



## Liver Care Foundation Annual Report 2006

**Vision:** To contribute to a world free of “liver disease”

**Goal:** To assist and support healthcare related to Liver Diseases.

**Mission:** To advocate and generate public awareness about liver health through information, education and communication. We commit to assist those living with a liver disease. Striving continuously, we aim to bridge the global gap in the field of academics and research relating to the liver and liver diseases.

### Message from our Founder Trustee, Dr. S.K. Sarin, MD, DM



‘Birth should be planned and the newborn nurtured and groomed with affection and care. The Liver Care Foundation, is two year old, and is learning to stand and walk. The parenthood in the hands of the trustees and board members had its own pleasures, problems and lacunae. Their collective vision is to take the Foundation to the needy, create awareness, promote science and advocate preventive and curative measures to make the life of those suffering or likely to suffer from liver diseases a shade better. The task is undefined, mammoth and hence needs generous support and encouragement from all sectors.

On behalf of all those who need liver care and support, we commit to work together and request you all to join hands. We do hope in the years to come, this Foundation would win the trust and affection of one and all.

Please do hold our hands in this march from infancy to childhood'.

### **AWARD OF PADMA BHUSHAN TO Dr. SHIV SARIN, MD, DM**

It is indeed a matter of great pride and honour, our Founder Trustee, Dr. Shiv Sarin, has been bestowed with the award of Padma Bhushan by the President of India, on the Republic Day, 2007.

We take this opportunity to congratulate Dr. Shiv Sarin for this meritorious achievement which speaks volumes of his selfless dedication and commitment in the field of medicine with special emphasis on gastroenterology and its related subjects. We hope the new generation will try and emulate him in excelling further in the study of medicine.

## Chapter 1 Introduction

**Organization:** The Liver Care Foundation (LCF) was established in 2005 as a non-profit organization to connect with the public, patient and provider as part of its focus towards prevention of liver disease[s].

The Liver Care Foundation aims at providing:

**Awareness:** The aim of LCF is to bring about an awakening in the minds of people about the importance of functioning of liver in a human body; and if not taken care of, can create a number diseases elated to liver and thus cause complications. It will also educate people about the treatment of liver disease and the availability of Doctors and Hospitals treating this malady

**Assistance:** LCF will endeavour to provide assistance in terms of financial aid (and through Donors) to those who are willing to donate their liver.

**Academics:** LCF also undertakes to promote upcoming Doctors, financially, who though, are well qualified to attend higher studies or present papers, but cannot do so for lack of funds. Each case is considered on merit through a screening body before providing them with any financial assistance

**Organization Values:** Competency, Credibility, Commitment, Care and Cooperation constitute the culture of Liver Care Foundation.

### LIVERCARE

*“Is life worth living? It all depends on the liver.” - William James.*

The liver is a very sensitive and an important organ in a human body. It has a crucial role to play in infusing in us, the zest for life. A spirit that we take for granted which could completely crash when the liver is afflicted.

It is quite startling to learn, that, more people die of Hepatitis B in a day than AIDS in an entire year, says a WHO report.

Dr. Shiv Sarin, joint Director of the ‘Hepatitis Day’ stated that, the national prevalence rate for Hepatitis B is 4.7 percent while, that of AIDS, is less than one per cent. Around 45 million people in India are infected with Hepatitis B and about 15 million with Hepatitis C. This, Dr. Shiv Sarin states, is primarily due to lack of awareness.

India recognizes this and has launched its fight against this killer disease by starting a Hepatitis B vaccination programme in 32 selected districts and 15 urban slums.

It is indeed a pity that the **ignorance about liver and its related disease is wide spread, nationally.**

There is thus a need to launch an awareness campaign with a view to educate people about Hepatitis, its prevention and cure as also its effect on the human body.

People hardly know that both Hepatitis B and C are spread in the same way as AIDS. Dr. Shiv Sarin states that the amount of blood needed to transmit Hepatitis B and C is much less as compared to HIV virus, therefore, the need to emphasise about Hepatitis on a priority basis.

**The most notorious of liver afflictions is Hepatitis**, which could cause a host of associated ailments that could endanger life. Many lives have changed beyond repair due to the disease.

There are three distinct categories of Hepatitis---Hepatitis A, B and C, of which, Hepatitis B is particularly virulent. In India alone, nearly 36 million people are severely affected by the Hepatitis B virus. On a Worldwide study, the figures are estimated at 300 to 400 million people, and the vulnerable areas are Southeast Asia, China, sub-Saharan Africa and the Indian subcontinent.

## **Chapter 2**

### **Thrust Areas--Awareness, Education, Networking and Communication**

#### **Awareness---Key Activities**

- Educating and encouraging various audiences for acceptance of organ donation, prevention of viral hepatitis, and treatment of other liver diseases with messages communicated through media channels, audio visual displays, and memorabilia.
- Educating the public on their rights related to liver issues.
- Taking up direct education programmes focusing on interactive activities with various audiences and patients to help them understand and retain information about liver diseases, their early treatment, prevention, and cure.
- Awareness on safe blood transfusion and donation practices with associated providers.
- IEC material for audiences in various languages as part of information services on various liver diseases and liver transplantation.
- Networking with other organizations to help streamline query and patient referrals to the various thrust areas.
- Creating awareness of the benefits of the hepatitis E vaccine.

#### **2. Excellence in Academics**

## **Key Activities**

- Financial support to Indian scientists and doctors for conducting and presenting research and scientific studies relating to the liver at local and international conferences, workshops and seminars.
- Sponsorship of awards, public lectures, conferences, fellowships, projects and reading material.
- A teleconferencing and web-based service for doctors to access latest liver-related research.
- Statistics on liver disease to be made available on a national and international level.

## **3. Emotional Supportive Services**

### **Key Activities**

- Peer groups creating a live forum for patients experiencing a liver disease to share information and provide support reassuring hope, emotional needs, depression, pain or other manageable symptoms.
- A virtual forum through the organization website for patients, caregivers, and all others linked with liver diseases for interactive support.
- An information resource that answers patient queries presented virtually and in print form.
- A helpline service that provides confidential, friendly and professional support and information to all those affected by a liver disease directly or indirectly.

## **4. Financial Supportive Services**

### **Key Activities**

- Financial assistance for liver patients from economically weaker sections of society who are incapable of paying for their treatment.
- Provision of free vaccines for hepatitis B to those at high risk.

## **5. Fundraising**

### **Activities**

- As part of an awareness campaign on World Hepatitis Day.
- Developing projects for the corporate sector as part of their corporate social responsibility.
- For building a corpus towards financing activities such as Hepatitis vaccination support programmes, rehabilitation of alcoholics, treatment services for impoverished patients.

## **6. Lobbying and Advocacy**

## **Key Activities**

- Lending support to implement Government policies, where there is lacuna.
- Recommendations to the Government, to frame policies that assist in prevention of liver diseases, such as immunization, and live liver related transplants.
- Recommendation to the Department of Education to include information on preventable liver diseases as part of school curricula.
- Campaigning for recognition of urgent requirements of liver patients.
- Teaming with other organizations in partnership for liver care advocacy where possible.
- Special assessment of current blood banking practices for any recommendation for safer practices.

## **7. Organ Donation**

### **Key Activities**

- A centralized registry and a system of donor cards to those who pledge their organs.
- A centralized registry for waiting recipients.
- A system of linkages to facilitate a smooth coordination amongst the hospitals in a city, specifically trauma centres with ICU facilities for organ removal and distribution.
- Educating with a view to encourage potential liver patients through peer support programmes.

## **8. Organization Policies**

- To allocate resources on liver related science, education, physical health, emotional / psychological health.
- To identify and recognize persons who are committed and ready to work for the cause of the organization.
- To create a database of recipients of awards from in the past of participation in Hepatitis Day as part of a potential volunteer list for Liver Care activities.

## **9. Future Plans**

- It is our endeavour to have a Liver Care Foundation office in every State in India
- Capacity building to help create more organizations focused on liver care.
- Developing a consortium with international linkages.
- Training on liver supportive services to relevant organizations in the health care sector.
- Special attention and thrust on Child Liver Care.
- De-addiction for alcoholic liver disease patients.

- Reaching out to the rural levels to understand the burden of liver disease.

## Chapter 3

### Key Activities of 2006-2007

#### APASL Meeting

Liver Care Foundation supported the 2007 Working Party meeting of the Asian Pacific Association-2007 Working Party meeting, for the Study of the Liver (APASL) held in New Delhi, India. The meeting held on 12 and 13 January 2007 was at the India Habitat Centre, New Delhi.

The Asian Pacific Association for the Study of the Liver (APASL) set up a *Working Party on Portal Hypertension* in 2002 with a mandate to develop consensus on various clinical aspects of portal hypertension.

For the Working Party meeting, experts predominantly from the Asia-Pacific region, were identified and requested to develop consensus guidelines on various aspects on diagnosis and management of *Non Cirrhotic Portal Fibrosis (NCPF)*, *Idiopathic Portal Hypertension (IPH)*, and *primary prophylaxis of variceal bleeding in cirrhosis*. These consensus guidelines were discussed and debated in the meeting and final consensus guidelines were prepared. Only those statements were finalized that were unanimously approved by the experts. The working party adopted the Oxford System for developing an evidence-based medicine approach. The consensus on NCPF/IPH has been sent for publication to the *Hepatology International*, the official journal of the APASL (likely to be published in the September 2007 issue).

Those who participated were:

<b>Australia</b> Dr. Peter W Angus	<b>Japan</b> Dr. Shozo Hirota Dr. H Maruyama Dr. Masao Omata	<b>Philippines</b> Dr. Jose Sollano	<b>Singapore</b> Dr. Hock F Lui
<b>Indonesia</b> Dr. L A Lesmana	<b>Pakistan</b> Dr. Mohammad Salih Dr. Hasnain Ali Shah Dr. Huma Qureshi Dr. Mobin Khan Dr. Saeed Hamid	<b>Sri Lanka</b> Dr. H Janake de Silve	<b>Taiwan</b> Dr. Ming-Chih Hou Dr. Masao Mata
<b>Egypt</b>	<b>India</b>		

Dr. Gamal Shiha      Drs Shiv Sarin, Y K Chawla, R K Dhiman, S S Baijal,  
Ashish Kumar, V Malhotra, D G Mazumdar,  
U Poddar, A S Puri, R M Raza, P Sahni, P Sakhuja,  
A Santra, B C Sharma, P Sharma

In addition, residents and staff of the Department of Gastroenterology, GB Pant Hospital helped in organizing the Meeting.

**2. Liver Care Foundation Financial Grants:** Our young medical professionals—doctors and researchers—need a wider international forum to meet the challenges of modern medical science. The interaction on the international platform, opens new vistas of medical advancement. A critical appreciation provides the boost to walk forward in their field of research.

In view of the above, LCF would like to give financial support to Indian scientists and doctors for conducting and presenting research and scientific studies related to the liver at local and international conferences.

Thus, LCF awarded six financial grants to young investigators (under the age of 45 years) to present their paper at the Annual Conference of Asian Pacific Association for the Study of Liver (APASL) held in Kyoto, Japan from 27 to 31 March 2007. The theme of the conference was: "Viral Hepatitis and Hepatocellular Carcinoma in Asia". The main objectives of APASL are to promote the latest scientific advancement and education of hepatology science, exchange of information and the development of consensus, encourage the practice of medicine in liver diseases and also coordinate scientific studies between various scientists and clinicians throughout the region.

Liver Care Foundation appraised the information about its Grants Programme to all the forty-four candidates, whose papers had been accepted for presentation by APASL. Twenty-one candidates applied for the grant. Of these the, six candidates were selected by a panel of eminent experts. They received full grant to participate and present their paper at the conference in Kyoto. These candidates were:

1. Mr. Amit Kumar, Junior Research Fellow, Department of Pathology, All India Institute of Medical Sciences, New Delhi. His paper entitled 'Development of Short Hairpin RNAs for Inhibition of Hepatitis E Virus Replication' was presented at the conference.
2. Dr. Chandana Pande, Research Associate, Department of Gastroenterology, GB Pant Hospital, New Delhi, presented her paper entitled, 'Small Intestinal Bacterial Overgrowth in Cirrhotics is related to Severity of Liver Disease'.
3. Dr. Lalbabu Gupta, Senior Resident (DM), Department of Gastroenterology, GB Pant Hospital, New Delhi. The paper presented

was titled, 'Effective Treatment of Hepatopulmonary Syndrome with Pentoxifylline'.

4. Dr. Nirupma Trehan, Senior Research Officer, Advanced Centre for Liver Diseases, GB Pant Hospital, New Delhi presented her paper, 'Role of Tumorigenic Gene Expression in CD4 T Cells in Chronic than Acute HBV Infection'.
5. Mr. Ranjit Chauhan, Research Scholar, Department of Gastroenterology, GB Pant Hospital, New Delhi. The title of his paper presented at the conference is 'Characterization of a Novel A and D Recombinant HBV Genotype in India: Full Genome Analysis'.
6. Ms. Shagufta Rehman, Senior research Fellow, Department of Pathology, All India Institute of Medical Sciences, New Delhi. Her paper is titled 'Subcellular Localization of Hepatitis E Virus Replicase and its Interaction with 3' End Viral RNA'.

Dr. Nirupma Trehan says, '**No scientific research is appreciated, if it is not validated by group of scientists belonging from the same field of research.**'

Ranjit Chauhan's comments: '**Ideas from the scientists coming from different countries help us to improve and further clear our vision to move our scientific thoughts and work in particular direction.**'

Dr. Lalbabu Gupta says that, 'APASL 2007 conference updated me regarding the various new developments in the field of liver diseases. There was a very useful session on management of hepatitis B. Management of hepatorenal syndrome gave me a new idea which I will discuss with my seniors and we will start a new protocol on this topic. Really, attending such a conference broadens your ideas and helps you to manage your patients better and start new research protocols that will help in the future treatment of disease.'

### **3. Awareness Survey:**

Information empowers us all. Liver Care Foundation understands the need for dissemination, not only to the medical fraternity, but also to the common man. LCF would therefore, like to raise the level of awareness among all people—young and old, rural and urban, parents and children, students and teachers, healthcare staff and all other professionals, with a view to enable all of us to manage our health better.

Keeping this in mind, LCF decided to check out the ground realities, by carrying out a survey with a view to ascertain the level of awareness, related to the liver and liver health, through a questionnaire.

The tool has been developed both in Hindi and English, with inputs for the questions coming from experts in the field of gastroenterology. It is proposed to pilot this tool over at least 500 persons. Based on the feedback from this pilot programme, the tool

will be finalized and then administered to almost 10,000 persons. From the analysis of the questionnaire, Liver Care Foundation plans to develop an awareness campaign, develop Information Education and Communication (IEC) material as well as plan its advocacy strategies and activities, in the coming year.

We will strive to have a healthy liver in every body through this awareness programme.

## **Chapter 4**

### **The Way Forward—Plans for 2007-2008**

1. **Helpline** – LCF will start a phone helpline for patients and caregivers affected by liver diseases. The aim is to inform, educate and empower patients on physical, psycho-social and spiritual aspects of liver diseases. This will help in allaying the fears and anxiety, among the patients and their families.
2. **Student Teacher Brigade** – This programme is aimed at creating community level volunteers or a brigade who are trained on liver awareness, its common diseases and preventions. The plan is to target school children, college students and teachers by building their capacities as communicators and providing them with information, which would enable them to create this awareness. It is proposed to have a 2-day workshop for master trainers from select schools and colleges, who would be provided with the relevant information, in order to train others, in their institutions.
3. **Hepatitis B Vaccines** – The Delhi Government provides free Hepatitis B vaccine to all newborns in government hospitals. The Delhi Chief Minister, Ms Sheila Dikshit, expressing her concern at the menace of Hepatitis virus, announced that this vaccination would be made mandatory for all students seeking admission to government schools in the Capital. While these efforts of the government will be able to ensure, that, all children entering school from now on, would have received the Hepatitis B vaccine.

LCF has decided to address those children who are already in school, but have not received this immunization. LCF proposes to advise and help private schools in immunizing children; and these children would then be asked to sponsor immunization for a child studying in the government school.

4. **Grants for APASL** – The Eighteenth Conference of APASL will be held in Seoul, Korea from 23-26 March 2008. The theme of this conference is *New Horizons in Hepatology*. The conference is co-hosted by The Korean Association for the Study of the Liver (KASL). LCF would provide grants to those candidates from India, whose papers would be accepted by the organizers and selected by the jury set up by LCF.

5. **LCF Website** – An informative website about LCF is being developed which will be soon announced. The website will provide information about all activities planned and undertaken by the Foundation. It will also provide important information on Liver and its related ailments and cure. It will provide a directory Of Hospitals and Doctors, treating on Liver ailments.
6. **Liver Transplants** – A number of patients suffering from liver failure can be given a new lease of life if they undergo liver transplant. In order to encourage cadaver liver donation, LCF will undertake a communication campaign to educate people about signing up as donors for organ donation especially liver. For this LCF will map out the stakeholders whose awareness and participation will be critical to ensure timely removal of the liver from the body of a person who would have signed up for this cause.
7. **Immunisation Campaign** – LCF plans to liaise with other state governments to adopt the Hepatitis B vaccination also, as a basic vaccine in the immunization schedule for all children.
8. **Survey on Liver Awareness** – The Liver Awareness Campaign will keep itself informed by an extensive survey, being planned by LCF. The LCF team has planned to collect data from respondents belonging to different age groups, income levels and across gender. The analysis of the survey will help identify key messages that need to be communicated through the awareness campaigns.

Statutory Auditors GSA & ASSOCIATES 13 Legal Registration Details Type of Registration: Public Charitable Trust Registration number: 3769 Date of Registration: 18 March 2005 Registration under: T-980/05/01 on dated 23-03-2005 section 12A of the Income Tax Act, 1961 of the India. Office details : Regd office : 88-G, Sector 8, Jasola, New Delhi-25 Working office : Liver Care Foundation C6 / 6205 , Pocket 6-7s Vasant Kunj, New Delhi 110 070 Email ID: livercare1@gmail.com Telephone: 98 998 26161 (Rita Vohra)