

Name of disease	Orphacode	Representative	Nationality	Website	Facebook Page	Email
CDKL5	ORPHA:1934	CDKL5 Austria (Patient support group)	Austria	http://cdkl5.at	https://www.facebook.com/cdkl5austria/	gademayr@immoadd.at
CDKL5	ORPHA:1934	CDKL5 Alliance Francophone	France	http://cdkl5.fr	https://www.facebook.com/CDKL5.fr	contact@cdkl5.fr
CDKL5	ORPHA:1934	CDKL5 Georgia (Patient support group)	Georgia	http://gsiem.ge	https://www.facebook.com/CDKL5GE	cdkl5georgia@gmail.com
CDKL5	ORPHA:1934	CDKL5 Deutschland e.V.	Germany	https://www.cdkl5-verein.de/	https://www.facebook.com/CDKL5DeutschlandOesterreichSchweiz/	info@cdkl5-verein.de
CDKL5	ORPHA:1934	CDKL5 Ireland	Ireland		https://www.facebook.com/cdkl5irl/	cdkl5ireland@gmail.com
CDKL5	ORPHA:1934	CDKL5 Insieme verso la cura	Italy	http://www.cdkl5insiemeversolacura.it	https://www.facebook.com/cdkl5insiemeversolacura	soci.cdkl5@gmail.com
CDKL5	ORPHA:1934	CDKL5 Nederland	Netherlands	http://www.cdkl5.nl/	https://www.facebook.com/groups/555857924496537/	pam@cdkl5.nl
CDKL5	ORPHA:1934	CDKL5 Portugal (Patient support group)	Portugal		https://www.facebook.com/cdkl5portugal/about	jpvieira88@gmail.com
CDKL5	ORPHA:1934	CDKL5 Russia	Russia		https://www.facebook.com/groups/CDKL5Russia/about	cdkl5russia@gmail.com
CDKL5	ORPHA:1934	CDKL5 Slovakia	Slovakia	http://www.cdkl5.sk/	https://www.facebook.com/CDKL5Slovakia	info@cdkl5.sk
CDKL5	ORPHA:1934	AACDKL5: Asociacion de afectados CDKL5	Spain	https://aacdkl5.org/	https://www.facebook.com/profile.php?id=100063533475207	info@aacdkl5.org
CDKL5	ORPHA:1934	L'association suisse CDKL5 (Patient support group)	Switzerland	https://www.cdkl-5.ch/fr.shtml	https://www.facebook.com/cdkl5suisse	kontakt@cdkl-5.ch
CDKL5	ORPHA:1934	CDKL5 UK	UK	https://curecdkl5.org.uk/	https://www.facebook.com/CDKL5UK	info@curecdkl5.org