

Patient associations across Europe unite to co-sign a manifesto



SCAN ME

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ABOUT

Lymphoedema is estimated to affect 250 million people worldwide¹, however there is still low awareness among the public and the health care professionals. Furthermore, patients are struggling to get a timely diagnosis and adequate treatment for this chronic disease. Patient associations across Europe wanted to raise the attention of the politicians, policy makers, health care professionals, researchers, and the general public towards the needs of those who live with, or who are at risk of developing, lymphoedema.

WHAT WE DID

We used the 6th of March - World Lymphedema Day, as a platform to reach the public, policymakers, clinicians as well as patients. In 2020, we came together for the first time to write and co-sign a Manifesto to express our opinions and urgent needs for those living with lymphoedema in Europe. In 2021 other associations joined our initiative and a total of 27 associations across 13 European countries co-signed the Manifesto and translated it into 11 languages. We managed the communication through emails and online meetings. The Manifesto was shared through social media, websites, and email lists of the associations, and when possible, in person. Patients, clinicians, and stakeholders supported our initiative and shared the local language manifesto on their own social media platforms.

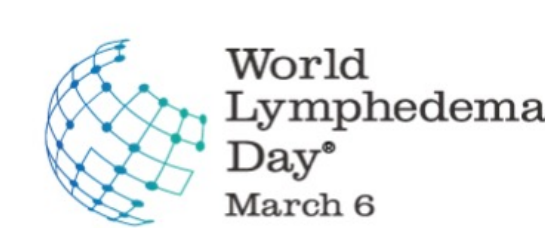
RESULTS

The Manifesto and the messages within were shared across the world by patients, clinicians, organizations, and the public. However, we consider that the greatest success was the commencement of a collaboration among the patient associations, united despite national borders, cultural and linguistic differences for the benefit of the patients. Since the last two years, we are working on various projects to support the statements of the manifesto.

WHAT WE WISH

As patient representatives of different patient associations in Europe, we decided to unite to initiate the change by stating our common needs and challenges in a co-signed manifesto, to raise awareness of lymphoedema and attempt to improve the current condition.

MANIFEST



World Lymphedema Day
March 6th 2021

- Lymphedema is a global health problem that affects more than 250 million people worldwide, women, men and children of all nationalities and populations.
- Lymphedema is a chronic and progressive disease of the lymphatic system that can cause severe deformity, disability and life-threatening complications, which can also cause psychological and economic burdens.
- Many health professionals are not fully aware of the disease, its signs and symptoms, causing people with lymphedema to suffer for many years before they obtain a diagnosis and begin treatment.
- There remains low public awareness and understanding of lymphatic diseases and health effects relative to its significant impact on the lives of people with lymphoedema.
- People with lymphedema need access to high-quality multidisciplinary specialised centers, with experienced health professionals, in order to receive appropriate treatment, including psychological and social care.
- There is a deep, unmet need worldwide to educate and support individuals affected by lymphedema, including their family members and caregivers, on basic self-management.
- Medical research efforts to find a cure for lymphedema and to improve treatments are lacking sufficient funding, in comparison with diseases of similar magnitude and severity.

Therefore, we support March 6 as World Lymphedema Day and the patient associations signing below call for the attention of politicians, policy makers, health care professionals, researchers and the general public towards the needs of those who live with, or who are at risk of developing, lymphedema. We ask for increased funding for medical research, educational programs for healthcare professionals, and improved access to specialised care for those living with lymphedema.



References

- Schulze, H., Nacke, M., Gutenbrunner, C. et al. (2018) Worldwide assessment of healthcare personnel dealing with lymphoedema. Health Econ Rev 8, 10.

GET IN TOUCH

- andLINFA (Portugal): <http://andlinfa.pt/>
- Asociación Adelprise en Alava (Spain): <http://www.euskoadelprise.es/>
- Asociación Adelprise de Sevilla (Spain): t.ly/8C2N
- Asociación Adpla de Aragón (Spain): <https://www.adplaragon.org/>
- Asociación Agadelprise en Guipuzkoa (Spain): t.ly/WjL1
- Asociación AMAL en Madrid (Spain): <https://www.amalmadrid.com/>
- Associação Bizadelprise en Vizcaya (Spain): t.ly/wORx

- Association lymphoedème Rhône-Alpes (France): <http://www.lymphoedeme-ra.fr/>
- AVML (France): <https://avml.fr/>
- AVML63 (France): <https://avml63.wixsite.com/avml63>
- DALYFO (Denmark): www.dalyfo.dk
- KIF11 Kids e.V. (Germany): <https://kif11kids.com/>
- LILL Aps (Italy): <http://www.lottalinfedema.org/>
- LIMFACALL en Cataluña (Spain): <https://limfacall.org/>
- Limfelleida de Lleida (Spain): <https://www.limfelleida.org/>

- LSN (UK): <https://www.lymphoedema.org/>
- L-W-O (UK): <https://lymph-what-oedema.com/>
- Lymphoedema Support NI (Ireland): <https://www.lymphoedemasupportni.org/>
- Lymphido ONLUS (Italy): <https://www.lymphido.it/>
- Lymphoedème Family (France): <https://www.lymphoedemefamily.com/>
- Lymphoedema Ireland (Ireland): <https://www.lymphireland.com/>
- LymphoSport (France): <https://www.lymphosport.com/>
- NLNET (The Netherlands): <https://www.lymfodeem.nl/>
- NLLF (Norway): <https://www.nllf.no/>
- SOS Linfedema (Italy): <https://www.soslinfedema.it/>
- Suomen lymfayhdistys (Finland): <https://www.lymfayhdistys.fi/>
- SÖF (Sweden): www.svenskaodemforbundet.se

