3 Years se-atlas - Mapping of Health Care Providers and Support Groups for People with Rare Diseases

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INTRODUCTION

Finding specialized health care providers is often a huge challenge for people with Rare Diseases (RD) and their relatives [1]. Helping to tackle this problem in Germany, the project se-atlas – Mapping of Health Care Providers for People with Rare Diseases started in 2013. The Federal Ministry of Health in Germany initially funded the project, being part of the National Plan of Action for People with Rare Diseases [2]. The objective of se-atlas is to present health care providers and support groups related to RD in Germany in an interactive map view as well as in form of a list [3]. Since its launch in 2015 the platform is online available at www.se-atlas.de.

METHODS

After developing and testing the platform, the database of se-atlas has still to be filled with specialized health care providers and support groups for RD. To achieve a high-quality-based dataset, an editor team took up the work, reviews new entries and updates the database periodically. In the course of the project period, different data sources were migrated. Besides data from disease related expert associations, German members of the European Reference Networks and data from the project partner Orphanet Germany, many data were transmitted from support groups to se-atlas. To underline the importance of support groups and their expertise for RD, they can additionally affirm health care providers, which are specialized for their disease. Furthermore, experts for RD registered by themselves and proofed by the editor team are part of the current database.

PROJECT PARTNER

Treatment and Research Center for Rare Diseases Tübingen, Frankfurt Reference Center for Rare Diseases, Orphanet Germany, Alliance of Chronic Rare Diseases e.V.

RESULTS AND OUTLOOK

Since the launch of se-atlas in March 2015, the database is growing steadily. Today the platform includes 1574 special consultations or special ambulances, more than 850 subordinated health care facilities and 198 parent facilities as well as 366 support groups for RD, including the members of Alliance of Chronic Rare Diseases (ACHSE e.V.). Besides the growing database, the number of visitors and external links are rising continuously which demonstrates the relevance of se-atlas and results in a better SEO-ranking at Google and other search engines.

Even after 3 years se-atlas.de the data is not completed. Therefore, the overall goal is continuing filling the database in particular with the help of active support groups and further ensuring the quality of the data in the long term.
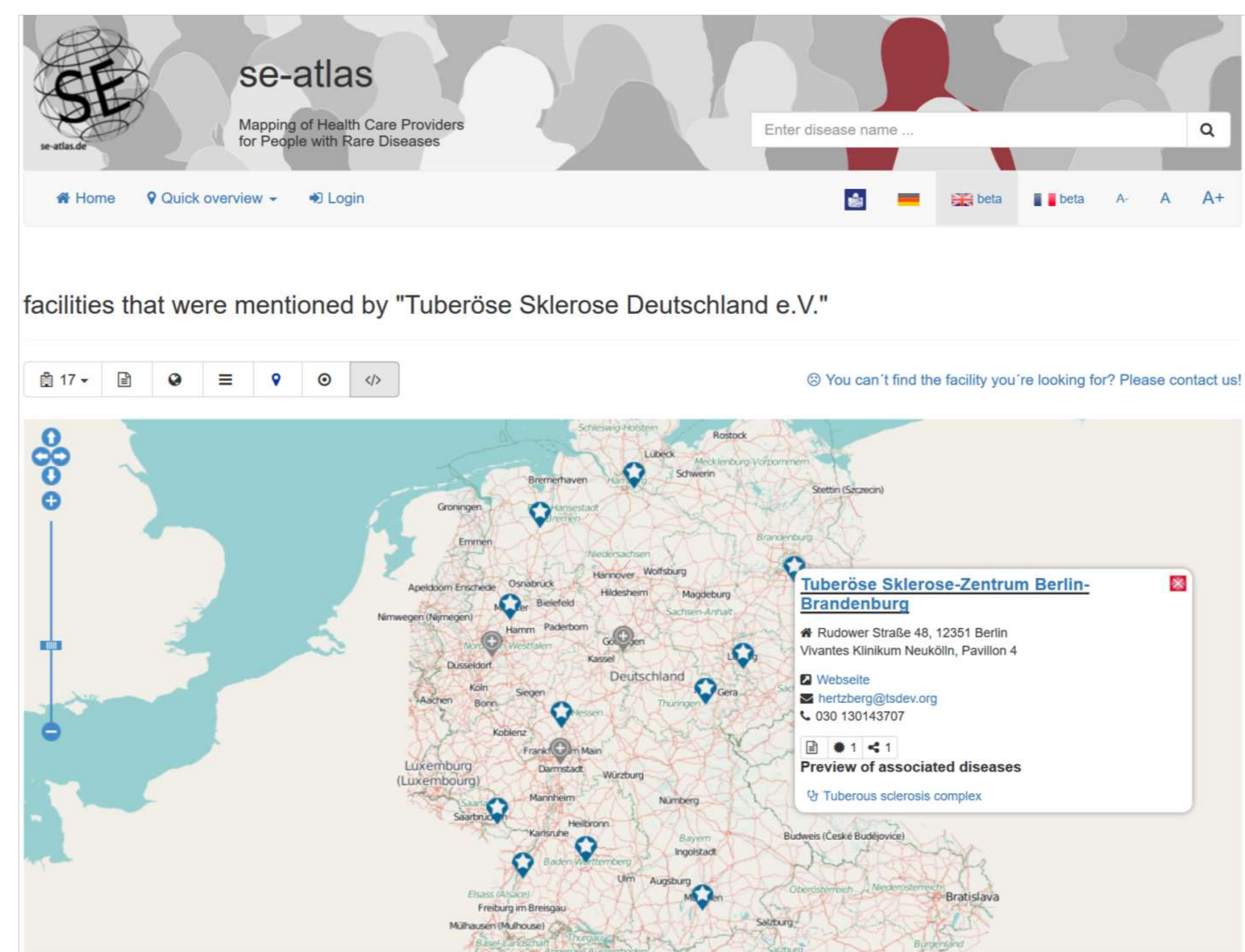

Figure 1 - Screenshot of se-atlas

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