



RARE
DISORDERS SOCIETY
SINGAPORE

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RARE DISORDERS SOCIETY (SINGAPORE) BENEFICIARY REGISTRATION FORM
 (Hereby known as "RDSS", undertakes to protect the confidentiality of the information contained in this form)

CHILD'S PARTICULARS

FULL NAME (underline surname) : _____

DATE OF BIRTH (DD/MM/YYYY) : ____ / ____ / _____ IDENTIFICATION NO : T / S X X X X ____ _

GENDER : FEMALE / MALE RACE : _____ NATIONALITY : SINGAPORE / PERMENANT RESIDENT

MAIN MEDICAL DIAGNOSIS : _____

LIST OF IMPAIRMENTS (if any) : _____ ATTENDING PHYSICIAN NAME : _____

_____ HEALTH INSTITUION : _____

_____ EMAIL ADDRESS : _____

_____ CONTACT NO : _____

_____ MEDICAL SOCIAL WORKER NAME : _____

_____ MEDICAL SOCIAL CONTACT NO / EMAIL : _____

SUPPORT/S REQUIRED (Tick in the boxes for the respective support(s) that the beneficiary needs)

EMOTIONAL SUPPORT INFORMATION OF THE RARE DISORDER SIBLING SUPPORT

BEFRIENDING SERVICE THERAPY SUPPORT OTHERS : _____

PARENT SUPPORT GROUP FINANCIAL SUPPORT

PARENT'S PARTICULARS

FATHER'S NAME (underline surname) : _____ OCCUPATION : _____

DATE OF BIRTH (DD/MM/YYYY) : ____ / ____ / _____ IDENTIFICATION NO : T / S X X X X ____ _

MOBILE NO : _____ EMAIL ADDRESS : _____

MOTHER'S NAME (underline surname) : _____ OCCUPATION : _____

DATE OF BIRTH (DD/MM/YYYY) : ____ / ____ / _____ IDENTIFICATION NO : T / S X X X X ____ _

MOBILE NO : _____ EMAIL ADDRESS : _____

MAIN CONTACT PERSON : FATHER / MOTHER (By default, information from RDSS shall be sent via EMAIL to the **father** of the child.)

RESIDENTIAL ADDRESS

BLK / NO : _____ UNIT NO : _____

STREET : _____ POSTAL CODE : _____

SPOKEN LANGUAGE(S) : _____ WRITTEN LANGUAGE(S) : _____

SIBLING(S)'S PARTICULARS (if any)

NAME OF SIBLING	DATE OF BIRTH DD/MM/YYYY	IDENTIFICATION NUMBER
		T / S X X X X _ _ _ _ _
		T / S X X X X _ _ _ _ _
		T / S X X X X _ _ _ _ _
		T / S X X X X _ _ _ _ _
		T / S X X X X _ _ _ _ _

CONSENT FOR DATA COLLECTION
<p>With this application to register my child as RDSS beneficiary, I consent to :</p> <ul style="list-style-type: none">* RDSS collecting the personal data that I have provided in the "Rare Disorders Society (Singapore) Registration Form", for the purpose of registering my child as a beneficiary of RDSS. While I have given consent for RDSS to collect the said information, I do understand that such application is subjected to the assessment of my child's eligibility. The criteria of the assessment shall be set by RDSS and may be subjected to changes from time to time;* RDSS collecting and using the personal data for the purpose of contacting me, in relation to this application/registration of my child to be a beneficiary of RDSS;* RDSS collecting, using and disclosing the personal data contained herein, for the purpose of assessing/administering this application and in providing the relevant services to the beneficiary and/or the family (if eligible);* Having the information collected herein, be uploaded to the "Rare Disorders Patient Registry" in the future.

SIGNATURE OF THE MAIN CONTACT PERSON : _____

NAME OF THE MAIN CONTACT PERSON : _____

DATE (DD/MM/YYYY) : _____

DOCUMENTS TO BE ATTACHED TO THE APPLICATION FORM UPON SUBMISSION :

- | |
|---|
| <ul style="list-style-type: none">(1) A duplicate copy of the child's diagnosis report (such as DNA or blood test result) if he/she has been formally diagnosed with a rare disorder.(2) For an undiagnosed case, please attach a letter from the attending doctor to confirm that the child's condition is unknown at the time of application.(3) Rare Disorders Society (Singapore) Indemnity Form (PAGE 3 OF APPLICATION FORM)(4) Rare Disorders Society (Singapore) PDPA Consent Form (PAGE 4 OF APPLICATION FORM) |
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IMPORTANT NOTE:

Please ensure that all the forms are completed accurately and no material information is omitted.

You may choose to scan the completed form and required documents to us (email to contact@rdss.org.sg) for our initial assessment.

Kindly note that the registration/eligibility of the child as a beneficiary of RDSS, is **ONLY completed** upon confirmation from the genetics medical team in KKH that the child's condition is rare, **AND when the hard copy of this application form with supporting documents is mailed in and received by RDSS.**

ONLY application form with attached diagnosis reports will entitle the child to receive financial support (if any) from RDSS.

PLEASE PROCEED TO FILL IN PAGE 3 AND PAGE 4 OF THIS APPLICATION FORM.



RARE DISORDERS SOCIETY (SINGAPORE) INDEMNITY FORM
(To be completed and signed by Parent/Guardian of Child/Ward)

I, _____ (T / S X X X X ____ _), the father / mother / guardian of my child,
(FULL NAME) (LAST 4 DIGITS OF IDENTIFICATION NO)

_____ (T / S X X X X ____ _), agree that I allow my child / ward to participate in any
(FULL NAME) (LAST 4 DIGITS OF IDENTIFICATION NO)

activities / programmes / outings / meetings / events organised by Rare Disorders Society (Singapore) (hereby known as RDSS) and / or its sponsors / supporters. I will not hold RDSS/organising committee responsible for any mishaps, accidents or aggravation of my child's / ward's medical condition, that may occur during such events, whether or not such mishaps, accidents or aggravation of medical condition result in personal injury or death to my child / ward.

I understand that there may be basic medical supervision available during some events as deemed necessary by RDSS / organizing committee / medical team.

I also understand that all information contained in this application form will be held in the strictest confidence by RDSS.

*** For the purpose of this indemnity, Rare Disorders Society (Singapore), encompasses its Advisor, Staff, Committee Members, Befrienders, Medical Personnel and all other volunteers / sponsors / supporters involved in the organisation of RDSS events.**

SIGNATURE OF PARENT / GUARDIAN : _____ IDENTIFICATION NO : T / S X X X X ____ _

NAME OF PARENT / GUARDIAN : _____

DATE (DD/MM/YYYY) : _____



RARE DISORDERS SOCIETY (SINGAPORE)
PERSONAL DATA PROTECTION ACT CONSENT FORM

1. In compliance with the Personal Data Protection Act (“PDPA”), Rare Disorders Society (Singapore), (“RDSS”), seeks your consent to use and/or disclose your child’s and/or your family members’ personal information for the purpose of providing a relevant service to your family.
2. RDSS will also collect and use your personal data to provide you with relevant services provided by RDSS, engaging services provided by other agencies/vendors, publicity matters or media coverage, events and programmes organised by RDSS and its partners, or charitable purposes as required by Government agencies.
3. At RDSS we will be collecting:
 - the personal data needed for the intake into RDSS and any additional personal data disclosed to us during our intake interview (if any) and
 - any personal data disclosed to us during any therapy that we arrange for your child and
 - any personal data disclosed to us during any other services provided to your child and/or your family by us and
 - any personal data disclosed to us during any RDSS programme or event in which your child and /or your family members may participate and
 - personal data provided to us during any social work assistance we provide to your child and /or your family. RDSS respects your privacy and assures that your personal data will be kept securely according to PDPA.
4. I hereby give my acknowledgement and consent to RDSS to use my personal data for the aforesaid purposes and services listed above. In the event that I have registered my Singapore telephone numbers(s) with the Do Not Call Registry and wish to withhold or withdraw my consent to RDSS in respect of receiving telephone calls and/or SMS, I endeavour to provide sufficient notice to RDSS of such as soon as reasonably practicable. I further agree to indemnify RDSS against any financial penalties imposed by the Personal Data Protection Commission or any court of law in Singapore as a direct or indirect result of my failure to inform RDSS of my registration with the Do Not Call Registry.
5. I agree that my consent will remain in place until my withdrawal by officially notifying RDSS in writing or email to contact@rdss.org.sg

SIGNATURE OF PARENT / GUARDIAN : _____ IDENTIFICATION NO : T / S X X X X _____

NAME OF PARENT / GUARDIAN : _____ CONTACT NO : _____

DATE (DD/MM/YYYY) : _____ EMAIL ADD : _____