

Conference on
PERSPECTIVES *in* **GNE-MYOPATHY**
Research, Clinical Management & Patient Care

February 16-17, 2018 at Indian National Science Academy,
Bahadur Shah Zafar Marg, New Delhi

GNE myopathy is an adult onset genetic disease in which there is progressive weakness of distal muscles of the limbs, eventually leading to severe disability.

To provide a platform for discussing different aspects of GNE myopathy, including potential therapies & patient care, we are organizing this two-day meeting of all stakeholders



A representation of Goddess Durga who is a symbol of power and strength

“Strength does not come from physical capacity. It comes from an indomitable will.”

Mahatma Gandhi

including neurologists, physiotherapists and other experts, basic scientists, patients, families and care-givers. The main theme of the meeting is “Finding a cure through sustained research”.

We invite you to participate in this multidisciplinary meeting and contribute towards its success.

We look forward to seeing you in Delhi in February

For Enquiries, please contact:

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Organised by:

School of Life Sciences,
Jawaharlal Nehru University
New Delhi-110067



Supported by:

World Without GNE Myopathy (India)



Programme

Day 1, Feb 16

Plenary Talk I:	Z. Argov Hadassah-Hebrew University Medical School, Israel	Technical Session III:	Molecular mechanism of pathophysiology in GNE-Myopathy
Plenary talk II:	Ichizo Nishino National Center of Neurology & Psychiatry, Japan	Speakers:	Stella M Rosenbaum Hadassah Hebrew University Medical Center, Mount Scopus, Jerusalem, Israel
Technical Session I:	GNE Myopathy in India: Clinical experience		Ranjana Arya JNU, New Delhi, India
Speakers:	S. Khadilkar Grant Medical College & Sir J J Group of Hospitals, India	Technical Session IV:	Therapeutic options in GNE- Myopathy
	A. Nalini National Institute of Mental Health & Neurosciences, Bangalore, India	Speakers:	Kausik Chakravarty IGIB, Delhi
Special Lecture	Nuria Carrillo National Institutes of Health Maryland, USA	Special lecture	Sujata Mohanty AIIMS, New Delhi
Technical Session II:	Diagnosis & Disease Monitoring in India: Possibilities for GNE- Myopathy	Panel Discussion on "Strategies for Treating GNE- Myopathy"	Nuria Carrillo, National Institutes of Health, USA
Speakers:	N.R Jagannathan AIIMS, New Delhi	Cocktails & Dinner	
	Ashraf Mannan Strand Life Sciences, Bangalore		



Programme

Day 2, Feb 17

Special Lecture Alok Srivastava
CMC Vellore, Tamil Nadu

Panel discussion on "Patient Power & Collective Will: Working Together to Treat GNE Myopathy"

Plenary Talk III: Umapathi N Thirugnanam
National Neuroscience Institute, Singapore

Technical Session V: **Alternate therapies**

Speakers: Bhavana Prasher
TRISUTRA, CSIR-IGIB, New Delhi

Ramniwas Prasher
Vedanta Ayurveda, New Delhi

Ms Vishnupriya
Yoga Practitioner

Harpreet Singh
AIIMS, New Delhi

**Rights of People
with Disabilities** Muralidharan V.
National Platform of Rights of the Disables

Patient Discussion & Sharing Session
Sponsored session on AFO

Sightseeing Tour & Dinner



Registration Form

All attendees to the meeting are required to fill out the following Registration Form and email it to gne.patientday@gmail.com or visit our website and register at www.gne-myopathy.org

This form should be filled out by each person attending: There are no registration charges

Title: Mr Ms Other

Patient Family member Doctor/Scientist Other Please specify _____

Surname/ Family Name: _____

First/ Given Name(s): _____

Address: _____

City: _____ State/ Province: _____ Country: _____

Postal Code : _____

Tel: _____

Email: _____

Please indicate whether you plan to attend the conference:

Only on the 16th(Friday)

Only on the 17th(Saturday)

On both the days

Sightseeing tour and dinner on 17th, Saturday

Please indicate whether you will require the following:

Accommodation at the conference venue

Some financial support for travel

Please specify special needs for transport/accommodation _____

Please specify special dietary requirements, if any _____

Important Information

How to Register (please fill out one form per participant)

By visiting our website: www.gne-myopathy.org and filling out the form online

By Email: Send your completed form to gne.patientday@gmail.com.

Insurance

The Organizing Committee is not liable for any personal accidents, loss/damage of private properties of registered participants during the conference. Participants should make their own arrangements with respect to personal insurance.

Letter of Invitation

Applicants requiring an official letter of invitation for the purpose of obtaining a visa or permission to attend the Meeting may submit the request to the Secretariat. The letter will be provided to the invited speakers without a formal request. The letter of invitation is not a commitment from the Organizer to provide any kind of financial support, hosting arrangement, nor does it guarantee an entry visa will be issued.

Accessibility

The Organizing Committee will try to make the venue and accommodation as accessible as possible. The Committee will also endeavour to provide any help that may be required. However, the Organizing Committee does not guarantee that all requested help will be provided.

Travel Support

We have limited funds for travel support within India. Please write to us in case you required support.

Accommodation

We can provide basic accommodation free of cost at the venue of the conference. Please let us know in case you would like to avail of it.

