

European patient organisations unite to put compression #underpressure
www.compressionineurope.org

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Introduction: In 2020, 24 patient associations from across Europe came together to create and co-sign a Manifesto outlining the challenges, wishes and needs for those living with lymphoedema. The manifesto was shared across Europe raising awareness. In 2021, a smaller group of patient associations produced a campaign for World Lymphoedema Day highlighting the one thing lymphoedema patients all have in common – compression garments. It was decided to put #compressionunderpressure.

Method: The patient associations organised a campaign, using social media to understand how patients, and their carers, obtain their compression garments. They were asked to rate a simple statement: *'I struggle to obtain the necessary garments to manage my lymphoedema or that of the person I care for'*. The statement could be answered on a scale from 1–5 with 1 being *'I strongly disagree'* and 5 *'I strongly agree'* with an additional option to write what struggles the patient/carer had experienced. A sub-working group was then created to understand how the results and information gathered could be used to improve the situation and tie all of the activities together.

Results: The statement got 1,102 responses, from across Europe, with 59% of the respondents saying they struggle to obtain the necessary compression garments. From the written answers the main challenges were identified as financial reasons, the prescription process and the measurement and fitting. Since correct measurement and fitting are universal for all patients, regardless of gender, age and type of lymphoedema, a website was created to help patients and their carers - www.compressionineurope.org The user-friendly website, currently available in 9 languages, contains information about measurements, fitting, compression types, maintenance of the garments etc. For the launch, at World Lymphoedema Day 2023, it was presented to the Swedish Minister for Health Care, Acko Ankarberg Johansson, holding the Council of the European Union, with the aspiration of further awareness.

Conclusion: Patient associations across Europe have come together since 2020 to raise awareness, inform and improve the quality of life for those with lymphoedema and their families. A website has been launched dedicated to informing the patients and their carers about the essential compression garments. Despite national borders, cultural and linguistic differences we are united for the benefit of the patients, we are stronger together.