

# Osse Registry for Patients with Lipodystrophy

run by the

## European Consortium of Lipodystrophy (ECLip)

Clinical Trials gov ID: NCT03553420



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### Conclusion

International co-operation is extremely important for research in the area of lipodystrophy.

Every center within and also outside of Europe interested in entering patient data is invited to participate in this registry.

### Background

- Lipodystrophies = heterogenous group of extremely rare diseases
- very small patient groups
  - Research in this area extremely difficult
  - international co-operation mandatory to accumulate data sets of sufficient size
- a registry for all patients with lipodystrophy was set up by ECLip – an association of European experts in the field of lipodystrophy

### Methods

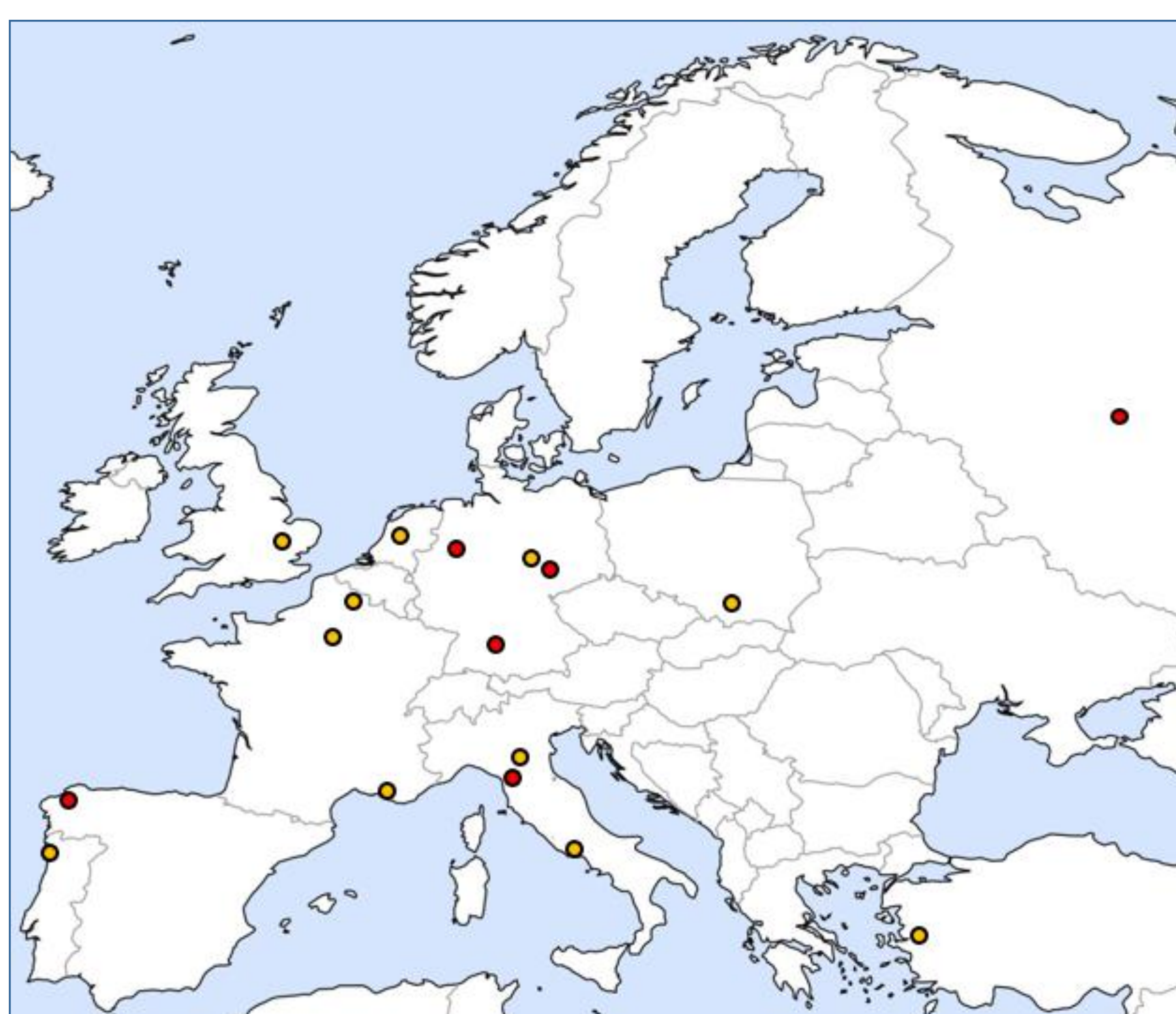
- Open Source Software OSSE ([www.osse-register.de](http://www.osse-register.de))
- easily accessible IT framework and organizational processes to set up a Rare Diseases Registry.
- web based
- data entered locally at each center
- data transferred via the internet to a central server.
- each patient is pseudonymized
- identifying data and medical data stored on different servers

### Aims

- enable international physicians to work together in the field of lipodystrophy
- accumulate sufficient data for sound research
- achieve a better understanding of the cause and course of lipodystrophy
- recognize optimal treatment strategies. .

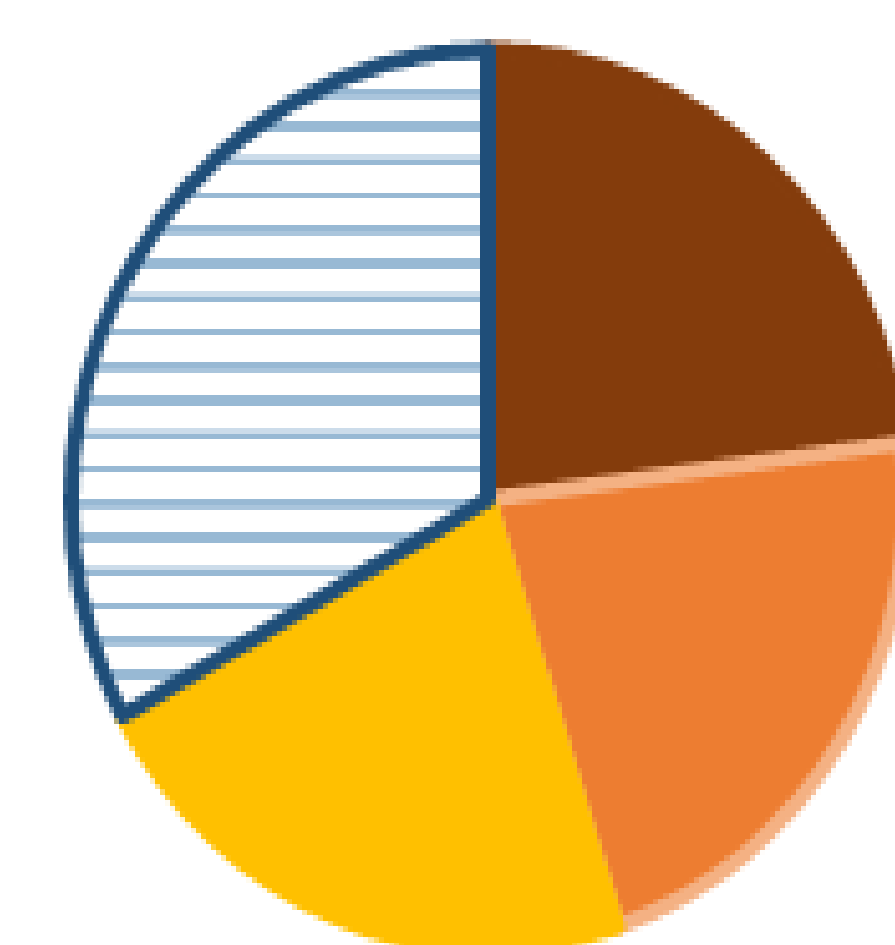
### Results

Registry started on the 16<sup>th</sup> of December 2017  
Over 15 participating centers with over 100 patients registered so far  
Registry presented at [www.european-lipodystrophies.org/en/](http://www.european-lipodystrophies.org/en/)



● = participating center, not yet recruiting  
● = participating center, recruiting

### Most common diagnosis in the registry



- Congenital generalized lipodystrophy type 2
- familial partial lipodystrophy type 6
- panniculitis
- 12 different diseases

### Contact

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### Disclosure

The authors have no relevant financial or nonfinancial relationships to disclose.

