

## INTRODUCTION

Malaysian Rare Disorders Society (MRDS) was formed in 2004, with the help and guidance of the Genetic Unit, Department of Paediatrics, University Malaya Medical Centre.

MRDS is a voluntary organisation set-up to represent and look out for the welfare of individuals including their families that are affected by rare disorders.

MRDS' target members are individuals affected by rare disorders, their families and any organisation that supports MRDS' objectives.

## WHAT IS A RARE DISORDER?

In Malaysia, there are 3% to 5% of babies that are born with birth defects. Among these birth defects are rare conditions or disorders for example, *Osteogenesis Imperfecta* (brittle bones), *Duchenne Muscular Dystrophy* (DMD), *Prader-Willi syndrome*, chromosomal abnormalities and many more.

Rare disorders include chronic genetic conditions that may lead to death. It has its own issues that would need great care in management.

As a guide for MRDS, a 'rare disorder' is defined as a genetic condition that occurs in less than 1 in 4,000 people in the community.

## MRDS' OBJECTIVES

- Create a network among individuals and families with rare disorders.
- Create a network among MRDS members with organisations, agencies and professionals involved in treating, educating and conducting research on rare disorders.
- Serve as a contact and resource centre on rare disorders.
- Promote the awareness on rare disorders among the Malaysian community.
- Support and assist individuals and families affected with rare disorders in terms of welfare, treatment, rehabilitation, education and social needs.
- Collaborate with agencies and organisations that diagnose, research and treat rare disorders to increase the quality of life for the individuals and families affected.
- Raise funds to support the activities and objectives of MRDS.

## MEMBERSHIP

As a member of MRDS, you get :

- To meet and share experiences with other members affected with rare disorders in Malaysia.
- Latest information on rare disorders especially from the field of genetics and other professionals.
- To participate in recreational activities such as painting and music classes, group trips and sports activities.

## TYPES OF MEMBERSHIP

- Ordinary Member  
Membership is open to Malaysian citizens above 18 years old affected with rare disorder and individuals that support the objectives of MRDS.
- Family  
Parents or guardians of children under the age of 18 years old affected with rare disorder.
- Corporate Member  
Corporate organizations, institutions registered societies or organizations that support the objectives of MRDS

## MEMBERSHIP FEE

Registration fee (once only): RM10.00

### Annual Fee

Ordinary member : RM 20.00  
Family : RM 20.00  
Corporate Member : RM 1000.00

## Application for Membership

### Member's Personal Details

Name: \_\_\_\_\_

NRIC No. \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Tel No. (R): \_\_\_\_\_

Tel No. (O): \_\_\_\_\_

Tel No. (H/P): \_\_\_\_\_

E-mail: \_\_\_\_\_

Occupation: \_\_\_\_\_

### About individual affected (if any)

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

NRIC No.: \_\_\_\_\_

Name of Disorder: \_\_\_\_\_

\_\_\_\_\_

I wish to be a member of Malaysian Rare Disorders Society and agree to abide by its rules and regulations. I enclose the sum of RM 30.00 as payment for the registration fee and annual membership fee (ordinary membership).

Signature : \_\_\_\_\_

Date: \_\_\_\_\_



### **MALAYSIAN RARE DISORDERS SOCIETY**

(Registration No. : 0064-07-WKL)

Please contact us at :

Malaysian Rare Disorders Society  
16, Lorong 5/10D  
46000 Petaling Jaya

Telephone : 019-7714543

Fax :03- 79588459

E-mail : [info@mrds.org.my](mailto:info@mrds.org.my)

Website : [www.mrds.org.my](http://www.mrds.org.my)

\*\* Payment by cheque to be made to Persatuan Penyakit Jarang Jumpa Malaysia

