



## NATIONAL ALLIANCE FOR RARE DISEASES SUPPORT MALTA (RDM) MEMBERSHIP APPLICATION FORM

The National Alliance for Rare Diseases Support – Malta (RDM) is committed to advocate for all rare disease patients, their families and rare disease groups. Its aim is to represent a higher number of patients speaking with one voice and thus provide a stronger voice than a single disease patient group.

Membership Criteria: Patients who have been diagnosed as suffering from a rare disease according to EU prevalence criteria of 5/10,000 and/or a maximum of two other close relatives or carers.

Please complete the form below and return completed with your yearly membership fee by cheque, payable to the National Alliance for RD Support Malta. Addressed to RDM 58, Zachary Street Valletta VLT 1130

Types of Membership:  New  Renewal  Individual (€5)  Family (€10)  Donation: € \_\_\_\_\_

<b>Personal Information</b>	
Name of Member diagnosed with a rare disease:	
Date of Birth:	ID No:
Member's Relative/Carer:	Relation to member:
Address:	Postal Code:
	Tel No:
Mobile No:	Work No:
Email Address:	
Rare Disease Name:	
Orphanet Code (For Office Use):	Name of Caring Consultant:

Tick the box if you also agree to use your data for the notification of research opportunities related to your rare disease, carried out by the Malta BioBank (BBMRI.mt) at the University of Malta or other recognised entities.

### DATA PROTECTION CLAUSE

I am hereby explicitly consenting to the processing and collecting of my personal and sensitive data by RDM, which is being provided herein or delivered at a later stage directly or indirectly through RDM's email. I understand that such information is processed and collected in order to pursue the honourable objectives of RDM as per its statute including education, promotion and awareness of rare diseases but also for the reasons stated in this application, including for internal identification and classification of Members, for statistical purposes, for identifying possible networking opportunities of a medical and professional nature which are in line with my needs or those of the organisation I am representing.

RDM shall retain the Member's Data for a maximum of three (3) years, subject to application of technical and appropriate safeguards. You shall be entitled to request access to your personal data, a copy of which will be provided by RDM together with the policy notice, and to correct or amend such data. Moreover, you may request RDM to restrict the processing of such data until data is corrected or amended. You have a right to request RDM to delete and remove any such data either when there is no good reason for RDM to continue processing it or when such a right ensues at law. You should contact RDM in writing at the below email address in order to exercise such rights. You shall also have a right to lodge a complaint with the supervisory authority responsible for data protection. Further information can be obtained by contacting RDM's Data Protection Officer on [alistair@rarediseasesmalta.com](mailto:alistair@rarediseasesmalta.com) or through our website.

I understand that my data will be processed in accordance with the EU General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679) and the Data Protection Act (Cap. 586). I guarantee the accuracy and truthfulness of the personal data provided and undertake to notify and keep RDM updated on any changes thereof. I confirm that I abide by the Membership criteria and I declare that I have read and understood the above provisions.

Consent signature: \_\_\_\_\_ Date: \_\_\_\_\_ Cheque No/Cash: \_\_\_\_\_