Basic information	
2025/2130(INL) INL - Legislative initiative procedure	Awaiting committee decision
EU rare disease action plan **Subject** 4.20.05 Health legislation and policy	

Meetings with interest representatives published in line with the Rules of Procedure

Rapporteurs, Shadow Rapporteurs and Committee Chairs

Transparency

Name	Role	Committee	Date	Interest representatives
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	16/10/2026	Fondazione Telethon ETS
KELLEHER Billy	Shadow rapporteur	SANT	30/06/2026	GSK
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	09/06/2026	European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	22/04/2026	Grifols, S.A.
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	22/04/2026	European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria
KELLEHER Billy	Shadow rapporteur	SANT	21/04/2026	European Society for Phenylketonuria and Allied Disorders Treated as Phenylketonuria
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	21/04/2026	Children's Eye Health Coalition
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	08/04/2026	Biogen
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	07/04/2026	European Patient Organisation for Dysimmune and Inflammatory Neuropathies
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	02/04/2026	EUROPEAN ORGANISATION FOR RARE DISEASES
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	24/03/2026	Federacion Española de Enfermedades Raras
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	23/03/2026	Ministerio de Sanidad (Spanish Health Ministry)
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	17/03/2026	EURORDIS
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	11/03/2026	Asociación Española de laboratorios Huérfanos y Ultrahuérfanos
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	03/03/2026	EUROPEAN ORGANISATION FOR RARE DISEASES
NEVADO DEL CAMPO Elena	Shadow rapporteur	SANT	11/02/2026	Federation of European Scleroderma Associations aisbl
NEVADO DEL CAMPO	Shadow			

Elena	rapporteur	SANT	14/01/2026	EUCOPE Kangaroo Group
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	25/11/2025	Fundació Sant Joan de Déu
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	06/11/2025	EUROPEAN ORGANISATION FOR RARE DISEASES
GONZÁLEZ CASARES Nicolás	Rapporteur	SANT	29/10/2025	Spanish Permanent Representation

Other Members

Transparency		
Name	**Date**	**Interest representatives**
KELLEHER Billy	24/06/2026	Merck Sharp & Dohme Europe Belgium SRL
SOKOL Tomislav	02/06/2026	Screen4Rare
PAPANDREOU Nikos	29/04/2026	EUCOPE
SOKOL Tomislav	16/04/2026	Children's eye health coalition
SOKOL Tomislav	08/04/2026	Zebra Diagnosis Coalition
NEVADO DEL CAMPO Elena	08/04/2026	Zebra Diagnosis Coalition