

SCLERODERMA

RESEARCH FOUNDATION

THE BUSINESS OF HOPE • THE SCIENCE OF MIRACLES

VOLUME 20 SUMMER 2002

It is with great sadness that the Scleroderma Research Foundation announces the passing of its founder and chairman, Sharon Monsky. At 48 years old, Sharon lived a life filled with more adventure and accomplishment than most people who have lived twice as long. After fighting a battle with scleroderma for nearly 21 years, she passed away on Saturday evening, May 11 in Santa Barbara, due to complications caused by the disease.

She was born on October 23, 1953 in Omaha, Nebraska. As a young girl, Sharon was a nationally ranked figure skater and one of the top Olympic contenders in the United States. In 1965, she was the youngest female figure skater to have ever achieved the Senior Ladies' Gold Medal Compulsory Skating Award.

Sharon met her best friend and future husband, Mark Scher, at Pitzer College, where she later received her BA in Economics, and graduated at the top of her class. As a new graduate, she

Sharon Monsky: A True Hero

October 23, 1953 - May 11, 2002



moved to San Francisco where she worked on the Pacific Stock Exchange for First Chicago and ran the most active options trading desk at the exchange – standing on a box to compensate for her petite 5-foot-1-inch stature as she barked out orders. Sharon received her MBA from Stanford University Graduate School of Business in 1980.

By 1982, she had been happily married for five years, was embarking on a career as a management consultant at the prestigious consulting firm, McKinsey and Co., Inc., and was considering starting a family. So when doctors told her that she had scleroderma and just two years to live, she was devastated.

Two decades later, Sharon had beaten the odds in every way. She valiantly battled the disease and used her time to wage a war against scleroderma. She lived twenty years beyond the doctors'

expectations and, with her gifts of charm, intelligence, perseverance, and incredible courage, dedicated her life to making a difference. That dedication to making a difference is the legacy that will, one day, save hundreds of thousands of lives.

At the time of her diagnosis, Sharon was shocked to learn that many professionals in the medical field had never even heard of her illness. Frustrated by the lack of awareness and scientific research, she put her business skills to work by founding the Scleroderma Research Foundation. The Foundation exists today as the only organization in the nation dedicated exclusively to finding a cure for scleroderma. Over time, she brought together many of

the nation's greatest scientific minds to build a unique and collaborative research program that is regarded as a model by the United States government.

Thanks to her work, more than \$14 million has been raised to date for innovative research. She believed very strongly in the Foundation's slogan, "Together we can make a difference."

Sharon was well-known across the country for her tenacity, her ability to motivate people and, most of all, her unwavering courage. Even after her passing, Sharon's battle with scleroderma continues to be fought by the ongoing efforts of the organization she began. With new fervor, the Scleroderma Research Foundation will press forward to fund and facilitate the most promising, highest quality research – and place the disease and the need for a cure in the public eye.

Sharon Monsky once said, "I'm in the business of finding a cure for scleroderma... And the best thing of all is that I'm in the

"Sharon Monsky was a true hero, not only to her friends and to those who loved her, but to the entire medical research community. She put scleroderma on the map, almost single-handedly."

business to go out of business." – Sharon is no longer with us, but her spirit and the Foundation she started – along with the scores of people who were touched by her life – will continue the fight until a cure is found.

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The Scleroderma Research Foundation is a nonprofit corporation dedicated to funding and facilitating the most promising, highest quality research and placing the disease & its need for a cure in the public eye

2002 Scientific Workshop Collaboration Brings Progress

The tenth annual workshop of the Scleroderma Research Foundation was a model of collaboration in scientific research. The meeting, held March 9-10 in San Francisco, gathered Foundation-funded investigators, members of its Scientific Advisory Committee, and expert guests to review research progress.

The San Francisco meeting reflected the Foundation's innovative—and powerfully effective—approach to research, which emphasizes collaboration and cooperation across scientific disciplines, institutions and public/private boundaries. In addition to top scientists reporting on and discussing Foundation-funded research, distinguished experts in the fields of



Chairman Sharon Monsky welcomed participants to the Foundation's 10th Annual Scientific Workshop.

vascular biology, neurology, and the private biotechnology sector participated as special guests.

Among the guests, noted vascular experts Dr. Michael Simons, Dartmouth Medical School, and Dr. Stephen Schwartz, University of Washington, were in attendance to provide insight into the vascular components of scleroderma. Dr. Paola Sandroni, Mayo Clinic, reported on the Foundation-funded study, "Evaluation of Autonomic Function in Scleroderma," and Dr. Ann Poncelet, University of California, San Francisco, reported on other neurological issues in scleroderma. Dr. Andrew Leask, FibroGen, Inc., shared his expertise on potential scleroderma therapies from the perspective of private industry. Also in attendance were two of the Foundation's new Postdoctoral Fellows, Dr. Laura Hummers and Dr. Hunter

Champion, both from Johns Hopkins University.

"What we've done beautifully at this meeting is to bring in experts who look at the world in new ways," said Dr. Bruce Alberts, President of the National Academy of Sciences and a member of the Foundation's Scientific Advisory Committee.

The dynamic, high level discussions among the scientists stimulated new ideas and directions for future research, clarifying the important next steps in the Foundation's mission to end the suffering caused by scleroderma.

The Foundation's focused research program addresses the autoimmune, vascular, fibrotic and inflammatory processes of this degenerative, often life-threatening disease. "Scleroderma is very complex," said Dr. Alberts. "It's a wonderful puzzle besides being a terrible disease. When we understand it, we'll understand more about human biology and tissue regulation."

This visionary approach to scientific research is the work of the founder and chairman of the Scleroderma Research Foundation, Sharon Monsky. She saw,



New Post-doctoral Fellows Laura Hummers, M.D., and Hunter Champion, M.D., Ph.D., attend the March workshop.

early in the Foundation's history, that collaboration across disciplines, and shared ideas and resources—from information to tissue samples—would advance the science more rapidly to a cure.

"Sharon inspires us to not only look at this disease, but helps us to do something more rational and effective on a variety of connections between basic science and clinical disease," Alberts said. "The major challenge is to make better progress by making better connections."

"Who raged more against the passing of the light than Sharon Monsky? Who fought harder for life, fighting until she had nothing left to fight with? Sharon fought for herself, for others who suffer from her terrible disease, for all of us.

She fought to let us see that every hour is a jewel; every friend a treasure, to be cherished while we still can.

She fought to let us see how to, as she would often say, "make a difference." To make a difference, she taught us all we have to believe with every fiber of our body, no matter how small. And she taught us we must never, never be ready to give up when someone says "No."

Perhaps she didn't really know this, but she taught us, taught all of us, the true secret of real happiness. It is to give freely without thought of recompense or reward.

The gifts Sharon gave us lay a burden on those of us who are scientists and doctors. We constantly ask ourselves, could we have done better, worked harder, thought more deeply to save lives? I know how Sharon would respond to that if she were here. Sharon would say in her practical, down to earth manner, "Reg, I don't see the usefulness of thinking this way. If you REALLY care about scleroderma, don't lament the past. Do something for the future...Go cure it now."

So let's do that. Let's cure this thing so that in the future, the Max's, Samantha's, and Montana's (Sharon's children) of the world can have their mothers longer; and the Reg Kelly's can keep their friends."

Regis Kelly, Ph.D.,
Executive Vice Chancellor,
Office of Research,
U.C. San Francisco



June 28, 2002

Dear Friends,

On May 11th, the Scleroderma Research Foundation suffered a great loss, one that has reverberated around the entire medical research community. Sharon Monsky, founder, Chairman and CEO of the Scleroderma Research Foundation, succumbed to her long and heroic struggle against this dreadful disease.

For all of us fortunate enough to have worked with her, Sharon was an inspiration – showing us how to live life fully, richly and gracefully. Sharon had a rare mix of energy, drive, vision, compassion, and passion. With these assets, she overcame the physical liabilities of her disease and built the Scleroderma Research Foundation into the leading non-profit institution focused on the research that will enable the cure. Her family and the Foundation – her proud achievements – mark her tremendous and exemplary life.

Sharon understood that research is a journey; one that likely would not be completed in her lifetime. She understood that the journey had to begin somewhere, that, ultimately, an understanding of scleroderma would emerge, and from there a cure would be found. Sharon assembled a world-class group of scientific advisors to help her identify the avenues to pursue. These same advisors are still committed to the Foundation, including such luminaries as Dr. Bruce Alberts, the current President of the National Academy of Sciences. Sharon also spearheaded the capital campaign to fund groundbreaking research – raising over \$14 million. A special thanks must be extended to our generous donors whose support has enabled the tremendous progress we have made. Today, the Foundation is funding a spectrum of projects in leading institutions from the University of California San Francisco to Johns Hopkins University. And, we have finally turned the corner on understanding the disease.

The Foundation staff and Board of Directors deeply feel the loss of Sharon's presence, but at the same time we want to convey to you our absolute commitment to continuing the pursuit of a cure for scleroderma. We have made changes at the Foundation to ensure our further advancement. I have been elected as Chairman and we will hire a President. In the interim, I will operate as President supported in a very large measure by the other members of the Board and the staff.

I have no illusions that I can fill Sharon's shoes. However, leveraging all the components of the organization that she built, including the scientific advisors, the donor roll, Cool Comedy – Hot Cuisine, the Board, and the staff, I look forward to helping the Scleroderma Research Foundation fulfill its mission. By way of introduction, I am currently a general partner and vice-chairman at MPM Capital, an investment firm focused on building and financing young healthcare companies. Over the past 12 years, I have been intimately involved in the creation and growth of many successful organizations and have raised the capital to support great entrepreneurs and scientists. I received my undergraduate scientific training in Molecular Biology at Princeton University and earned my Ph.D. at UCSF in the Department of Biochemistry. In 1998, I was diagnosed with scleroderma. On behalf of the more than 300,000 Americans who suffer with scleroderma, I am dedicated to our goal: We are in business to go out of business.

I speak on behalf of the entire Board of Directors in saying that I truly believe, with your sustained support, the Foundation is poised to make tremendous progress. It is clear to all that the research we have supported – and you have funded – is just now beginning to yield an understanding of this complicated disease. Our scientists and scientific advisory board are among the most celebrated in the nation and their commitment to a cure is unwavering.

As Chairman and Acting President of the Scleroderma Research Foundation, I assure you that the mission Sharon Monsky has articulated will remain our mission until a cure is found. Her legacy will carry on and her perseverance will continue to inspire us.

With warmest regards,

Luke Evnin, Ph.D.
Chairman of the Board of Directors
Scleroderma Research Foundation

Scleroderma Scramble

A Big Success

dollars toward cutting-edge research and hundreds of golfers have enjoyed every minute on the green. After the turn (9th hole), participants were treated to refreshing food and drink, and then sent back out to compete for prizes to be awarded at the gourmet dinner that immediately followed. In a post-

The Fourth Annual Scleroderma Scramble Golf Outing was held June 1st in Cleveland Ohio.

Tim Dziak and his family inaugurated this successful fund-raising event in 1999 to honor the memory of their mother, Patricia, who lost her battle with scleroderma in 1998. With regard to his tournament, Tim likes to say "it's a small thing we do." Not to us! This fundraiser has helped to raise thousands of



event interview, Tim was excited to share that the 2002 event welcomed many new participants who learned about scleroderma for the first time and enjoyed the party at the 19th hole. The Scleroderma Research Foundation would like thank Cure Advocates like Tim who really do make a difference!

You Can Make a Difference!

Cure Advocates Partner with SRF

Volunteers in the Foundation's Cure Advocate Program have raised over \$452,000 since its inception in 1996! In the last two years alone our Cure

Advocates help both to fund basic research and to further the Foundation's mission of bringing the need for a cure to the public eye. Individuals partnering with their own families and friends—using their creativity and resources—to hold events such as bowling tournaments, dinner dances, and rummage sales. They donate the proceeds to support our research efforts. From a 300-participant golf tournament held at a country

club to a simple craft show in someone's backyard, the commitment of these individuals to make a difference has played a major role in SRF's continued success.

If you would like more information about this vital program to raise awareness and funds, please contact the Foundation at (805) 563-9133 or visit sclerodermaresearch.org.

Cure Advocates help both to fund basic research and to further the Foundation's mission of bringing the need for a cure to the public eye.

Advocates have raised over \$200,000 toward critical research that has helped leading scientists to understand the mechanisms of this life-threatening disease. Cure Advocates help both to fund basic research and to further the Foundation's mission of bringing the need for a cure to the public eye.

The uniqueness of this program lies in its struc-

Special Recognition and Appreciation

The Scleroderma Research Foundation gratefully acknowledges the many individuals, corporations & foundations whose generosity helps fund our critically needed research program. The following list reflects gifts the Foundation received between October 1, 2001 and April 30, 2002.

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Mr. Ronald Carminati
Mr. & Mrs. Norman Casini
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Mrs. Ursula Fairchild
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Cure Advocate Event Schedule

Event	Date	City/State	Contact
6th Annual Ricky Clark Memorial Celebrity/Amateur Golf Tournament	10/31/02	Adairsville, GA	Vickie Goswick - rcm4hope@aol.com
6th Annual Ricky Clark Memorial Dinner Banquet/Auction/Dance at Barnsley Gardens	11/1/02	Adairsville, GA	Vickie Goswick - rcm4hope@aol.com
Wine Tasting/Dinner - In Memory of Vicky L. Zbrezny-Robbins	Fall 2002	Vermilion, OH	Kent Hageman/Sandra Kovach
Christmas Craft Raffle	Winter 2002	Rohnert Park, CA	Terry Courtney
Patricia Dziak Memorial Scleroderma Scramble Golf Outing	6/1/02	Cleveland, OH	Tim Dziak - tjdziak@ameritee.net
Summerfest '02 - Potluck/Picnic/Raffle	8/24/02	Cuyahoga Falls, OH	Margaret Kiniatis
Pinnacle Construction of Austin - Golf Tournament	10/14/02	Austin, TX	Beth Selby-Lasita
The Captain's Corner Open	6/14/02	Menesha, WI	Mary and Jack Fulton
Sandra Hazlehofer Memorial Golf Tournemant (www.bayareasclero.org)	6/21/02	Livermore, CA	Jerry Hill - jelyhill@att.net
"Scare Out Scleroderma" - Joan Kosmach Memorial Benefit	10/27/02	Houston, TX	Diane Schumacher
"Strike Out Scleroderma" - Joan Kosmach Memorial Benefit	11/2/02	Lombard, IL	Bill Kosmach/Diane Schumacher
Perona Farms Annual Dinner	1/14/03	Andover, NJ	Mary Avondoglio
September Reverse Raffle to Benefit the Scleroderma Research Foundation	9/20/02	North Royalton, OH	Diane Casini

Research Progress Update

Scleroderma Coming Into Focus

A clearer picture of scleroderma came into focus when investigators, advisors, and expert guests met in San Francisco this past spring for the Scleroderma Research Foundation's scientific workshop. With Foundation scientists addressing the major components of this complex, mysterious disease—fibrosis, autoimmunity, vascular defects, and neuropathy—important new ways of thinking about scleroderma are emerging.

Scleroderma, which is Greek for "hard skin," has long been studied from the angle of the fibrosis process, which hardens and scars tissue and, as it

progresses, leads to the serious often fatal complications of the disease. It may be true, however, that other underlying processes are contributing to tissue damage. The fibrosis process may not be aberrant as first hypothesized, but instead is the body's healing method after abnormal damage has occurred. In fact, increasing evidence suggests that scleroderma may have an underlying vascular pathology.

Emerging from the workshop is the view that the fundamental defect may be in the vascular system, particularly in smooth muscle cells that regulate the response of arter-

ies to chemical (adrenaline) and environmental stimuli (cold). For most scleroderma patients, the initial symptom is a vascular crisis. Over 95% of scleroderma patients have serious Raynaud's Phenomenon in their hands, feet, and occasionally

nose and tongue. Exposure to cold causes a decrease in skin blood flow in everyone and is a normal, protective response to reduce heat loss. However, individuals with Raynaud's Phenomenon have an exaggerated response to cold and their skin blood vessels constrict

too much and for too long. In the last year, Dr. Nicholas Flavahan at Ohio State University has uncovered the molecular mechanism of why

blood vessels constrict when exposed to cold. He has identified a natural thermometer or thermosensor in skin blood vessels. This thermosensor is a protein called the alpha2C-adrenergic receptor (alpha2C-

Growing evidence suggests that scleroderma may have an underlying vascular pathology.

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research: continued from page 5

AR). At normal temperatures, this protein is retained inside cells and is not functional; in the blood vessels, it is silent and doesn't regulate blood

that small blood vessels isolated from scleroderma skin have a selective defect in alpha2-AR activity. Even as Dr. Flavahan continues to further define the defect, a private company is conducting late stage clinical trials on a specific inhibitor for alpha2C-ARs. If the inhibitor is specific, and if it

is true that this subtype of the alpha2 receptor does mediate the hyper-reactivity to cold, the drug may prove to be a treatment for Raynaud's. It could also potentially have a fundamental impact on the progression of scleroderma.

Scientists in Dr. Antony Rosen's lab, at Johns Hopkins University, have primarily been focused on characterizing the unusual autoantibodies that are generated in scleroderma. Evidence supports the case for destruction of cells by natural "killer" cells. These cells secrete granzyme B, a protease or enzyme that hydrolyzes proteins. The protein fragments left after granzyme B digestion are seen by the immune system as foreign and antibodies are generated to these fragments. By detecting the unique cleavage activity of granzyme B, Dr. Rosen has observed signatures of granzyme B activity in scleroderma tissue, suggesting that this enzyme may be playing an important role in the disease. Dr. Rosen has also determined that granzyme B cleaves fibrillin-1, a critical component of the extracellular matrix. The matrix is the scaffolding that supports the cells of the blood vessel wall. Drs. Flavahan and Rosen, are collaborating to determine the role of the extracellular matrix and the fibrillin system in the vascular dysfunction associated with scleroderma. Indeed, decreased activity of fibrillin is associated with the destruc-

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Cool Comedy-Hot Cuisine

The Legend Continues...



Robin Williams provides comedic support at the first annual Cool Comedy-Hot Cuisine in 1987.

The Scleroderma Research Foundation is proud to announce the return of its star-studded spectacular, Cool Comedy – Hot Cuisine. The 12th annual event is scheduled for November 1, 2002 at Loews Santa Monica Beach

Cool Comedy-Hot Cuisine has raised millions of dollars for critical disease research.

You won't want to miss the mouth-watering cuisine of celebrity chefs Susan Feniger and Mary Sue Milliken, in addition to once in a lifetime live auction opportunities and some of Hollywood's brightest stars!

Cool Comedy – Hot Cuisine is the premier fundraising event for the Foundation. It has raised millions of dollars for critical disease research and garnered national media attention helping place scleroderma in the public limelight. Entertainers already scheduled to perform include some of the biggest names in the industry. For ticket information, call (805) 563-9133.



The late John Candy lends his amazing talent at Cool Comedy-Hot Cuisine.

Hotel on the Southern California coast. This year's gala, "A Celebration of Life," will honor the precious gift of life.



Bob Saget, the Olson Twins and other guests enjoy Cool Comedy-Hot Cuisine 2001

In Honor

Contributions made in honor of special people and occasions make a significant impact on our research funding abilities. The following individuals were honored between October 1, 2001 and April 30, 2002 by family members and friends who acknowledged their loved ones by making a gift to the Scleroderma Research Foundation.

Nancy Abrams
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Your continued support really makes a difference!

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Many corporations will match charitable gifts made by individual employees. If you are considering a gift, why not double your contribution by asking your employer if they offer a Matching Gifts Program?

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The Scleroderma Research Foundation is a write-in for the United Way. Don't miss this easy method of making donations to SRF when you

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Your support of scleroderma research through Cool Comedy-Hot Cuisine sponsorships is greatly appreciated and always needed to support our vital work to stay on the cutting edge of science. Since a great number of our supporters and event guests are celebrities and Fortune 500 executives, we are in a position to genuinely promote your business and create something unique that will make for a highly successful and mutually beneficial experience.

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The Scleroderma Research Foundation welcomes stock donations through the receiving firm of Merrill Lynch: 50 West San Fernando Street, 16th Floor, San Jose, CA 95113. The DTC Transfer Code is 5198. The Foundation's receiving account number is 233-07C83. To contact Merrill Lynch call Michael Craig at (800) 459-9632 or fax (408) 283-3129.

Online Giving

The SRF Web site offers a fast, secure, and convenient way to make credit card donations. Visit us at sclerodermaresearch.org to donate.

"Sharon Monsky had enormous vision and foresight, as well as the inspiration and tenacity that it takes to make the unnatural happen.

Unfortunately, the breakthroughs that we anticipate in therapies have come too late to save her life. But leading scientists have high hopes that others afflicted with scleroderma will live longer, healthier lives in no small part from a continuation of the research that would not have been started without her. Sharon has made a momentous difference, both to science and to all who were fortunate enough to touch her life.

We [the scientific community] all loved and admired Sharon. She may have thought that our nation's leading scientists were being altruistic to volunteer their time toward helping with the Scleroderma Research Foundation's goals. In fact, we returned from our many interactions with Sharon inspired by her demonstration of the power of human will over adversity — each gaining much more in spirit than we gave through scientific advice."

Dr. Bruce Alberts, President, National Academy of Sciences

Dazzling Artist Donates to SRF

Artist Paul Leasure has generously offered to create and donate an exceptional painting incorporating the theme for this fall's Cool Comedy-Hot Cuisine gala, "A Celebration of Life." Designed as a stunning rural landscape, the piece



Sample detail of Paul Leasure's artwork

will be highlighted by beautiful vistas, rose gardens, and babbling brooks from a renowned California botanical garden.

SRF Founder Sharon Monsky fell in love with Paul's work when first introduced to it two

continued on back cover

SRF Web Site Useful Tool to Learn More!

The Scleroderma Research Foundation encourages you to visit our updated Web site at sclerodermaresearch.org. In addition to a revised interface, we have redesigned the SRF research and science section to include up-to-the-minute prog-



SRF's new Web interface.

ress information and program highlights.

Additional new features include detailed sections on our Government Affairs, Public Relations, Cure Advocate, and Sponsorship programs.

Site visitors can also click on a new "slide show" link to view exciting images from past Foundation events and browse our innovative Available Resources section for a list of key contacts and other important information.

As always, we offer an easy and secure way to donate online and accept Visa, MasterCard, and American Express.

research: continued from page 6

tion (catabolism) of functional blood vessels, as occurs in scleroderma. The granzyme B mediated cleavage of fibrillin is potentially a very important finding and provides a mechanism whereby the immune system could contribute to blood vessel catabolism in scleroderma.

There remains intriguing evidence that one of the defects in scleroderma is in the transforming growth factor-beta (TGF-beta) pathway that likely contributes to scleroderma's signature fibrosis process. TGF-beta is a critical growth factor in many cellular processes including wound healing. Dr. Pascal Goldschmidt of Duke University Medical Center has found that a key protein—Smad7—which is normally responsible for regulating the activity of TGF-beta, is missing in scleroderma cells. Dr. Goldschmidt is now working to understand the molecular mechanism underlying the observed Smad7 deficiency

Early intervention could significantly extend the life span of scleroderma patients.

in scleroderma. An important question is whether the defect is in the initiation of fibrosis or in the maintenance of the fibrotic reaction.

Supporting these basic research investigations in the laboratories of the Foundation's East Coast Center is the clinical core at Johns Hopkins University, directed by Dr. Fredrick Wigley, who collaborates on several of the projects. The university's scleroderma clinic, one of the largest in the country, recruits research subjects and secures tissue and serum samples for these high level investigations. The marriage of extensive clinical facilities with



state of the art basic research has added immeasurably to the Foundation's progress in understanding the processes at work in scleroderma. The same is true for the Foundation's Bay Area Center, at University of California San Francisco, where Dr. Kari Connolly collaborates on key investigations and directs the Scleroderma Patient Registry and Tissue Data Bank, supplying tissue, serum, DNA and RNA for several Foundation-sponsored projects.

Genetics studies at Stanford University School of Medicine make excellent use of tissue samples from Dr. Connolly's program and are helping to characterize the disease. Postdoctoral Fellows Drs. Michael Whitfield and Ashley Chi are working with the new and extremely powerful tools of microarrays, which allow for the gene expression state of every gene in a cell to be interrogated. By taking cells from patients

at different sites and taking cells from patients at different stages of disease, an understanding of the genetic elements of scleroderma can be determined. Beyond characterization, these experiments should also illuminate the early events in the disease progression and may even define a genetic predisposition, so that common precursors such as Raynaud's phenomenon could be followed more closely in particularly susceptible genetic backgrounds. It is possible that early intervention in the disease process could substantially blunt the lethality or in any case, significantly extend lifespan for the patients.

A collaborative study with Dr. Connolly and Drs. Philip Low and Paola Sandroni at the Mayo Clinic was conducted this past year to determine possible autonomic nerve dysfunction in scleroderma patients. By most measures, the study showed no remarkable autonomic dysfunctions with the exception of thermoregulation. Seven out of the ten patients showed clearly abnormal results in the thermoregulatory sweat test. A significant finding showed many of the sweating deficits were in areas where the patients' skin was seemingly uninvolved or unaffected by scleroderma. This finding, coupled with other observations during the workshop that uninvolved skin is defective, raised questions about a possible systemic

New research opportunities in vascular biology hold promise for future progress.

problem above the obvious symptoms. This points again to the possibility of identifying an underlying problem earlier in the disease progression and opening up the opportunity for early intervention.

Discussions at the March scientific workshop helped clarify the critical next steps for the Foundation's program. The Scientific Advisory Committee and Board of Directors are already considering strategic new research directions in order to pursue new opportunities—particularly in vascular biology—and complement the outstanding progress the Foundation's investigators have achieved in bringing the science closer to a cure.

Cruise For a Cure Help Fund SRF Research!

Through the generosity of Seabourn and Cunard Cruise Lines, SRF is pleased to offer you the opportunity to explore the western Mediterranean's Italian isles, ancient Spanish strongholds and the glittering resorts of the French Riviera...



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On board accommodations will be in a spacious 277-square foot Seabourn Suite, complete with a five-foot picture window overlooking the sea. Experience luxurious touches such as a private on-deck massage and revitalizing in-suite baths. Gourmet Magazine recently named Seabourn and Cunard the 'Best Floating Hotels' at sea, proclaiming that they "have created a style that is often imitated, but never equaled."

continued on back cover



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Art: continued from page 12

months ago. Honored by her admiration and compelled by the cause, Paul thoughtfully offered this donation, worth an estimated \$25,000, to help raise the funds necessary to further the Foundation's mission. Upon its completion this summer, SRF will unveil the donated



Sample detail of Paul Leasure's artwork

masterpiece on our Web site sclerodermaresearch.org. Be sure to check the site often so that you don't miss an exclusive opportunity to make an advance bid on this gorgeous, original painting!

Paul's work is remarkable. His educational background in electronic engineering enhances the precise architectural perspectives and intricate details he so beautifully illustrates. This valuable piece will be available to SRF supporters and will be auctioned off at this October's Cool Comedy-Hot Cuisine event. Paul's commissioned works are in constant demand and he has been featured in numerous newspapers and television interviews. A limited edition of full-color reprints of *A Celebration of Life* are scheduled to be released prior to the Cool Comedy-Hot Cuisine event. Please contact the Foundation at (805) 563-9133 if you are interested in receiving additional information about the painting or the release date for reprints of this outstanding work of art.

Cruise: continued from page 13

Seeking More Adventure?

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