

YOU ARE NOT ALONE

Rare diseases may sometimes be unseen or “invisible”, however, it is often life-threatening in children.

In Singapore, approximately 2,000–3,000 people are currently diagnosed with a rare disease.² Of these, approximately 700 are children.² Although rare diseases are uncommon, affected individuals collectively represent a sizeable population who require support across many aspects of their lives.

Better understanding and early diagnosis of rare diseases leads to better health outcomes.



Other resources:

Club Rainbow (Singapore)



Club Rainbow³



Supports children with chronic illnesses and their families by providing compassionate services in their journey

Core services:

- Social work intervention to create an individualised, holistic care plan for each patient
- Therapy intervention to address the diverse needs of children and achieve developmental milestones and independence
- Educational support to instil positive learning values in children’s academic pursuits
- Arts engagement and exposure programmes to develop interest towards independent living and community inclusivity
- Strength-based and interest-based activities to equip youths with essential life skills for a smooth school-to-workplace transition



Rare Disease Fund²

A charity fund managed by KK Women’s and Children’s Hospital Health Fund (KKHHF)

Eligibility criteria (non-exhaustive):

- Singapore citizenship
- Treated at a Public Healthcare Institution
- Clinical criteria for initial or continuing treatment with medicines covered under the fund
- Currently, 5 conditions and 7 medicines are eligible (this list is evolving, please refer to the KKHHF website for the latest information)



The Learning Guidebook⁴

Offers tips for those caring for their loved ones including persons living with disabilities, and aims to help caregivers navigate the complexity of caregiving



Enabling Guide⁵



An online resource providing information and advice on schemes, services, support, and resources related to disability

Resources:

- Information on disability support, including schemes and services for persons with disabilities
- Information regarding disabilities, according to the type of disability
- Caregiving advice on common caregiving issues, and developing good care skills
- The Caregiving Learning Roadmap helps caregivers better understand the needs of those with disabilities and gain skills for sustainable caregiving

References

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4. Agency for Integrated Care, and SG Enable. Learning Guidebook (for Caregivers), 2023. Available from: <https://www.aic.sg/>. [Accessed: Dec 2023]
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CaringSG⁶

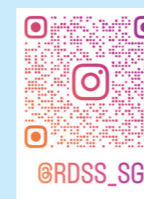


A caregiver-led initiative to connect, enable, and empower caregivers by building an inclusive, compassionate, and supportive community

Core services:

- CAREconnect provides access to emotional support, resources, and connections among caregivers through webinars or events
- CAREbuddy regularly engages caregivers to work through personal and family needs and issues to bring about positive changes
- CAREwell involves a multidisciplinary team of professionals to support caregivers in navigating access to care and services

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An initiative by:



For more information, please visit www.rdss.org.sg

Content partner:



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Rare Disorders Society (Singapore)

EMPOWERING LIVES: ASSISTANCE FOR NEWLY DIAGNOSED RARE DISEASE PATIENTS IN SINGAPORE

WHO WE ARE

RARE DISORDERS SOCIETY (SINGAPORE) (RDSS)

An IPC charity established in 2011, inspired by the advocacy work of its founders for their daughter who was diagnosed with Pompe disease.

Currently cares for more than 180 beneficiaries and their families who live with them, impacting more than 700 lives, and this number continues to grow.

HOW WE CAN HELP YOU

We bring together patients of different rare conditions, caregivers, and families, who share similar caregiving needs, to support one another.

PURPOSE

To improve the lives of patients living with rare diseases, and their families

1

VISION

To be an empathetic and effective patient organisation by advocating for equity and inclusivity to empower our beneficiaries to live a good quality of life

2

WE SERVE

Patients, caregivers, siblings, and families

WE SPEAK TO

Corporate organisations, the general public, and the government to advocate for awareness and an inclusive society, on behalf of the rare disease community

4

Hear more about how RDSS has supported families or caregivers of those diagnosed with a rare disease:

MIKKEL'S STORY (20 YEARS OLD)

- Mikkel was diagnosed with West syndrome with epileptic disorder at 8 months old.
- Mikkel's caregiver, Karen, shares the support she's received from RDSS:



Informational

"There's a lot more support now that Mikkel is 20 years old. Mikkel joined RDSS around 2010 and RDSS has **definitely provided us with the information we need.**"

Emotional and psychological

"We become **life-long friends** with caregivers whose children have similar conditions. It's good to know that someone has something in common with you to **understand what you're going through.**"

Financial

"Mikkel's on the **Medical Intervention Subsidy**. We were very happy when we found out there was **therapy support** as well; it started 2 years ago. It really is helpful for us as **up to 75% of our budget** for Mikkel's medical or therapy spending can be covered by RDSS."



BENEDICT'S STORY (3 YEARS OLD)

- Benedict was diagnosed with HIDEA syndrome at approximately 4 months old and is currently on 24/7 ventilator support.
- Benedict's caregiver, Mabel, shares the support she's received from RDSS:

Informational

"Jasmine and Wendy are there when I need to talk or when I need any kind of information. I usually ask them **how to take care of Benedict**, including the **type of therapy support** or **daily routine** that is suitable for him."

Emotional and psychological

"We're in a group chat together with other families or parents under RDSS, and it helps with **networking** and **sharing of experiences**. They share a lot so I **learnt and picked up some skills** from them."

Financial

"The **Medical Intervention Subsidy** covers **medical consumables** and **Power for Life** covers **electricity**. The recent one is for **therapy**. It's like receiving an ang bao during Chinese New Year, it's something extra and I feel **very happy.**"

WE OFFER FINANCIAL SUBSIDIES

Medical Intervention Subsidy
(up to \$400/year)

Special Formula Subsidy
(up to \$960/year)

Therapy Support Subsidy
(up to \$1,200/year)

Power for Life Subsidy
(up to \$960/year)

Optical/Dental Subsidy
(up to \$960/year)

Home-based Learning
(in progress)



*Fundraising for a single patient is currently not offered.

OUR ANNUAL EVENT LINE-UP AND SUPPORT NETWORKS



ENGAGE – Raise awareness through events (e.g., **Carry Hope** and **The Purple Parade**) and school outreach programmes (e.g., under **YOUths for RARE**)

Carry Hope

- An annual fundraising campaign organised by RDSS to raise awareness for the rare diseases community
- Carry Hope 2022 successfully raised \$227,000 for the charity, of which \$70,000 was donated to the Rare Disease Fund¹

The Purple Parade

- The Purple Parade is Singapore's largest movement to support inclusion and celebrate the abilities of Persons with Disabilities



EMBRACE – Networking events (e.g., Year-End Party, Mother's Day, Father's Day, Sibling's Day Out, etc.)

- Organised on special occasions to connect member families and provide caregivers the opportunity to share their experiences and support one another



EMPOWER – Empower patients, caregivers, and youths through trainings, workshops, and seminars

- Organises rare disease talks and seminars to equip patients and caregivers with up-to-date knowledge
- Organises trainings and workshops to equip siblings of those diagnosed with a rare disease with leadership, self-confidence, and self-resilience skills