

WORLD LIPODYSTROPHY DAY



MANIFEST

1. That the Public Health Institutions of Spain disseminate among healthcare professionals information about the Reference Centers for Metabolic Diseases, which includes the Lipodystrophy Reference Unit at the Complejo Hospitalario Universitario of Santiago de Compostela, and that they provide doctors with all the information necessary to refer individuals with lipodystrophy to this specialized unit.



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MANIFEST

2. That specific training on these disorders be implemented in the programs for specialists in Pediatrics and Endocrinology, or that stays of resident physicians in reference centers for Lipodystrophies be encouraged. That Public Institutions promote in their postgraduate programs projects aimed at understanding the molecular bases of lipodystrophies and the search for specific therapeutic targets.



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3. The establishment of a map of experts/professionals in lipodystrophies worldwide.



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4. That the National and International Scientific Societies of Endocrinology, Diabetes, Pediatric Endocrinology and Family and Community Medicine include topics related to lipodystrophies in their respective congresses and symposia, that they promote the creation of working groups on lipodystrophies; and that they create scholarships or other types of economic aid to promote research and the dissemination of knowledge about lipodystrophies. That they include information on lipodystrophies on their websites (scientific reviews, national and international reference centers, diagnostic and treatment guides, diagnostic tools -LipoDDx-).



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5. Institutional support for the European Consortium of Lipodystrophies, a European network of clinical and basic groups that work in the field of lipodystrophies.



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6. Ensure equitable access to orphan drugs aimed at improving the quality of life of patients with lipodystrophies And in particular, we urge the Spanish health authorities and the pharmaceutical company Chiesi to restart negotiations to reach a price-reimbursement agreement for metreleptin, as is already the case in countries such as the UK, Italy, France, Germany, and Portugal.



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