



SCLERODERMA FOUNDATION

SUPPORT · EDUCATION · RESEARCH



Stepping Out to Cure Scleroderma ♦ Minnesota Chapter Walk

2003 Annual Report



2003 Annual Report Table of Contents

Statements by the Chair of the Board and President & CEO *page 3*

Our Mission: Support, Education, and Research *pages 4-6*

2003 National Conference & Capitol Hill Day *page 7*

2003 Scleroderma Foundation Gift Report *pages 8-18*

2003 Income and Expense Statement *page 19*

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as of 12/31/03

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Elaine Furst, Chair of the Board of Directors

When I reviewed just the headlines from our website news archives, I was reminded how much the Scleroderma Foundation accomplished in 2003.

- Nearly 5,000 people participated in 22 “Stepping Out to Cure Scleroderma” walks nationwide, raising over \$600,000 to support our three-fold mission of support, education, and research.
- We received 4 stars from Charity Navigator, their highest rating.
- We produced a video, “Yoga for Scleroderma,” which proved to be extremely popular.
- We had a growing presence in national media, highlighted by a November feature in *Parade* magazine (circulation 9 million) that led off with comments by the chair of our Medical Advisory Board, and concluded with quotes by a woman with scleroderma.
- On our Capitol Hill Day, our volunteers brought scleroderma to the attention of Congress, leading to *Congressional Record* language stating the need for more scleroderma research monies.
- Lenny Moore, NFL Hall of Famer, testified before a congressional subcommittee about his experience losing a son to scleroderma, and spoke on our behalf at numerous benefits.
- Our national Gala in Boston honored Dr. Joe Korn, noted scleroderma physician and researcher, and Actelion Pharmaceuticals, maker of Bosentan, the first drug specifically targeting scleroderma lung disease.
- Our weekly e-newsletter now reaches 5,000 subscribers, our website has grown to over 1,500 pages of scleroderma information and news, we mailed out 8,000 Scleroderma Information Packets, and responded to 12,000 inquiries from patients and families, up from 9,600 in 2002.

Elaine A. Furst, RN, BSN, MA



Donna Kohli, President & CEO

Despite the financial challenges facing nonprofit organizations, 2003 was another banner year for the Scleroderma Foundation. We continued to grow at the grassroots level, by starting new chapters and support groups in parts of the country that had previously been underserved. We continued to press ahead by serving more people with our existing programs, and starting new programs such as our popular weekly electronic newsletter.

Constantly focused on our mission, we strived to tighten our belts and become more efficient in raising money and delivering our services to those who need them most. We were pleased that our efforts have earned us Charity Navigator's highest rating, 4 stars. As we move forward, we will continue to find innovative and effective ways to carry out our three-fold mission of support, education, and research.

None of this would be possible without the dedication and commitment of our volunteers. Working with the Foundation's volunteers is both a humbling and inspiring experience. I would like to take this opportunity to thank the volunteers at every level of our organization. This year was a success due to the help of our volunteers on the National Board of Directors, the physicians on our Medical Advisory Board, and the members in our chapters and support groups nationwide!

Donna Kohli



Support: Helping One Person at a Time

The Scleroderma Foundation has 25 chapters and over 160 support groups, providing a national network of local organizations to provide personal support to patients and their friends and families.

Our chapters perform the full range of our three-fold mission of support, education, and research (by helping to fund our research program, administered nationally). Larger chapters have paid staff, which is a goal for all of them.

Our support groups are led by volunteers who coordinate local patient support meetings and educational programs. The support groups report to their state or regional chapter or (if there is none) to the national office.

At the same time, the Foundation's national office employs full-time staff to answer questions by telephone toll-free at 800-722-HOPE (4673) and by email at sfinfo@scleroderma.org.

Our chapters at the end of 2003 included:

- | | | |
|------------------------------------|-------------------------------|--------------------------------|
| ■ Arizona Chapter | ■ Michigan Chapter | |
| ■ Central New York Chapter | ■ Minnesota Chapter | |
| ■ Western New York Chapter | ■ Missouri Chapter | |
| ■ Colorado Chapter | ■ Nevada Chapter | |
| ■ Delaware Valley Chapter | ■ New England Chapter | ■ Southeast Florida Chapter |
| ■ Georgia Chapter | ■ New Mexico Chapter | ■ Southern California Chapter |
| ■ Greater Chicago Chapter | ■ Northern California Chapter | ■ Tennessee Chapter |
| ■ Greater San Diego Chapter | ■ Ohio Chapter | ■ Texas Bluebonnet Chapter |
| ■ Greater Washington, D.C. Chapter | ■ Oregon Chapter | ■ Washington Evergreen Chapter |
| | ■ South Carolina Chapter | ■ Western Pennsylvania Chapter |

PROFILE Daniel Furst, M.D.



Dr. Daniel Furst answers a patient's questions after one of his talks.

Daniel Furst, M.D., Carl M. Pearson Professor of Rheumatology at UCLA School of Medicine, is equally in demand to speak at professional conferences and patient education seminars and workshops.

Dr. Furst is a pioneer in the leading-edge technique of autologous stem cell transplantation to treat scleroderma. In this procedure, suitable only for patients with serious, progressive cases of systemic sclerosis, the patient's own stem cells are harvested and later reintroduced in an attempt to recreate a healthy immune system.

The Scleroderma Foundation's chapters and support groups form a nationwide support network for patients.

Education: In Person, In Print, and Online

The Scleroderma Foundation works continuously to educate patients, their families and friends, medical professionals, legislators, and the public about scleroderma.

To get the word out, the Scleroderma Foundation combines traditional methods of education with new Internet-based initiatives.

IN PERSON

- To provide personal service to patients and others with questions, we offer a toll-free number, 800-722-HOPE, staffed full-time.

- We answer questions sent to us by email at sfinfo@scleroderma.org.

- The Scleroderma Foundation holds an annual National Conference (see page 7) for patients, where medical experts lead general sessions and workshops on the latest scleroderma treatments and research.

- We hold an annual Capitol Hill Day in Washington, D.C. (see page 7), when we visit House and Senate offices to educate legislators about scleroderma.

- Our 25 Chapters nationwide offer medical seminars and workshops, often supported by members of the Foundation's Medical Advisory Board and national office staff.

- Our 160+ Support Groups provide person-to-person education at the grassroots.

IN PRINT

- We publish a quarterly national magazine, *Scleroderma Voice*, for our members.

- We publish a wide range of medical liter-

PROFILE Our two poster children



In 2003, Samantha Murray of Massachusetts (left) received the baton of National Poster Child from Lauren Beeson of Florida. Lauren was named our new Teen Ambassador.

ature, much of it available for free download on our website.

- In response to inquiries, we mailed out 8,000 Scleroderma Information Packets in 2003.

ONLINE

- Our website, www.scleroderma.org, offers over 1,500 pages of authoritative medical information and scleroderma-related news. The site receives almost 40,000 hits per day.

- Since July 2003, we have published a weekly online newsletter of medical information and news. The Scleroderma Foundation E-Letter has over 5,000 subscribers.

- Twice a month we host an online Chat, often with guest medical experts, open to the public.

The Scleroderma Foundation uses **traditional and Internet-based** educational methods.

Scleroderma Research: The Search for a Cure

In January 2003, the Scleroderma Foundation announced the recipients of \$1.25 million in new research grants. The grants continue 15 years of leadership in funding new scleroderma research, fulfilling a vital part of the Foundation's three-fold mission of support, education, and research.

Funding new research is the Scleroderma Foundation's largest single budget item.

Our 2003 research grant recipients were:

- Laura D. Carbone, M.D., University of Tennessee, the 2003 Mark Flapan Award for the highest-scoring grant proposal, "Pamidronate Inhibition of SSc Fibroblast Precursors."
- Barry Gruber, M.D., SUNY at Stonybrook, a 2003 Marta Marx Eradication of Scleroderma Award for "Mast Cells Activate Fibroblasts in Scleroderma via Protease Activated Receptors."
- Vladimir Yurovsky, Ph.D., University of Maryland, a 2003 Marta Marx Eradication of Scleroderma Award for "Role of TRAIL in Pulmonary Fibrosis in Scleroderma."
- Keith Elkon, M.D., University of Washington, a two-year award for "The Role of Akt and the Regulation of Apoptosis in Scleroderma Fibroblasts."
- Anna Ludwicka-Bradley, Ph.D., Medical University of South Carolina, a two-year award for "The Role of Thrombin and Its Receptor on Myofibroblast Differentiation in Scleroderma Lung Fibrosis."
- Virginia D. Steen, M.D., Georgetown University, a two-year award for "Outcome Studies in Systemic Sclerosis Using the Pittsburgh Scleroderma Databank."

PROFILE Joseph Korn, M.D.



Dr. Joseph Korn receives the 2003 Founder's Research Award from Elaine Furst, Chair of the Board of the Scleroderma Foundation.

Joseph Korn, M.D., Alan S. Cohen Professor of Medicine in Rheumatology at Boston University, is one of the world's leading scleroderma researchers and clinicians.

The author of over 100 research articles, publications, and textbooks, Dr. Korn is also a physician for thousands of scleroderma patients in New England and beyond.

According to Dr. Korn, "Never has the picture been more promising for finding improved treatments for scleroderma. Scleroderma is a treatable disease and treatment will get better."

- Maria Suarez-Almazor, M.D., Ph.D., Houston Center for Quality of Care and Utilization Studies and the University of Texas Health Sciences Center, a two-year award for "Outcome Assessment in Scleroderma."
- Kenneth Warrington, M.D., University of Tennessee, a two-year award for "Anti-fibrogenic Type I Collagen-Specific Th 1 Lymphocytes in Scleroderma."

The Scleroderma Foundation is the largest nonprofit funder of scleroderma research.

2003 National Conference & Capitol Hill Day

The Scleroderma Foundation's 2003 National Conference (June 21–23) was held in Washington, D.C., in conjunction with our annual Capitol Hill Day (June 24).

NATIONAL CONFERENCE

About 300 people attended this year's event, with the theme "Stepping Out to Cure Scleroderma." The keynote speaker was Steven Hausman, Ph.D., Deputy Director of NIAMS, a division of NIH.

In addition to 33 patient-oriented workshops on a wide variety of topics related to scleroderma treatment and research, general sessions were led by John Varga, M.D., of the University of Illinois; and Arnold Postlethwaite, M.D., of the University of Tennessee.

CAPITOL HILL DAY

Over 100 SF members stayed in Washington for an extra day, "stepping out" to Capitol Hill to meet with federal legislators and their staffs. Sen. Kit Bond (R-Mo.), Sen. Patty Murray, (D-Wash.), and Rep. Kendrick Meek (D-Fla.) spoke to our group during lunch in the U.S. Senate Russell Building.



National Conference, June 22: John Varga, M.D., receives the Doctor of the Year award from Donna Kohli, SF President & CEO.



Capitol Hill Day, June 24: Scleroderma Foundation members enjoy the sunshine while walking from building to building in Washington, D.C.

Scleroderma Foundation 2003 Gifts Report

Diamond (Connie) Ascani, former national Board member and former Delaware Valley Chapter President, passed away in 2002. Connie received numerous awards, including the Scleroderma Foundation's Lifetime Achievement Award. During her lifetime she worked tirelessly to help countless patients, continuing to answer the Chapter phone herself despite declining health. With her generous bequest of \$500,000, Connie Ascani is still helping others to fight scleroderma.



Connie Ascani, 1927-2002



Creative Science for Advanced Medicine®

OUR CORPORATE SPONSORS

The good news is, we began to receive major attention from pharmaceutical companies—the big corporations that develop new drugs to treat scleroderma and its symptoms.

Why are we getting attention now? We believe there are many reasons, including:

- Our growing media presence, with mentions in major magazines, newspapers, and TV.
- Our strong advocacy program, including our annual Capitol Hill Day.
- Increased federal funding for scleroderma research, which we believe is partly due to our



In 2003, we rolled out our new, nationwide signature event, "Stepping Out to Cure Scleroderma." A total of 25 Walks were held by our Chapters and Support Groups, most of them during June, which is National Scleroderma Awareness Month. Most of the Walks were held for the first time.

We met our two goals of raising public awareness of scleroderma, and raising

funds to find a cure. Nationwide, 5,000 walkers and 680 volunteers combined to raise \$622,719.

The walkers showed tremendous spirit, rain or shine. The turnout was excellent, and we look forward to the continued growth of this event in future years.

2003 WALKS

(alphabetical by state)

- Scottsdale, Arizona
- Los Angeles, California
- Sacramento, California
- San Diego, California
- West Hartford, Connecticut
- Washington, D.C.



Ruth Cohen, 78, Worcester, Mass.



own efforts to educate federal legislators.

- The growth of our own research program, which funded \$1.25 million in 2003.

- The increasing professionalism of our website and publications.

In February 2003, the Scleroderma Foundation's Board of Directors voted unanimously to accept paid advertising in our national magazine, *Scleroderma Voice*. In line with the policies of the American College of



Rheumatology and other highly respected med-

ical organizations, we have adopted the highest ethical standards: for example, any drugs advertised in our publications must be FDA-approved. Non-FDA-approved treatments such as vitamins, untested therapies, etc. will not be advertised in our publications.

We are grateful to our first three advertisers for their generous support during 2003: Actelion Pharmaceuticals, Accredo Therapeutics, and Daiichi Pharmaceutical Corporation.

PLANNED GIVING

There is no better way to help the effort to cure scleroderma than making a planned gift to the Scleroderma Foundation, the leading nonprofit funder of scleroderma research.

For more information, please call us toll-free at 1-800-722-4673. Or visit us on the Web at www.scleroderma.org/development/supportsf.shtm.

- Geneva, Illinois
- Highland Park, Illinois
- Dartmouth, Massachusetts
- Worcester, Massachusetts
- Detroit, Michigan
- Duluth, Minnesota
- Minneapolis, Minnesota
- Omaha, Nebraska
- Leonia, New Jersey
- Spring Lake, New Jersey
- Binghamton, New York
- Buffalo, New York
- Long Island, New York
- Durham, North Carolina
- Columbus, Ohio
- Philadelphia, Pennsylvania



These Michigan Chapter walkers spelled out why they were there.



These two young Delaware Valley walkers were wet but determined.



Mary Mannillo and West Hartford (Conn.) Mayor Jonathan Harris.

SCLERODERMA FOUNDATION 2003 GIFTS REPORT

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This colorful clown gave a festive air to the Texas Bluebonnet Chapter Walk, but these two young walkers look like they mean business.

SCLERODERMA FOUNDATION 2003 GIFTS REPORT

Gifts of \$1,000 to \$4,999

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When it rained on the Tri-State Chapter's parade, these cheerful walkers donned yellow duck bills and named themselves "Team Quack."

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Gifts of \$500 to \$999

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 Dongjun Won
 World Reach, Inc.
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 Sena Yamuder
 Amelia Yaussy



These Chicago Chapter walkers enjoyed fine weather as they passed under a balloon arch.

Gifts were made in 2003 in honor of:

Alan Abram
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 Joseph Amato
 Butch Anderson
 Edwin Anderson
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 Marty Appleby
 Leticia and David Armstrong
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 Ruth Ashmore
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SCLERODERMA FOUNDATION 2003 GIFTS REPORT

Gifts Made in Honor of *continued*

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Dana Delany
Rebecca Denlinger
Marti Derleth
Brianna Dewitt
Stephanie Doctrow
Deirdre Driscoll
Diane Drolet



The Omaha (Nebraska) Support Group Walk Committee (from left): Kevin Ramplin, Jan Bosen, Barb Heenan, Pat Pfeifer, and Michael Devish.

Jack and Audrey Duffy
Steve Dumas and Family
Caroline Duvall
Keith Dykes
Marie Ann Easley
Tyler Edell
Cliff Edwards
Thomas Elich
Joel Elasowich
Family Friend
Regina Fanning
Heidi Ferguson
Mr. and Mrs. Antonio Ferri
Cynthia Fillers and Tyler Hensley
Bonnie Finn
Fox Family
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Irma Gallie
Elaine Garcia
Krissey Garthe
Pamela Gayaldo
Joyce Geiss
Keith Gilman
Valerie Giroux
Lisa L Glover
Patricia Gonos's Birthday
Daisy Gonzalez
William and Joi Goodbread
Julia Goode
Alberta Goodman
Julie Goodman
Gordon Family
Granddaughter
Grandson (new)

Kami Gray-Scott Savitt Marriage
Great-granddaughter
Karen Greenspan
Joyce Grigonis
Terry and Jackie Grogan
Gail Gruen
Ms. Gummerus
Shirl Halpern
Halpern Family
Cealianne Hamilton
Gail Hardy
Lynn Harms
Holly Hartman
Douglas Hayes
Dorothy Head
Barbara Jo Heenan
Robert Heinze
Kathie and Dick Helser
Nancy Hendricks
Michelle Hennessey-Kantruss
Joseph Henty
Trish A. Higdon
Betty Hilgenberg
Marilyn Hill
Audrey Hogan
Sara Holgate
Hollie Holmes
S. F. Holt
Stacy Hunt
Roberta Hunter
Amy L. Inbody
Patricia Irwin
K. K. Jag
Marybeth Jamison
Linda Jeleniewski
Thomas Jenkins Jr.
Kathy Kinnear and Jim Smith

Mary Joe
Vicki Judd
Robert Kasman
Joyce Kass
Heather Kaufman
Saul Kaufman's 85th Birthday
Christine Keever
MaryAnn Keisler
R. Ernestine Kennedy
Jack and Yvette Kessler's
Anniversary
Margaret Kinaitis
Jane King
Paige Kinsella
Alyson Kish
K. A. Kish
Patricia Kissell
Robin Kleeman
Joseph Korn
Jayme Kornfeld
John Koziol
Kathy Koziol
Toni Krewson
Lynn Kubal
David Kulakofsky
Kushner
Sylvia Laird
Barbara Lankosz
Bonnie Leibowitz
Bobbie Leitner
Lynne Lichter
Alton R. Little
Mario Loiacono
Lolita Lopez
Betsy Luck
Bobbie Luise
Debra Lurvey

Gifts Made in Honor of
continued

John C. Mahoney
Barbara Manning
Ruth Ann Mariano
Ruth Marino and Katie Fireovid
Rosemary Markoff
Jeanne Maselli
Clifford Mason
Mr. and Mrs. Gene Masters
Frank McBee
Bill and Jean McCall's 50th Anniversary
Tom McClure
Jimmy McCutcheon
Kay McNeill
Kaleigh McPartland
Patrick McVey
Betty Metts
Ruth Meyer
Gwenn Miller
Susan Mitchell
Carol Mondo
Donna Moore
Ronald Moore
Marian Morgan
Mabel Morodomi
Dee Moroney
Carla Mortimer
Anne Murphy
Rita Murphy
Murray Family
Samantha Murray
Rose Muscariello
Karen Mychalchyk
Karen Engel Newberger
Pamela Jean Newman
Elizabeth Hall Nguyen
Claire Niedermeyer
Frank O'Connell
Irene Mathilda Olsen-Nelson
Marsi Olson
Our Children Amy and Joseph
Lydia Page
Stephen Pahner
Jaci Pappas
Louise Parker
Maria Parker
Theresa Parulan
Ken and Natalie Pellegrino
Frances Onice Pickett
Ashley Pitts
Polinsky Family
Bethany Przestrzelski
Steve, Amy and Katie Raetz
Jack Randle's Birthday
Lori Rapsky
Corinne Reif

John Reilly
Sylvia Renda
Jack Renn
Betty Reynolds
Christine Reznick
Lail Riddle
Frank Roberts
Cathy Robnett
Geneva Roland
Lilly Rose
Ira and Judith Rosenberg
Loretta Ross
Mark and Barbara Ross
Lisa Neary Roth
Faith Rubenstein
Judy Rusin
Marion Ryan
Casandra Salazar
Hilda Sanchez
Ruth Sanchez
Dorothy Sansom
Brian and Erin Scalia
Harriet Schiele
Robert Schwartz
Nancy Scicilliano
Eva Scott
Juanita Scott
Joseph Sedoris
Phyllis Semegran
Shapiro Family
Gladys Sharp
Donna Shea
Michele Sheehan
Jane A. Simpson
Harry Singletary
Ethel Smilkstein
Barbara Smith
Shelly Smith
Shawn Smith
Harry Spiera
Norma Stanfill
Tanya Stanley
Chresanthe Staurulakis
Gayle Stephens
Betty Swartz
Barbara Sykes
Steve Taylor
Zara Taylor
Sigrid Thoem
Joe Thomason
Mary Tompkins
Kathleen Toquigne
Armelinda Tower
Georgia Tsopelas
Diann Unverdorben
Chelsea Valadez
Mary Van Neste
Alice Vandevender
Mary Vanneste



The Scleroderma Striders, runners and walkers who raise funds for scleroderma, was formed in 2003, and raised over \$26,000 their first year.

Jeanne M. Volk	Bonnie Allen
Lee Roy Ward	Elsa Allen
Sharon Waugh	Linda Amber
Ilene Wax	Anna Ammirabile
Whitney Wedel	Mr. Ancono
Wedding of Daughter and Son-in-Law	Nancy Anders
Joyce Weinberg	Edwin Anderson
Randi Weinberg	Elain Anderson
Beatrice Weiner's 80th Birthday	Elsie Anderson
Jason Weisman	Cheri Anderson
Ken Weiss	Charles Arceneaux
Carolyn Weller	Martha (Marty) Armistead
Aisha West	Pauline Celia Brooks Armitage
Arline Wetter	Dora Armstrong
Nancy Whited	Mary Arnold
Kristin Whiteman	Gertrude Arthurs
Brenda Wilkins	Akira Asano
Diane Williams	Connie Ascani
John and Kathy Williams	Dean Augspurger
John and Lynn Williams	Donald Bacon
Julie Williams	Denise Badajos
Ann Williamsen	Juanita Badgett
Ann Wilson	George Baker
Mary Lou Wood	Barbara J. Baker Sanford
Vincent Wood Jr.	Suzanne Balbo
Denise Wooten	Alba Baldi
Amelia Yaussey	Lena Baldi
Nina Young	Gus Bansmer
Scott Zemachson	Robert Barrios
Marianne Zitella	Margaret Jane Bartlett
Jeanne Zolezzi	Elaine Marie Barton
	Clarice Bartz
	John Bill Bassett
	Patricia Baxter
	Ruth Becker
	Annie Bediako
	Kathleen Belina
	Jean Bendat
	Fern Bender
	Janie Benner
	Bill Bergman
	Edith Berlin
	Arnold Sonny Berman
	Ed Berman

Gifts were made in
2003 in memory of:

Nancy Achille
Anita Adams
Linda Jayne Adams
Sandra Adams
Phyllis Adamson
Ezmee Adversalo
Loretta Albert
Catherine Alderman

SCLERODERMA FOUNDATION 2003 GIFTS REPORT

Gifts Made in Memory of *continued*

Margot Belmont	Cecil Burcham	Casey Conner	Barbara Doughty
Patricia Berner	Robert Burda	Kathleen Connor	Frances Downs
Annie Berner	Robert E. Burda	Elizabeth Connors	Lenora Dragutsky
William Bernhard	Sylvia Burgess	Beverly Cook	Linda Dressen
Sandra Kay Bernicken	Theophilus (Ted) Burke	Jessie Cook	Irene Dreyer
Antoinette Berwald	Alice Burns	Robert Corbett	Dennis Duff
Rita Besbekos	Dorothy Burritt	Melvina Corso	Charlotte Dumas
Davi Biaggio	Bonnie Busse	Joseph Costa	Betty Dunn
Timothy Bianculli	Eloise Mitchell Butler	Edward Cottier	David Dysinger
Rhoda Bier	Lyndon Byrd	Patricia Cowan	Marie Ann Easley
Lorayne Bigham	Mae Lou Byrne	Donald Cox	Lyle Easterday
Phyllis Billman	Nancy Caci	Jackie Cox	Carla Ebright
Louis Binder	Kathleen Caikaukas	Phyllis Crandell	Lenore Edelman
Nancy Bissinger	Regina Callahan	Thomas Craney	Robert Edmunds
Dr. Mark Bissonnette	Jeff Cameron	Virginia Rebecca Crist	Margaret Egan
Peter Blaser	Margaret Cameron	Sophia Critcher	Irene Elhard
Gertrude Bluestein	Sharon Cameron	Engeborg Crook	Jane Elsaesser
Ruth Blumberg	Albert Campanaro	Ada Cucchino	Maria Rosalia Enne
Eugess Bodin	P. Grey Cane	Norma Cunningham	Marie Margaret Enos
Joanne Bologna	Michael Capello	Renee Cutler	Susan Ericson
Connie Bommarito	Marilyn Carminati	Alba Danesi	Kay Etow
Joseph Bommarito	Carol Carpentiere	Carol Ann Danforth	John Evans
Peter Rene Bonnette	Larry Carr	Gerogina DaPena	Beverly Faino
Helen Booky	Vincent Caruso	Tony D'Asero	Elizabeth Falkner
Jean Booth	Maurice Caruthers	Jean Davis	Joseph Peter Faran
Tom Booth	Mildred Cary	Jerome Davis	Philip Fasone
Gertrude Borenstein	Carol Castillo	Max Davis	Mr. Favole
Raymond Bottano	Fannie Cavadias	Joyce Janette Davis	Dolores Feany
Phyllis Bousquet	Lucy Cera	Vivian De La Torre	James Fecko
Karen Bradley	Florence Chait	Vera De Mayer	Ella Mae Fee
Thomas L. Bragg	Ratna Chandrasekhar	Kathleen Dean	Josefa Feilmeier
James Brandoline	Jane T. Chang	Donna Deaton	Jennie Fichtenbaum
Beatrice Brandon	Val Chapman	Mrs. Dedulio	Sally Fields
Bob Bray	Terry Chappell	LaDon DeFreece	Leon Fine
Orville Bray	Lydia Marie Chassells	George DeGrange	Sylvia Finegan
Marie Brennan	Gloria Chernoff	Bonnie Delange	Dolores Fiordiliso
Nelda Bricker	Robert Chilson	Vivian Delatorre	Ann Fiorenza
Dan Lee Bristow	Virginia Chowdhry	Barbara DeMark	Doreen Fitzgibbon
Beverly Brito	Phyllis Chrismer	Cecile Denham	Norma Flammmond
Singleton Broadus	Robert Christie	Troy Dennis	Pearl Fleischman
Debbie Brockhoff	John Ciancotti	Olivia DeRosa	Barbara Fletcher
Mary Brooke	Nancy Ciccotelli	Livia DeRosa	Florence Fletcher
Karen Brooks	Diane Circelli	John Derse	Velma Flowers
Eileen Brown	Geraldine Ciszon	Rose DeStefanis	Ruby Floyd
Helen Brown	Nancy Clement	Joyce Dettmers	Donna Ford
Laura Brown	Cheryl Clifford	Phyllis Devine	Jerry Fox
Rose Brozowski	Sharon Clifford	Don Dickey	Marianne Fox
Sharon Bruckman	Bernice Clifford	Sandra A. Dietrich	Melvin Fox
Helen Brugman	Goldie Cohen	Vita Dilluvio	Filomena Frabotta
Jay Brukman	Michael Cohen	Fred Dimeo	Aunt Freda
Martha Brun	Sonia Colen	Jeanette Dimick	Yvette Fredette
Robert Bryant	Phyrne Jones Coil	Mary DiTerlizzi	Mrs. Freedman
Loyolu Buckley	Emily Collan	Edith Doerfler	James Freeman
Harold Buell	Robert Collin	Linda Dolce	Nathaniel Freeman
Geraldine Buford	Ernest Collins	Dorothy Donovan	Rodger Fretz
Marie Buksa	Josephine Colon	Kenneth Dople	Robert Fuller
	Deborah Comb	Roseann Dormmann	Dorothy Funderburke
	Debbie Comer	Joyce Dorsey	Theresa Funk
	Marta Compton	Fawzia Dossani	Lois Furlong

SCLERODERMA FOUNDATION 2003 GIFTS REPORT

Gifts Made in Memory of

continued

Kim Gaiser	Bob Guerin	Vi Horan	Frances Kodrick
Mattie Maness Gaither	Margie Gunter	Celia Horn	Penny Jean Kolb
Irene Galecki	Judy Gusinda	Michael Houghton	Grace Konisiewicz
Emilia Gallagher	Mary Lou Guyer	Chuck Howard	Francis Kotchkowski
Helen Gallagher	Carolyn Gwin	Al Hoyle	Joyce Kozlowski
Margaret Gallagher	Maclay Gwinn	Margaret Hoyle	Julia Krasovec
Helen Gallas	Robert Haake	Theresa Huck	Jo-Ann Kretzinger
Betty Gambon	Barbara Tuttle Hale	Sally Ann Huffman	Norman Kristic
Ruth Gardner	David Hall	Hazel Hughes	Marilyn Kristie
Barbara Garrett	Bob (Leroy) Hall	Mary Jane Hummell	Virginia Krolack
Dorothy Gates	Col. & Mrs. Charles E. Hall	Marilyn Hunt	Joan Kroutil
Pat Gay	Richard Hamilton	Zella Huntbatch	Richard S. Krutel
Kathleen Geaeager	Joan Hammond	Diane Hurd	Lynn Kubal
Angela Pressly George	Sharon Hammons	Sally Hutchins	Barbara Kwiatkowski
Kathleen Georger	Albina Hansis	Jeannie Ito	Sharon Laberge
Helen Gerd	Ruby Hanson	Jennifer Christine James	Mildred LaConte
Treva Germann	Dee Hardy	Mary James	James Lahr
Luisa Paoli Getty	Tressie Harpool	Thomas Jenkins	Sylvia Laird
Annell Gey	Charlene Sue Harrer	Sierra Jenkins	Fred Lambeck
Donald Gibb	Beth Hart	Thomas J. Jenkins	James Lannon
Manolo Gil	Harold Hart	Elaine Helen Johns	John Lansker
Judy Giles	Frances Harter	Janice Johnson	Kerry Adair Larkin
Theresa Gill	Judy Haslinger	Roger Johnson	Robert Lavallee
Irene Gillis	C. Virginia Hatcher	Marcia L. Johnson	Anne Lavelly
Esther Mae Glunt	O. W. and Hoyt Hatfield	Mildred I. Johnson	Jackie Lawson
Daai'ya Salaam Gola	Delores Haughey	Linda Jones	Genevieve N. Lechliński
Irving Goldstein	Ellen Hawkins	Martin Joseph	Steven LeClaire
Harriett Goldstein	Phyllis Hawkins	Jane Joyce	Christian Lee
Isabelle C. Gomez	Theresa Hawry	Andrea Jurczyk	Donald Lee
Rosette Gonzales	Deanna Haws	Carolyn Kakish	Harold Lee
Rebeca Gonzales	John Hay	Linda Kale	O. Sue Lehman
Julie Goodman	Bart Hazlett	Karen Karl	Tom Lehman
Ruth Gorelick	Elaine Heath	Joyce Kass	Hilda Leikam
Susan Goroski	Robert Lee Heavисid	Kazuo Kato	Rose Leitman
Marge Gorrell	Roy Hendricksen	Alvin Katz	Vivianne Lemaire
Barbara Gottfried	John Henry	Allan Kaufman	Mercy LeMay
Bruno Gotthardt	Faye Henschel	Phyllis Kaufman	Ethel Lemerond
Joan Gottstein	Edna Herbert	Joanne Kay	Robert Leonard
Crystal Graffunder	Susan Herman	Marian Keller	E. Carwile Leroy
Robert Graham	Loretta Hermann	Sid Keller	Eleanor Leslie
Thomas Graham	Sheila Herstein	Jeanne Kelly-Callahan	Helen E. Lever
Carol Grant	Art Heunemann	Larry Kenny	Jeanne Leverence
Maurice Grassia	Paul Hickman	Ronelva Kimber	Paul Levine
Al Graves	Naomi Hicks	Rebecca Kinard	Manny Levine
Marie LaBella Graziano	John Hilbe	Jack Kindt	Alan Lewis
Camille Greco	Anna Hinerman	Diana King	Carla Lewis
Jackie Green	Vicki Lynn Hintz	Francis King	Leslie Lewis
Lillian Green	Mary Hockman	Kathleen King	Tom Lewison
Janis Green	Donna Hodge	Loren King	Genevieve Lichliński
Dr. Roger Greenlee	Margaruite Hodnick	Lou Ann King	Lynne Lichter
Joyce Grigonis	Mary Hogan	Patricia Bendall King	Martha Liebold
Alice Griner	Ronald Holfield	Mary Kinnear	Kathy Linder
Leona Grossklas	Mildred Brant Holland	Benson Kirchoff	Linda Lindner
Beverly Grossman	Camille Holland	Kayoi Kitajima	Paul Linquist
Laura Gruen	Cynthia Holley	Ann Kleban	Edna (Iggy) Little
Josephine Guarino	Dorothy Holley	Catherine Kline	Shawn Livesay
	Josh Holley	Charlsie Knedlik	Loraine Loid
	Susan Holt	Marvin Knell	Rita Lombardo
	John Hooker	Tammy Knodel	Patricia Loper

SCLERODERMA FOUNDATION 2003 GIFTS REPORT

Gifts Made in Memory of

continued

Marcos Lotufo	Shirley McKee	Don Neager	Frances Onice Pickett
Marcia Lough	Cambell McKenna	C. Connors Negron	Reno Piel
Tiffany Louvins	William McKenna	Evelyn Neildosser	Carmela Pirillo
Vivian Deda Love	Carole McKenzie	Clara Nelson	William D. Pischke
Marie Lozier	James Mckno	Elizabeth Nelson	Mary Jeanne Poirier
Karen Luedke	Doris McLaughlin	Irv Neverman	MaryAnn Polacik
Carmela Lufrano	Kay McMahon	Karen Engel Newberger	Jerry Pollatos
Genevieve Luhlinsky	Michael McNulty	Gloria Newlin	Myrtle Presson
Juanice Lumpkin	Thomas McVaugh	Bonnie Newman	Frank Profeta
Junieve Lund	Jean Mitchell Mellish	Pamela Jean Newman	Antoinette Proto
Thomas Lusby	Doreo Mellusi	Sandra Nicholas	Vincenza Puccio
Barbara Lusk	Richard Mendonca	Valerie Niles	Donna Dinkle Pullman
Winnifred Ann Lydon	Martha Mervis	Peter Noeth	Carlo Quartara
Dorothy Lydon Britt	Rudi & Peter Meyer	Valerie Noles	Linda Quash
Robert Mack	Ruth Meyer	Julia Norman	Lena Raduege
Margaret Mackey	Tim Meyer	Ruth Oettinger	Rose Rafferty
Saul Maidens	Rick Meyers	Lucille Olafson	Barbara Railey
Virgil Maier	Arthur Meza	Larry Oliver	Suzanne Rakoff
Martin Majestic	Eve Milani	Letricia Ann Oliver	Addie Emma Ramplin
Sozanne M. Malbo	Ann Miller	Sharon Olson	Wesley Randolph
Frank Mallin	David Miller	Geraldine O'Malley	Jacob Raphael
Joyce Mandel	Gwenn Miller	Helen O'Neal	Manny Raposa
Rita Manganaro	Hortense Miller	Phyllis O'Neill	Jean Rath
Gwen Mangum	Jean Miller	Joanne O'Quinn	Mary Raymond
Margaret Manion	Louis Miller	Mildred Orschell	David Reed
Thelma Manning	Regina Miller	Kathie Ortiz	Ellen Reed
Inelle Manning	Lillian Millstone	Morema Oseguera	George Reed
Mary Jane Marbut	Audrey Mimms	Bill Owen	David Reid
Irene Marcinkiewicz	Josephine Minutello	Diane Pace	Jessica Reif
Herman Margulies	William Raymond Mitchell	Robert Padilla	Sally Reiken
Jamie Marie	Flora Modica	Lois Palagi	Mildred Ray Reissener
Daniel Mark	Nancy Moltz	Mary Palino	Jack Renn
Valentine Markusic	Sonny Monosoon	Rose Paloolian	Irwin Reyer
Cindy Martin	Dianne Montemerlo	Sara Pane	Donald Rhoads
Shirley Martin	Don Monzingo	Maria Rosa Panetta	Guido Riccioni
Eugene Martinitz	Donna Moore	Eva Parelli	Robert Rice
Emma Jane Maschino	Les Moore	Geneann Parenti	Anthony Ricevuto
Jeanne Maselli	Lidia Moore	Josephine Parisi	Doris Richards
George Massari	Willa Moore	Shirley Parker	Mrs. Nelwyn Richardson
Marion Massey	Dorothy Moore	Anastasia Parthenis	Peter Ricketts
Ruth Mathews	Barbara Jean Reese Morgan	Kay Passaneau	Lail Riddle
Laurel Kristine Mathis	Maurine Morgan	Madeline Paszkiewicz	William Riechmann
Mabel Mathis	Elizabeth Morris	Glenda Pate	Mary Jo Rigby
Alda Matroni	Patrick Mortell	Ona Payton	Mary Riley
Laurel Kristine Mattis	Pat Morton	Anette Payton	Virginia Riley
Lori Mattos	Andrew Mosca	Steven Pearlman	Quadalupe Rios
Jill Mayer	Ida Dolly Moschella	Grace Pedrosa	Beverly Rivkin
Ruby McCall	Morris Moskowitz	Edward Pelic	Bob Roberts
Richard McCarty	Lucille Mulford	Rudolfo Pena	Lillian Roberts
Dorothy McClendon	Diane Munro	Linda Pendergast	Barbara Robertson
Ida Mae McClure	Ted Murcheck	Shirley Perkins	Sharon Robertson
Joan Bury McCollister	Elizabeth Murphy	Steven Perlman	Priscilla Rock
Joan McCollister	Jack Murphy	Jerry Perry	Marlyn Block Rodgers
JoAn McDaniel	Kevin and Anne Murphy	Charles Petersen	Arlene Rodrigues
Elizabeth McDonald	Linda Murphy	Mary Peterson	Helen Rodriguez
Clare McGrail	Rose Muscariello	Norma Petz	Geneva Roland
	Ricardo Myers	Marie Phillips	Linda Roller
	Marian Naiditch	Maureen Pickard	Stanley Romero
	Hugh Naylor	Howard Pickersgill	Frank Rondante

SCLERODERMA FOUNDATION 2003 GIFTS REPORT

Gifts Made in Memory of *continued*

Janie Rosalez	Beverly Seibert	Mary Stewart	Frankie Webb
Mr. Rosen	Pauline Seid	Doris Stiles	Ruth McFadden Webb
Elayne Rosendall	Elaine Shaheen	Doris Stine	Lillian Webb
Heidi Rosenfield	Suzanne Shahun	Helen Stokes	Elizabeth Weber
Tim Rosenthal	Carol Shannon	Del Stoltzfus	Jeanne Weigel
Ilona Rosner	Eva Shapiro	Donna Stone	Barbara Welch
Mark Rosner	Janet Shaw	Sylvia Stro	June Welch
Salamon Rosner	Ann Marie Shea	Phyllis Stroup	Sheryl Welch
Diane Ross	Muriel Sheffel	Thomas Stucky	Mary Welsh
Jean Ross	Kathy Shetter	Debbie Hulbirt Summers	Shelly Westbrook
Jan Ross	Martha Shirk	Mary Swirka	William Wetzel
Barbara Rosswaag	Monte E. Shomaker	Sybil Swirsky	Mary Jo Whaley
Arlene Roth	Margaret Shuart	Max Swita	Russell White
Edward Rudnick	Lora Bontempo Shuchat	Ethel Sytsma	Richard A. White
Ann Ruggiero	Alma Sifuentes	Dorothy Syzdzak	Donald Whitfield
Doris Rundberg	David (Chico) Silva	Anthony Tarentino	Joan Widmar
Gary Rundle	Joe Silva	Arthur Tarlow	Kathleen Wielt
Kelly Russell	Clarence Simmons	Gertrude Tattelbaum	William C. Wienkop
Edith Rice	Monica Simpson	Laurel Terry	Arla Wiest
James Ryan	Kimberly Singletary	Constance Thim	Joan Wilander
Robert Ryan	Barbara Siniski	Crysteen Thomas	Brenda Wilkens
Eldon Sabin	Christine Skopos	Dorothy Thompson	Dorothy Wilkerson
Ruby Sackman	Nadia Skorohod	Ruth Thompson	Putsye Wilkins
Ruby M. Sackman	Patricia Ann Slade	Axel Thyrum	Brenda Wilkins
Richard Sacoco	Michael Slonim	Dora Tievy	Rita Wilkinson
Steven L. Sagen	Marilyn Smith	Connie Tindal	James Williams
Barbara Sanford	Mary Smith	Debbie Tipton	Joyce Williams
Dorothy Sansom	Wayne Smith	Patty Trierweiler	Deborah Williams
Marion Saule	Wanda Smith	Betty Trimble	Marie Williams
Suzanne Saupp	Lee O. Smith Sr.	Deborah Trol	Jean Williamson
Beverly Saylor	Shirley Smoot	Judith Truxillo	Nora Lee Wilson
Patrick Scarantino	Josephine Solorzano	JoAnne Turton	Ronald Wilson
Ted Schaeffer	Max Sonkin	Dr. Geraldine Sullivan Tyler	Tevi Winthrop
Betty Schafer	Gloria Sonnier	Vicki Vaccaro and	Rachel Withers
Irene Schaffer	Marjorie Spain	Kevin, Michael & Brian Exten	Joan Wlodarski
Dolly Schaub	Eva Sparavalo	Arleen Vail	Debbie Wolfman
Muriel Scheffel	Carole Spaugh	Mirna Valentin	Joyce Wood
Matt Schenone	Wilma Spear	Joseph Valentino	Tanya Wood
Kathleen Schetter	Ray Spencer	Leona Vanek	Donald Woodruff
Giuseppe Schettino	Colleen Spencer	Tom Van Holstyn	Betty Woods
Kathleen Scheufele	Joseph Speranza	Jacqueline Vasselin	Jack Wright
John Schon	Sidney Spielvogel	Juanita Vasselin	Kathleen Wright
Robert Schreiner	Luciano Spina	Rachel Ver Steegh	Gloria Yahn
Lou Schuelke	Daisy Spitz	Joyce Anne Victor	Carole Yankowski
Albert Schultz	Lois Sprayberry	Joyce Victor	JoAnne Yoney
Donna Schultz	Royal Edward Spurlark	Jenny Vitale	Diane York
Adama Schulz	James Stallworth	Jane Vitangeli	Vicki Jordan Yost
Fiorino Sciaini	Kathie Stamper	Barbara K. Vitelli	Daniel Young
Ann Sciascia	Isabel Stange	Stephanie Vostrizansky	Peggy Young
Hila Scott	Marilyn Stanton	Georgia Waddell	Gerald Yunker
Juanita Scott	Irene Statz	Ruth Wallins	Yolanda Garza Zammiello
Larry Scott	Norma Stebbins	Thomas Walsh	Shirley Zanco
Naomi Scott	Ruth Stecker	Peggy Clany Wanner	Dolores Martin Zarzana
Joseph Sedoris	Ann Stein	Lee Roy Ward	Rosalie Zerman
Irwin Segal	Marilyn Stein	Roy Ward	Grace Zile
Darlene Segerstrom	John Stelly	Sallie Ware	Al Zimmerer
	Elizabeth Stephenson	Phyllis Watt	Beverly Zimmerman
	Ronica Stern	Shireen Watt	Donna (Sherman) Zorici
	Izetta Stewart	Leita Mae Weaver	Mary Zorzi

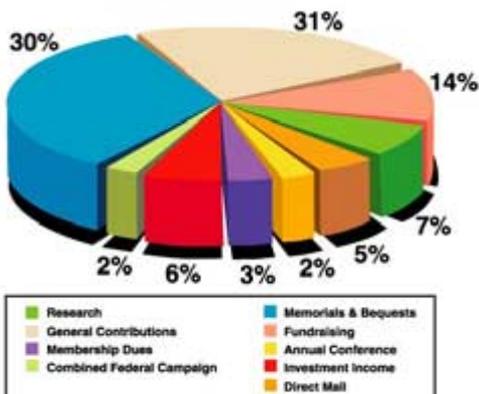
2003 Income and Expense Statement

	Unrestricted	Temporarily Unrestricted	Total	%
INCOME				
Research	\$58,490	\$178,386	\$236,876	7%
Memorials and Bequests	582,265	486,384	1,068,649	30%
General Contributions	1,047,977	36,201	1,084,178	31%
Fundraising	466,402	13,686	480,088	14%
Direct Mail	175,457	0	175,457	5%
Membership Dues	108,683	0	108,683	3%
Annual Conference	70,182	0	70,182	2%
Combined Federal Campaign	69,923	0	69,923	2%
Investment Income	227,284	0	227,284	6%
Net Assets Released from Restrictions:				
Satisfaction of Program Expenses	1,269,890	(1,269,890)		
Total Revenues and Other Support	4,076,553	(555,233)	3,521,320	
Net Realized and Unrealized Loss on Investments	<u>885,095</u>	<u>0</u>	<u>885,095</u>	
Total Revenues	\$4,961,648	(555,233)	4,406,415	100%

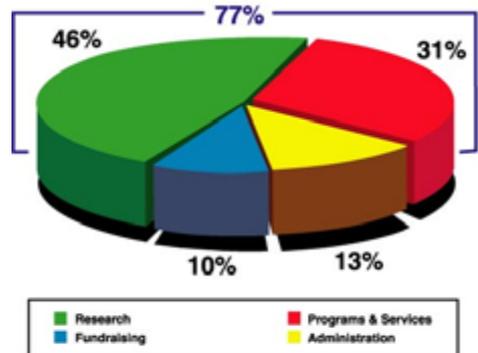
EXPENSES

Support, Advocacy, and Education	\$1,279,155	\$0	\$1,279,155	31%
Research	1,942,538	0	1,942,538	46%
Fundraising	404,655	0	404,655	10%
General and Administration	<u>559,465</u>	<u>0</u>	<u>559,465</u>	<u>13%</u>
Total Expenses	\$4,185,813	0	\$4,185,813	100%

2003 Income



2003 Expenses





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978-463-5843 ♦ Fax 978-463-5809
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Website www.scleroderma.org