



# Lymphatic Research MATTERS

A PUBLICATION OF THE LYMPHATIC RESEARCH FOUNDATION

FALL/WINTER 2002-2003

## Launch of LRF's Official Journal: Lymphatic Research and Biology

### Why Everyone Should Care About Lymphatic Research

The lymphatic system is the human body's first defense against invaders. Lymphatic vessels orchestrate the interaction between foreign substances (called antigens) and the immune cells that produce antibodies to destroy invading organisms. Research into the lymphatic system promises preventive and therapeutic benefits for a broad array of diseases:

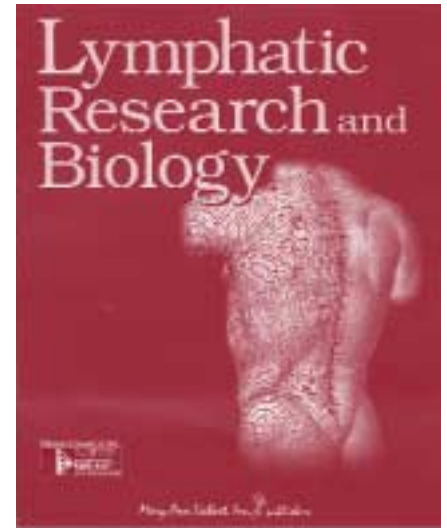
- The lymphatic system is crucial to the body's surveillance against cancer. Comprehension of lymphatic function may facilitate better prevention, diagnosis and therapy for all malignant diseases.
- Ironically, the lymphatic system is an efficient avenue for the spread of cancer through the body (metastasis). Understanding this process will aid in the development of effective therapies.
- The immune surveillance of the lymphatic system also impacts inflammatory and autoimmune diseases, like rheumatoid arthritis, systemic lupus erythematosus (SLE), scleroderma, Wegener's granulomatosis, and many others.
- AIDS wages a direct assault on the lymphatic system. The ability to effectively control HIV requires increased knowledge of the lymphatic system and newer therapeutics that will interface directly with it.

What we can learn from the study of the lymphatic system will benefit everyone – not just those with lymphatic disease.

**M**ary Ann Liebert, Inc., Publishers has announced the launch of a new, quarterly, peer-reviewed journal, *Lymphatic Research and Biology*, to be published in print and online ([www.liebertpub.com/lrb](http://www.liebertpub.com/lrb)). The Journal is the official publication of the Lymphatic Research Foundation. "A new and authoritative peer-reviewed journal will provide a forum to foster research on lymphatic research and biology," said **Mary Ann Liebert**, President and CEO of Mary Ann Liebert, Inc. "An understanding and advancement of research has important implications not only for lymphedema, but for diseases such as AIDS, wound healing, and autoimmune disorders. This Journal will be an important contribution not only to the literature, but to the field."

**Stanley G. Rockson, M.D.**, Chair of LRF's Scientific/Medical Advisory Board has been appointed Editor-in-Chief of the Journal. "The biological importance of the lymphatic system has historically been under-recognized," said Dr. Rockson. "With the recent exponential growth in our comprehension of the development and function of this system, the Journal will provide a much needed vehicle for the publication of new developments in the field."

Original papers will come from a variety of investigative disciplines, including genetics, biochemistry, cellular and molecular biology, physiology and pharmacology, anatomy, developmental biology, and pathology. *Lymphatic Research and Biology* will also include state-of-the-art reviews in such special areas as vasculogenesis and angiogenesis, the genetics of lymphatic disorders, muscle cell biology, interstitial signaling mechanisms, and others. *Instructions for authors and manuscript submission information may be reviewed on-line at [www.liebertpub.com/lrb](http://www.liebertpub.com/lrb). Authors with questions should address them to the Editorial Office at (914) 686-0365 or by e-mail to [journal@lymphaticresearch.org](mailto:journal@lymphaticresearch.org). To subscribe to the Journal, contact Mary Ann*



Liebert, Inc., Two Madison Avenue, Larchmont, NY 10538; (800) M-LIEBERT; Fax: (914) 834-1388.

*"The launch of a new journal dedicated to the study of lymphatic endothelium and the lymphatic system, signals the emergence of a new field of research. Recent elucidation of molecules and factors which regulate lymphatic endothelial growth, discovered by methods and logic developed for angiogenesis research, has enabled the uncovering of mechanisms for lymphangiogenesis.*

*Increasing basic research on the lymphatic system and its pathology will lead to translation to clinical applications which may alleviate suffering in the many patients afflicted with diseases of the lymphatic system."*

— Judah Folkman, MD  
Andrus Professor of Pediatric Surgery  
Professor of Cell Biology  
Director, Surgical Research Laboratory  
Children's Hospital Boston  
Harvard Medical School

— Arja Kaipainen, MD, PhD  
Post Doctoral Fellow  
Surgical Research Laboratory  
Children's Hospital Boston  
Harvard Medical School

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## From The President

When we founded LRF, lymphatic research was limited. Breakthroughs in tissue engineering to produce new lymphatic vessels and in lymphangiogenesis to grow new lymphatics are on the horizon. Now, more than ever, there are reasons to hope. Each day, I awaken knowing we are one day closer to finding improved treatments and a cure for lymphatic disease and lymphedema.



I'm proud of the contribution LRF has made to the field of lymphatics in just four short years. And I know that – with increased funding and volunteer support – LRF can accomplish so much more. Our accomplishments thus far include the following:

- Launched an international, peer-reviewed journal, *Lymphatic Research and Biology* that facilitates sharing of information among researchers and clinicians across a variety of disciplines

- Sponsored two international “think tank” conferences, co-sponsored with and held at the National Institutes of Health (NIH). These conferences brought together leading researchers from around the world resulting in the creation of a national research agenda and fostering significant collaborations

- Advocated for congressional and federal agency support for lymphatic research, resulting in the creation of a Trans-NIH Coordinating Committee for Lymphatic Research, a congressional directive encouraging the NIH to significantly increase its support of lymphatic disease and lymphedema research and a 4 million dollar commitment from NHLBI toward lymphatic vessel function research for FY2003

- Instrumental in the NIH's issuance of a Program Announcement calling for grant applications on the Pathogenesis and Treatment of Lymphedema that will stimulate research on the biology of the lymphatic system to discover new therapeutic interventions for primary and secondary lymphedema

- Developed outreach programs to target

pharmaceutical and biotechnology industries, increasing attention and resources focused on lymphatic disorders

- Formulated a *Coalition for the Advancement of Lymphatic Research* to expand the frontiers for lymphatic disease

- Established a Lymphatic Research Grants and Awards Program to increase support for young researchers and recognize leaders in the field

- Produced an award-winning video, *Mobilizing Efforts for Hope, Research and Cure* to generate support of lymphedema research

Your continued support, whether financial or as a volunteer, is imperative to accomplishing our mission. For those of you considering a major gift, we have volunteer estate-planning specialists who would be happy to discuss such giving opportunities with you and your advisors.

May you be blessed with good health.

Wendy Chaite, Esq.

## LRF Advocates For Congressional Support

LRF is pleased to announce that through our advocacy on behalf of lymphatic disease research, and our work with Chairman Senator Tom Harkin's committee staff, the U.S. Senate's Appropriations Subcommittee on Labor, Health and Human Services and Education has included language in its committee report (Rpt.107-216) on the 2003 Appropriations Bill (S.2766) to support research for lymphatic disease and lymphedema. This is a significant step that will kick-start the federal government's backing of lymphatic disease research, and it lays the necessary groundwork for additional Congressional support in the future!

Special thanks to **Kris Moorman** of Ames, Iowa who was so instrumental to the success of this effort. Set forth below is select excerpts from the report:

“[Congress] commends the NIH for co-sponsoring The Lymphatic Continuum conference in May 2002 and for establishing a trans-NIH coordinating committee to focus on the lymphatic system, with particular emphasis on lymphedema and related lymphatic disorders. Research and medical care for lymphatic diseases has long been neglected; therefore, the Committee strongly urges the NIH to stimulate and support intramural and extramural programs for basic and translational research relating to lymphatic diseases, including but not limited to: insufficiency of lymphatic circulatory function (to include all forms of lymphedema, both primary and secondary), complex congenital vascular proliferative diseases of the lymphatic vasculature, including...lymphangioma, cystic hygroma, lymphangiosarcoma, lymphangioliomyomatosis...lymphangiectasia, chylous reflux and complex vascular malformations, such as Klippel-Trenaunay Syndrome. The Committee requests the Director to provide a report...outlining both short- and long-term plans to stimulate and support basic and translational research for lymphatic diseases. Furthermore, the Committee urges the NIH to examine whether experts on lymphatic research are adequately represented on CSR peer review panels and relevant Institute study sections.”

This is a major addition to LRF's previous advocacy efforts, whereby Congress had created a Trans-NIH Coordinating Committee to focus on the lymphatic system, with particular emphasis on lymphedema and related lymphatic disorders. (Making Omnibus Consolidated and Emergency Supplemental Appropriations for Fiscal Year 2001; National Institutes of Health, Office of the Director)

## NHLBI Commits \$4 Million to Lymphatic Research

We're pleased to announce major progress toward LRF's goal of increasing government funding of lymphatic research. The National Heart Lung and Blood Institute (NHLBI) of the NIH has announced its intention to commit approximately \$4 million in 2003. According to the NHLBI, “the outcome of these studies should lead to a better treatment of...lymphatic diseases, and may also lead to the development of highly specific and dynamic imaging probes that will provide for more accurate diagnoses and assessments of treatment.”

The NHLBI will fund eight to ten new and/or competitive continuation grants in response to a request for applications (RFA) entitled Functional Heterogeneity of the Peripheral, Pulmonary and Lymphatic Vessels. This funding is a direct result of LRF's close working relationship with LRF's Co-NIH Liaisons, **Drs. Stephen Goldman** and **Henry Chang**.

This RFA seeks to support fundamental studies of the cellular and molecular mechanisms that contribute to the heterogeneous (different) nature of the adult peripheral, pulmonary and lymphatic vessels. In the RFA, NHLBI acknowledges that, “the economic and public health burdens of peripheral and pulmonary vascular diseases and diseases of the lymphatics are immense, contributing to increased morbidity and mortality especially as people age.”

The RFA explains an important observation, “arteries, veins and lymphatics are structurally and functionally heterogeneous, at the regional, tissue, cellular and molecular levels [and that] it is likely that these...similarities and differences contribute to the etiology [(cause)]

(continued on p.5)

# LRF's Second NIH Conference A Triumph

*The Lymphatic Continuum*, held May 3-4, 2002, at the National Institutes of Health (NIH), was hailed by many participants as the best lymphatic-related conference they had ever attended and some considered it to be the best biomedical conference of their career. For those suffering from lymphatic disorders, the conference offers hope that researchers are making tremendous progress.

During LRF's international think tank conference, physicians and scientists from all corners of the world shared their expertise in lymphatic biology, lymphatic disorders, molecular medicine, genomics, tissue engineering, and vascular and lymphatic growth factors. *The common thread among the presentations is that understanding of the lymphatic system, the quest for improved treatments and a cure for lymphatic disorders is advancing at a remarkable rate.*

**Dr. Eve Slater, MD**, Assistant Secretary for Health at the U.S. Department of Health and Human Services, gave the welcoming address. **Mary Woolley**, President of Research!America and a member of the Institute of Medicine, **Dr. Judah Folkman, MD**, Professor of Cell Biology, Harvard Medical School, **Mary Ann Liebert**, President of Mary Ann Liebert, Inc., and **Dr. Barbara Alving, MD**, Deputy Director of the National Heart, Lung and Blood Institute (NHLBI) addressed the audience at the Grants and Awards Program. Ms. Woolley presented **Drs. Henry Chang, MD** and **Stephen Goldman, PhD** of NHLBI *The LRF-Lymphatic Research Leadership Award* for their tireless and continuous efforts to develop research programs and initiatives within the NIH. Dr. Judah Folkman, MD and **Mrs. Susan Moisoiff** presented *The LRF-Andrew Moisoiff Young Investigator Award*. The award selection committee, organized by the NIH, selected three recipients this year: **Susan Dagenais, PhD**, **Natasha Harvey, PhD** and **Sujata Bhatia, MS**. Ms. Liebert, president of a biotechnology publishing company with over 60 journals, announced the launch of *Lymphatic Research and Biology*, LRF's official publication, which will be published quarterly. Dr. Alving spoke in very complimentary terms of LRF's accomplishments, especially within the NIH, stressing that LRF is proceeding strategically and very effectively.

*"It was an amazing group you put together. My fundamental understanding of lymphatics was changed in at least two important areas. That happens at very few conferences."*

*The Lymphatic Continuum* was chaired by **Dr. Stanley G. Rockson, MD**, Director, Stanford Center for Lymphatic and Venous Disorders, Stanford University Medical School and co-chaired by **Dr. David Zawieja, PhD**, Associate Professor in the Department of Medical Physiology at the Health Sciences Center of Texas A&M University. Conference presentations and discussions were stimulating and included such topics as: Tissue Engineering for Lymphatic Insufficiency Disorders [Lymphedema]; Growth Factors and Gene Programs for Lymphangiogenesis; Pre-Clinical Models of Lymphatic Disease: The Potential for Growth Factor and Gene Therapy; Adipogenesis and Its Relationship to Lymphatic Pathology; Physiologic Aspects of Lymphatic Contractile Function; The Role of Interstitial Stress in Lymphangiogenesis; The Pathogenesis of Filariasis Lymphedema; and Proteomics.

The proceedings of the meeting will be published as a dedicated volume of the *Annals, New York Academy of Science*. *The Lymphatic Continuum* was hailed as such a success that plans are already underway for future research conferences.

*"I have recently entered into the field of lymphatic research and this conference gave me an amazing insight into the excellent research being done. I will continue to participate in this area of research in the future."*



*Research!America President, Mary Woolley presents the first-ever LRF-Lymphatic Research Leadership Award to Stephen Goldman, PhD [left] and Henry Chang, MD [middle], both of the National Heart, Lung and Blood Institute, NIH*

*The Lymphatic Continuum Conference was made possible through the generous support of:*

- Bio Compression Systems, Inc.
- CircAid
- Genomics Collaborative, Inc.
- Greenberg-May Foundation
- Lenore & Sydney Bland Charitable Foundation
- National Institutes of Health
  - National Heart, Lung, and Blood Institute
  - National Center for Research Resources
  - National Cancer Institute
  - National Institute of Allergy and Infectious Diseases
  - National Institute of Child Health and Development
  - Office of Rare Diseases
- National Lymphedema Network
- New York Academy of Sciences
- Pfizer, Inc.
- Regeneron Pharmaceuticals, Inc.
- Susan G. Komen Breast Cancer Foundation
- Wollowick Family Foundation
- Yablick Charities, Inc.

*The Lymphatic Research Foundation would also like to thank the many patients, families and their friends who responded to our special appeal to support the conference.*

## Conference Proceedings Available

The proceedings of the 2002 Lymphatic Continuum Conference will be published as a dedicated volume of the *Annals, New York Academy of Science*. To order a copy, contact: **New York Academy of Science**, 2 East 63rd St., New York, NY 10021 Phone: 800.843.6927 Fax: 212.888.2894 E-mail: [publications@nyas.org](mailto:publications@nyas.org) Website: <http://www.nyas.org>

## LRF Stimulates Study of Lymphatics

Reaching out to the scientific research community to stimulate interest in lymphatic research is an important goal of LRF. Throughout the year, LRF's leadership has met with distinguished research labs that promise to play an important role in lymphedema and lymphatic-disease research. Meetings and presentations have been held at **Cold Spring Harbor Laboratory, The Jackson Laboratory, The Mount Desert Island Biological Laboratory**, and at **Harvard's Children's Hospital of Boston**. Additional meetings and presentations are planned for the future. *If readers have access to relevant audiences that could directly advance lymphatic research, please contact LRF to set up meetings. Such audiences include biotech companies, pharmaceutical firms, research labs, medical schools, and hospitals.*

In an exciting exchange of ideas, Cold Spring Harbor Laboratory (CSHL) at Cold Spring Harbor, New York expressed interest in supporting lymphatic research, in particular by sponsoring specialized intense meetings on specific lymphatic issues. Research at CSHL is a collaborative effort and has global impact, enriched by interactions fostered through approximately 20 scientific meetings at the lab each year. CSHL scientists work with researchers at other laboratories and universities, and collaborate with their counterparts in the biotech and pharmaceutical industries in a quest to translate advances in basic research into applications that are life saving and life enriching. The primary research focus at CSHL is the molecular biology of cancer.

Through the efforts of LRF Board Member **Maureen Giffin**, a presentation was made to researchers at The Jackson Laboratory (JAX) and Mount Desert Island Biological Laboratory (MDIBL) in Bar Harbor, Maine.

JAX is one of eight institutions designated by the National Cancer Institute as a Cancer Center to perform basic research on the genetic factors underlying cancer. Each year, the Laboratory supplies approximately two million mice from over 2,700 stocks and strains to universities, medical schools and research laboratories worldwide. MDIBL is a private marine biomedical research institute and has become known worldwide as a center for investigations in electrolyte and transport physiology, developmental biology and electrophysiology.

LRF's leadership team also met with researchers from the Surgical Research Laboratory and clinicians from the Vascular Anomalies Center at Children's Hospital of Boston. This institution is well known for its discoveries on the mechanism of angiogenesis. This research opened the field of investigation now pursued worldwide and has led the way to the newly discovered concept of lymphangiogenesis, which has a direct impact on patients suffering from lymphedema and lymphatic disease.

## LRF Young Investigator Award

**Susan and Steve Moisoff**, who recently lost their 12 year-old-son, Andrew, to brain cancer, generously selected LRF to receive donations in Andrew's name. The Lymphatic Research Foundation established the *LRF-Andrew Moisoff Memorial Fund* and created the *LRF-Andrew Moisoff Young Investigator Award* to honor his life and to recognize meritorious research performed by scientists-in-training within the field of lymphatic biology. At a ceremony during *The Lymphatic Continuum*, **Susan Moisoff** and **Dr. Judah Folkman**, considered the father of angiogenesis and the subject of the book *Folkman's War On Cancer*, presented the 2002 Young Investigator Award to **Susan Dagenais, PhD**, **Natasha Harvey, PhD**, and **Sujata Bhatia, MS**.

For those who wish to honor a friend or family member, a memorial gift can be an effective tool toward finding improved treatments and ultimately a cure for lymphedema and lymphatic disease. Please contact LRF if you wish to establish a fund or send a contribution.

*"I have derived a great deal of confidence and encouragement from the young investigator award. The award reaffirms my belief in the importance of disease-oriented research, an area of research that is often overlooked by physician-scientists. I hope to use the stipend to purchase textbooks on cellular and tissue engineering, as well as to attend meetings that will improve my understanding of the lymphatic system."*

— **Sujata Bhatia, MD/PhD Student**, Institute of Medicine and Engineering, University of Pennsylvania



**Judah Folkman, MD [left] and Susan Moisoff [right] present the first-ever LRF-Andrew Moisoff Young Investigator Award to Natasha Harvey, PhD, Thomas Glover PhD (for Susan Dagenais, PhD), and Sujata Bhatia, MS**

*"Recently, the discovery of molecules that specifically control lymphatic development and lymphatic vessel growth (lymphangiogenesis), and the identification of new lymphatic endothelium-specific markers have facilitated key scientific advances and provided new insights into the molecular mechanisms that control lymphatic development and function. As a direct consequence of these progresses, the research on lymphatic biology has received a new and fresh impulse that is represented by the number of original publications and review articles published recently in major journals, as well as by specific support provided by the NIH."*

— **Guillermo Oliver, PhD**, Department of Genetics, St. Jude Children's Research Hospital.

*"In recent years, major progress has been achieved in lymphatic research and increasing opportunities are recognized in the biotechnology industry that have significantly increased interest in the lymphatics. The importance and uniqueness of the field is now recognized at the National Institutes of Health, which has introduced calls for application in lymphatic research and introduced special study sections for lymphatic research."*

— **Geert Schmid-Schonbein, PhD**, The Whitaker Institute for Biomedical Engineering, University of California, San Diego School of Medicine

## Patient & Family Reflections

By Dottie Morris

"It will go away." That's what doctors at Boston Children's Hospital told us after our first child was born with a puffy foot 8 years ago. That was just the beginning of years of misinformation surrounding our daughter's lymphedema. Looking back, I find myself grateful for this period of ignorant bliss that allowed me to fall totally in love with every inch of this perfect newborn child without complication or fear.

We learned when she was 6 months old that it would be lifelong. "She may walk," they said, "but not well." According to a top pediatric vascular specialist, she would never be an athlete or dancer, but might live a near normal life with any luck. They offered us few answers, speaking about a pump and stockings that might help if the condition worsened down the road. We began doing our own research on the Internet and found little. One doctor told us there was more in the medical literature about ingrown toenail than lymphedema. We literally searched the world for just one medical professional that might offer some real support, but were unsuccessful. The garments that were supposed to help were hard to find, poorly designed, and hurt more than helped her, often cutting off circulation enough to turn her leg blue.

We found ourselves asking how this could be. Growing up, we always believed in the security that comes with hard work, medical insurance, and living in one of the medical meccas of the world. We recalled numerous accounts of children from far and wide receiving desperately needed care in this great city. So why were specialists at Children's Hospital of Boston asking us for copies of medical literature on lymphedema? A doctor once told us that our daughter would have been better off if she'd been born with a heart defect because medical support was available for that. We became painfully aware that we were alone in handling our daughter's condition. We realized that things would only change if we worked to change them.

I began networking with other parents of children with lymphedema, gaining and offering support, eventually working with another mom, **Wendy Chaite**. Wendy and I located and opened lines of communication with interested clinicians and researchers, in hopes of helping them to further research. Before long, we were in Washington, pleading with the National Institutes of Health to take interest in this long-neglected condition.



*Lymphedema patient Melissa Morris with her father Bill and brother Keith*

I am proud of my small contribution to this effort, which planted seeds for a more hopeful future for people with lymphedema. It is my dream that one day these seeds might produce a medical breakthrough providing for improved treatments and a cure.

As for our daughter, not a day goes by that we don't worry about her. Spring and summer bring the threat of injury and the potential of infection from insect bites. Fall and winter bring the challenge and emotional exhaustion of finding school shoes and boots to fit her enormously swollen foot. She struggles with feelings of inadequacy and isolation on a daily basis. At an age when children begin to experience self-consciousness, she is painfully aware that she can't walk, run or play games as fast as the other kids. Normal childhood attempts to fit in, bring an overwhelmingly heightened sense of the reality that she looks very different than other children. These daily emotional challenges chip away at the foundation of her self-esteem, leaving her more and more defeated. But through it all, she maintains hope that things will be better for her future.

In the pure and simple spirit of an 8-year old, she recently told me that someday she hopes to make a difference in the world, and that if she becomes rich, she won't spend the money on a big house or a fancy car. "These are things that people WANT," she said, but she would spend the money "on things that people NEED." She would "spend the money finding a cure for lymphedema" she assured me, "so that people with lymphedema might have a "regular leg like everyone else." With strong volunteer and financial support, I am certain LRF will beat her to it!

## NHLBI Commits \$4 Million to Lymphatic Research

(cont. from page 2)

of peripheral vascular, pulmonary and lymphatic diseases." The RFA expressly recognizes that "new opportunities abound in unraveling this field with the tools and approaches that are currently available to the investigator." The RFA further acknowledges that, "the lymphatic circulation has a unique position in its relationship to the arterial and venous circulations in terms of vascular permeability, fluid transfer, macromolecular homeostasis and immunity in that there is no heart to provide hemodynamic pressure and propulsion, flow is obstructed easily, and collaterals may not form. In congenital cases, lymphedema may be asymmetric, even though a mutation is present throughout the body. [And that,] the outcome of these studies ultimately should lead to better treatment of...lymphatic diseases, and may also lead to the development of highly specific and dynamic imaging probes that will provide for more accurate diagnoses and assessments of treatment."

For more information, visit: [www.grants1.nih.gov/grants/guide/rfa-files/RFA-HL-03-004.html](http://www.grants1.nih.gov/grants/guide/rfa-files/RFA-HL-03-004.html)



*Maureen Giffin proudly represents LRF at National Lymphedema Network Conference*

## Organizing an Awareness Meeting, Conference or Seminar?

If you are organizing a lymphedema or lymphatic disease conference, meeting, or support group, LRF would like to help. For research-related information, contact Julie Geller at [lr@lymphaticresearch.org](mailto:lr@lymphaticresearch.org). LRF can provide written materials and exhibit displays or arrange for speakers who can address a variety of topics.

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Founded in July 1998, LRF is a 501(c)(3) not-for-profit, tax-exempt organization whose mission is to promote and support research that will lead to therapeutic advance and, ultimately, a cure for lymphatic disease, lymphedema, and related disorders. LRF's program goals include: fostering related medical and scientific disciplines to participate in lymphatic research; increasing public and private funding and support for lymphatic research by government, industry, foundations and individuals; fostering collaboration and the exchange of information and resources within the scientific and medical community; providing research grants and awards; and promoting a national tissue bank and patient registry.

# Fundraising Matters

## HOSTING A PARLOR PARTY – AN INTIMATE AND EFFECTIVE FUNDRAISER

To benefit LRF and to raise awareness of lymphatic disease and lymphedema, **Ted and Janis Slepian** hosted a lovely cocktail reception in their home. This personal gathering, was a seasonal highlight. **Wendy Chaite**, founder of LRF and the mother of a child with lymphatic disorders, spoke to the group about the personal impact of lymphatic disease and lymphedema. **Dr. Stanley G. Rockson** gave a presentation showing an overview of the field of research and revealing how numerous diseases are impacted by the lymphatic system. Ms. Chaite and Dr. Rockson stressed the importance of supporting LRF. LRF is very appreciative of the outpouring of funds, in excess of \$20,000, that resulted from this magnificent evening. *Anyone interested in hosting a parlor party should contact Calina Burns at [missc29@aol.com](mailto:missc29@aol.com).*

## SHARED TREASURES

Eight-year-old **Melanie Chaite** knows lymphatic research is important. She knows it promises a brighter tomorrow for all those suffering from lymphatic disorders—herself included. Seeing opportunity where others saw junk, Melanie set out to raise money for lymphatic research. She started in her grandmother's basement, and then canvassed the neighborhood for donations of “upscale junk.” When her tag sale was over, she had raised over \$1000 in a single day. So successful was the first event Melanie recruited her younger brother **Daniel Chaite** for a second tag sale at Grandma's house netting another \$1300 for LRF. Melanie's mother,



*Melanie Chaite holds tag sale to benefit LRF, raising over \$2,300 selling “junk”.*

**Wendy Chaite**—founder and president of LRF—was thrilled to receive the donation. She was also impressed with all the lessons Melanie learned along the way, “She learned about display and marketing. And she found that salesmanship is harder than it looks.” She also had a great time working with her grandma. If anyone wants to have a tag sale of their own to benefit LRF, Melanie has graciously offered to make signs on the computer.

## BREAKFAST AND BOUTIQUE FUNDRAISER WAS A HUGE SUCCESS

A group of New York volunteers organized a Breakfast and Boutique Fundraiser at a restaurant for the benefit of LRF. The event was highly successful; indeed, tickets were sold out more than a week before the event. The standing-room-only crowd spent a lovely morning enjoying the delicious breakfast foods and vendor shopping – which featured items such as jewelry, clothing, stationary, and handmade crafts. Local merchants donated various items for raffle prizes. More than \$6,000 was raised to promote and support research. Special thanks to **Lisa Aberle, Joan Adler, Stacey Lane-Pion, Carolyn Lederer, Sheree Levy, Caroline Lindenman, Susan Moisoff, Debby Sunshine, Lori Sands, and Elissa Yegelwel**



*Volunteers Caroline Lindenman, Susan Moisoff, Lisa Aberle and Elissa Yegelwel sell raffles at breakfast fundraiser.*

for their commitment to this important cause. *If you are interested in organizing a similar event in your community, contact Calina Burns at [missc29@aol.com](mailto:missc29@aol.com).*

## LRF Is Beneficiary Of Walk For Women Breast Cancer Fund

The Lymphatic Research Foundation is a beneficiary of the *Walk For Women Breast Cancer Fund* through Long Island's **WALK FM** radio station 97.5 and **Newsday** newspapers. The station's commitment to produce a custom CD and donate 100% of sales proceeds to breast cancer-related organizations won the heart of New York listeners. The CD featured hits from Celine Dion, Faith Hill, Cher, and others. At a presentation luncheon, **Wendy Chaite** representing LRF, was awarded a handsome plaque and a greatly

appreciated donation of \$4,500. **Dianne Sackett Nannery**, lymphedema patient and co-author of *Coping With Lymphedema*, was also recognized for her advocacy efforts. LRF is proud to announce that it has been selected as a featured organization in the 2002 Campaign, and highlighted during Breast Cancer Awareness Month in October.

*There may be a radio station or service organization in your community willing to support lymphatic research; it's worth inquiring!*

## CHAMPIONS FOR CHARITY: SHOP TO SUPPORT LRF DECEMBER 4 – 8, 2002

*Champions for Charity 2001*, an annual holiday shopping benefit designed to raise funds for over 50 Long Island, NY not-for-profit organizations, was highly successful, contributing more than \$3,500 to LRF. Participating stores of **Americana Manhasset** and **Wheatley Plaza** donated 25% of designated pre-tax purchases to an organization of the customer's choice. LRF will be holding a breakfast reception at **Millie's Restaurant** on December 5 to kick-off the 2002 *Champions* event. Participating stores include: Ann Taylor, Athlete's Foot, Baby Gap, Banana Republic, Barney's of New York, Brooks Brothers, Burberry, Coach, Dana Buchman, Donna Karan, Escada, Estée Lauder, Fendi, Gap, Giorgio Armani, Gucci, Hermes, Hirschleifer's, Kate Spade, Louis Vuitton, MaxMara, Nicole Miller, Origins, Prada, Ralph Lauren, Talbots, Williams-Sonoma, and many others.

*If you live outside the area, you can support LRF by making purchases via a Personal Shopper, simply by contacting 800-818-6767. Registration for the complimentary 2002 Champion Card can be completed on-line at [www.championsforcharity.org](http://www.championsforcharity.org).*

## Rising to the Challenge



**Stephanie Rodin** of Arizona understands the challenges of living with primary lymphedema. Her symptoms appeared 30 years ago while she was pregnant with her second child.

Although the years since have brought health issues, physical difficulties and unsuccessful treatments, Stephanie continued to share as full and productive a life as possible with her husband, Lee. She managed their home, raised their children, and established her own career.

In spite of the challenges she faced, Stephanie is now blessed to see her family grown with babies of their own (she is a proud grandmother of two). Because Stephanie wanted to help those suffering with lymphedema and related disorders, she joined LRF's fundraising campaign. Stephanie's letters to friends, family and colleagues – especially those who were familiar

with her medical challenges – generated an overwhelming response. She received donations and heartfelt good wishes that reminded her how much the people in her life care. She continues to send letters to people she knows.

But Stephanie's fundraising does not stop there. Stephanie is involving all of her family in fundraising for LRF. Her daughter's employer, a county club, may sponsor a charity golf tournament and dinner to benefit LRF. She engaged her mother-in-law in fundraising activities in Illinois. Indeed, her mother-in-law read Stephanie's appeal from the pulpit of her church, where she has been a member of the congregation since 1955.

Stephanie is a role model for all of us who have a stake in seeing that lymphatic research surges forward. From the Board of the Lymphatic Research Foundation and the millions of people who suffer from lymphedema and related disorders, we celebrate you, Stephanie Rodin.

*Sample letters are available for those interested in writing a personal appeal to raise support for lymphatic research. Contact Myrna Barzelatto at [mbarzel@aol.com](mailto:mbarzel@aol.com).*

## Volunteer to Be A Regional Representative for CFC

LRF has been selected to participate in the Government's Combined Federal Campaign (CFC) in two regions of New York. We are seeking volunteers to represent LRF in other regions and states. CFC is the annual giving campaign promoted in every federal and military agency throughout the nation. Employees choose charities to donate to via payroll deductions or one-time cash donations. There are multiple CFC's within each state that include local charities particular to that region, in addition to statewide and national charitable organizations. Our objective is to get LRF into as many of these regions as possible, and it is fairly simple to do. *If you are interested in representing LRF in your community or state, contact Guy Lamberti at [gulamberti@fdic.gov](mailto:gulamberti@fdic.gov).*

### I WANT TO CONTRIBUTE

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_

Tel \_\_\_\_\_

Occupation \_\_\_\_\_

I have enclosed my tax-deductible donation in the amount of \$ \_\_\_\_\_

My gift is made:  
 in honor/memory of  
 on the special occasion of

Send LRF Note Card to:  
 \_\_\_\_\_  
 \_\_\_\_\_

Please charge my donation:  
 MC/Visa  AMEX

Card Name \_\_\_\_\_

Account # \_\_\_\_\_

Exp Date \_\_\_\_\_

Signature \_\_\_\_\_

My employer will match my gift; employer form enclosed.

Contact me, I can provide services, resources and/or skills.

Make checks payable to Lymphatic Research Foundation, Inc. and mail to LRF, 39 Pool Drive, Roslyn, NY 11576

**THANK YOU VERY MUCH FOR YOUR GENEROUS SUPPORT!**





**LYMPHATIC RESEARCH FOUNDATION**  
 39 Pool Drive  
 Roslyn, NY 11576-2038  
 T: 516/625-9675  
 F: 516/625-9410  
 E-MAIL: [lr@lymphaticresearch.org](mailto:lr@lymphaticresearch.org)

NON PROFIT ORG.  
**U.S. POSTAGE PAID**  
 PERMIT NO. 50  
 GREAT NECK, NY

*"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."*

## Leadership Matters

LRF's accomplishments are a direct result of the hard work and exceptional talent of its volunteers. That legacy continues with the addition of three new board members. This news is tempered by the retirement of two board members who will be greatly missed.

**Myrna Barzelatto**, RN, MA, MEd., is a retiree and has been a committed LRF volunteer since its inception. Myrna began her nursing career providing direct patient care before running the nursing school at the Hospital for Special Surgery in NY. She later owned and operated a local religious radio station in Providence, RI, before another career change where she applied her talents to develop successful off-site fashion distribution outlets in the northeast.



**Maureen Giffin**, RN, BSN, OCN, a lymphedema patient, is an Oncology Certified Nurse with more than 22 years of oncology clinical experience. She worked as a Bone Marrow Transplant Nurse at New England Medical Center in Boston, Mass. for many years. She is a member of the Oncology Nurses Society Special Interest Group on Lymphedema and Co-Founder and Vice President of the Northern Maine Oncology Nurses Group. She founded and serves as Executive Director of the Maine Lymphedema Network (MLN), a statewide non-profit organization that provides education and resources for healthcare



professionals and patients. Maureen currently works at Maine Coast Memorial Hospital in their Breast and Oncology Clinics.

**Francine Kaskel** has been involved in the implementation and management of medical and pharmaceutical projects for the last 14 years. She has been responsible for logistics of meetings as well as print spin offs from those meetings. Fran recently was responsible for the execution of *The Lymphatic Continuum*, LRF's successful conference held this past May at the NIH. Fran also worked for four years in the non-profit sector as the staff liaison to the allied health professional membership of the National Kidney Foundation. In this capacity, she sat on three executive committees with nephrology nurses, social workers and dietitians to help them achieve their education goals and implement annual national association meetings.



This year brings the retirement of two volunteers whose contribution to the success of LRF cannot be overstated. Both joined the LRF board of directors in 1999. Both have helped the organization shape its vision and develop into a successful research foundation. **Margaret Beery** of San Antonio, Texas has added great value to the organization. In particular, we will miss her elegant writing for this newsletter. We are also very grateful to **Dale Gregory** of Boca Raton, Florida who served on the board as Treasurer and as LRF's National Director for 2000-1. Dale applied his considerable business experience to establish our financial systems and develop-

ment program. We wish Margaret and Dale health and happiness.

## Communications Consultant Joins LRF

Journalist, public relations professional and educator **Richard Ziff** has joined LRF as a volunteer communications consultant. Mr. Ziff will help develop and implement a public relations/publicity program designed to promote research in the lymphatic field. "The decision to volunteer was an easy one for me to make. I am a breast cancer survivor and received a lot of support from various organizations throughout my recovery. I want to pay back and felt LRF could best use the skills I developed over 50 years in the communications businesses," he said. Mr. Ziff is presently a senior adjunct professor teaching writing and public relations at CW Post campus of Long Island University. He is president of Richard Ziff Communications, a specialized agency, whose clients are other advertising and public relations agencies.



## LRF Re-Establishes Headquarters in NY

LRF is pleased to announce the re-establishment of its offices in Roslyn, New York, where its grassroots efforts first began in 1998. Moving into larger rent-free offices, **Wendy Chaite** has reassumed her position as President and Executive Director. Assisting Wendy is **Julie Geller**, who has significant experience in office management and non-profit organizations. Julie is currently President of the Port Washington Public Library Board of Trustees.