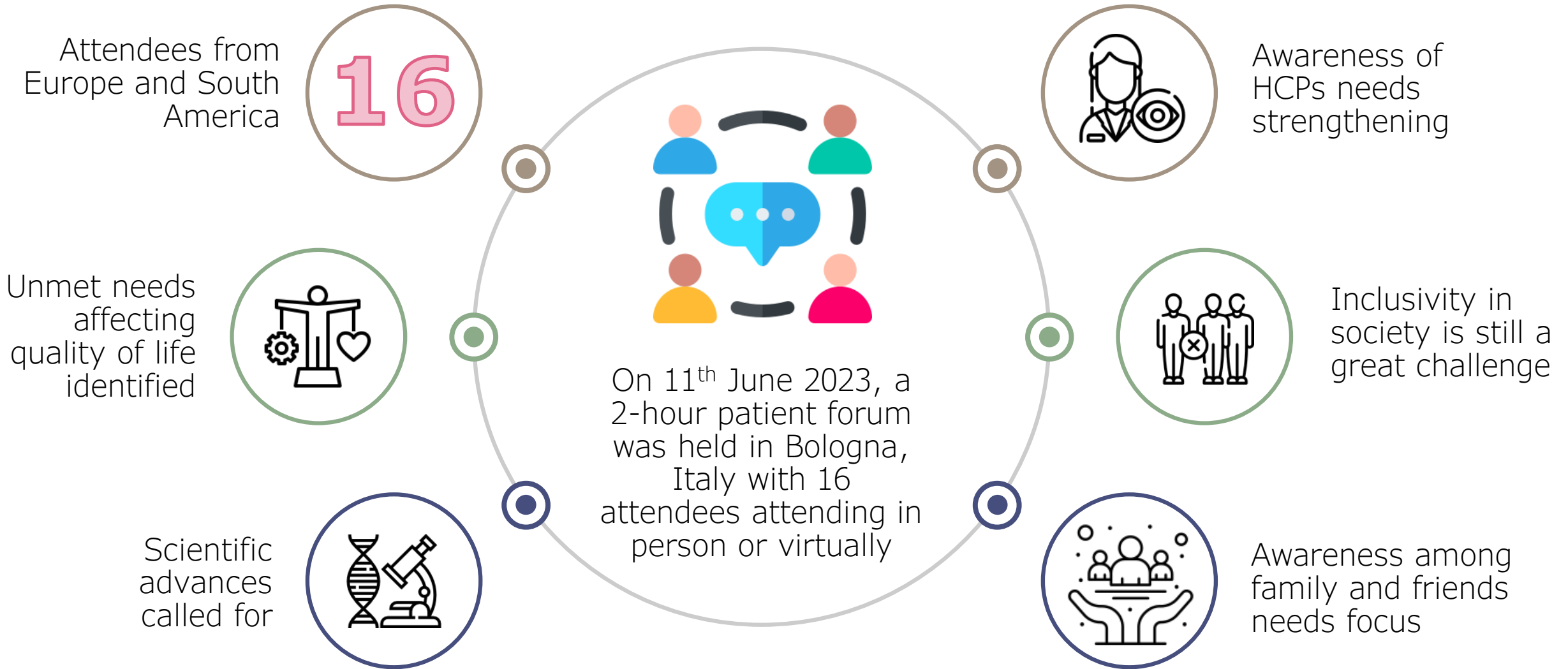




Summary



The priorities



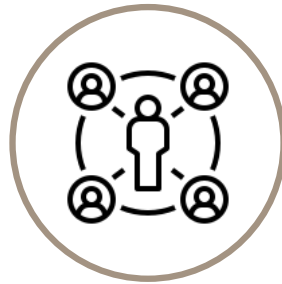
To identify the priorities with greatest impact, the attendees were asked what they would change if they had a 'magic wand' to improve the lives of people with LHON



Quality of Life
and 'Normal
Life'



Scientific
advances



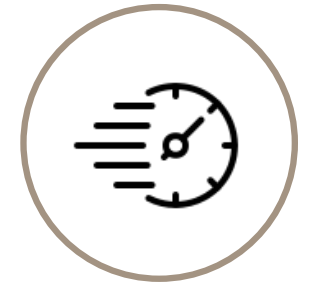
Improve
inclusivity in
society



Prevent
children
inheriting
LHON



Better
awareness of
LHON



Quicker
diagnosis

The priorities



To identify the priorities with greatest impact, the attendees were asked what they would change if they had a 'magic wand' to improve the lives of people with LHON

Quality of Life and 'Normal Life'

- Employment opportunities the same as others
- Active in sports, hobbies
- Family activities

Scientific advances

- Regain vision
- Search for a cure
- Improved treatments
- Prevent more vision loss

Improve inclusivity in society

- Cities more accessible
- Less stigma
- More understanding from society

Prevent children inheriting LHON

- A way to stop LHON being passed onto children

Better awareness of LHON

- Physician knowledge of LHON
- General awareness
- More info for people with LHON

Quicker diagnosis

- Prevent misdiagnoses
- Faster diagnosis of LHON
- Related to awareness of physicians

The priorities – quotes*

"If it is not possible to recover our vision, people with LHON can benefit from more inclusivity in society and living in cities that are more accessible for people with vision loss"

"Raise awareness of LHON. We need a cure, not just a therapy. Not enough knowledge on LHON, we need awareness so people are more sensitive to the issues."

"I would wish for patients being spared the consequences of LHON. I also wish for people being able to live a normal life."

"I would really want to be the first and last person in my family to have LHON. ... I needed to learn and adapt to another way of working and I wish this opportunity for other people"

"I am still mourning that I cannot see my daughter and family. ... Inclusivity is a big deal and we need to really keep focusing on this and make people aware."

"What I would wish to have vision back but also that there is more knowledge from the basic practitioner to the top experts and that knowledge is passed from one doctor to the other."

Awareness - HCPs



The concept of 'awareness' was raised by all participants. A key challenge is that ophthalmologists and other healthcare professionals are unaware of LHON, leading to misdiagnoses and very long times to an accurate diagnosis

Few doctors know about LHON

- There are few specialists
- Older, knowledgeable doctors are retiring

Very poor experience of some people with LHON

- Dr: "There is nothing we can do"
- Leads to people with LHON dropping out of healthcare

HCP education needs to be improved

- Some doctors do not know that the science has moved on
- May not be giving best advice

Impact on diagnosis

- Misdiagnosis is common - lack of awareness
- Can be far too long to be referred to someone who knows about LHON

Awareness HCPs – quotes*

"I believe that awareness should be spread amongst doctors because expert doctors and geneticists know about LHON, but general ophthalmologists know very little about it."

"When people first start to experience vision loss, they see a general ophthalmologist - so this work of awareness needs to be extensive to reach all doctors dealing with vision diseases."

"It is extremely important that doctors around the world are educated so that we can have speedy diagnosis. ... It seems that doctors do not always want to work together and share information as well as the patients do."

"My concern is that we can count mitochondrial disease experts on two hands, at the most - and many are soon to retire. We need to train more young researchers. We need to go to the schools and universities."

"We need to work on raising good knowledge around our experience between patients and experts, between neurologists and ophthalmologists."

"I joined MitoCon and then IMP - and now we can all get together and speak to doctors because things are moving and we can alert them to this."

Awareness – People with LHON and family/friends



Another aspect of awareness is around the knowledge and understanding that people with LHON, their family and friends have about the condition and the impact that it has on a person's life and daily activities

Awareness and information about LHON

- There needs to be more information that people diagnosed can access
- More awareness of support groups and associations

LHON is a hidden disease

- It is not obvious to an outsider that someone with LHON is affected
- This can lead to stigma or negative assumptions

Family members do not always understand

- Family members are very supportive, some do not understand the daily burden of living with LHON
- More communication guidance needed

Sharing advice and experiences

- Sharing tips such as lifestyle and nutritional advice is hugely helpful
- Networks through WhatsApp or social media are a life-line

Awareness – People with LHON and family/friends - quotes

“There are choices you can make in daily life that relate to lifestyle and nutrition that can greatly benefit our lives and symptoms. I would encourage everyone to record and share their experiences with others.”

“MitoCon organises 1 or 2 meetings per year where we get a chance to meet, exchange feelings, ideas. Nutrition and food is really important. We had food experts which MitoCon provided for free at meetings.”

“We need to keep in mind that when we develop the disease and lose our sight, we need someone who is very understanding next to us, such as a member of the family.

People don't understand what it is like to have LHON. We are not easily understood by our family members - they have no idea what we are going through. And so, what happens is that it creates a huge problem.”

“When I received my diagnosis, I started wanting to travel all over the world, but there was no cure and there still is no cure. So after a few years I said ‘what is the point’ of going to the doctors when there is nothing that they can do for you. So I stopped going until 15 years later. I ran into a patient organisation talking about LHON and mitochondrial disease - that's when I found out that LHON was a mitochondrial disease - 15 years after my diagnosis!”



Inclusivity was the most cited concern raised at the meeting. Inaccessible cities, stigma and misunderstanding all contribute to a feeling of isolation. Many highlighted the need for better public education around vision loss as this affects all people with impaired vision, not just those with LHON

Education in schools and universities

- To ensure that young people are sensitive to the needs and realities of those with vision impairment

'Sounded' signs should be standard

- Signs that also emit audio or voice would really help people navigate cities more safely
- Even a taxi is an issue. What happens when you get out?

Better town and city environments

- Even ground would prevent falls
- Generally considering vision impaired when designing streets would be needed

Awareness campaign

- Public campaigns around vision impairment and guidance for how to assist would be welcome
- Vision impairment is a hidden condition

Inclusivity- quotes*

"Among the group of people with some kind of disability, visual loss has the most amount of people. Yet, my impression is that the accessibility for people with vision loss is worse than for other kinds of disabilities."

"LHON is very underestimated, because people look at us and we don't look disabled. So when you look at a person with disability you expect to see the disability, but with LHON you don't and this goes against us."

"We need more textured ground surfaces that helps people who are blind or with low vision navigate. Also, better education in schools, and better inclusion for students at schools and universities."

"We need signs that are sounded - for example in a bank or supermarket when you are waiting in a line, there are only visual signs to indicate when it is your turn. Sounded signs are really necessary worldwide "

"One big thing that we all miss is independence in mobility, being free to go when you want. We can't just use a taxi - the taxi driver cannot take us directly to the door. We still need to navigate to our destination."

"Some people with LHON are not able to work any more, they have abandoned their careers and don't have a social life. We have to fight to bring people into jobs and society."

LHON Networks



Members of the forum expressed how important the existing networks are to support individuals and the community of people with LHON. Though there was reflection that compared to cancer, there is still a lot of work to do to strengthen networks

The LHON associations are really important

- IMP, MitoCon, LHON European groups and the work of other Mito organizations all help
- MitoCon monthly Zoom meeting

Bring in experts when needed

- Not just the specialist physicians but also nutritionists
- Sharing lifestyle knowledge is as important as scientific knowledge

Awareness days and videos

- LHON awareness day is greatly valued
- Video projects featuring both people with LHON and families will help spread understanding

Need more testimonials

- Explaining the impact such as abandoned careers and social life
- Highlighting stigma and prejudice

LHON Networks– quotes*

“The associations are so important both nationally and internationally. All of the things we have discussed, inclusion, awareness and empowering patients can be facilitated by these associations.”

“We need to work around communications and education. We need to leverage our social media channels. We need to work on raising good knowledge around our experience between patients and experts.”

“I really see IMP as the umbrella organisation that envelops 19 mitochondrial disease associations around the world. In the last 4 years we have formed pretty good LHON European group. This is the 4th year of the LHON awareness day. IMP is the best organisation for bringing together these communities. Through IMP we connect to other mito organisations around the world and through these we find other LHON patients.”

“The more we share, the faster we get to a solution. Education not only to patients but also doctors, is very important. Look at the cancer associations and see what they achieve. That is what we want from our networks.”

“We really value the support from the associations. MitoCon nutritional support is one example. This is so important. All associations are really needed and helpful and I am very thankful to them.”