** Please post photos of your local monument or home with our hashtags **#LightUpForMito2026**, **#PuttingMitoOnTheMap** and **#WorldMitoWeek2026**. You can also share them with us by email: [info@mitopatients.org](mailto:info@mitopatients.org).

**Download the toolkit to read more and get involved!**

**Download**

# The Global Mito Map

## Mitochondrial disease affects people everywhere and now, for the first time, you can see it!

The Global Mito Map brings this year's theme, Putting Mito on the Map, to life by creating a visual picture of the worldwide mito community. Through patient stories, organisations, events, awareness activities, research projects, and Light Up for Mito locations, the map showcases the people, places, and initiatives helping to raise awareness and drive change.

As more pins are added, the map becomes a powerful reminder that mito is a global issue affecting communities around the world. Together, we can make mitochondrial disease more visible, recognised, and understood.

Every pin tells a story and every contribution helps Put mito on the Map.



# The Mito Pin

Download



The pin is the campaign's central symbol, featured on the global mito map and all campaign assets. It is available for download here and is also included in the social media assets on Canva. While the primary pin is mitochondrial green, other colors have been developed to represent different sections of the map. You are welcome to use these alternative colors, following the provided guidance.



**Patient Stories** - Real experiences from people living with mito around the world



**Patient Organisations** - The groups and networks supporting the mito community globally



**WMDW Events & Awareness Activities** - What's happening near you during Mito Week



**Research & Collaborations** - Scientific work and partnerships advancing mito understanding



**Light Up for Mito** - Landmarks, buildings, and homes lighting up green in solidarity



# Get Involved

You can help raise awareness during World Mitochondrial Disease Week by:

- Add your country, organisation, event, or activity to the **global mito map** and help show the worldwide impact of the mito community
- Share the official campaign logo and assets
- Use and adapt the campaign resources for your local community and digital channels
- Translate and share awareness materials in your language
- Share your activities and stories on social media
- Take part in Light Up for Mito
- Support TK2d Awareness Day
- Support LHON Awareness Day
- Use the official hashtags **#WorldMITOWeek2026** and **#PuttingMitoOnTheMap**

**Raise awareness this World Mitochondrial Disease Week,  
14-20 September!**



# Logo

Download



The World Mitochondrial Disease Week logo should be included on all materials related to the week's events. Below are downloadable logo options for use.

The logo is available in multiple color versions. The full-color logo should be the primary choice and must not be altered. If needed for contrast, white or black versions may be used depending on the background.



# Logo use

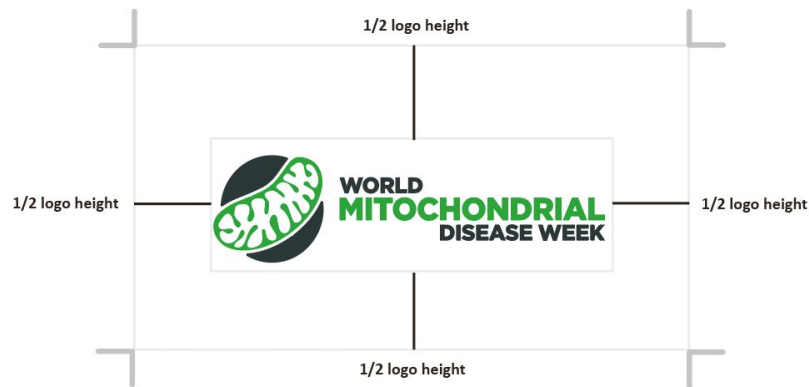
## Minimum Size

The minimum relative height of the logo for print should be 20 mm and for screen the minimum size is 50 pixel.



## Clear Space

There should be enough space around the logo for it to be easily identified, equivalent to  $\frac{1}{2}$  the total height of the logo.



# Logo use

## Scale and Placement

The logo must always be scaled proportionally and should never be stretched, rotated, or altered. Avoid placing the logo on busy or cluttered backgrounds. Do not rearrange or remove any elements of the logo, and refrain from applying effects such as drop shadows.





# Colour Scheme

World Mitochondrial Disease Week uses the following colour pallet:



**WORLD  
MITOCHONDRIAL  
DISEASE WEEK**



R: 34 G:49 B:49 **#223131**



R: 14 G:180 B:53 **#0EB435**



R: 247 G:241 B:78 **#F7F14E**

# Typography

WMDW 2026 primary font is:

OPEN SANS NORMAL

OPEN SANS SEMI BOLD

**OPEN SANS EXTRA BOLD**

Download



# Social Media Assets

## Posts

Download

Edit in Canva  
1080 x 1350 px

A library of social media assets is available for use across your channels. It includes themed images and key message templates that can be customised with local content, personalised messages, and translated text.



# Social Media Assets

## Covers

Download

Edit in Canva



Facebook



X (Twitter)



LinkedIn

# Social Media Content Calendar

Download

A Social Media Content Calendar is available for download. You can use the content without any changes, personalise and edit it, translate it or simply use it as a guide. You can also simply share our posts directly from our channels. There is content for Facebook, Instagram, X (Twitter) and LinkedIn. You can use the content on any other social media platforms.

World Mitochondrial Disease Week 2026 Social Media Schedule   Theme: Putting Mito on the Map Last Update: 19th June 2026							
Date	Post Type		Facebook	Instagram	LinkedIn (HCP)	X (Twitter)	Char count
Tue 23 Jun	Save the Date		<p>World Mitochondrial Disease Week is back – and we want you to be part of it.</p> <p>Save the Date: 14-20 September 2026.</p> <p>This year, under the theme Putting Mito on the Map, we are calling on patients, families, advocates, researchers, and healthcare professionals around the world to come together – to raise awareness, share stories, and ensure that mitochondrial disease is seen, heard, and understood everywhere.</p> <p>Whether you have been part of the mito community for years or are hearing about mito for the first time, there is a place for you in this movement.</p> <p>Visit <a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a> for updates, resources, and ways to get involved.</p> <p>#WorldMitoWeek2026 #MitochondrialDiseases #PuttingMitoOnTheMap #Mito</p>	<p>World Mitochondrial Disease Week is back – and we want you to be part of it.</p> <p>Save the Date: 14-20 September 2026.</p> <p>This year, under the theme Putting Mito on the Map, we are calling on the global community to come together – to raise awareness, share stories, and ensure that mitochondrial disease is seen and heard everywhere.</p> <p>Visit <a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a> via the link in our bio for updates, resources, and ways to get involved.</p> <p>#WorldMitoWeek2026 #MitochondrialDiseases #PuttingMitoOnTheMap #Mito</p>	<p>World Mitochondrial Disease Week is back – and we want you to be part of it.</p> <p>Save the Date: 14-20 September 2026.</p> <p>This year's theme, Putting Mito on the Map, is a call to action for healthcare professionals, researchers, and advocates to raise the profile of mitochondrial disease globally.</p> <p>An estimated 1 in 5,000 people live with a mitochondrial disease, yet diagnostic delays of five to seven years remain common. Greater clinical awareness changes that.</p> <p>We look forward to your support. <a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a></p> <p>#WorldMitoWeek2026 #MitochondrialDisease #RareDisease #PuttingMitoOnTheMap</p>	<p>Save the Date: World Mitochondrial Disease Week 2026 – 14-20 September 2026</p> <p>Join the global effort to put mitochondrial disease on the map.</p> <p><a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a></p> <p>#WorldMitoWeek2026 #PuttingMitoOnTheMap #MitochondrialDiseases #Mito</p>	259
Tue 07 Jul	Theme Reveal		<p>We are delighted to reveal the theme for World Mitochondrial Disease Week 2026: Putting Mito on the Map.</p> <p>Mitochondrial disease affects people in every country and every community. Yet for too many, it remains unrecognized, undiagnosed, and without the support it deserves.</p> <p>This World Mitochondrial Disease Week, we are calling on everyone: patients, families, advocates, researchers, and healthcare professionals to help change that. Together, we can make sure that mito is recognized in every healthcare system, every research agenda, and every conversation about rare disease.</p> <p>Throughout the campaign, we will be sharing stories, events, awareness activities, research, and ways to get involved. Explore the Global Mito Map to discover patient stories, organisations, research collaborations. Light Up for Mito locations, and activities taking place around the world. Every pin helps put mito on the map.</p> <p>Visit <a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a> to explore the theme, find resources, and get involved.</p> <p>#WorldMitoWeek2026 #MitochondrialDiseases #PuttingMitoOnTheMap #Mito</p>	<p>We are delighted to reveal the theme for World Mitochondrial Disease Week 2026: Putting Mito on the Map.</p> <p>Mitochondrial disease affects people in every country, every community, every family. Yet for too many, it remains unrecognized, undiagnosed, and without the support it deserves.</p> <p>Throughout the campaign, we will be sharing stories, events, awareness activities, research, and ways to get involved. Explore the Global Mito Map to discover patient stories, organisations, research collaborations. Light Up for Mito locations, and activities taking place around the world. Every pin helps put mito on the map.</p> <p>Visit <a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a> via the link in bio to explore the theme and get involved.</p> <p>#WorldMitoWeek2026 #MitochondrialDiseases #PuttingMitoOnTheMap #Mito</p>	<p>We are delighted to reveal the theme for World Mitochondrial Disease Week 2026: Putting Mito on the Map.</p> <p>Mitochondrial disease is one of the most common inherited metabolic disorders, affecting an estimated 1 in 5,000 people worldwide. Yet many patients face diagnostic delays of five to seven years, and clinical awareness remains limited in many settings.</p> <p>This year, we are calling on healthcare professionals and researchers to help put mito on the map – in clinical practice, in research agendas, and in rare disease policy.</p> <p>We look forward to your support throughout the week.</p> <p><a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a></p> <p>#WorldMitoWeek2026 #MitochondrialDisease #RareDisease #PuttingMitoOnTheMap #ClinicAwareness</p>	<p>This year's World Mitochondrial Disease Week theme is Putting Mito on the Map.</p> <p>Mito affects people everywhere – yet awareness, diagnosis, and care remain uneven across the globe. Join us in changing that.</p> <p><a href="http://www.mitopatients.org/mito-week">www.mitopatients.org/mito-week</a></p> <p>#WorldMitoWeek2026 #PuttingMitoOnTheMap #MitochondrialDiseases #Mito</p>	261

# Members

World Mitochondrial Disease Week 2026 is proudly supported by International Mito Patients (IMP). We stand with our members worldwide in their efforts to raise awareness and increase understanding of mitochondrial disease.



# Contact

E-mail:  
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**WORLD  
MITOCHONDRIAL  
DISEASE WEEK**



international mito patients

# THANK YOU

