



Lymphatic Research MATTERS

A PUBLICATION OF THE LYMPHATIC RESEARCH FOUNDATION

FALL/WINTER 2003 - 2004

Plans Underway for Establishment of a National Patient Registry and Tissue/Cell Bank for Lymphatic Diseases

A new program initiated by LRF will provide scientists with much-needed fresh tissue, cell samples, and clinical data to study the development and functioning of the lymphatic system. Plans are underway for the establishment of a National Lymphatic Disease Patient Registry and Tissue/Cell Bank (PRTCB), to be housed at **North Shore-Long Island Jewish Research Institute NSLIJ** in Manhasset, New York, affiliated with **New York University School of Medicine** and **Albert Einstein College of Medicine**.



Task force members for National Patient Registry and Tissue/Cell Bank

The program will be a multi-center, national program designed to stimulate and support basic and clinical research for lymphatic diseases. It will eventually serve as a clinical trial recruitment mechanism as therapeutics and technologies are developed. The registry and tissue bank will incorporate a broad spectrum of diseases, including but not limited to, lymphatic circulatory insufficiency (e.g., primary and secondary lymphedemas); lymphatic anomalies (e.g., developmental overgrowth and undergrowth); and some mixed lymphatic/blood vasculature anomalies.

A patient registry is a database that will include clinical patient

information gathered over several years from hundreds, likely thousands of patients having primary or acquired lymphatic disease. The purpose of the patient registry and tissue bank is to speed the development of new therapies and health-care services by facilitating research in the area of lymphatic disease, and reducing the time and cost of clinical trials and research studies.

NSLIJ Research Institute, located within 5 miles of LRF's headquarters, has enthusiastically agreed to

host this national lymphatic disease patient registry and tissue bank. NSLIJ is a nationally recognized, growing university-affiliated biomedical research center, equipped to conduct research in patient-oriented basic biomolecular biology. NSLIJ has state-of-the-art repository equipment and systems and a well-established infrastructure to support our program.

A PRTCB Planning Committee Task Force recently met to outline the scope and direction of the program. Attendees included **Francine Blei, MD (NYU)**; **Wendy Chaite (LRF)**; **Robert Ferrell, PhD (Pittsburgh)**; **David Finegold, MD (Pittsburgh)**; **Steven**

Continued on Page 4.

SEEKING ENDOWMENTS: NAMING OPPORTUNITIES!

The National Lymphatic Disease Patient Registry and Tissue/Cell Bank (PRTCB) will be a beacon in the galaxy of researchers and companies mining for improved treatments and cures in the world of lymphatic and related diseases. A limited window of opportunity exists to be a part of the recognition that will come to those who have made significant monetary contributions to insuring the PRTCB's future. Cures and improved therapies for lymphatic diseases, lymphedema as well as for cancer, and other infectious and immune-related diseases will, we believe, credit this program as a central reason for their discoveries. If you or someone you know would like your name involved in such scientific breakthroughs, please contact Wendy Chaite for a personal tour of the limited dedication opportunities available.

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- Congressional Support

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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.

From The President

It is extremely gratifying to see the progress in the field of lymphatic research since founding LRF in 1998. In part due to the advocacy of LRF, lymphatics are gaining the attention of the medical, scientific and government communities – not to mention growing numbers of people in all walks of life.

In this issue, you'll hear about major conferences addressing lymphatics and how the United States Congress is supporting our efforts. And we'll fill you in on some of the creative fundraisers that are helping us accomplish our mission. Glance through "The Cutting Edge - Research Abstracts of Interest" and you'll share my excitement about the very real progress being made in the field.

One of our major initiatives this year is to establish a National Lymphatic Disease Patient Registry and Tissue/Cell Bank. This is a stepping-stone for an even bigger agenda. We are working each day to help mature and build a platform for what will become a sustainable field of research and clinical care for those with lymphatic disease. The tissue bank will provide researchers with essential information using patients' blood, DNA, and tissues to better understand lymphatic diseases. The patient registry will help to entice industry (biotech and pharmaceutical companies) to address lymphatic diseases and will eventually serve as a clinical trial recruitment mechanism to test new technologies, drugs, and therapeutics. This is a critical resource to advance science and medicine for lymphatic diseases and thus, LRF is marshalling every resource to assure the success of this important project.

With each month, my optimism grows that treatments and cures will be found for lymphatic disorders. As we round the corner of our fifth anniversary celebration, we hope you'll include LRF in your year-end giving plans. Please give generously by enclosing a contribution in the envelope that accompanies our newsletter. We thank you for your support.

May you be blessed with good health and happiness in the coming new year!

Wendy Chaite, Esq.
Founder and President

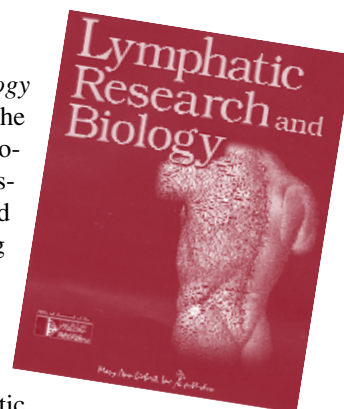


JOURNAL MATTERS

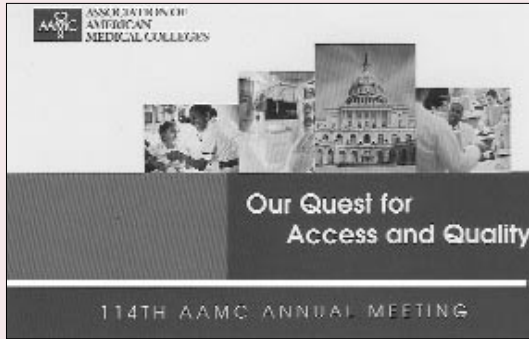
In the current issue of *Lymphatic Research and Biology* (LR&B), Amann-Vesti *et al.* describe yet another facet of the investigative link between lymphedema and heritable pathology. A strong association has been described between the presence of intrauterine and congenital lymphatic dysfunction and a variety of heritable chromosomal abnormalities, including Turner syndrome, Klinefelter syndrome, Noonan syndrome and Trisomy 21, among many others. Genetic and molecular study of such inherited, syndromic manifestations of human lymphatic vascular insufficiency has proven to be a fruitful area for basic and applied investigation into lymphatic biology. The authors present a first investigation of functional lymphatic morphology in Fabry's disease patients with lymphedema.

In Fabry's disease, the capillaries of the dermal papillae just below the epidermis are markedly dilated, and the classical description of the capillaries, venules, and arterioles includes evidence of abnormal lipid storage. The finding is provocative, when one considers the acknowledged abnormalities of lipid transport and subcutaneous adipose accumulation that accompany both primary and secondary forms of chronic lymphatic circulatory insufficiency (lymphedema).

The third issue of LR&B brings us to an exciting new threshold. Steps are underway for journal indexing to ensure international dissemination of important scientific discoveries. A wider audience will encourage researchers to submit abstracts – thereby accelerating the exchange of information and thus the pace of discovery. To submit manuscripts or subscribe to the journal, visit www.liebertpub.com/lrb.



First Ever: Medical Education Leadership Addresses Lymphatics



At the request of LRF, “*Lymphatic Biology and Disease: Is It Being Taught? Who Is Listening?*” is a subject in the discussion program of the 2003 Annual Meeting of the **Association of American Medical Colleges (AAMC)** this November. An association of medical schools, teaching hospitals, and academic societies, the AAMC works to set a national agenda for medical education, biomedical research, and health care.

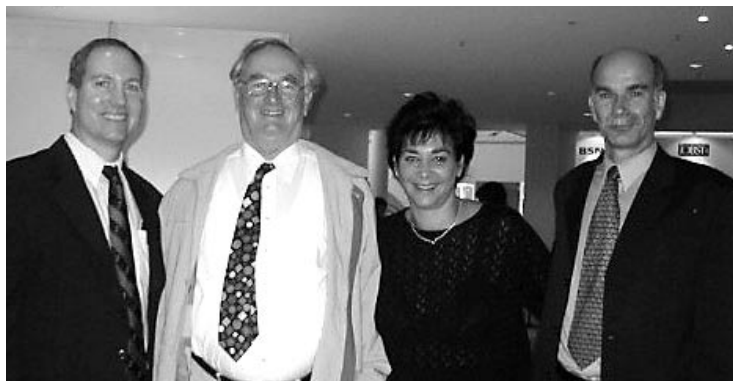
Despite the exponential research advances of the last decade that have revolutionized our understanding of lymphatic development, function and pathology, this vital biological system still receives little attention in the formal undergraduate and postgraduate medical curriculum. Patients with forms of primary and secondary lymphatic

diseases most often encounter responses from medical caregivers that reflect ignorance (‘I’ve never seen that’), disbelief (‘There’s nothing wrong with you’), or (‘There is no treatment for that’), and frustration (‘I don’t know anyone who can help you’). Accordingly, LRF has created a conference program designed to begin the process of changing this educational imbalance.

Wendy Chaite, Esq., Founder of LRF, will lead a discussion on the responsiveness by the medical educational system (lack thereof) to the needs of the patient community. **Daniel N. Granger, PhD**, Head of the Department of Physiology & Biologics at Louisiana State University Health Sciences Center, Shreveport, Louisiana, will bring his extensive experience in lymphatic biology and research to a discussion of the issues that surround pre-clinical education (“bench science”) in the field of lymphatics. **Stanley G. Rockson, MD**, Director of the Stanford Center for Lymphatic and Venous Disorders will demonstrate a successful program for introduction of lymphatic core content into the medical curriculum (“translational” – bench and clinical). **Kelly Skeff, MD, PhD**, Program Director of the Residency Program in Internal Medicine at Stanford University, a world-renowned medical educator, will lead a discussion defining the issues that would make a medical education curriculum more responsive to the evolving needs of both medical and patient communities.

LRF Presents at International Congress

Members of LRF’s Scientific/Medical Advisory Board and lay Board of Directors attended the **International Society of Lymphology (ISL) Congress** (conference) recently held in Frieberg, Germany. The Congress serves as a venue for scientists, clinicians, lymphedema therapists, and patients to interact on subjects of research and clinically relevant lymphological problems. During the Congress, **Wendy Chaite** gave an inspiring presentation about LRF during “The State of the Art of Lymphology Today: Physicians Report” Plenary Session of the World Forum for Lymphology. Special thanks to **David Mishkin** of Northwest Airlines for donating two first class tickets to enable attendance at the conference and to **Dr. Ethel Foeldi**, ISL Congress President, for her extraordinary support of LRF.



Michael Bernas (Arizona), **Terence Ryan, MD (UK)**, **Wendy Chaite** and **Neil Piller, MD (Australia)**

Participants from around the world visit the LRF booth at ISL Conference.

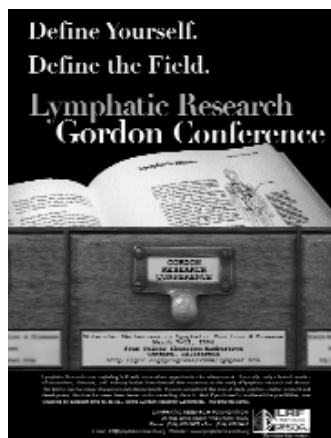


Wendy Chaite and Congress President, Dr. Ethel Foeldi share a special moment at ISL Conference



RESEARCH MATTERS

Register Now: Gordon Research Conference



An accomplishment in which LRF takes great pride is the creation of the newly established **Gordon Research Conference (GRC) Series: *Molecular Mechanisms in Lymphatic Function and Disease***. The first of such conferences will be held March 7-12, 2004, in Ventura, California. LRF Scientific Medical Advisory Chairperson, **Stanley Rockson, MD** (Stanford University School of Medicine) will serve as the Chairman of this meeting, aided by Vice-Chair, **Kari Alitalo, MD, PhD** (University of

Helsinki). The 2006 GRC will be held at a European site and will be led by Dr. Alitalo.

Gordon Research Conferences are the leading international forum for the presentation and discussion of frontier research in the biological, chemical, and physical sciences, and their related technologies. *Molecular Mechanisms in Lymphatic Function and Disease GRC* is devoted to an in-depth exploration and discussion of the emerging disciplines related to lymphatic research and biology, with special emphasis upon lymphatic development, vasculogenesis and therapeutic lymphangiogenesis (creation of new vessels resulting in alternative lymph transport). The physiology and human genetics of the lymphatic system will be explored and there will be a focus upon mechanisms of cancer metastasis and its relationship to lymphatic function and lymphangiogenesis. The meeting, held every even year (biennially: 2004; 2006; 2008), will alternate between a GRC site in the United States and Europe.

The Gordon Conference Program Committee is comprised of the Chair, Vice-Chair and the following individuals: **Daniel N. Granger, PhD** (Louisiana State University, Shreveport); **Mihaela Skobe, PhD** (Mount Sinai School of Medicine); **Geert Schmid-Schoenbein, PhD** (University of California-San Diego); **Melody Swartz, PhD** (Northwestern University); and **David Zawieja, PhD** (Texas A&M University). To view the conference program and/or to register, visit www.grc.org/programs/2004/lymphat.htm.

The biennial Gordon Research Conference (GRC) Series on *Molecular Mechanisms in Lymphatic Function and Disease* gives this embryonic field a much-needed forum for the exposure of

new concepts among a very focused group of scientists. It fosters the collaborative efforts among such individuals that are crucial to the continued advancement of this field. This conference is good news for patients and their families. It brings together researchers and physicians from a wide spectrum of disciplines to focus on the issues that have a direct impact on new therapies, new discoveries, and new cures.

GRC GORDON RESEARCH CONFERENCES

2004 MEETING ANNOUNCEMENT

MOLECULAR MECHANISMS IN LYMPHATIC FUNCTION & DISEASE

March 7 - 12, 2004
Four Points Sheraton: Harbortown, Ventura, CA

Chair: **Stanley G Rockson**
Vice Chair: **Kari Alitalo**

<http://www.grc.org/programs/2004/lymphat.htm>

TOPICS AND SPEAKERS:

Functional Tumor Lymphangiogenesis vs. Invasion
(*K. Alitalo / M. Pepper / R.K. Jain / M. Skobe*)

Molecular Mechanisms of Lymphangiogenesis
(*J. Wilting / K. Alitalo / M. Detmar / M. Karkkainen / M. Achen / W. Olszewski*)

Mechanisms of Lymphatic Metastasis
(*M. Skobe / G. Christofori / D. Bates / S. Rafii / T. Ohhashi*)

Mechanisms of Lymph Formation and Propulsion
(*N. Granger / D. Negrini / G. Schmid-Schonbein / R. Reed / N. McHale / D. Zawieja*)

Role of the Interstitium in Lymphatic Biology
(*G. Schmid-Schonbein / M. Swartz / D. Jackson / V. Hascall / L. Leak*)

Biomolecular Modulators of Lymphatic Development
(*D. Bates / G. Oliver / G. Thurston / J. Kitajewski / J. Wilting / T.W. Glover*)

Lymphatic-Related Pathogenesis
(*S. Rockson / P. Mortimer / E.A. Deitch / D. Ganem / D. Kerjaschki / S. Fishman*)

Immune Cells, Inflammation, and the Lymphatics
(*P. Mortimer / G.J. Randolph / D. McDonald / C.M. Pond / S. Miura*)

(discussion leaders in italics)

visit the frontiers of science at:
www.grc.org

National Patient Registry and Tissue/Cell Bank for Lymphatic Diseases Continued from Page 1.

Fishman, MD (Harvard-Children's Hospital, Boston); **Thomas Glover, PhD** (Michigan); **Peter Gregerson, MD** (NSLIJ-Program Director); **Lorraine Hallihan** (NSLIJ-Program Coordinator); **Leonard Kahn, MD** (NSLIJ-Chief of Pathology); **Ralph Kelley, MD** (Genzyme Corporation); **Joel Moss, PhD** (National Institutes of Health); **Jonathan Perkins, DO** (Children's Hospital, Seattle); **Stanley Rockson, MD** (Stanford); **Vivien Schacht, MD** (Harvard-Mass General); **Gavin Thurston, PhD** (Regeneron Pharmaceuticals); and **Robin Wittenstein** (NSLIJ-Chief Operating Officer).

This is a highly significant development for the patient community. A national patient registry and tissue/cell bank program paves the way for future clinical trials of experimental drugs and therapies designed to treat lymphatic disease in human subjects. Accomplishing this long-sought after goal is a major milestone in LRF's progress. We encourage all patients to participate in this important initiative once it is fully launched. Patient information is the key to finding a solution and it a critical resource to advance science and ultimately, medical care.

MAKE A DONATION IN CELEBRATION OF LRF'S FIFTH ANNIVERSARY (1998 - 2003)

RESEARCH MATTERS

The Cutting Edge – Research Abstracts of Interest

Exciting Breakthroughs in Lymphatic Research

Molecular Mechanisms in Lymphangiogenesis: Model Systems and Implications in Human Disease. Kim H, et al. *Clin Genet.* 2003 Oct; 64(4): 282-92. Within the past decade, great strides have been taken to identify a number of molecular signatures unique to the lymphatic system. To this end, the timeline for lymphatic development has now been redefined at the molecular level, and diseases associated with lymphatics now have a molecular basis. With this knowledge, the current modes of treatment for diseases such as lymphedema, lymphangiomas, and metastatic progression can now be augmented with potential molecular therapies that have currently been tested in a number of animal models.

Comparison of Dendrimer-based Macromolecular Contrast Agents for Dynamic Micro-magnetic Resonance Lymphangiography. Kobayashi H, et al. *Magn Reson Med.* 2003 Oct; 50(4):758-66. Few methods are currently available to visualize the entire lymphatic system. A method known as micro-magnetic resonance lymphangiography (MRL) was recently developed for use in mice, and certain contrast accents can be used to identify lymph nodes and lymphatic vessels. Their rapid excretion makes these compounds potentially attractive for human use.

Treatment of Postmastectomy Lymphedema With Low-level Laser Therapy. Carati CJ, et al. *Cancer.* 2003 Sept 15; 98(6): 1114-22. Two cycles of laser treatment were found to be effective in reducing the volume of the affected arm, extra cellular fluid, and tissue hardness in approximately 33% of patients with postmastectomy lymphedema at 3 months after treatment.

Genesis and Pathogenesis of Lymphatic Vessels. Jeltsch M, et al. *Cell Tissue Res.* 2003 Aug 27, 2003 [E-pub ahead of print]. An overview of the structure, function, and development of the lymphatics, with special emphasis on the recently discovered lymphangiogenic growth factors.

Lymphangiogenic Growth Factors, Receptors and Therapies. Lohela M, et al. *Thromb Haemost.* 2003 Aug; 90(2): 167-84. Recent novel findings on the molecular mechanisms involved in lymphatic vessel development and regulation allow the modulation of the lymphangiogenic process and specific targeting of the lymphatic endothelium. This suggests that the distinct phenotypes of cells in the adult vascular endothelium are plastic and sensitive to transcriptional reprogramming, which might be useful for future therapeutic applications involving endothelial cells.

T1alpha/podoplanin Deficiency Disrupts Normal Lymphatic Vasculature Formation and Causes Lymphedema. Schacht V, et al. *EMBO J.* 2003 Jul 15; 22(14): 3546-56. Studies in cultured endothelial cells indicate that T1alpha/podoplanin promotes cell adhesion, migration and tube formation, whereas small interfering RNA-mediated inhibition of T1alpha/podoplanin expression decreased lymphatic endothelial cell adhesion. These data identify T1alpha/podoplanin as a novel critical player that regulates different key aspects of lymphatic vasculature formation.

A Model for Mechanics of Primary Lymphatic Valves. Mendoza, et al. *J Biomech Eng.* 2003 Jun; 125(3): 407-14. Recent experimental evidence indicates that lymphatics have two valve systems, a set of primary valves in the wall of the endothelial cells of initial lymphatics and a secondary valve system in the lumen of the lymphatics. The model illustrates the mechanics of valve action and provides for the first time a rational analysis of the mechanisms underlying fluid collection in the initial lymphatics and lymph transport in the microcirculation.

Call For Nominations: Lymphatic Research Leadership Award

The LRF-Lymphatic Research Leadership Award recognizes individuals, including elected and appointed officials; organizations, including non-profit and for-profit corporations; foundations; and institutions that have made a significant contribution toward promoting and supporting lymphatic research, at the national, state or local level. Honorees are those who work to advance the field of lymphatic research and/or to find improved treatments and cures for lymphatic disease, lymphedema, and related disorders. The award shall be announced at the *Lymphatic Research Foundation Grants & Awards Luncheon* on Monday, March 8, 2004 at the *Gordon Research Conference: Molecular Mechanisms in Lymphatic Function & Disease*, Ventura, CA. Nominations should be in the form of a letter, accompanied by the following information, along with any supporting materials that the nominator might deem useful to the Selection Committee.

- Candidate's name, address, and phone, and organizational affiliation (if any)
- Candidate's primary contribution to lymphatic research, at the national, state or local level, to advance the field of lymphatic research and/or to find improved treatments and cures for lymphatic disease, lymphedema, and related disorders
- Nominator's name, address, and phone, and organizational affiliation (if any)

Nominations must be received on or before January 15, 2004. Letters of nomination should be sent to: Lymphatic Research Foundation, 39 Pool Drive, Roslyn, New York 11576, Attention: LRF-Lymphatic Research Leadership Award Committee; Fax: (516) 625-9410.

Call For Applications: Andrew Moisoff Young Investigator Award

The LRF-Andrew Moisoff Young Investigator Award was established by LRF in 2002 to recognize meritorious research performed by scientists-in-training within the field of lymphatic biology. The purpose of the award is to encourage excellence in lymphatic research by investigators in the developmental stages of their career. Two stipend awards will be presented at the *Lymphatic Research Foundation Grants & Awards Luncheon* on Monday, March 8, 2004 at the *Gordon Research Conference: Molecular Mechanisms in Lymphatic Function & Disease*, Ventura, CA.

Individuals interested in applying should visit us at www.lymphaticresearch.org/grantsawards/html.

Applications must be received on or before December 15, 2003. Encouraging the study of lymphatics by young investigators is a very important part of LRF's mission.

We hope to give these awards for many years to come to young people who are devoted to research for lymphatic disease. For those interested, LRF welcomes your generous memorial gifts and donations to help perpetuate the Andrew Moisoff Memorial Fund.

SUPPORT AND FUNDRAISING MATTERS



Join Our Team Be Part of a Cause That is Changing History

LRF is a unique organization. In five years it has revolutionized the state of science as it relates to lymphatic research. LRF is a catalyst for change and is powerfully effective. It is an exciting, dynamic organization that is truly making a difference.

LRF is establishing a President's Committee in the metropolitan tri-state area, including New York City, Long Island, Westchester, Connecticut and New Jersey. Members will serve as an integral part of the organization's fundraising and development team. We are looking for individuals who want to be active members and who have a strong desire to give back to the community.

If you possess good standing in the business world, recognition in the community, political expertise and clout, organizational affiliations, a strong desire to give back to the community, and/or economic resources, you can help LRF achieve its goals. Explore the possibility of joining a prestigious and enjoyable group of committed individuals who are changing history. Contact us.

LRF Gifts-In-Kind Wish List

- Airline Ticket Frequent Flyer Certificates
- Major Chain Hotel Voucher Certificates
- Printing
- Digital Camera
- Portable LCD Projector
- Office Space (North Shore, Long Island)

Please contact us if you can donate other tax-deductible gifts-in-kind and/or services.

LRF Participates in New York State Lymphedema Awareness Day

New York State Governor **George Pataki** issued a proclamation recognizing October 17, 2003 as Lymphedema Education and Awareness Day in the State of New York. **Wendy Chaite** participated in this important public awareness event with NYS Assemblyman **Michael Spano**, and key lymphedema activists, **Annie Togli**a and **Bonnie Lasinski**, both of whom were responsible for the success of this initiative. Assemblyman Michael Spano is promoting legislation to mandate expanded insurance coverage for diagnosis and treatment of primary and secondary lymphedema. He has also been instrumental in supporting legislation establishing lymphedema education and wellness programs. LRF is excited about working with key lymphedema activists, Assemblyman Spano and other New York State leaders to initiate similar support for research-related programs; plans are underway.



Annie Togli, Wendy Chaite, NY Assemblyman Michael Spano, and Bonnie Lasinski at NY State Lymphedema Awareness Day.

Ride for Lymphatic Research Bike-a-thon

LRF recently received this e-mail from **Heather Medlin** of Gastonia, NC:

My name is Heather Medlin and I am twelve years old. My mother has recently found out that she has lymphedema and she had never heard of it before. She learned about it through research on the Internet. I am interested in donating money to a research foundation and came across your website while searching the Internet. I myself cannot donate any large sum of money to you and therefore decided to organize a fundraiser. I had the idea of organizing a bike ride that people could pay to participate in. I would then send the money to you. . .

On October 4, 2003, Heather did what she had set out to do. At 12 years old, Heather raised a total of \$630 for LRF. Many thanks to Heather for caring to make a difference!

Fundraising is vital to LRF's goal of promoting research to find improved treatments and cures for lymphatic diseases. LRF encourages you to become involved in grassroots fundraising. Here are some ideas: send personal appeal letters to friends and family, hold a brunch and silent auction, run a garage sale; there are many others. LRF has produced two very informative fundraising tools, a 15 minute video and a brochure. To obtain a copy contact LRF.

For more fundraising ideas and/or support, contact Myrna Barzelatto at mbarzel@aol.com or (914) 686-0365.



Heather Medlin

*Fundraising is
vital to LRF*



Something for You and Something for Us

100% proceeds of monies raised through the *Butterfly Truly Jewelry® Campaign* benefits LRF research programs. For a donation (\$10 request), you will receive a delightful butterfly jewel pin (national symbol for lymphedema).*

The pins can be worn by everyone, not just activists. They make perfect gifts, especially for the holiday season. Won't you please support LRF and treat yourself or someone you know to this wonderful adornment?

We are also looking for volunteers to help promote this campaign. It's simple, easy and takes virtually no time. It is a great way for individuals, support groups, service providers, vendors, schools, civic associations, and others to help raise funds for research. For more information, contact Myrna Barzelatto at mbarzel@aol.com or 914-686-0365.

* Please add \$2 for shipping and handling.



Calling All Federal Employees: New York, New Jersey, Connecticut, Maine, and Ohio

CFC is the annual giving campaign promoted in every federal and military agency throughout the nation. Employees choose charities for donations via payroll deductions or one-time cash contributions. LRF is a participant in the Federal Government's Combined Federal Campaign (CFC) in the following regions: New Jersey (Essex and West Hudson); Northern New Jersey (as far south as Monmouth); New York City (including the 5 boroughs); Long Island (Nassau and Suffolk); Taconic Valley (Westchester, Putnam, Dutchess and Ulster); Western Central Connecticut (New Haven, Middlesex, Litchfield and Fairfield); Northeast Ohio; and Maine.

If you are a federal employee, LRF asks for your support via this program. If you are a federal employee and work *outside these regions*, please ask your employer's CFC coordinator whether you can designate LRF as your charity of choice. For all *non-federal employee* patients and their families, you may want to ask your postal carrier to support LRF. The CFC donation period is from September 1 to December 15. Please give generously and encourage your federal employee friends at work to donate, too! For more information, contact Myrna Barzelatto at mbarzel@aol.com or (914) 686-0365.

Shop for LRF – 2003 Champions for Charity®

The Lymphatic Research Foundation will benefit once again from the *Champions for Charity®* holiday shopping event scheduled for Wednesday through Sunday, December 3-7. The event, organized by **Americana Manhasset** in Manhasset, Long Island raises funds for over 50 New York area not-for-profit organizations. LRF will be holding a breakfast reception at **Millie's Restaurant** on December 3 to kickoff the 2003 *Champions* event. Special thanks to **Sheree Levy** and **Phyllis Lentini** for co-chairing this important fundraiser.

Participating stores of **Americana Manhasset** and **Wheatley Plaza** will donate 25 percent of pre-tax purchases to customers who designate LRF as their charity choice. LRF received over \$10,000 from the December 2002 event. Participating stores include: AnnTaylor, Athlete's Foot, Banana Republic, Barneys New York, Brooks Brothers, Burberry, Coach, Dana Buchman, Donna Karan, Escada, Estee Lauder, Fendi, Gap Kids, Georgio Armani, Gucci, Hermes, Hirschleifer's, Kate Spade, London Jewelers, Louis Vuitton, MaxMara, 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 2003 Champion Card can be completed on-line at www.championsforcharity.org.*



The Gift of Hope

A GENEROUS DONATION HAS BEEN MADE TO THE
LYMPHATIC RESEARCH FOUNDATION
 IN HONOR OF _____
 ACKNOWLEDGEMENT CAN BE MADE TO:

In loving memory of _____

The family has requested that donations in his/her memory be made to the
Lymphatic Research Foundation

LYMPHATIC RESEARCH FOUNDATION
 39 POOL DRIVE
 ROSLYN, NEW YORK 11576
 (516) 625-9675

Memorial & Gift Cards Available

Please contact LRF if you wish to send a contribution in someone's honor or memory. LRF provides gift card notification to acknowledge gifts made. Pre-printed funeral cards are available upon request. Your gift will honor someone you love and affirm the hope of a healthy future for millions suffering from lymphatic diseases and lymphedema!

I WANT TO CONTRIBUTE!

Name: _____

Address: _____

City: _____

State: _____ Zip: _____

Tel: _____ E-mail: _____

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 Acknowledgement Card of Gift to:

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.
 39 Pool Drive, Roslyn, NY 11576

THANK YOU SO MUCH FOR YOUR SUPPORT!

✂ CLIP AND MAIL ✂

MAKE A DONATION IN CELEBRATION OF LRF'S FIFTH ANNIVERSARY (1998 – 2003)



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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.”*

PUBLIC POLICY MATTERS



We Are Being Heard: LRF Advocates for Congressional Support

LRF's efforts to encourage the National Institutes of Health (NIH) to develop new research initiatives for lymphatic research and diseases took another step forward this year. Inclusion of language in the *Senate Appropriations Committee Report 108-81 for FY 2004* directs the NIH to give higher priority to this area of study and to stimulate and support basic and translational research for lymphatic research.

Lymphatic Diseases and Lymphedema: The Committee urges the NIH to consider programs that will provide essential resources to sustain this field and will stimulate the future study of the lymphatic system, with particular emphasis on the abnormal development thereof. The Committee notes that the key factors limiting such study include the lack of: (a) suitable animal models; (b) functional imaging of the lymphatic system; (c) a national patient registry and tissue bank; and (d) academic career development in the area of lymphatic diseases... The Committee encourages a broad, trans-NIH involvement in all these efforts, given that a greater understanding of lymphatic function and disease will also contribute to a greater understanding of many interrelated diseases, such as cancer, AIDS, and autoimmune diseases, and of related processes, such as inflammation and infection.

This language is important to patients as well as scientists. It calls for essential tools and resources that will ensure an exponential impact on future research:

- “Suitable animal models” will provide important specimens for study and experimentation.
- “Functional imaging of the lymphatic system” will allow doctors to see inside the patient, as well as in animal models, to the lymphatic system and to test the effectiveness of new therapies and technologies.
- “A national patient registry and tissue bank” will serve as an essential resource for scientists and as a clinical trial recruitment mechanism as new drugs and technologies develop.
- “Academic career development in the area of lymphatic diseases” will mean more young men and women will enter the field and will eventually devote their careers to the study of lymphatic diseases.

And, most importantly, research for improved treatments and cures for lymphatic disease will be interwoven within the scientific and medical community and remain viable into the future.

LRF is enormously pleased to see Congressional support grow for the Trans-NIH Coordinating Committee, created by Congress in 2001 to focus on lymphatic research and diseases as a result of LRF's previous advocacy efforts. Special thanks to **Senator Tom Harkin** (D-Iowa) and his staff for their commitment to lymphatic disease and lymphedema research.

MAKE A DONATION IN CELEBRATION OF LRF'S FIFTH ANNIVERSARY (1998 – 2003)