

CALL TO ACTION

TO ALL EU PARLIAMENT CANDIDATES



Quicker access to diagnosis

Support for national healthcare services to get top-of-the-art human and financial resources in order to reduce diagnosis wandering EU support for national implementation of European Reference Networks (ERNs) and to get state-of-the-art national healthcare services and related financial resources on a long-term-bases in order to reduce diagnosis delays for people living with dysimmune and inflammatory neuropathies (DINs)*

01



Equitable treatment access

Get adequate EU Pharma Regulation and Directive to support national availability of medicines, particularly plasma-derived medicinal products (PDMPs), which represent the main treatment without alternatives for people living with DINs; enable EU's Critical Medicine Alliance to support equitable, non-disruptive access to PDMPs

02



More EU plasma collected

EU support in implementation process of EU SoHO Regulation to establish a strong public-private system of plasma collection in EU countries, able to timely generate significant increases, by respecting principles which fulfill "dual ethics" approach: patients' product supply need ethics, along with ethics of strictly regulated plasma donors protection

03



Data sharing in confidence

EU support for adequate implementation of EU Health Data Space Regulation with regard to the European Reference Networks, to enable patient data sharing for better care purposes within a robust, safe regulatory framework, including patient representatives in ERN's management and strategy approach

04



Effective participation in EU decision making

Creation and strengthening of impactful inclusive participatory mechanisms that allow patient organisations to bring the value of their expertise into EU decision-making processes

05