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## Introduction

A nationwide disease registry with medical history, interventions and relative outcomes after treatment, represents a pivotal instrument for the development of shared clinical management protocols, aiming an optimization of the clinical and research sources and having as ultimate goal the wellness of the patients. In this context, this instrument can play a key role for the physicians who deal with the so called “rare diseases”

The chronic inflammatory demyelinating poliradiculoneuropathy (CIDP) is a rare neuromuscular disease. Typical CIDP is defined by symmetric proximal and distal weakness with sensory signs and symptoms in both arms and legs in the presence of electrophysiological features consistent with demyelinating neuropathy. The natural disease course of CIDP is largely unpredictable as it can run a monophasic, relapsing – remitting or progressive course. In addition to motor and sensory symptoms, fatigue, pain and tremor can also lead to significant disability in CIDP patients. Atypical CIDP phenotypes are often recognized

## Methods

The chronic inflammatory demyelinating poliradiculoneuropathy (CIDP) actually lacking, in Italy, of an own disease registry.



Hence, we present a web platform (“RareBOX.org”) as a model of innovative interactive disease registry.

### CARICA DOCUMENTI

Seleziona il Documento  Nessun file selezionato  
 Selezionare file: JPG, JPEG, PNG, PDF, DOC, DOCX

Tipo di documento  
 Biopsia del nervo surale  
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**Elettromiografia**  
 Esami del sangue  
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Descrizione del documento  
 Inserisci le tue note...

Documenti medici caricati

Data documento	Nome documento	Descrizione
Nessun documento caricato		

Fig 1: web data storing system

Clinical, laboratory and electrophysiological data stored by physicians (Fig.1) are enriched by daily self reported data from patients about their disease, using the rapid and simple visual method of the “smiles”. In this way you can monitor the clinical course, in particular the response to the therapy (e.g. related to the frequency of infusion of intravenous immunoglobulins). (Fig 2)

In addition, chronic or acute comorbidities and relative therapies could be noticed. Therefore, the physicians can discuss with the patients any real interference with the neurological disease course, offering useful data for epidemiologic or clinical research purposes. Data are stored and utilized according to the standards for privacy.



Fig.2 : visual method “smiles” for self reporting «How are you?» for therapy and clinical wellness monitoring

## Conclusion

This “web box” springs up on an idea of the Italian CIDP patients association (<http://www.cidp.it/cidp-italia-onlus/>) with the expertise offered by a team of neurologists, biotechnologists, multimedia and communication technologists. Therapy monitoring, clinical data sharing and a continuous “face to face” between physicians and patients represent peculiar aspects of this project, as compared to other active registries, making it a new original transversal tool.

The project, actually in a preliminar test phase, has the goal to act as a modern, simple and fast integrated model exploitable in different healthcare settings, with their continuous challenges related to the standard of care, with active and interactive involvement of the patients.

## References

1. Stangel M, Baumann U, Borte M, Fasshauer M, Hensel M, Huscher D, Kirch W, Pittrow D, Reiser M, Gold R.. Treatment of neurological autoimmune diseases with immunoglobulins: first insights from the prospective SIGNS registry. J Clin Immunol. 2013 Jan;33 Suppl 1:S67-71.
2. Filip Eftimov and Ivo van Schaik . Chronic inflammatory demyelinating polyradiculoneuropathy: update on clinical features, phenotypes and treatment options . Curr Opin Neurol 2013, 26:496

