

LET'S COLOUR LYMPHOEDEMA: a patient advocate project for children with rare disease

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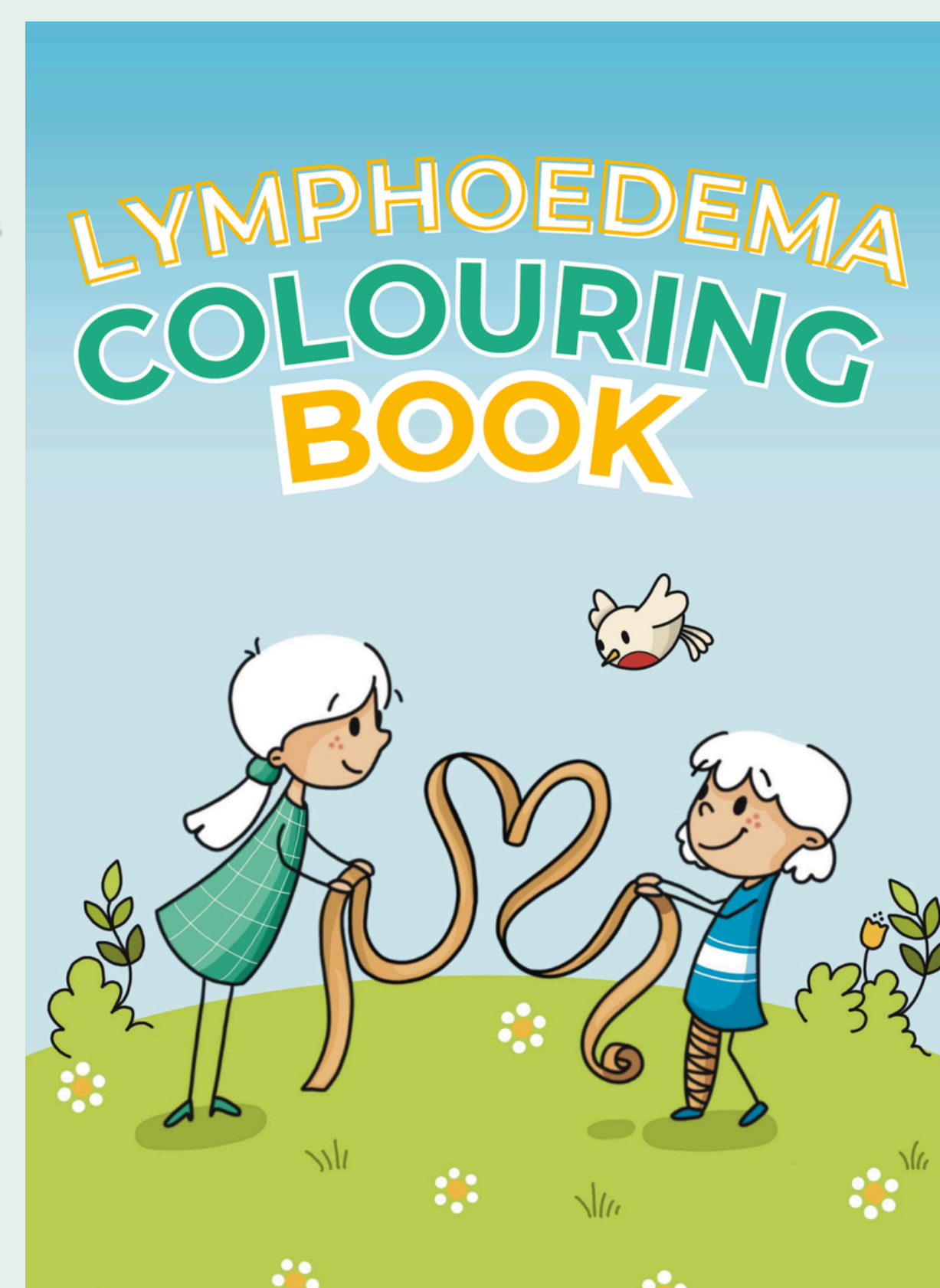


Introduction

As rare disease patients or carers, we are sometimes faced with difficulties to obtain information and, when we finally find it, understanding the basic concepts and recommendations for our daily lives can be challenging. In the European Reference Network (ERN) for Rare Multisystemic Vascular Diseases (VASCERN) the Working Group Paediatric and Primary Lymphoedema (PPL) collaborated to develop guidelines for optimal care in patients with lymphoedema. The Do's and Don'ts factsheets are created to assist both patients and the medical community in understanding the essential dos and don'ts. Among the missions of the European Patient Advocacy Group (ePAG) is to make these messages accessible and disseminate them

aim

The goal of this project was to build upon these documents (Do's and Don'ts) and focus on two key aspects of lymphoedema: compression and skin care, making them simple and more appealing to children, parents, and carers. We aimed for these resources to serve not only as practical tools but also as bridges for healthcare providers



Methods

The Do's and Don'ts factsheets were shared with an illustrator who could make the content visually simple yet technically accurate, conveying essential daily care messages. We selected ten key messages, which were transcribed through illustrations. All of this work was validated by the entire PPL WG of VASCERN

CHOOSE THE SUBJECT

WORK WITH THE ILLUSTRATOR

CHOOSE THE KEY MESSAGES

VALIDATE WITH PPL WG

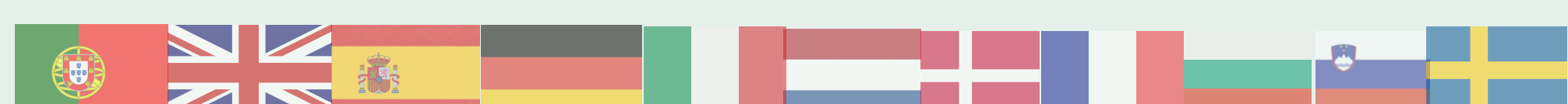
results

The result of this journey is the release of two valuable resources designed to support children with lymphoedema and their caregivers: The Lymphoedema Do's and Don'ts Infographic and the Lymphoedema Colouring Book. These resources contain the Do's and Don'ts as a foundation, but also include illustrations that children can colour. The results were shared at the Third International Children's Camp of ILF in France in July 2024, during a Vascular Surgeon Conference in Portugal, and also at the 12th International Lymphoedema Framework Conference 2025, in Canada.

Conclusion

We hope that these tools have proven to be an excellent aid for parents in explaining the importance of care. We look forward to the next phase and the sharing of translations of this work in ten european languages. We are proud of the multidisciplinary team's journey to simplify the technical language for patients and carers, and we believe this is just the beginning we are proud to share with you.

Translations & collaborations



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