

---

# **Multiple Sclerosis and other Demyelinating Disorders Special Interest Group (SIG) Inaugural Meeting Report**

The WFNR Multiple Sclerosis and other Demyelinating Disorders Special Interest Group (SIG) Inaugural Virtual Meeting was conducted on Saturday, 10th October 2020 at 09:00 - 10:30 (CEST) / 12.30 - 2.00 PM (IST) on Zoom.

Agenda of the meeting was,

- Need of the SIG
- Formal Inauguration
- Work Done since Inception
- How to take it forward
- Future Plans: 2020 -2022
- Any other point for discussion

The meeting was chaired by the SIG Chair Dr. Abhishek Srivastava and co-chaired by Dr. Nirmal Surya. Dr. Jurg Kesselring the other co-chair was not able to attend the meeting and has sent the apology for the same.

Dr. Abhishek Srivastava welcomed all the participants from across the globe.

## **Need of the SIG**

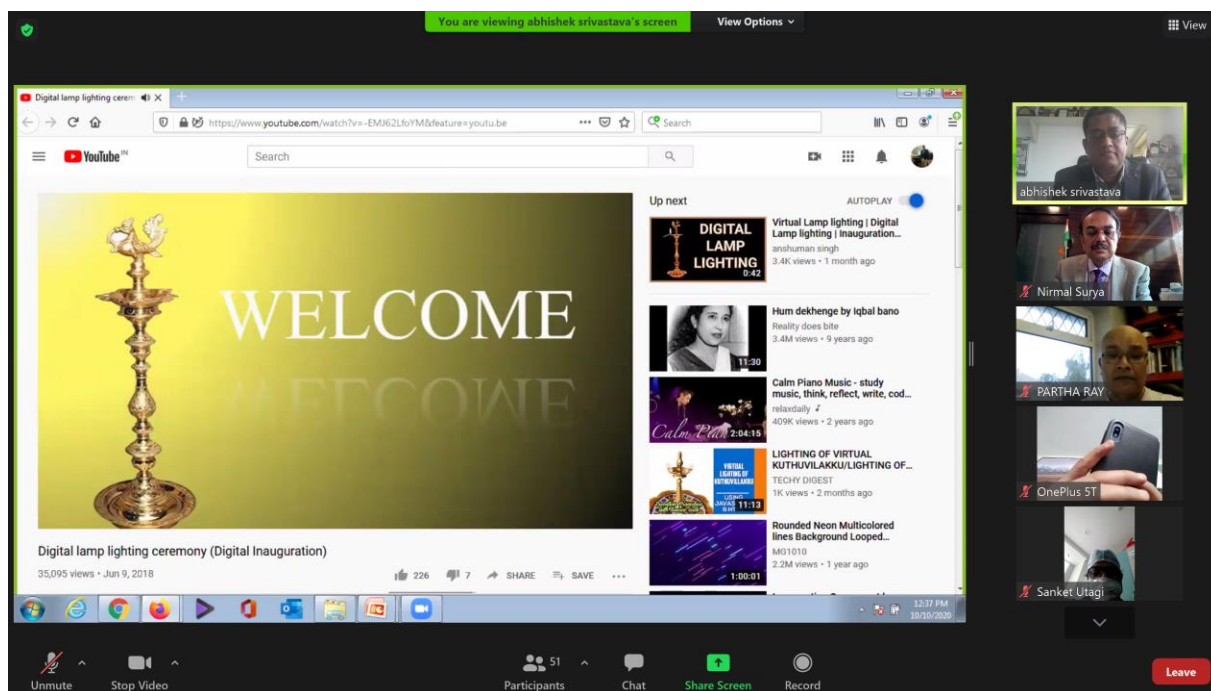
Dr. Srivastava talked about different types of Demyelinating Disorders, geographical variance about these disorders across the world and their symptom profiles, availability of rehab professionals in the developing world and various domains of Multiple Sclerosis Rehabilitation and highlighted that MS Specific Rehab programs are not available in the developing world. All these were the reasons to formulate a new SIG.

## **Formal Inauguration**

**WFNR Executive Director had sent the confirmatory email for the formulation of the new 36<sup>th</sup>**

**SIG on Monday, Mar 9, 2020 at 5:16 PM**

The chair formally inaugurated the new SIG on Multiple Sclerosis and other Demyelinating Disorders with applause from all the participating members.



Dr Srivastava shared the Mission of the new SIG:

- Multiple Sclerosis is most common autoimmune disorder of central nervous system and third leading cause of disability in young adults.
- Incidence of other demyelinating disorders is rising.
- Biological agents seem promising and can reduce disability burden in demyelinating disorders.
- Rehabilitation and optimization of functional status are important components of medical care of demyelinating disorders.
- Multidisciplinary rehabilitation program improves the activity and participation of the persons with demyelinating disorders.
- Regular evaluation and assessment of rehabilitation programs is recommended.

Dr Srivastava shared the Vision of the new SIG:

- To generate epidemiologic data of Multiple Sclerosis and other demyelinating disorders from around the globe.
- To generate trend and variables to determine long term outcome.
- To generate data on treatment outcome to newer biological treatments.

- To determine domain specific early rehab programs.
- To evaluate appropriate outcome measures, optimal intensity, frequency, cost and effectiveness of multidisciplinary rehabilitation.
- To formulate guidelines for low cost models of multidisciplinary rehabilitation.

## Work Done since Inception

The chair informed the members about the work done since inception.

It was difficult time as strict lockdown was implemented all across the globe at the same time the SIG was formed. Only online activities on the virtual platforms were possible during this time.

Indian Federation of Neurorehabilitation in association with Neurorehab Subsection of Indian Academy of Neurology and WFNR SIG on Multiple Sclerosis and other Demyelinating Disorders organized a Webinar on Rehabilitation in Multiple Sclerosis on 14<sup>th</sup> April, 2020. The session was moderated by SIG Chair Dr Srivastava and has eminent speakers Dr Singhal, Senior Neurologist from India who spoke on the Multiple Sclerosis in India and Prof Kesselring, the SIG Co Chair on Rehabilitation in Multiple sclerosis. 2923 Mutidisciplinary participants from all over the world including from USA, UK, Slovenia, Australia, UAE, Iraq, Philippines, Malaysia, Indonesia, Nepal, Bangladesh, Sri Lanka, India. The participants included Neurologist, Rehab Physicians, Psychologist, Occupational therapist, Physical therapist, Speech pathologist, Orthotist, MS Survivors and their families. The two talks were followed by an interactive discussion.

**Neurorehab Webinar from 06<sup>th</sup> – 14<sup>th</sup> April 2020 from 4pm-5pm**

**Speaker :** Prof. B. S. Singhal, Director of Neurology, Bombay Hospital & MRC, Mumbai  
**Topic:** MS Issues in India

**Speaker :** Prof. Jurg Kesselring, HOD Neurology & Neurorehabilitation, Rehabilitation Centre, Kliniken Valens, Switzerland.  
**Topic:** Rehabilitation in MS

**Day:** Tuesday \* **Date:** 14/04/2020 \* **Time :** 04.00pm to 05.00pm

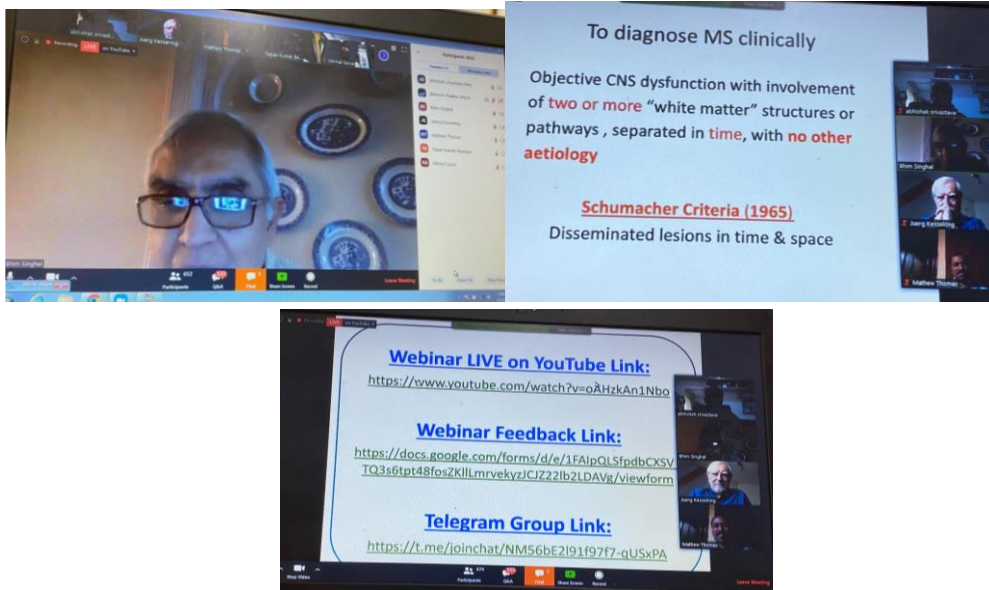
**Chairpersons:** Dr. Mathew Thomas, Bangalore / Dr. Tapas Banerjee, Calcutta  
**Moderator :** Dr. Abhishek Srivastava, Mumbai

Time	Topic
04.00pm – 04.05pm	Introduction by Chairperson
04.05pm – 04.15pm	Lecture by Prof. B. S. Singhal
04.15pm – 04.45pm	Lecture by Prof. Jurg Kesselring
04.45pm – 05.00pm	Q/A

**Zoom Webinar link for all days:-** <https://zoom.us/j/199238185>  
**Webinar code:-** 199-238-185 **Password:-** neurorehab

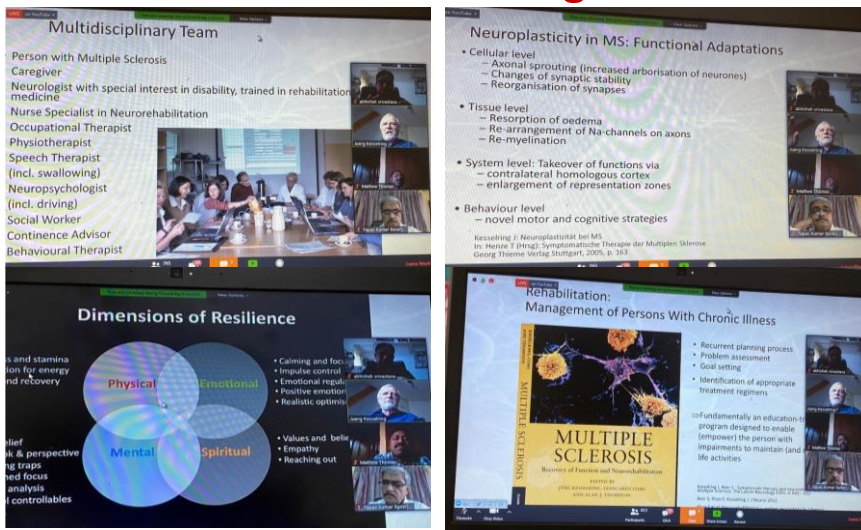
# MS issues in India

Prof B S Singhal



# Rehab in MS

## Prof Kesselring



Prof Gagandeep Singh, Secretary Indian Academy of Neurology spoke on “Addressing the MS Disability: Case Based Approach”, in the Neurorehab Webinar Series on 29<sup>th</sup> MAY, 2020. The session was co chaired by SIG Chair Dr Srivastava and Co Chair Dr Surya. The session was attended by approximately 100 multidisciplinary participants from across the SAARC countries,



ICON: IFNR Case Discussion on the Net

Neurorehab Webinar...Every Friday

ICON 4- Date: 29th May 2020 / Time: 4.00pm to 5.00pm (IST)

## Indian Federation of Neurorehabilitation



Chairperson: Dr. Nirmal Surya, Mumbai / Dr. Abhishek Srivastava, Mumbai

Time	Topic	Speaker
4:00-4:15pm	Addressing MS disability with EDSS : Case based approach.	Prof. Gagandeep Singh, Neurologist, Ludhiana
4:15- 4:20pm	Question and Answer	
4:20-4:30pm	<b>Case – I</b> Post-surgical Rehabilitation of Falcine Meningioma.	Dr Karthik Babu S, Physiotherapist, Bengaluru
4:30- 4:40pm	Discussion	Panelist- Dr Sharan Srinivas, Neurosurgeon, Bengaluru Special invitee- Prof. Maya Sanghi, SLP, Mumbai
4:40- 4:50pm	<b>Case – II</b> Neurorehabilitation of Aphasia in Eloquent cortex Epilepsy.	Ms Sonal Chitnis, SLP, Pune
4:50-5:00pm	Discussion	Panelist- Dr. Sujit Jagtap, Neurologist, Pune Special invitee- Prof. Maya Sanghi, SLP, Mumbai

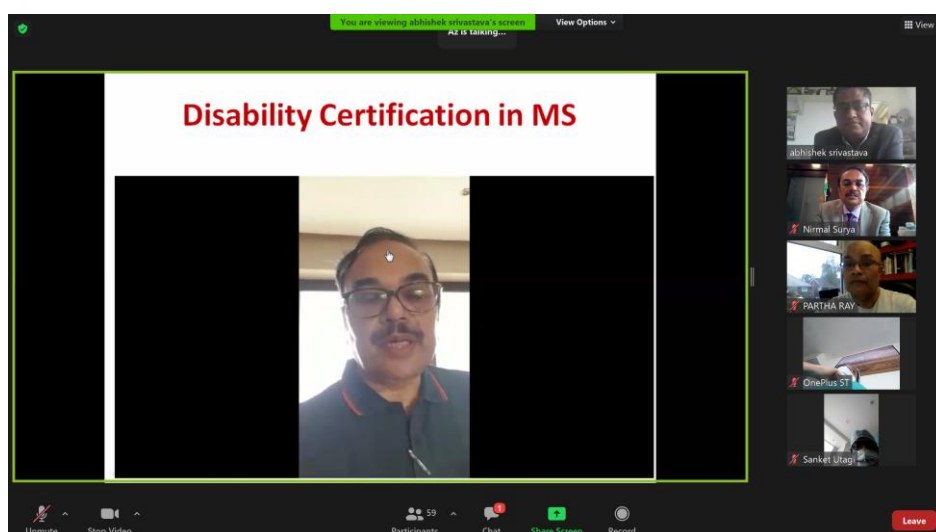
Zoom Webinar link: <https://zoom.us/join/zoom/J38yRZo1TQ2UQgkXJEJDnA>

Password:- neurorehab

The World MS Day was celebrated on 30<sup>th</sup> May, 2020.

The theme for World MS Day 2020-2022 is connections and the campaign will be called **MS Connections**. The campaign is all about building community connection, self-connection and connections to quality care. The campaign tagline is '**I Connect, We Connect**' and the campaign hashtag is **#MSConnections**.

We worked closely with the Multiple Sclerosis Society of India (MSSI) in spreading awareness about the disease and also approached Government of India and States regarding easing disability assessment and certification process for persons with MS.



---

The SIG in collaboration with Multiple Sclerosis Society of India (MSSI) celebrated their 35<sup>th</sup> Foundation day and organized a multidisciplinary webinar on “Home care in Multiple Sclerosis” in view of the ongoing pandemic on 25<sup>th</sup> July 2020.

The session was chaired by Dr Abhishek Srivastava, SIG Chair, WFNR and Mr Sandeep Chitnis Vice President, MSSI and moderated by Dr Bhatkhande, Hon Secretary MSSI. The session had three speakers who spoke on different facets of home care in persons with multiple sclerosis. Dr Nirmal Surya spoke on challenges in MS Rehab, Sneha Patel on home based physical therapy and P S Dantala on orthotic and adaptive solutions. This was followed by an interactive discussion with 250 active members of MSSI. Dr Srivastava proposed vote of thanks and summarised the session.



---

**The Multiple Sclerosis Society of India (MSSI) celebrates 35<sup>th</sup> anniversary**

**Webinar on Physiotherapy at home**

**Saturday, 25th July at 4 PM**

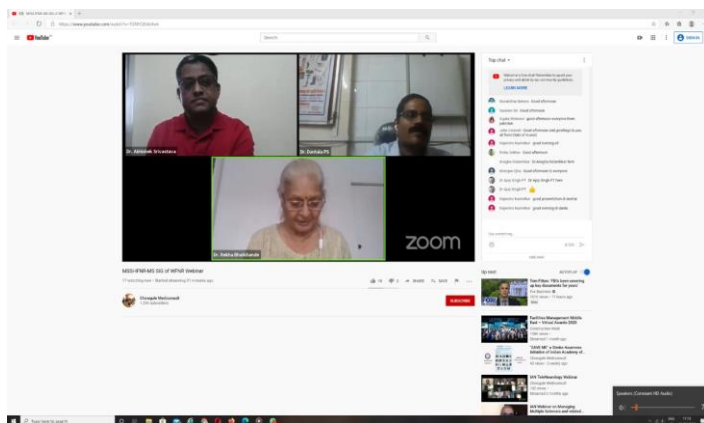
**(A joint webinar by MSSI, Mumbai Chapter with IFNR & MS SIG OF WFNR)**

---

**CO-Chairs: Mr. Sandeep Chitnis and Dr. Abhishek Srivastava**

**Moderator: Dr. Rekha Bhatkhande, Hon. Secretary of MSSI, Mumbai**

Time	Topic	Speaker
4.00 – 4.10pm	Welcome	<b>Mr. Sandeep Chitnis</b> , National Vice President, MSSI Chairperson, Mumbai
4.10 – 4.25pm	Challenges in Rehabilitation of Multiple Sclerosis	<b>Dr. Nirmal Surya</b> , Neurologist President, IFNR
4.25 – 4.40pm	Physiotherapy management in Multiple Sclerosis	<b>Dr. Snehal Patel</b> , MPT Joint Coordinator, Women Cell, IAP
4.40 – 4.55pm	Orthotic Management in Multiple Sclerosis	<b>Dr. P. S. Dantala</b> Orthotist and Prosthetist
4.55 – 5.05pm	Formal Summing	<b>Dr. Abhishek Srivastava</b> , Chair, MS SIG, WFNR
5.05 – 5.30pm	Q/A	



## How to take it forward



### Multiple Sclerosis and other Demyelinating Disorders

#### Special Interest Group (SIG) Inaugural Meeting

Saturday, 10<sup>th</sup> October 2020

09:00 - 10:30 (CEST) / 12.30 - 2.00 PM (IST)

Chair: Dr Abhishek Srivastava

#### Agenda

- Need of the SIG
- Formal Inauguration
- Work Done since Inception
- How to take it forward
- Future Plans: 2020 -2022
- Any other point for discussion

#### Zoom Meeting

Link: <https://zoom.us/j/93601959141?pwd=Mjg1VVoZkdkdzc2TTF6c1ZtVHVOQT09>

ID: 936 0195 9141

Password: 633325

---

Dr. Srivastava opened the platform for discussion, comments and suggestions.



Dr Nirmal Surya said that there multiple problems when it comes to identifying MS as disability and providing respective healthcare and associated benefits to it. He talked about the Govt. of India's Disability Law Nov. 2016 as per which, MS is part of Disability; still many MS patients have not received the disability certificates. He suggested we can train a group of people and have facilities all around the country to facilitate assessment for MS patients and providing the appropriate disability certificates, and this can be replicated in other developing country.

Dr. Mehndiratta congratulated the team on the formation of the new SIG and pointed out that in Asia; we have joint as well as nuclear family structure and hence, family based rehabilitation should be given importance.

Dr. Partha Ray shared his views on MS Rehab in UK and suggested, we can look into the vocational aspect of the patients as most of the people affected with MS is middle age group and suggested to plan for low cost medication and therapy model.

Dr. Mehndiratta, seconded Dr. Ray and pointed that, we need to have better human approach while dealing with MS population. He suggested making use of Artificial Intelligence and wearable devices, as nowadays many advanced technology equipments are coming.

Dr. Sivraman Nair, congratulated the team on the formation of the new SIG and shared his views on MS Rehab in UK. He expressed that all parts of the world should have access to the MS Rehab and standard guidelines should be available. He suggested to classify the evidence based treatment based on their cost effectiveness, availability and necessity.

Mr. Suresh shared his views on MS rehab from public health perspective in UK and suggested doing the systematic review of epidemiological data of lower and middle income group countries. This will help us to plan out resource allocations and to set priorities.

Ms Daphne Kos, President of European Section of Rehabilitation in Multiple Sclerosis (RIMS) congratulated the Chair on the formation of the new SIG catering to the need of persons with



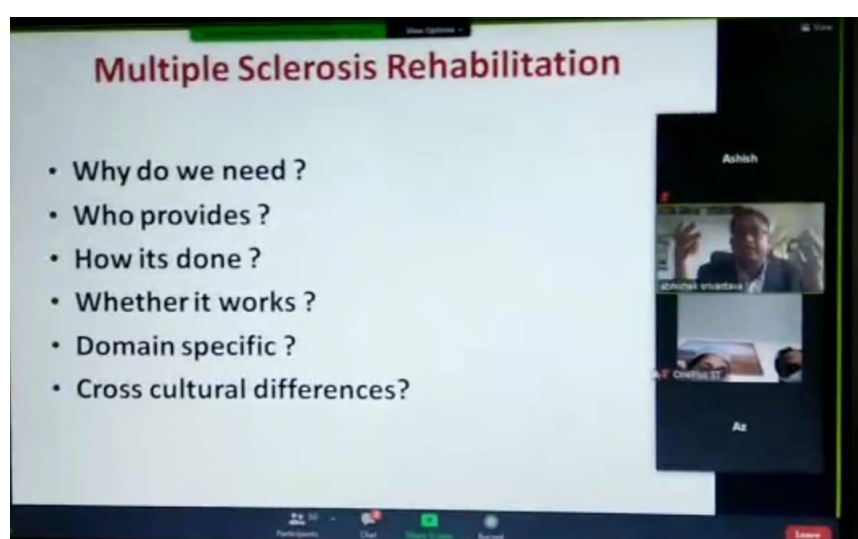
---

demyelinating disorders. She also briefed about the work done by RIMS and wish to collaborate and the initiative for ward.

Dr Abderrazzak congratulated the team on new SIG and discussed in creating more awareness about the disease in Africa.

Ms Shiela Chitnis, President of Multiple Sclerosis Society of India (MSSI), an NGO working for Rehab in persons with MS spoke about the difficulty in getting disability certificate and simplifying the guidelines for disability assessment especially for persons with MS. She congratulated the chair for the new initiative and wants to work closely in this new endeavour.

Mr Roshan Nair congratulated the team on the formation of the new SIG and expressed his views about domain specific guidelines especially for the psychological impact and cognitive deficits in persons with MS and shared his perspective of the work done in UK.



Dr. Srivastava, while responding to the comments, said that- MS affects at various levels, including- cognition, mood, behaviour, vision, motor function, speech, swallow, movement, tone, sensations, bladder, bowel, gait, etc. And to deal with it, we need a multidisciplinary which will have- neurologist, physicians, psychologist, physiotherapists, occupational therapist, speech therapists, nurses, orthotist, etc. Dr. Srivastava pointed out that, even if we start rehab early, we are still not sure if we can reduce the impairment, hence lot of work and study needs to be done.

Mr. Sid Conjurer expressed his views on MS Rehab and awareness in Canada and also added of the need to look into the role of virtual reality to minimize/ improve effects of cognitive & perceptual deficits, which can be supported by Neuro-plasticity.

Dr Navita Purohit spoke about the pain and fatigue in MS and how newer treatment regimens should be developed to manage pain. She also discussed regarding the availability medical marijuana in the developing world for helping persons with MS in coping with pain.

Dr Muralidharan PC spoke about the incidence if MS in Southern India and low awareness of MS rehab and need to develop disease specific programs.

---

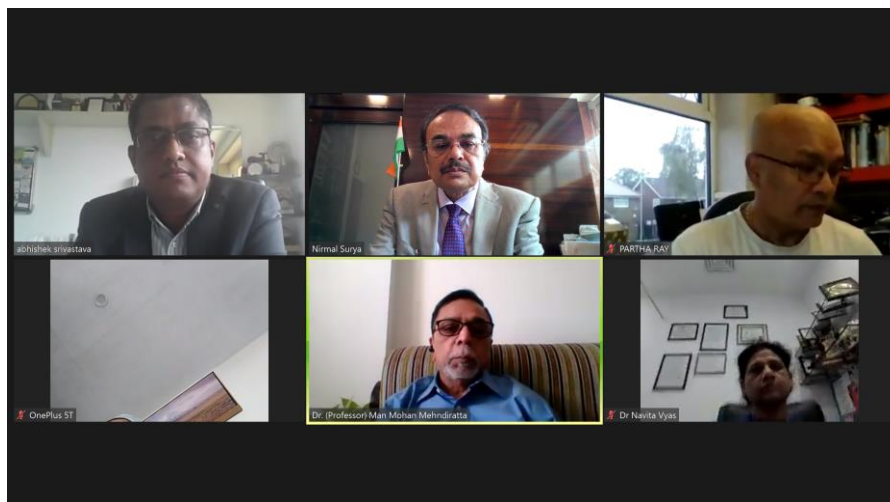
Ankita Bhuatada discussed the swallow and speech problems in persons with MS, shared her experience from USA and need to develop more research on impairment specific domains.

Suchi Gupta congratulated the team for this novel initiative and talked about the motor problems in MS and shared her experience from Canada on how newer technology can play a role in MS Rehab.

Dr Harleen Uppal suggested creating more awareness of the disease in public at large.

Dr. Abhinav Singh, suggested that community based rehabilitation needs to be given some attention to provide more benefits to the patients as well as to their families.

Ms Sumathy spoke about the problems with insurance coverage for MS patients in India.



Dr Srivastava responded that In-patient medical and integrated neurorehab care is included in the insurance but for outpatient rehab, only first 60 days post discharge therapy is covered. Re-admission or extended outpatient therapy is not covered by medical insurance. He told that the team is working with IRDA and insurance companies to include inpatient re-admission and outpatient care in the insurance.

Mr Purushottam Dantala said that for MS patients, many assistive devices and special adaptive devices are available from orthotic perspective. He pointed out Govt of India has started Disability helpline, which can be helpful to promote telerehab. We also need to address access to the resources for respective population.

Ms. Shashi Oberoi said that we need to spread more awareness along with some specialized centres in different areas so that to promote neuro assistive technology and to train people about how to use it.

Dr. Partha Ray suggested that we need to have more basic science research done in MS and also suggested that developing countries like India can provide help including technology, rehabilitation aids, collaborative means to various regions in Africa where MS is still unrecognized.

Ms. Hutoxi pointed out that, we need to emphasize on the psychological effects on MS patients and their caregivers and need for proper evaluation and management of the sequel.

---

Dr. Urvashi Shah described the situations patients face in their daily routine and the limitations which affects their family and professional life. She added that patients face lots of restrains in their life due to lack of predictability, unclear prognosis and worries of future, etc. She suggested conducting community studies to underline the facts and needs to help such population with necessary intervention.

Ms. Priyanka Mehta (Special Educator) said that MS significantly impact daily life and education. She said that there is a need to work on their learning, memory, socialization. She suggested that certain aids can be developed for various academic as well as ADL activities and behaviour modification plans etc.

Dr. Nirmal Surya congratulated all the thoughts coming in association with cognition, mood, behaviour, etc of MS patients, with reference to the mental health day being observed on the same day.

Prof. Mehndiratta summarised the meeting and said that the suggestions made today are doable, and we can plan to do the remaining ones, referring to one- like insurance coverage for MS patients. He emphasized on role of physicians in MS and shared concern areas like misdiagnosis and delay in treatment. He suggested the patients who can't afford treatment can be referred to Govt institutes as some of the medication/ facilities can be made available for either free or at low cost in such setups. He highlighted that it's a team work and we need to work together to provide necessary rehab program and intervention for people with MS.

While concluding Dr. Srivastava seconded that it was a fruitful discussion and we should take the initiative forward by joint collaborative work with all stakeholders. There were 80 professionals from multiple disciplines, including neurologists, rehab physicians, physiotherapists, occupational therapists, psychologists, music therapists, swallow therapists, orthotists, advocacy groups MSSI with representation from RIMS Europe, UK, USA, Canada, North Africa, India and South East Asia.

### **Future Plans: 2020 -2022**

The future plan for next 2 years was outlined as consensus:

1. Cross cultural dialogue and more epidemiological studies from the developing world
2. Formulate early rehabilitation program for MS patients
3. Effect of COVID 19 on persons with MS
4. Telerehab guidelines for MS rehab
5. Evaluate cost effective of rehab programs and community based rehab

Dr. Srivastava thanked co-chair, senior associates and all the attendees to taking out time to join the meeting and their valuable inputs and feedbacks.