



1<sup>st</sup> World Lymphoedema Day, an initiative of US based LE&RN -Lymphatic Education and Research Network was celebrated at AIIMS ON 6<sup>th</sup> March 2016

This was organized by the Department of Surgical Disciplines, AIIMS in partnership with NGO SATHI (Society for Administration of Telemedicine and Healthcare Informatics), the India Chapter of LE&RN with support from NVBDCP (National Vector Borne Disease Control Program).

As part of ENDO-SURG – also called AIIMS Surgical week, a special session was allocated, so as to engage not just clinicians, but also public health functionaries, the media and patients.

All eminent speakers stressed the need to bring forth the need and consequent positive impact of early detection and treatment.

Master of ceremonies, **Dr Shivangi**, Junior resident in Surgery, introduced the topic and the speakers and managed the flow of presentations.

The first session was for clinicians. **Prof. Sneh Bhargava** as ex Director of AIIMS and presently, Patron of NGO SATHI emphasized the need of providing missing links that impeding care delivery to patients consistent with current research outcomes.

**Prof. Anurag Srivastava**, HOD of Surgical Disciplines, AIIMS, clearly explained in Hindi, how lymphedema builds into a clinical condition. A translation of his message in English is being provided here as this can be used across the world for a tacit understanding of the problem when engaging the public and lay press and ultimate lead to better selfcare.

*“Lymph – the accumulation of which causes lymphedema, is the body’s sewage system. Compare with clean water in blood. Like blocked sewage, lymphedema or lymph accumulation is a flood teaming with disease causing bacteria. Prevention is in making sure there are adequate channels remaining when doing surgery or through methods to restore flow. Measures like compression and antibiotics, assist the body’s own inner mechanism of cleaning this water before recirculation.”*

**Prof Maneesh Singhal**, HOD Plastic Surgery, AIIMS described the incidence of lymphedema in India and across the globe. Filaria and Breast Cancer surgery are the biggest reasons though Venous disease and Trauma also contribute. At an estimated incidence of around 2 crore, the overall incidence is around 1-2 % of the population

**Dr S B Gogia**, Surgeon and Lymphologist next explained the pathogenesis of Lymphedema with intricate details of anatomy, physiology and how its derangements lead to a continuing vicious cycle of Lymphedema and Elephantiasis. He listed relevant investigations which can help. He said that the management approach is essentially infection control and compression therapy. Even while treatment is effective, there is a chance of recurrence due to small pockets of “sewage” remaining behind in what he called Lymphatic lakes. Lymphedema hence is a chronic disease for which long term home based care is required with intermittent monitoring.

**Dr Rakesh Kumar**, Additional Professor of Nuclear Medicine showed how lymphoscintiscan helps evaluate patients before after treatment.

**Prof S Misra**, Plastic Surgeon from Puducherry next demonstrated some inexpensive and affordable indigenous innovations useful for home based care.

**Dr Anita Dhar Bhan**, Additional Professor of Surgery at AIIMS, talked about situations where surgery is helpful. She showed some good results following nodo venous shunts as well as the new, but still under evaluation, method of silicone tube implants

**Dr Yuri Dias Amborcar**, HOD Plastic Surgery at Goa Medical College, demonstrated additional procedures which can be done in advanced cases.

**Ms. Arun Rekha** Chairperson LE&RN India, then discussed how the management approach should be balanced as patients suffer from disease burden and emotional Intelligence. These patients suffer social boycott, they are lonely and have poor QOL. Treatment plans should consider the actual working condition of the patient making sure that they improve Quality of Life and not interfere with the same. She said that only 10% of care is by an actual doctor, 20% by a Trained therapist while 70% is self-care. Especially for the last bit, much motivation and counseling is required for this otherwise depressive disease. She also shared that, a well managed patient quickly turns into a very persuasive counselor.



*Results can be excellent with good management, but he has to continue care for a long term*

A community level clinic to this effect was established in Pisawan block of Sitapur District U.P. with joint efforts of SATHI and local NGO Sangtin Samooh. A four-month follow-up of 35 patients following self care in a resource poor community brings forth a model that can be a useful tool for planning future clinics in endemic areas.

Physiotherapist **Ms Ashima Naval** highlighted the limited training opportunities for therapists' in managing Lymphoedema.

**Dr Karishma De** – a fresh graduate doing fellowship at AIIMS similarly shared her view about lack of information on the management of this huge problem during her MBBS. She was delightfully surprised to see that it is treatable.

The next session was for the patients public. **Dr Akshay Dhariwal**, Director of National Vector Borne Disease Control Program (NVBDCP) explained the public health perspectives for prevention of this disease this problem and how the government is eagerly and intensively working on this huge public health problem. He emphasized that his own department is exclusively working on only one cause namely Filariasis, which is highest in the list of causes Lymphoedema, is only an after effect and does not get corrected fully after the worm dies. Hence a sustained and possibly separate effort maybe required for Lymphoedema wherein management is directed to all causes.

NVBDCP Joint Director **Dr P K Srivastava**, next extrapolated on the actual efforts and outcomes of the National Filariasis Control Program. Dr Srivastava stated that the Program is based on the twin pillars of MDA (Mass Drug Administration of DEC and Albendazole) as well as Morbidity Control. Efforts on both these fronts have showcased excellent results. Starting 2005, the number of endemic districts has fallen from 255 to 137 and the India's commitment to WHO that Filariasis will be eliminated by 2020 is well within purview. However, he cautioned that new districts - areas not in the previous 255 are possibly cropping up and probably we need to broaden the focus of the program. Regarding Morbidity control, he showcased what the government is doing which is as per WHO recommendations, He invited proposals and suggestions if more needs to be done but also stated that such efforts should provide a complete implementation plan. The government, he said has to offer a complete solution so thinking about funds, materials and personnel required cannot be left untouched.

**Dr Maneesh Singhal** suggested the need for Lymphoedema clinics with AIIMS as a starting point. He also listed out the infrastructure requirement for such clinics

**Dr S B Gogia**, who is also president of SATHI, which is running community based limb care clinics demonstrated the role of Telemedicine for monitoring as well diagnosing these patients in remote areas. The entire session was being broadcast through Teamviewer™ with members of the NGO Sangtin Samooh, Residents of Goa Medical College and a few others connected online. An actual patient was also examined online. There were 10 online participants along with over 120 physically present.

The last session was an open house session where three representative patients from a large group being managed at AIIMS, namely **Neha, Banita** as well as **Prabhkin** shared their journey from despair to discovery and finally with guidance, control of the disease and its associated psycho social problems. They placed a series of petitions which are worth highlighting – (see below)

#### PETITION from patients

- Information should reach all sections of society - through TV, Radio, Social Media etc.
- Patients do learn from each other, so Group Therapy sessions should be encouraged.
- Clinics should be organized at Panchayat/ Taluk level to provide awareness to all people
- All concerned doctors should be made aware of Lymphedema and its treatment methodology
- Affordable treatment with latest research advances should be within the reach of those in need

A recorded special message of **Mr. William Repicci** Director LE&RN was played whereby he told that Lymphoedema is a neglected problem affecting million across the globe.

In recognition of the extent of this chronic disease, a resolution declaring 6<sup>th</sup> March as the 1<sup>st</sup> World Lymphedema day was passed in the US senate as well as the New York State Assembly. This was corroborated by **Linda B Rosenthal** New York State Assembly member, and **Martin J Golden** New York State Senator. He congratulated AIIMS and India for celebrating First World Lymphedema Day.

#### Conclusions of the Seminar

- Such awareness programs need to be organized more often
- Co-ordination of Govt Programs with Clinicians and Public is necessary to fight a dreaded and neglected disease.
- Partnership is also required to disseminate knowledge about differential diagnosis and modern treatment techniques available at AIIMS.
- AIIMS can be a center for training and guidance for creating many more such clinics.
- According to Dr Srivastava, each District should have at least one Lymphoedema clinic.
- There is a definite role of Non Profit agencies like SATHI in linking Government programs with Institutions like AIIMS to deliver services to the suffering humanities. And also advocating awareness and education to all concerned.
- The patient's testimony further strengthens the view that knowledge information dissemination can change the course of many young and misdiagnosed individual's lives. Lack of knowledge can be crippling

## Annex Detailed Program

Day 3, Sunday 6<sup>th</sup> March 2016 Program:- Lymphedema Symposium Venue:- LT-1 First Floor

**Moderators Prof Anurag Srivastava** Prof and HOD, Department of Surgical Disciplines, AIIMS, **Prof Sneh Bhargava**, Former Director AIIMS, Patron SATHI **Prof Chintamani** Prof of Surgery SJ Hospital, **Dr Mahesh Mangal** President Delhi Chapter of APSI

Time	Topic	Speaker	From
9:30-9:37	Introduction to the topic and the role of AIIMS	Prof Anurag Srivastava	HOD Surgery AIIMS
9:38-9:45	Incidence of Lymphoedema	Maneesh Singhal	HOD Plastic Surgery AIIMS
9:45 -10:00	Anatomy, Pathophysiology, management principles	S B Gogia	Surgeon and Lymphologist
10:00 – 10:10	Lympho-scintiscanning	Rakesh Kumar	AIIMS Dept of Nuclear Medicine
10:10-10:20	Approach for resource poor areas	Satya Misra	Plastic Surgery MGM University Puducherry
10:20-10:30	Role of surgery, Nodo-venous shunts, Silastic tube	Anita Dhar Bhan	AIIMS Surgery
10:30-10:40	Debulking and newer advances like plastic Surgery	Yuri Dias Amborcar	Plastic Surgery, Goa Medical College (GMC)
10:40-10:55	Conservative treatment and home based Care	Arun Rekha Gogia	Chairperson LE&RN India
10:55 -11:00	Therapists session	Ashima Naval	Physiotherapist
11:00– 11:10	Open House discussion on Clinical Care		
11:10- 11:30	Tea Break		

### Session for public and patients 11:30 to 1:10 PM

**Moderator Dr S Dhariwal** Director National Vector Borne Disease Control Program (NVBDCP)

11:30 -12:00	Filariasis – incidence and government programmes	P K Srivastava	NVBDCP
12:00 – 12:10	Running a Lymphoedema Clinic, global scenario and possibilities in India	Maneesh Singhal	HOD, Plastic Surgery, AIIMS
12:10 – 12:25	Telemedicine and Community based care - Role of NGOs supplemented with direct transmission from Sitapur	S B Gogia, <i>N Sudha, Richa Singh</i>	SATHI, Sangtin Samooh Sitapur, UP
12:25 – 12:55	Patients perspective, demo of selfcare with online transmission from GMC	Patients, Residents ( <i>Raskah</i> )	AIIMS, GMC
12:55 – 1:15	Open House discussion interspersed with recorded messages from across the globe	LE&RN representatives & Media	US and other places
1:15 onwards	Lunch	Recorded talks and messages continue	



Some photos from the event

