ONLINE MEETING

Nordic Advisory Board for Persons Living with LHON

9 November 2023

Chiesi
global rare diseases

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Participants from Sweden and Norway living with LHON met online to discuss about the challenges of living with this rare condition.

The meeting was organized by Chiesi.

Leber’s hereditary optic neuropathy or LHON is a rare inherited condition that results in rapid central vision loss. In the Nordics it is estimated that LHON affects around 1 in 50 000 persons.

NORDIC ADVISORY BOARD MEETING FOR PERSONS LIVING WITH LHON

The objective of this Nordic Advisory Board meeting was on one side to gather insights from those who live with LHON on how the real situation in our countries is and what is important for them to be changed. On the other side the objective is to share this information with healthcare professionals, clinics, healthcare organisations, patient associations, as well as to upload it to Chiesi websites for healthcare professionals or public.

HIGHLIGHTS/QUOTES

Regarding the persons living with LHON

”We need to think of awareness in relation to acceptance. In order to find a solution first is needed to accept that there is something to solve.”

”LHON = Live Here and Now. Take care of yourself.”

”Some people tend to blame LHON for not giving them a good life instead of looking forward. Vision rehabilitation and awareness are important, not to define ourselves with the disease.”

”We have no time to lose, we only have one life and need to make the most out of it.”

”The first day when I have got the diagnosis I have decided that I will continue my studies at university.”

”When I was 18 and got LHON I was told that I should be an early pensioner, but instead I applied for a job and got it.”

”Physical training is important due to mitochondria. We should not drink alcohol or smoke.”

”Important that carriers know that smoking or drink alcohol might lead to LHON symptom.”

”Vision impairment affects life but not who I am.”

”It is also important to have representation in society. I recently read an article written by a lawyer who still practice law despite blindness. It was an inspiration to me. We have a responsibility to show others that we can live a full life.”

”When you get a disease like this it is important you aquire as much knowledge as possible. For example, I was advised not to have a boy (child). You need to keep up with new research and what is happening within the disease area.”

”It is important to have people to look up to. And to remember that you are not using your eyes for thinking.”

”We need to be aware what kind of help we need – people want to help, they are helpful. We just need to say it – for example at school I´ve asked the other to say my name when they want me to respond, instead of looking at me or nodding.”

”You cannot decide what life throws at you, but you can decide how to handle it.”

”We need a LHON patient organisation on European level to coordinate activities.”

HIGHLIGHTS/QUOTES

Regarding healthcare

”The medical support is often not sufficient.”

”The time to diagnosis takes often too long time.”

”Ophthalmologists need more knowledge about LHON.”

”It took 8 months to have my diagnosis and I had to look by myself for a doctor who knows about LHON. Even though I had the gene, the first doctor I met said it could not be LHON since I was a girl.”

”We really lack an expert center for LHON.”

”We need a broader program/guidelines for healthcare regarding what should be done at each step.”

”Finding the right specialist should not be a matter of chance or being able to search by yourself, it should be the way the system works.”

HIGHLIGHTS/QUOTES

”It would be great if Chiesi and other pharma companies could help to inform eye doctors of the need for persons living with LHON to meet good doctors.”

”There are different specialties taking care of my diseases, which means that the possible mitochondrial disease and connection is missed. I am followed up by three different hospitals. A mitochondrial reference center is really needed, where all specialists are in the same place.”

”Knowledge is generally too low, even at Eye Clinics. In many cases, a white cane is given far too early to the newly diagnosed.”

HIGHLIGHTS/QUOTES

Regarding inclusivity in society

”Inclusivity in society is important.”

”I believe that an introduction chain to newly diagnosed is important – exchange of experience. Information about the disease, research and experiences. It is important to have a strategy in place regarding inclusivity in society.”

”Employers should shift focus to how we can contribute, and not focus so much on our disease.”

”We need representation in society to get our voices heard and our needs fulfilled, and actually what also is our rights.”

”We should be better in the Nordics and work together across borders, especially important within a rare disease.”

”Even the family and relatives need to meet others.”

”In Sweden we are pretty god at accessibility policy wise, it is important to do more work to implement in practice.”

”It is common that universities do not know how to facilitate people like me. I have to fight for extra time on exams, for example. I believe we should cooperate more over the boarders.”

”It is important thar employers know about the disease – we should not get jobs because people feel sorry for us.”

Important aspects for persons living with LHON in the Nordics and changes that would be most impactful on their lives

REGARDING
THE PERSONS LIVING WITH LHON

- Self-empowerment by not letting ourselves being defined by this condition.
- It is important to have representation in society to get our voices heard but also to inspire and show it is possible to have a normal life.
- Patient organization for LHON at European level to coordinate activities for this rare disease.
- When you get a disease like this it is important you acquire as much knowledge about it as possible.

REGARDING HEALTHCARE

- Creation of expert centers for LHON/ mitochondrial diseases is needed.
- National guidelines on diagnosis, management, rehabilitation programs with broader/ step-by step information.
- More education on LHON for ophthalmologists and other specialists involved along the way.

REGARDING INCLUSIVITY IN SOCIETY

- Employers should shift focus to how we can contribute.
- Broader awareness about LHON in education institutions so that they know how to facilitate people like me.
- In Sweden we are pretty god at accessibility policy wise, it is important to do more work to implement in practice.
- It is important to have a strategy in place regarding inclusivity in society, and work together across borders.

DO YOU WANT TO KNOW MORE ABOUT LHON?

Visit the website LHONaware.se

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