



THE COMING TOGETHER of 10 rare disease groups marked this year's event. It was attended by 200 patients and their caregivers, as well as physicians, allied healthcare professionals, patient support organisations, pharmaceutical representatives and policy strategists from Singapore. Other event highlights include a kids' play session at Playeum, the launch of World Through My Eyes - a regional photo exhibition and a focus group discussion for rare disease patients and caregivers.

This year's theme '**Patient Voice**' recognises the crucial role that patients play in voicing their needs and in bringing about change that improves their lives and the lives of their families and caregivers. The slogan 'Join Us in Making the Voice of Rare Diseases Heard' appeals to a wider audience - to those who are not directly affected by a rare disease.


The event was organised by Rare Disorders Society (Singapore) in partnership with Rainbow Across Borders (RAB) and Club Rainbow (Singapore).

A MOSAIC

...of activities offered a mix of informative and creative workshops for patients, their families and caregivers. It was a great opportunity for building awareness, mutual encouragement, strengthening bonds and preparing for the journey ahead.




LET'S
PLAY!



Fun games & crafts for
rare disease kids at
Playeum



LET'S
SHARE!



Focus groups sessions allowed patients and caregivers to share their experiences on coping with rare disease. It was also an opportunity for them to identify gaps in the chain of care that can be worked on in order to bring about a better quality of life for patients and caregivers.

"It's most inspiring & heartwarming for Pulmonary Hypertension Singapore (PHSG) to be part of this meeting of like-minded individuals, with the shared vision of doing more for patients with rare diseases."
- David Lim, Chairman, PHSG

LET'S WORK TOGETHER!

"Our slogan "Join Us in Making the Voice of Rare Diseases Heard" appeals to a wider audience: those that are not living with, or directly affected by, a rare disease, to join the rare disease community in making known the impact of rare diseases. But it is still one voice. We are not a cacophony or even a chorus of voices. We are Together in One Voice!"
- Gregory Vijayendran, Chairman, RAB



"The synergy of RAB's and RDSS's extensive network and experience enabled our advocacy work to soar to greater heights." - Patricia Mah, President, Rare Disorders Society (Singapore)

Mr Esta Rino from SingHealth presented on the efforts to close the gap between patient care and research, namely to: build on awareness of problems and knowledge of solutions; to create Asia-wide data registries and sample repositories; and to involve patients and their families as drivers in the process.



"Platforms such as this enables us to build on the patient's voice to bring about greater awareness and understanding, and empower patients to better manage the disease." - Rajakanth, Executive Director, RAB

We asked the questions, the **PATIENT VOICE** has spoken. Patients, caregivers and allied healthcare professionals shared their experiences and opinions about living with a rare disease in Singapore through a survey conducted by RAB on Rare Disease Day. With this, stakeholders, together with the wider community at large, will be able to understand the needs of rare disease patients and their families, as well as identify the next steps in caring for them. Here's a summary.

THE PATIENT VOICE

It's been a journey fraught with challenges and uncertainty...

A DIFFICULT DIAGNOSIS

Although some cases were diagnosed at birth, most took between one month to three years. 75% said they encountered difficulties in getting their illness diagnosed. There were many tests to do, many were not conclusive and involved several disciplines.

LOST IN THE DARK

75% felt information was insufficient. They had to plough for it online themselves or link up with families overseas. Information, if given, came in piecemeal fashion or was hard to understand.

LEFT BEHIND

Patients and caregivers often have to take leave for tests and treatment. Employers are not always supportive. The academic and social development of patients were affected. Younger children have difficulties gaining admission to schools as most were not able to cope with their special conditions.

RUNNING LOW

Most respondents felt emotional and social support lacking. Many receive support from Club Rainbow (Singapore), Rare Disorders Society (Singapore) and KK Women's and Children's Hospital. Financial assistance is very much needed as care is expensive.

WE APPRECIATE

- Good infrastructure in NUH & KKH
- Easy access to professionals in hospitals & appointment times
- Rapid turnaround time for tests
- Most treatment available
- Availability of financial support, homecare support & support groups
- Expertise & medical equipment have improved
- Availability of specialists in different fields

WE WISH FOR

- Links to overseas support groups
- Quicker diagnosis & immediate support referral
- More follow-up for existing patients
- More awareness & media support
- A support hotline/counselling
- A patient registry
- More information on what to expect & treatment options
- An integrated approach in the provision of financial, emotional & social support
- Regular engagement of patients & networking through social media and/or meetings

OUR HEARTS, HOPES & AIMS

WE NEED MORE

- 1 Financial support
- 2 Information
- 3 Emotional support
- 4 Education/employment opportunities
- 5 Social activities

(ranked in order of importance)

WORLD THROUGH MY EYES



...the photo exhibition which tells stories of rare diseases patients, was launched on Rare Disease Day across cities in Asia, including Thailand, Malaysia, India and Hongkong. Patient stories can deepen our understanding of the impact that rare disease has on their lives. They can also create strong emotional connections between patients, their families and anyone who is concerned. We hope that with this, the quality of health and social care of rare disease patients will improve.

Look out for more stories which will be accessible online in May at www.worldthroughmyeyes.org.sg



"I love going to the beach and spending time with my family, even though it is a challenge. I cannot do many things because it is not safe for me. I try to be strong and keep a smile on my face."

- Branden Lim, 6

"Mummy always prepares the most delicious breakfasts for me. My hope for the future is for my mum to be happy every single day. She is always there for me ensuring that I get all the comfort I need. I hope that I will be able to live independently and enjoy my life to the fullest."

- Kelly Ng, 15



"It was difficult for my parents to find help and answers. After I got treated, I began to feel much better. I was talking, jumping, climbing and running around again. My family was really happy to see me playing like the other children."

- Queen Zinna, 6

