

# SUPPORTING FAMILIES WITH CHILDREN WITH PRIMARY LYMPHOEDEMA IN SCANDINAVIA – A COLLABORATION AMONG PATIENT ASSOCIATIONS

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## 1. Background

Primary lymphoedema is a rare disease with little known prevalence but estimated 1- 5/10.000<sup>1</sup>.

There is no cure for lymphoedema but daily management is necessary and includes wearing medical compression garments, bandaging and meticulous skin care.

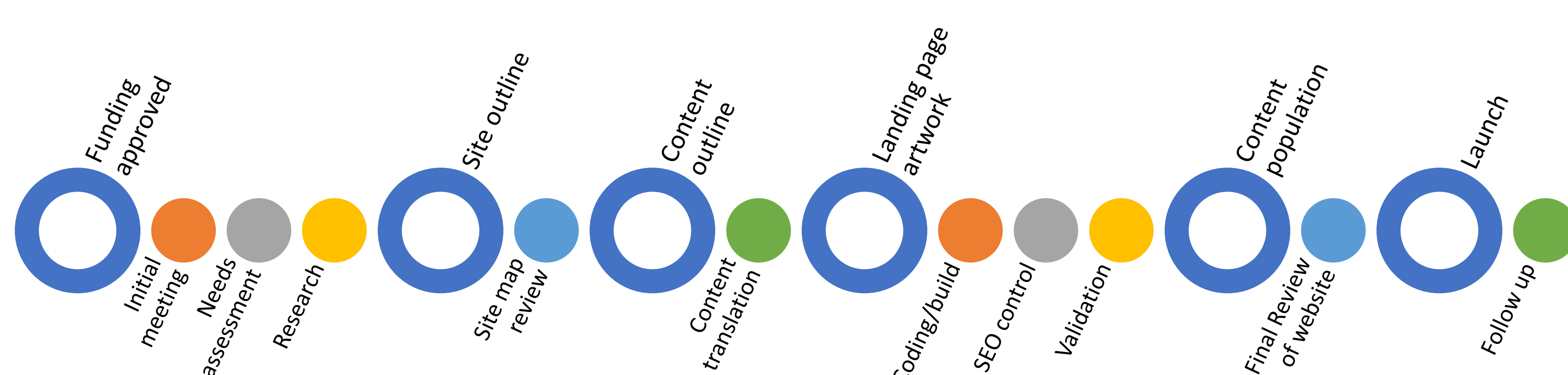
Daily management can be timely and a financial burden on the families. There can be seemingly simple struggles such as finding suitable shoes but also cosmetic and psychological problems.

Assessing suitable information is difficult<sup>2</sup> leading to inequalities<sup>3</sup>.

It is important to connect with other families and get reliable information in your own local language as most information about primary lymphoedema on the internet is in English and for adults.

## 4. Our missions

- Provide support to patients (<18 years old), parents/carers and siblings in local language, style, and content.
- Empower patients to obtain a better quality of life.
- Increase awareness of lymphoedema in the Nordic countries with the public, clinicians, school- and recreational systems.
- Strengthen the collaboration across the Nordic countries by leveraging the information and the resources among the patient associations.



## 2. Collaboration

The patient associations from Sweden, Norway and Denmark felt there was a real need for *patient driven support written in an easy to understand "plain"<sup>4</sup> and empathetic language*. Jointly we applied for a grant with the Nordic Welfare Centre and was awarded SEK 70.000 to build a website to support our missions.

## 3. Aim

The aim was to support families with children with lymphoedema in Scandinavia by providing reliable and up to date information in local language and be a point of reference.



## 5. What we will create

- An easy to use, colourful and inspirational website.
- In local languages (Swedish, Norwegian and Danish).
- Based on the needs of families caring for children with lymphoedema and the individual members of the families.

## 6. The process

It is estimated that there will be 3 phases.

- **Phase 1:** Identification of working group, creative brief, content creation, building website and translations.
- **Phase 2:** Advertisement via social media and mainstream media.
- **Phase 3:** Consideration and discussion for additional languages to be added.