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)
  - 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 16th of December 2017
Over 15 participating centers with over 100 patients registered so far
Registry presented at www.european-lipodystrophies.org/en/

Most common diagnosis in the registry
- Congenital generalized lipodystrophy type 2
- Familial partial lipodystrophy type 6
- Pancreatitis
- 12 different diseases

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