

AIDS Law Project helps Altoona man get new liver after Medicaid denies coverage

When William Jean Gough, 46, of Altoona learned he needed a liver transplant to save his life, he thought the biggest obstacle would be a donor match.

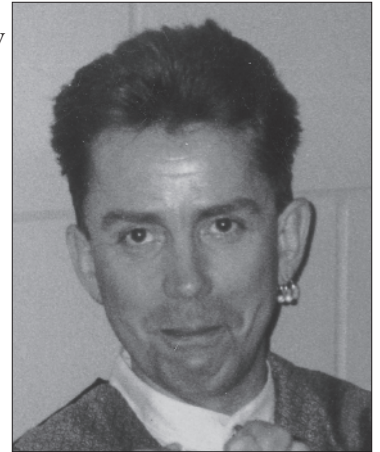
But then a devastating letter arrived: Medicaid refused to pay for Jean's surgery because he was HIV-positive.

Jean (*pictured at right*) had been diagnosed with hepatitis C in 1996. While Jean's HIV was under control through anti-retroviral therapy, his hepatitis had severely damaged his liver. By summer 2003, Jean's hepatitis was so advanced that he suffered from end-stage liver disease and was expected to die within a year without a liver transplant. In August, Jean was evaluated at the University of Pittsburgh Medical Center's Thomas E. Starzl Transplant Institute and was considered a strong candidate for transplant surgery.

But in late September, the Pennsylvania Department of Public Welfare's Medicaid program denied coverage for the procedure, interpreting a 1991 departmental policy statement on kidney transplant to mean that someone with a "severe life-limiting condition" is not eligible for a transplant.

Crushed, Jean appealed the decision — and called the AIDS Law Project of Pennsylvania for help. "I started researching medical journals right away," recalled AIDS Law Project Managing Attorney Yolanda French Lollis, who fought the case with an attorney from Lambda Legal in New York. "The medical literature clearly shows that people with HIV can successfully receive transplanted organs without heightened risk."

Since the advent of anti-retroviral therapy to treat HIV disease, dozens of reports and case studies have concluded that organ transplant should not be denied to people with HIV, Yolanda said.



On Dec. 2, Administrative Law Judge Bernadene Kennedy ruled that Medicaid must pay for Jean's liver transplant, stating that "a severe life-limiting disease is an illness that no longer responds to curative treatment." Jean's HIV had responded well to medication for years, the judge said, and his most imminent life threat was hepatitis C, not HIV. The judge cited Jean's work as an AIDS advocate and said he could live 30 more years with a liver transplant, adding: "It is reasonable to expect that [he] will make many more valuable contributions to society."

Jean underwent successful liver-transplant surgery at the Starzl Institute on March 16. He is currently recovering in Pittsburgh.

"This case challenges the way insurers view people with HIV," Yolanda said. "After this case, insurers can no longer say in good faith that they didn't know better."

Board of Directors

Sandra L. Thompson, *President*
Bruce Flannery, *Vice President*
Patricia S. Kim, Esq., *Secretary*
Kimberly Y. Chainey, Esq., *Treasurer*

Gregory M. Fliszar, Esq.
W. J. Freshwater, CPA
Sean M. Halpin, Esq.
Joyce Hamilton
Nicholas Ifft, MD
Geraldine Jones
Gregory L. Liacouras, Esq.
Frank M. McClellan, Esq.
W. Gillies McKenna, MD
Bryn L. Michaels, Esq.
James Thompson
Kahiga Tiagha, Esq.
Sara Velazquez, Esq.

Ronda B. Goldfein, Esq.
Executive Director

Staff

Toni Anastasia
Brenda Canales, Esq.
Lakeya Chambers
Rodney Cunningham, Esq.
Yolanda French Lollis, Esq.
Ngozi Ibeh
Cathryn Miller-Wilson, Esq.
Asaf Orr
Iraisa Orihuela-Reilly, Esq.
Darrianna Proctor
Derrick Russell
Sue Scotese
Arlene Vasquez

Martha McDonald, *Editor*
Laz Manou, *Designer*

1211 CHESTNUT STREET
SUITE 600
PHILADELPHIA PA 19107
TEL 215.587.9377
FAX 215.587.9902
www.aidslawpa.org

MESSAGE FROM THE EXECUTIVE DIRECTOR

In this issue, we introduce a new feature, “Navigating the System.”

As the drawing that accompanies the article suggests, trying to weave through the myriad avenues and byways of governmental and healthcare bureaucracies can be like trying to navigate a gondola with roadblocks at every turn. For someone living with HIV/AIDS, the gondola may seem to be made of lead and the byways quicksand.

Here at the AIDS Law Project of Pennsylvania, we have a staff of experienced and able navigators to help clients move more swiftly toward their goals.

The stories we will tell in “Navigating the System” are not necessarily the most shocking or the most newsworthy. A story told there probably would not be selected as a cover story, like this issue’s extraordinary report about an Altoona man whom we helped to get a new liver. That victory clarified the rules for Medicaid, and also proclaimed that people with AIDS have futures and can keep making valuable contributions to society.

For clients whose lives are improved by a roadblock removed or a heap of quicksand tossed aside, our efforts are just as meaningful. After all, navigating the system constitutes the nuts and bolts of our daily work at the AIDS Law Project. For every William Jean Gough who gets a new liver, we serve thousands of Pennsylvanians who otherwise might not have the ability or the energy to get health care or housing or financial assistance.

We pledge to continue helping folks navigate the system, whether their stories make the front page or not.



A handwritten signature in cursive script that reads "Ronda B. Goldfein".

This newsletter is lovingly dedicated to the memory of AIDS Law Project Board Members Michael Greenberg and Jonathan Lax, Intake Advocate Arnold Jackson and VISTA Volunteers Gary Bailey and David Bertugli.

If you know someone who would like to receive a copy or need to let us know of an address change, please call 215.587.9377

Good Counsel is published seasonally by the AIDS Law Project of Pennsylvania for our friends, volunteers and colleagues committed to protecting the rights of people with HIV and AIDS. The AIDS Law Project provides free legal services to nearly 1,800 people with HIV/AIDS each year, many of whom have nowhere else to turn for help. We help people navigate the legal system, the welfare system, the housing system and the worlds of public and private insurance. We provide education and training to thousands of professionals who work with people with AIDS.

City gets reprieve from names reporting

In March, following an extended standoff between city and state health officials, the Pennsylvania Department of Health granted the Philadelphia Department of Health a one-year waiver from the regulatory requirement of name-based HIV reporting. For the next year, the city will report HIV cases to the state using code-based identifiers, which maintain anonymity, while the rest of the state will continue to use the name-based reporting system begun in October 2002.

Rejecting the name-based system because of privacy concerns, Philadelphia had refused to supply data to the state health department. Because Philadelphia has about 50 percent of Pennsylvania's HIV cases, the stalemate jeopardized the state's information-gathering process.

Under the agreement, the city's code-based reporting program will be evaluated after the first year for accuracy, confidentiality and effectiveness, including demonstrated linkages to care,

before the program is made permanent. The year-end evaluation must "occur through an outside medical record audit performed by a contractor whose costs will be paid by [the city]," the agreement states.

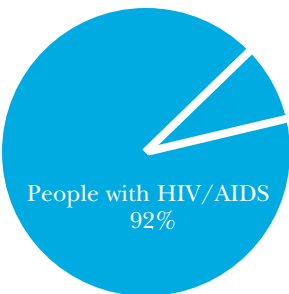
The AIDS Law Project of Pennsylvania supports the decision and hopes the code-based system can be expanded statewide, once it is shown to work in Philadelphia.



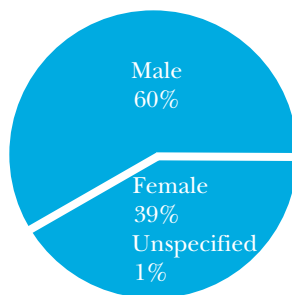
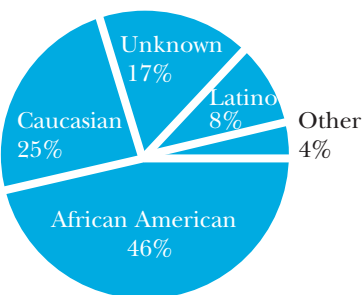
Kline & Specter donates \$50,000 to AIDS Law Project

Kline & Specter, P.C., a personal-injury law firm representing catastrophically injured people and their families, has made a \$50,000 donation to the AIDS Law Project of Pennsylvania. "We feel strongly about helping people who need vigorous advocacy," said Shanin Specter, a partner in the firm. "And the people represented by the AIDS Law Project need our help." Thomas R. Kline, a partner in the firm, added: "We've been impressed by the tireless work done by the AIDS Law Project, and want to contribute to its ongoing growth and progress." Kline & Specter, P.C., has offices in Philadelphia and in Cherry Hill, New Jersey. Pictured here with AIDS Law Project Executive Director Ronda B. Goldfein are Thomas R. Kline (left) and Shanin Specter (right).

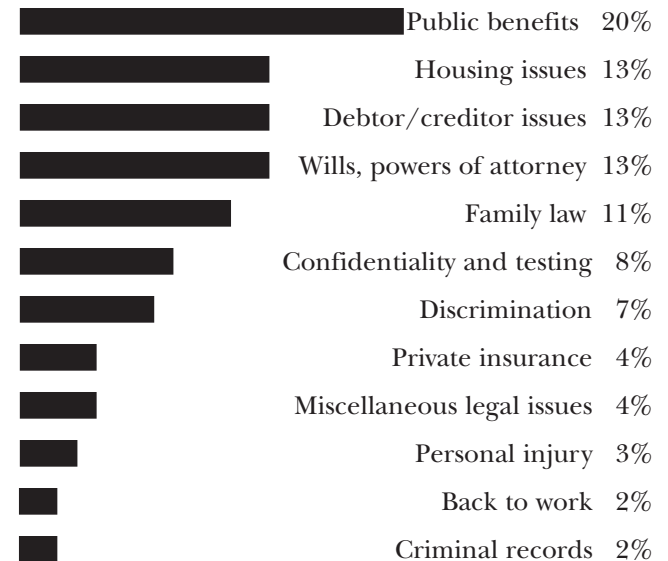
2003: LEGAL ASSISTANCE



TOTAL REQUESTS: 2,222
 Friend/Family member 2%
 Social worker/Case manager 2%
 Healthcare worker 1%
 Attorney 1%
 Other 2%



LEGAL SERVICES



Navigating the system

A new feature spotlighting cases in which the AIDS Law Project of Pennsylvania helped clients navigate the legal, welfare and housing systems and the bureaucratic worlds of public and private insurance.

Many low-income Medicare beneficiaries don't realize they are entitled to have Medical Assistance (MA) pay for their Medicare premiums. A man who recently came to the AIDS Law Project for help on another legal issue discovered, courtesy of paralegal **Lakeya Chambers**, that he had been eligible for this benefit for an entire year. Lakeya arranged for the Department of Public Welfare (DPW) to pay for his ongoing premiums and successfully advocated for a reimbursement of the premiums he had paid unnecessarily during the year. Medicare premiums were costing Lakeya's client about 10 percent of his monthly Social Security disability payment. Not only did she save him a substantial expense, but she also educated the DPW case worker, who was unfamiliar with this benefit.

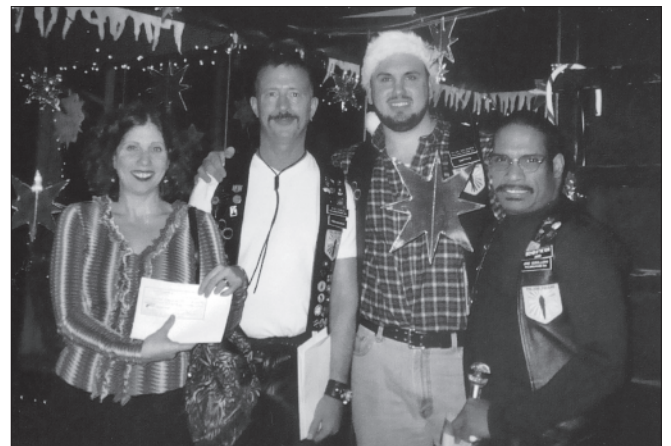
An older man with HIV received an unexpected inheritance from a deceased relative but felt he couldn't accept it because it would make him financially ineligible for the MA benefits he depended upon. He sought our assistance to return the money to his relative's estate. We determined that the money was not enough for him to live on and pay for his health-care expenses, but that he may be eligible for a Special Needs Trust that would allow him to receive his inheritance without jeopardizing his health care.

AIDS Law Project Executive Director **Ronda Goldfein** and **Dennis C. McAndrews** of the McAndrews Law Offices in Wayne, Chester County, created a Special Needs Trust for him. The trust lets him use the inheritance for expenses related to his disability, and still receive his health care from MA. Upon his death, MA would be reimbursed from the trust for the cost of his health care and the balance would pass on to his granddaughter.

The Homeowners' Emergency Mortgage Assistance Program (HEMAP) and Direct Emergency Financial Aid (DEFA) are government programs that help low-income people. But the two agencies seldom interact — which had one woman on the brink of homelessness when she turned to the AIDS Law Project for help.

She had applied to HEMAP for a loan for her mortgage arrearage. HEMAP approved a loan for part of the outstanding balance, contingent upon her ability to raise the rest of it. She then asked DEFA for a grant to cover the balance. DEFA approved the request, but required a letter from HEMAP confirming that she had been approved for the loan. HEMAP, unfamiliar with DEFA's requirements, issued a letter, but did not include the specific language that DEFA needed. As a result, DEFA did not release the funds, and the HEMAP loan was rescinded.

That was when Staff Attorney **Cathryn Miller-Wilson** stepped in. Cathy got HEMAP to send an appropriate letter to DEFA and reissue the loan. DEFA then provided the necessary funds. Each program thanked Cathy for taking the time to explain the situation and agreed to work together in the future.



The Philadelphians Motorcycle Club expressed its gratitude to the AIDS Law Project for helping one of its members by donating the proceeds of its annual holiday party. Pictured with Ronda Goldfein are Club members Richard D'Amico, Ryan Goldner and Jose Cebollero.

Have Expertise Will Travel: AIDS Law Project staff members train others

Throughout its 15-year existence, the AIDS Law Project of Pennsylvania has provided legal information to more than 25,000 people across the state. Its activities extend to training case managers, medical staff and other professionals in health-care delivery systems in a wide spectrum of issues, including public benefits, legal concerns and custody and permanency planning.



In February in Middletown, PA, Ronda Goldfein gave a two-day training in public benefits attended by publicly funded case managers and supervisors from throughout the state. The Philadelphia AIDS Consortium (TPAC) organized the event, funded by the Ryan White C.A.R.E. Act. Left to right: Wilma Ferdinando of TPAC; Ronda Goldfein; Yolanda Quinones of Harrisburg; Maureen Mulenga of State College.



On April 15, AIDS Law Project Staff Attorney Irais Orihuela-Reilly conducted a public-benefits training, sponsored by the AIDS Activity Coordinating Office of the Philadelphia Department of Health, for case managers from AIDS service organizations in Philadelphia.

Free Seminars: Now more convenient than ever

Based on client feedback, we've changed the times of our popular free seminars to make them easier to attend. All seminars are held in Center City Philadelphia at 1211 Chestnut Street, Suite 600. To register, call 215.587.9377.

Tuesdays: DEBT MANAGEMENT

Poor health can ruin a person's financial well-being. Debt incurred as a result of illness can become an overwhelming problem for people living with HIV/AIDS. This seminar, held on the second Tuesday of each month, will help you handle debt and understand your rights.

May 11	5 - 7pm	Sept 7	5 - 7pm
June 8	12 - 2pm	Oct 12	12 - 2pm
July 13	5 - 7pm	Nov 9	5 - 7pm
Aug 10	12 - 2pm	Dec 7	12 - 2pm

Wednesdays: LEAVING YOUR JOB

This seminar, held on the second Wednesday of each month, is designed for people thinking of leaving their jobs because of disability. It provides information you need if you are considering applying for disability benefits.

May 12	5 - 7pm	Sept 8	5 - 7pm
June 9	12 - 2pm	Oct 13	12 - 2pm
July 14	5 - 7pm	Nov 10	5 - 7pm
Aug 11	12 - 2pm	Dec 8	12 - 2pm

Thursdays: BACK TO WORK

Evolving drug therapy has given a new lease on life to thousands of people living with HIV/AIDS. This seminar, held on the second Thursday of each month, answers questions about returning to work without losing critical health coverage.

May 13	5 - 7pm	Sept 9	5 - 7pm
June 10	12 - 2pm	Oct 14	12 - 2pm
July 15	5 - 7pm	Nov 11	5 - 7pm
Aug 12	12 - 2pm	Dec 9	12 - 2pm

WELCOME NEW BOARD MEMBERS



Kimberly Y. Chainey is an associate in the Business Transactions Group at Morgan Lewis. After graduating from Harvard College, Kimberly earned an MBA from the University of Pennsylvania's Wharton School of Business and a law degree from the University of Pennsylvania Law School. Prior to joining Morgan Lewis, she was a manager in the Customer Business Development Division of Procter & Gamble.



Gregory M. Fliszar, Esq., is an associate at Ballard Spahr Andrews & Ingersoll, and a member of the Health Care Group. He is also a licensed clinical psychologist. Prior to entering law school, Greg was on the staff of the Allegheny University and Hahnemann University Hospitals and a clinical instructor of psychiatry at MCP-Hahnemann School of Medicine. He has counseled HIV/AIDS patients and run educational groups on HIV prevention. Greg is a graduate of the University of Notre Dame, Texas Tech University, and the University of Pittsburgh.



Geraldine Jones recently retired from ActionAIDS, where she worked as case management coordinator for 10 years, supervising case managers, coordinating intake and conducting quality assurance. She also developed ActionAIDS's intern program with graduate schools of social work. A graduate of the University of Pennsylvania School of Social Work, Geraldine serves on Penn's Field Cabinet, a group of field instructors who provide feedback on improving field placement for social work graduate students.



Bryn L. Michaels, Esq., is an associate in the Business & Finance Department at Ballard Spahr Andrews & Ingersoll, and a member of the Investment Management Group and the Securities Group. She is a graduate of the University of Maryland and the University of Pennsylvania Law School, where she served as Associate Editor and Articles Editor for the *Journal of International Economic Law*.



Philadelphia FIGHT will host its Tenth Annual AIDS Education Month in June. For a complete listing of the month's programs and to register for events online, please check out www.fight.org/aem.

PUBLIC BENEFITS UPDATE

The Pennsylvania Department of Public Welfare (DPW) recently lifted its lifetime ban on Food Stamps and Temporary Aid for Needy Families (TANF) for people convicted of drug-related felonies after August 22, 1996. This change took effect February 21, 2004. We encourage anyone who was denied Food Stamps or cash assistance because of a felony drug conviction to reapply for benefits.

Welcome two new staff members

Staff attorneys honored

Congratulations to **Rodney Cunningham** and **Cathryn Miller-Wilson** of the AIDS Law Project of Pennsylvania, who have won awards: Rodney, Supervising Attorney of the Family Law Unit, received the Philadelphia Bar Foundation's first Morris M. Shuster Fellowship. The \$5,000 award is designed to help public-interest lawyers who have completed five years or more of service to repay student loan obligations. Cathy is slated to receive the Young Alumni Award from the University of Pennsylvania Law School on May 14. The award is presented to an attorney who has graduated from Penn Law within the last 10 years, for professional achievement and service to the Law School. Cathy's award cites her "extraordinary success in the world of family law, HIV/AIDS projects and child advocacy so soon after law school graduation."

Derrick Russell joined the AIDS Law Project of Pennsylvania as finance and operations manager in November 2003. As fiscal director for the Philadelphia AIDS Consortium for six years, Derrick is no stranger to the Philadelphia HIV/AIDS community. He brings nine years of public accounting experience and an additional nine years as an auditor, serving many non-profit clients in the Philadelphia area. After spending the last four years in a corporate environment including Chemical Heritage Foundation, Comcast Cablevision and Gamble-Huff Music, Derrick was eager to return to the HIV/AIDS field which he says provides him with "a great deal of personal and professional satisfaction."



Ngozi Ibeh joined us in October 2003 as the paralegal for the new Criminal Record Resolution Program, which works with people with HIV/AIDS whose outstanding criminal matters prevent them from getting health care and other benefits. A certified paralegal, Ngozi spent six years working with homeless, truant and adjudicated youth through Youth Services of Bucks County.



Ngozi conducts daily outreach at Prevention Point Philadelphia's needle-exchange sites, helping people with outstanding criminal issues to get health care and cash benefits, and referring them to drug treatment and other services. Ngozi already has helped 13 people resolve outstanding warrants and violations of probation or parole to access benefits and move on with their lives. "It's really stressful for people with AIDS to be looking over their shoulders all the time worrying about

the parole officer coming after them. The stress makes them sicker," Ngozi says. "Taking care of unresolved matters and being able to receive an SSI check can really change the quality of your life."

Even clients in prison have benefited. "One man surrendered and is serving the remainder of his sentence," she says. "He was very concerned about interrupting his treatment regimen, so I was able to negotiate for him to walk into prison with his HIV medications."

Thanks to our funders and donors

Major Funders

AIDS Fund
City of Philadelphia,
Department of Health, AIDS
Activities Coordinating Office
Claneil Foundation
First Hospital Foundation
Independence Foundation
PA MidAtlantic AIDS Education &
Training Center
Patricia Kind Family Foundation
Pennsylvania Department of
Public Welfare
Pennsylvania Interest on
Lawyers Trust Account Board
Philadelphia Bar Foundation
Philadelphia Foundation
The Pew Charitable Trusts
The Philadelphia AIDS Consortium
Valentine Foundation

Gifts of \$ 1,000 or more

Ed Ciolko
James L. Dean & Joseph M. Montella
State Representative
Babette Josephs
Frank McClellan & Phoebe Haddon
Philadelphians MC
Sandra Lee Thompson

Gifts of \$ 500 to \$ 999

James & Karen Bailey
Leon Chubin
Sean M. Halpin
Fredric Nicholas Ifft
Frances Reiner Lax
Jan P. Levine
The Philadelphia Contributionship

Gifts of \$ 250 to \$ 499

Patricia Deitch
David Fedor
Trivia Night at the Bike Stop
Timothy W. Harper &
Michael J. Rutkowski
Leon Husock, Howard Husock &
Robin Henschel
William Ives
Kent & Yolanda Lollis
Susan E. Sherman
Ann Strauss
Carmela Terlingo Concert Fund
Elizabeth T. Trego
Robert J. Upton
V2 GfK, LLC

Corporate Matching Gifts

Aventis Pharmaceuticals
Law School Admission Council
Merck Employee Giving Campaign

Gifts of \$ 100 to \$ 249

Samuel & Marcy Abloeser
Jennifer Aldrich & Raynard Cheng
Sara Allen
Mark Ansley
Christina E. Bach
Gary Baker & Mark Kaplan
Rebecca Baranowski
Richard L. Berkman
Craig R. Blackman
Charlotte Bliss
Edwin Bomba
William Brown III
Michael Burke
Gregory R. Chandler
Andrew Chirls
Kris Clagston
Sue Lage Cost
James Cowden
Randal Cowles & Eusebio Batan
Daniel Dex
Katharine & Graham Finney
Jeremy C. Gelb
Gloria M. Gilman
June Goldfein
Del C. Guilfooy
Mary Hanssens
William Martin Heinzen
Sylvia Hepler
Lawrence Indik & Sharon Eckstein
David & Beth Kagan
Kairys, Rudovsky, Epstein & Messing
Lawrence Kashi
Daniel M. Kiley-Zufelt
Patricia Kim & Christopher Yoo
Dennis Klaus & Renny Lyons
Alan & Pamela Kosansky
Donald & Vicki Kramer
Kurt & Amy Kramer
Nancy B.G. Lassen
Jeffrey Less
Jeffrey Lonoff
Robert A. Lopes, Jr
Cletus Lyman
Bruce Mann & Elizabeth Warren
Jeff Maskovsky & Sidney Donnell
Frederica Massiah- Jackson
Martha McDonald
Rachel L. McOwen
Mark Mechowski & James Keller
Joseph Micucci
Donald Millinger
Modern Eye
John Oberholtzer
James Phillips
Jean & Donald Quataert
Rochelle Quiggle
Paul Rafail
Abraham L. Reich
Barry Rucks
Harris J. Sklar
Susan Spencer
Audrey C. Talley
Kahiga A. Tiagha
Wayne Varnadore
Cornelia Vinson
Jeffery Whitt
Eric L. Wichner
Wyoming Valley AIDS Council
Gabriel Zashin & Mihoko Samejima

Gifts of \$ 50 to \$ 99

Judith Algeo & Frank Cervone
William Babcock
Karl & Judith Baker
Earl Beach
Marc Bender
Mark Benko
Patrick L. Bell
Eric Bernard & Janice Hinkle
Anne Blanchard
Amelia Boss
Frederick J. Bostwick
Maryann Brown
Howard Childs
Charlene F. D'Amore
Mark Davis
Mark Delowery & Jack Dembow
Patrick Egan
Gail & Henry Hauptfuhrer
Allan L. Goldberg
Dick Goldberg & Deborah Weinstein
Ron Hauser
Mark Hemling
Amy Hirsch & Jessica Robbins
Helen & Kim Hunt
J. Dennis Hyde
M. Ippoliti
Alan Iser & Sharon Liebhaber
Katayun Jaffari
Leigh Jerner
David Kairys & Antje Mattheus
Prashant K. Khetan
Eugene Klotz & Carole Netter
Harry Kosansky
Lawrence Kovnat
Amy Kramer
Paul & Jane Kronick
Victor Laushance
Irwin Love
Kathleen Loveland
Thomas Risbon Mendicino
Fernando Chang Muy
Mekves Tilahun
James O'Toole
Barry D. Parsons
Melissa Rasman & Thomas Hurley
Jessica M. Riccio
Leonard Rieser
Alba Rodriguez
Edgar & Sylvia Rosenthal
Jerry & Carole Rothstein
Ruotolo Spewak & Co.
Joseph Ruzic
John Sakamoto & Jan Spauschus
Peter Schneider & Susan DeJarnatt
Carolyn Silver
Janet Stotland
Eileen Talone
Lee Traband
Judy A. Turetsky &
F. Scott Beadenkopf
Richard Watkins
James A. & Rita F. Wright
Mary Yee & Paul Uyehara

Gifts to \$ 49

Bernard Applebaum
Jerome & Ruth Balter
Maria & Rudy Battle
Jean & Dean Bauer
Gary Bell
Stephanie & Joshua Bilenker
Jerry Brown
John & Joan Carlson
Morris & Lillian Cherrey
Joel & Joan Chinitz
Michael Coates &
Nancy Roecker-Coates
Jarrod & Juana Collins
Katherine Conlon
Mr. & Mrs. Ajay J. Creshkoff
Caroline & F. Cunningham Jr
Jeffrey Dooley & Patricia McGlone
Aurelia Douglas
Esther Easton
Daniel Eberly & Pamela Lazos
Jules M. Epstein
Donald Friedman
James Garber
Henry G. Garfield
Linda Garfield
William Glosser
Brian Gordon
Gerald & Rochelle Gornish
Marc Harrison
Karen Marie Hawkins
David J. Hellman
Michael E. Kachur
Annamae Kattner
James Kelly
John F. Kelly
Marlis Kraft-Zemel
Linda Levin
Michael Lombardi
Kenneth Lynn
Mark MacDonald
William & Lynne Matles
Donald N. Meyers
Silvestre & Amy Jo Meza
Minie G. Murphy
Charles Pennacchio
Joanna Pennypacker
John F. Pollino
Gerald & Judith Porter
James Riley
Cindy Rosenthal & Arthur Read
Dorothy Ruth
Michael J. Schardt
Randi Shayne
James Shepherd
Kevin Parker Storey
Walter Tsou
Steve Turner
John W. Wetterau
Sallie Winters
Geraldine, James & Steven Wodock

Combined Federal Campaign

William A. Bradley
Stacey L. Conyers
Victor DiPietro
Patricia C. Felix
Stephanie R. Martin
LaVonne M. Nickens
Michael R. Oswald
Maureen E. Uhnait

Contributions received September 25, 2003 to April 14, 2004.