



Lymphatic Research MATTERS

A PUBLICATION OF THE LYMPHATIC RESEARCH FOUNDATION

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Finding a Cure for Lymphedema is Goal of LRF

With this first edition of *Lymphatic Research Matters*, the Lymphatic Research Foundation (LRF) proudly announces its arrival as a new and dynamic force in the cause of finding a cure for lymphedema and related lymphatic disorders. Founded by a dedicated group of patient and family advocates in July of 1998, LRF has already achieved an impressive stature in the field. Its accomplishments during the last two years and its goals for the immediate future are the subject of this inaugural issue.

The lymphatic system is one of the most misunderstood of human systems, although it ties into virtually every tissue and organ in the body and impacts most diseases, especially cancer. Consequently, the study of the lymphatic system will benefit everyone, not just those with lymphatic disease and lymphedema.

LRF's mission is to help unlock the mysteries of the lymphatic system and especially to promote and support biomedical research for lymphedema and related disorders. To do this, the Foundation is acting as a catalyst and common meeting ground for scientists involved in research, providing information to lay people, and working to raise funds so that the necessary research can go forward. Subsequent issues of *Lymphatic Research Matters* will include important research information and news of the Foundation's activities and plans. ■

LRF Sponsors "Think Tank" at National Institutes of Health

A highly successful "Think Tank" conference on lymphatic diseases, particularly lymphedema, was held at the National Institutes of Health, on May 11-13, 2000, in Bethesda, MD. It was initiated and organized by the Lymphatic Research Foundation and co-sponsored by several National Institutes of Health.

The conference entitled "Conquering Lymphatic Disease: Setting the Research Agenda" was groundbreaking. It engaged scientists from around the world in exploring and characterizing the key unknowns about lymphatic disease and lymphedema. Scientists summarized the current state of knowledge about lymphatic function and disease, and developed a research plan to systematically address key unknowns. The conference focused on formulating an action plan for bringing dispersed investigational efforts together in order to make the most effective use of resources.

Ultimately, the goal of the conference was to create an agenda aimed at finding a cure for lymphatic disorders.

The "Think Tank" was a huge success according to LRF Scientific Advisory Board Chair, Dr. Stanley Rockson, Stanford University School of Medicine. "It harnessed the breadth of existing knowledge in a collaborative effort that will increase understanding and offer improved treatments for millions who suffer from lymphedema and other lymphatic disorders." A complimentary critique of the conference by Professor Jack Hay of the University of Toronto may be seen at www.lymphovenous-canada.com.

LRF is grateful to Dr. Marlys Witte of the University of Arizona College of Medicine, who served as the Principal Investigator on behalf of LRF. Her creativity and scientific leadership were invaluable to the success of the meeting. ■



At the "Think Tank" conference in May are (l-r): LRF Founder Wendy Chaite, LRF Scientific Chair Dr. Stanley Rockson, Dr. Marlys Witte, Principal Investigator, and LRF President Jeffrey Barash.

MESSAGE FROM THE PRESIDENT

We have come a long way in two years. We have organized and established a volunteer Board of Directors and a Scientific Advisory Board, and sponsored a very successful NIH "Think Tank" Conference. We have a commitment from NIH/NHLBI to issue a Program Announcement on lymphatic research and are making inroads for government funding through the political process. We have created a professional video and brochure and raised funds to support a professional Director of Development.

We have been able to jump-start our mission to find cures for lymphedema and other lymphatic disorders through the generous support of the Barash, Chaite, Gregory and Krevis families as well as many other friends of LRF. We thank all of you who have contributed financial resources as well as those who have donated their time and expertise to our cause. Volunteer services provided in the areas of medical education, legal, accounting, bookkeeping, administrative, website maintenance, printing, fundraising, computerization, video production, and other areas have been greatly appreciated.

Of course, there is much more to do. We want to fund the research that our Scientific Advisory Board recommends; stimulate research funding by government, private industry and foundations; establish a tissue and blood bank so researchers can have access to specimens necessary for their research; support the National Lymphedema Network to promote the study of the lymphatic system and lymphedema in medical school curricula; facilitate the collaborative efforts of researchers through a central secure website; and much more.

Your continued support and help is imperative to accomplishing our mission.

A. Jeffrey Barash, Esq.

Dale Gregory Becomes LRF's National Director

The Lymphatic Research Foundation is proud to announce the appointment of Mr. Dale Gregory as its new National Director. Mr. Gregory, former Board Treasurer, is a corporate business leader with over 25 years as a senior executive in the telecommunications industry. As LRF's National Director he will assume responsibility for overall management and operations, fundraising, marketing and public relations. Wendy Chaite, founder of LRF, is stepping down as Founding Executive Director and will take on new duties as Director of Scientific Research and Government Relations. Of Mr. Gregory's appointment, Ms. Chaite

says: "We are extremely pleased to have found an individual with such extensive experience, significant resources, and a deep commitment to our cause to lead our efforts."

Dale Gregory's experience includes leadership in sales, marketing, finance, corporate development, operations and engineering. During his 25 year telecommunications career he was with Rochester Telephone Corporation, Centel Corporation, Advanced Telecommunications Corporation and Frontier Corporation. He retired from Frontier Corporation in 1997 as Senior Vice President – Corporate Development.

A member of Mr. Gregory's family developed lymphedema five years ago. ■

Scientific Community Responds to LRF's Advocacy Initiatives

One result of LRF's "Think Tank" conference at the NIH in May is that more scientists have begun to collaborate with one another. Such collaborations will significantly increase opportunities for improved understanding and progress in lymphatic research, and in a cost-effective manner.

A very significant and immediate outcome of the conference is that the Director of the National Heart, Lung and Blood Institute (NHLBI) made a commitment to issue by year's end a Program Announcement (PA) addressing lymphatic research and lymphedema. A PA is a formal statement to the research community that the NIH has an interest in a particular area of research and is seeking

grant applications from qualified researchers to address the subject matter. The scientific research issues identified at LRF's "Think Tank" will be incorporated in the PA.

LRF has also been working with other NIH Institute officials and senior staff. Based upon personal meetings with the Director of the National Cancer Institute (NCI) and the Deputy Directors of the National Institute of Allergy and Infectious Disease (NIAID) and the National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS), Wendy Chaite and Dr. Stanley Rockson believe these Institutes and others will soon follow the lead of NHLBI in addressing this historically neglected field of research.

LRF is also seeking the formation of a Trans-NIH Coordinating Committee for lymphatic research and lymphedema. In addition to making this request to NIH officials, LRF recently initiated a letter-writing campaign to Congress making a similar request.

LRF will continue to undertake these advocacy initiatives. We are being heard. ■

NHLBI Director Dr. Claude Lenfant on LRF:

"The groundwork that is being established by LRF will enhance the chances for success in obtaining government funding through the process of peer review and in facilitating data gained from clinical trials. Establishing a registry of patients is an excellent idea since more patients would then be available for follow-up, greater in-depth genetic studies, and enrollment into clinical trials as potentially useful drugs are developed. We commend LRF for its commitment to fostering lymphatic research."

A Report from the Scientific Advisory Board

The lymphatic circulation is a fascinating, complex and vital component of human health and function. Over the last three centuries, we have witnessed a slow evolution in our dynamic understanding of the structure, function and pathobiology of this intricate system that maintains the body's internal milieu. Now, almost 400 years after Asellius first delineated the lymphatics of the mesentery, we are truly poised to begin the revolutionary development of lymphatic science.

I feel privileged to serve as the Chair of LRF's Scientific Advisory Board at this very exciting juncture in the history of lymphatic research. Just as two decades ago, we saw the birth of molecular cardiology, it seems clear that the day of molecular lymphology is dawning. The explosion of knowledge in the field of lymphatic genetics, alone, lends tremendous optimism to the notion that we will soon have exquisite, scientifically determined solutions for the devastating illnesses that can accompany lymphatic maldevelopment and malfunction. Not only have the genetic loci been determined for several of the autosomal dominant mutations that produce hereditary lymphedema, but, in addition, it has become evident that, at least in some cases, these mutations determine a faulty molecular signaling mechanism for new lymphatic vascular growth (lymphangiogenesis). These and other exciting observations suggest that the governing molecular forces can be harnessed and manipulated in the future to produce cures for both inherited and acquired diseases of the lymphatic system.

This has been a very important era for

concerned scientists as well. Through the efforts of LRF, the year 2000 witnessed an epochal event on the campus of the National Institutes of Health. During the course of a remarkably productive 3-day meeting, scientists from around the world were able to convene and discuss the state-of-the-art of lymphatic science in the interrelated realms of genetics and development, physiology and pharmacology, lymphatic imaging, and lymphangiogenesis. Each of these disciplines is ripe for explosive development and, together, we have attempted to set a research agenda for the immediate future of lymphatic research. Several important collaborations were born during the course of this important "Think Tank" conference and the intellectual excitement during and after the meeting has already aroused substantial interest in the future directions and funding for lymphatic research within various of the Institutes at the NIH.

The next 24 months promise to be very exciting as LRF endeavors to carry forth the imperatives created during the "Think Tank" meeting in May. Through the combined efforts of scientists, health care professionals and the financial support of donors and the biomedical community it seems that, as never before, the burgeoning interest in solving the mysteries of lymphatic health and disease will provide hope for the millions of individuals who suffer the consequences of lymphatic disease. It is, indeed, a privilege to help LRF to assume its pivotal role in providing hope, answers and, one day, a cure. ■

Stanley G. Rockson, M.D.

Leading scientists and clinicians from around the world gather at the National Institutes of Health to help the Lymphatic Research Foundation develop a national research agenda to promote and support lymphatic research.



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The Lymphatic Research Foundation is a 501(c)(3) tax-exempt, not-for-profit organization whose mission is to find a cure for lymphedema and related lymphatic disorders. Founded by patient and family advocates, LRF is dedicated to promoting and supporting biomedical research for primary and secondary lymphedema and related lymphatic disorders.

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“One person can have a dream; when joined by others it becomes a vision; when put into action it becomes a movement. Movements change history.”

Fundraising is Key to Achievement of LRF’s Goals

Since starting with only a dream just two years ago, the Lymphatic Research Foundation has raised more than \$300,000 and received numerous in-kind donations, enabling it to become established as an important new advocate for lymphatic research. To continue to make things happen, LRF must have the financial support of all who care about finding a cure for lymphedema and related lymphatic disorders.

There are a great many ways to help. In addition to simply writing a personal check, LRF is encouraging its supporters to become involved in grassroots fundraising. This will expand our base of support and educate people about this disease and its devastating effects.

Here are some of the ways that individuals

raised money for LRF last year: sending personal appeal letters to friends, family and colleagues; holding a brunch and silent auction at a restaurant; soliciting sponsors for a marathon runner; having a local merchant sponsor a “Lymphedema Day”; designating LRF in memory or in honor of loved ones.

Other possibilities for simple but effective grassroots fundraising that can be undertaken by our friends is encouraging service clubs or religious organizations to support lymphatic research as one of their charities, rummage sales, parties or simply spreading the word at informal gatherings. To facilitate these activities, LRF has produced two very informative fundraising tools, a 15-minute video and a brochure.

THE VIDEO: With newsman Sam Donaldson, a lymphedema patient, providing the introduction, and first-hand testimonies by lymphedema patients, the parents of children with lymphedema, and professionals in the field, LRF’s excellent professionally produced video vividly portrays the suffering that this disease causes and the urgent need to support lymphatic research.

THE BROCHURE: As a handout or enclosure, this concise, highly informative brochure



on lymphedema and the goals of LRF, is an excellent way to introduce people to our cause.

Production and national distribution of LRF's video and brochure has been made possible through the generosity of Bandages Plus, Bio Compression Systems, Freeman Manufacturing, Juzo, Peninsula Medical, Rally Graphics, and Todd Street Productions.

To obtain a copy of the video and a supply of brochures, contact LRF ■



LRF supporters enjoy a champagne brunch and silent auction fundraiser.



News correspondent Sam Donaldson, a lymphedema patient and supporter of LRF, with Founder Wendy Chaite.