

## RAGAMS Newsletter June, 2023

*"Rotarians can make a difference"*

### **RAGAMS Australia.**

#### **Melbourne Convention May 26-31,2023**

- RAGAMS Exhibition Booth No 527 had many visitors. Mainly people who knew someone living with MS.
- We are following up Booth visitors to continue relationships and boost our group membership.
- Australian Rotary Health 3<sup>rd</sup> PHD Scholarship has been advertised and now waiting for applicants.
- Collaborating with RAWCS (Rotary Australia World Community Services) for a project with RAGAMS (India). Considering resumption of Vocational Exchange with fledgling MS Society of India (MSSI).
- During May RAGAMS team participated in MS 50 Km Walk fundraiser and raised \$A3203.



### **RAGAMS (India)**

The theme for 2020-2023 World MS Day campaign was **MS CONNECTIONS**. This year in Bangalore, The Rotary International, RAGAMS (The Rotary Action Group Against Multiple Sclerosis) and Bosch partnered with MSSI to celebrate the lives of People with MS, celebrated support networks and advocated for better services for people living with MS.

This year we had an impactful & enlightening session on Government Schemes & Benefits of UDID card by Mr. Umesh, Superintendent – Department of Empowerment for the Disabled & Senior Citizens . More than 100 people attended the program along with leading Neurologist & Rehabilitation Specialists from the city along with Rotary & Bosch representatives. There was also display of Arts submitted by MS persons which added more significance to this event.

The evening also witnessed felicitations of the Chief Guest, Guest speaker, Bosch CSR team, Bosch RBAI Team, RAGAMS, Rotary International & IFRM Music group.

Finally had an enthralling musical program by the IFRM Team along with Dinner.

Link for the photos of the event:

<https://drive.google.com/drive/folders/1N3Wep90PHndBiqSUMb1VWpcBC6LZnA6?usp=sharing>

- RAGAMS (India) main focus is to promote MS Awareness, improve Social media, website content and presentation refer [www.rotary-ragmsa.org](http://www.rotary-ragmsa.org).
- As India is a large country with more than 1.2 billion population we need to expand our reach to other counties and states. We are considering resource required.





Rotary Action Group  
Against Multiple Sclerosis



WORLD MULTIPLE SCLEROSIS DAY

## Meagre data on multiple sclerosis affects policy, patient welfare

**NAMRATA SINDWANI** @Bengaluru  
LACK of knowledge and little data over multiple sclerosis (MS), a neurological disorder, has hindered policy and programme formulation for the diseased. MS is a disease affecting the central nervous system (CNS) — an immune-mediated disorder in which the immune system attacks healthy tissues in the CNS.

Arun Mohan, governing

council member, Multiple Sclerosis Society of India (MSSI), has been suffering from MS for ten years. "From leading a normal life to being diagnosed with a disease I was clueless about, the shift has been extremely hard. I was often mistaken for turning up drunk at work as I struggled to walk straight."

Awareness about MS disease continues to be very low. There is no proper research conducted to understand how many

people actually suffer from it, which makes it difficult to formulate policies and programmes for them. On World MS Day, celebrated on May 30, Mohan urged the government to take necessary measures to perform a survey and introduce policies benefiting them.

According to MSSI, the prevalence of MS in India stands at 8-9 people per 1 lakh. It is esti-

ated that the approximate number of persons with MS is close to 1.8 lakh in India. Cases are now increasingly detected with the availability of MRI at affordable prices. People with the MS suffer more than other disabled. Mohan said, A person with a visible 40 per cent disability is eligible for a Unique Identity Disability card (UIDID). Since

symptoms for people with MS vary from time to time, many of them face difficulty in availing UIDID. There is no reservation for such people in office spaces, educational institutes, government programmes and insurance schemes either, Mohan added.

MS is more common among women: 8 out of 10 people suffering from MS in the 20-25 age group are women. Some of the symptoms include blurred vi-

sion, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness and more. They vary from person to person and are very unpredictable. Sometimes the symptoms persist every day, disappear completely for some days or even worsen from time to time. Dr Netravathi M, professor of neurology, MS specialist, explained.



**STATE**

### Lack of govt support slows down detection of Multiple Sclerosis

**Unique Disability ID must for receiving financial aid**

**NAVYA P K**  
BENGALURU, DHNS

ment, etc.

Ahead of World Multiple Sclerosis Day on May 30, *DH* spoke with patients and doctors to understand the way forward.

In the absence of comprehensive studies, estimates of cases in India vary widely, says neurologist Dr Col J D Mubhera. "Smaller studies have shown prevalence to be 1-8 per lakh of population but the national registry for MS, launched last year, shows prevalence of 20-40 per lakh," he says.

The lack of data also means poor patient support. MS was recognised as a disability only when the RPD Act came into effect, in 2016. "As per the Act, the government should conduct surveys to identify people with all disabilities including MS. But the last available data is from the 2011 Census which did not include MS patients," says S Babu of the NGO Association of People with Disability.

Those with MS should ideally get Unique Disability ID (UIDID) cards, which are compulsory for receiving any disability-related benefit including financial aid. The cost of MS treatment can vary from Rs 3 lakh to Rs 3 crore annually, which is hard to bear for most.

But as per data from the Department for the Empowerment of Differently Abled and Senior Citizens, only around 700 people in the state have got a UIDID card out of the 2,347 who have applied. While many applications are still under process, 806 have been rejected.

According to patient support organisation MS Society of India (MSSI), the UIDID assessment guidelines are problematic. The guidelines consider only permanent physical impairment, whereas MS symptoms change day-to-day. "The benchmark for getting a UIDID card is 40% disability, but some get assessed as having only 10-15% disability because their symptoms are better that day," says Arun Mohan, MSSI Governing Council member.

Long-winding card issuance procedures and non-consideration of cognitive impairment are other problems. Of the 150 members in MSSI Bengaluru chapter who applied for UIDID, only half have got the cards.

**About MS**

**EARLY DIAGNOSIS CAN IMPROVE OUTCOMES**

Early symptoms include blurred vision, difficulty in walking and numbness/weakness in limbs, which can all be transient.

**MORE COMMON AMONG WOMEN THAN MEN**

without treatment, 80% of people with aggressive MS will have permanent disability.

Prepared by: Martin, Diana and Shankar

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Against Multiple Sclerosis

