#### **MISSION STATEMENT**

Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

Patient Advocate Foundation serves as an active liaison between the patient and his/her insurer, employer and/or creditors to resolve debt crisis matters relative to his/her diagnosis through professional case managers, doctors and healthcare attorneys.











# PATIENT ADVOCATE FOUNDATION 700 Thimble Shoals Boulevard, Suite 200

Newport News, Virginia 23606 Tel: (757) 873-6668 Fax: (757) 873-8999

> 1-800-532-5274 www.patientadvocate.org E-Mail: info@patientadvocate.org

PAF is a tax-exempt 501(c)3 non-profit organization Federal Tax ID Number: 54-1806317



### PATIENT ADVOCATE FOUNDATION

**Providing Professional Services since 1996** 

"You certainly brightened my future and provided relief from the worry of how I could receive the medication that enabled me to recover and obtain a long wished for job with improved insurance coverage. The medication has prolonged my life and was my only choice of treatment for my diagnosis."

--Wilmar, AR

"You were able to connect me with many services both state, federal and private that can fulfill any need one has. Your service really helped my stress level and depression by helping me resolve a very critical aspect of my battle with cancer, funds to live on and help pay my bills." --Marietta, GA

"My case manager is an angel. She understood all my needs and handled them with love and care." -Vero Beach, FL

"Your foundation is an answer to one's unsure feelings about tomorrow. I was struck with cancer with no medical insurance at the time of diagnosis. I contacted the Patient Advocate Foundation and received moral support as well as help talking to the creditors. Your foundation makes a difference in people's lives." --Mendenhall, MS

"I cannot express the burden that has been lifted by the help of PAF. I thank God for his help through all the trials of life and for provding for me through PAF. The Patient Advocate Foundation has been a miracle in my life." --Muskegon, MN



A Letter
from the
CEO
A Year
of Relationships...

As the Harvard study, *Medical Bills Leading Cause of Bankruptcy*, Feb. 3, 2005 relayed to all of us this year, fifty percent of all Americans whose families have a sustained, chronic, life-threatening illness that requires one or both spouses to stop working for six months or longer, the result is personal bankruptcy. We at Patient Advocate Foundation felt a burden had been lifted, for this reality is the world in which our case managers and health care attorneys work daily to assist our patients who often find themselves confronting this stark reality.

Relationships with our patients this year illustrated to us there is a continued lack of access to prescribed healthcare that both our insured and uninsured patients are confronting. A total of 3.8 million people brought their issues and questions to Patient Advocate Foundation this year. Our case managers and leadership team members have reported that the acuity of the problems we have handled this year is accelerated from previous years. Changes in plan language for insured patients that cap annual benefits that will not sustain treatment for six months for an average cancer patient; formularies that require step therapy for critically ill patients, forcing higher payments for branded drugs that may reduce secondary effects and enhanced effectiveness and adherence to the treatment protocol; and reduced access to state Medicaid coverage due to complex and restrictive application procedures for our uninsured patients are but a few of the issues successfully resolved by our PAF team.

The relationships established by our staff with patients is one that fosters trust, confidence and loyalty as our team works collaboratively and cooperatively with our patients, their medical providers, their insurers and employers to achieve favorable resolutions that remove obstacles to needed healthcare, restore financial dignity and confidence for the patient and their family and address job retention issues to assure a future for the patient.

This year also brought to PAF a significant increase in the number of healthcare professionals who sought guidance from our professional staff through our real time on-line chat line that is staffed by PAF professional case managers. One in five internet requests for assistance, or 20% of our on-line requests, were from hospital social workers, Medicaid and Medicare counselors, oncology nurses, practice managers and practice administrators. The requests ranged from simple requests for local resources to assist in creating a safety net of services for an under-insured or uninsured patient to assistance in resolving coordination of benefits issues, coding and billing errors resulting in loss of sustained treatment access and requests for co-payment assistance for insured patients with prescription drug benefits unable to access the benefits due to no funds to pay co-payments.

Relationships with our healthcare colleagues across this great nation provided a mutual opportunity for our staff to benefit from the exchange of professional information while problem-solving with others in the nation charged with addressing many of the same problems we handle daily. PAF attended over 1,100 educational outreach events and professional healthcare provider meetings including Oncology Nursing Society Annual Convention, American Society of Clinical Oncologists, Association of Oncology Social Workers and the Intercultural Cancer Council as keynote speakers, professional panelists and exhibitors.

Our Co-Pay Relief Program (CPR) served 2,035 patients this year. The CPR program became a vehicle that allowed us to further serve seniors as well as other insured Americans as we provided cash co-payment assistance for pharmaceutical agents for medically and financially qualified patients. Through this program, we have built relationships with oncology practices and pharmacy providers in each of our fifty states meeting new colleagues through training calls as PAF served their patients through the CPR program.

Patient Advocate Foundation enhanced our relationships with the Centers for Medicare and Medicaid Beneficiaries as we opened our Senior Services Division to assist Seniors with their enrollment in the Medicare Replacement Drug Demonstration (MRDD) program. PAF enrolled 12% of the total patients enrolled in this program nationally and developed relationships with the program directors at Trailblazers charged with populating this program. CPR assistance was provided to both the patients PAF enrolled in the MRDD as well as to those referred by the agency and by Trailblazers.

Our team considers it a privilege to develop relationships with those who touch the lives of more insured citizens than any single organization in the United States. Their responsibilities are compelling, their resources limited continued

and their compassion for those they serve parallel to that of our professional staff. Our relationships have resulted in increased educational opportunities for our team with CMS personnel in Listening Sessions and Open Door Forums as the Agency leads us in understanding the implementation of the MRDD and the Medicare Prescription Drug Benefit program.

The CPR program also added to our relationships with national news journalists such as The Wall Street Journal, "Price Becomes a Factor in Cancer Treatment", Santa Maria Times, "Cancer Patient Finds Hope in New Program", USA Today, "Medical Costs Prove a Burden Even for Some with Insurance", Ladies Home Journal, "The Health Gamble More Families are Taking", The New York Times, "Cancer Drugs Offer Hope, But at a Huge Expense", All You Magazine, "Win a Fight With Your Insurance Company" who generously informed patients nationally of our services through CPR. These relationships continue to sustain our national presence in the media as annually PAF is featured in multiple national print outlets as well as television, cable network programming and radio programs such as The Inspired Survivor, a weekly radio show for people with cancer.

Internal relationships within the PAF organization have grown as the Foundation established a formal Leadership Team comprised of the Executive Vice Presidents of Resource Development, Alan Richardson; Patient Services Operations and Clinical Affairs, Donna M. Sternberg, RN, OCN; Patient Services Programs, Cynthia Hucks; Finance, Cindy McDaniel; Controller, Debbie Andrus; Information Technology, Aaron Marshall; Special Programs, Ruth Anne Reed; Communications, Tracy Andrus; Administrative Services, Melynda Obergfell; Chief Operating Officer, Fran Castellow, MSEd; Chief Program Officer, Beth Darnley; Chief Development Officer, John H. Ennis, Jr.; and Chief Executive Officer, Nancy Davenport-Ennis. Together, this Team has moved PAF into enhanced systems of accounting, improved internal educational programming in information technology resources and applications, patient service programs and personal development programs such as the establishment of the CEO Cancer Gold Standards, a program addressing tobacco use, screening and early detection, diet and nutrition, physical activity and access to quality treatment and clinical trials. Each member of this team is committed to enhancing employee satisfaction and sustaining the collegial working environment that makes PAF a sensitive workplace committed to personal development and success. As our staff grew from 39 to 54 this fiscal year, including personnel in Iowa, Florida, California, New

York and Rhode Island, positive relationships between our team members remain an integral ingredient to our success.

Those individuals, corporations, non-profit volunteer health agencies, benevolent foundations and local, state and federal agencies, commissions and governments who provide gifts, grants and annual appropriations to Patient Advocate Foundation indeed have a very special relationship to every patient we serve, every staff member we employee, every member of our Executive, Scientific and Honorary Boards of Directors, for without their support, we could not provide our services to America. Thank you to the United States Congress and most especially our Senator George Allen and Senator John Warner for our Appropriation; Centers for Disease Control for our two annual multi-year grants; the State of Virginia for our grants to conduct outreach to Virginians; to our hometown governments in Newport News for their annual patient services grant; to US Oncology for their multiyear support of our programs and services and also to Amgen, Inc., AmerisourceBergen, AstraZeneca, Bristol-Myers Squibb, Eli Lilly and Company, Eyetech Pharmaceuticals, Genitope, GlaxoSmithKline, Novartis, Pfizer, Roche, and sanofi-aventis. Thank you to local businesses for their support of our Promise of Hope including the City of Newport News, Coastal Forms and Data Products, Inc., Dominion Virginia Power, Ferguson Enterprises, Inc., Hall Automotive, JP Morgan Chase Bank NA, BB&T bank, Northrop Grumman, Old Point National bank, Pomoco Auto Group, Powers Business Machines, Riverside Health System, ViCOM and Wachovia Securities and Wachovia Bank and to individual donors. These relationships provide strength to each of us through intellectual exchange of new ideas and funding for exciting opportunities to introduce new programs while sustaining our fundamental direct patient services.

Relationships. Without them, Patient Advocate Foundation would not be looking forward to celebrating ten years of providing services to Americans in 2006. We look forward to strengthening our current relationships and building new ones as we begin our next decade of seeking to insure access to quality healthcare for all Americans.

With Sincere Appreciation, I remain...

Nancy/Davenport-Ennis, CEO

#### A Word from Our Chief Operating Officer

Dear Friends,

As I write this letter to you all, PAF is on the eve of its 10th Anniversary, celebrating the beginning of a revolutionary Foundation that has touched the lives of millions since its inception. It is never far from my mind and heart the humble beginning from which PAF came, opening its operations in 1996 in one ten by ten office space, with our founder and current CEO, Nancy Davenport-Ennis implemating her vision as a volunteer. In February of 2002, the demand for Patient Advocate Foundation direct patient services reached such a height that it warranted the relocation of our National Headquarters into a ten thousand square foot office space in order to accommodate the necessary staff expansions. This move was made possible by the generous gifts of the local and national communities, including the office build out labor and materials which came in the form of an in kind donation from the office space owners! Now, at the end of the FY2004-2005, we are again in the midst of expanding our operations in to an additional forty five hundred square feet to accommodate our rapidly growing Co-Pay Relief Program (CPR), a mere sixteen months after its launch. Amazing is the only word that is adequate to describe the leadership and vision that have brought to such a place as we find ourselves now enjoying.

In order to ensure quality, timely service to all patients nationwide who seek our assistance, PAF has continued to make investments in staff expansion the top priority with the goal of expending as much of our budget as fiscally possible on the addition of case managers and CPR Call Counselors. The PAF staff grew to and beyond the 50 employee mark this year, ending the year with 54 employees. Some of our newest staff editions have expertise in Oncology Nursing, Professional Coding and Billing and Social Work. We increased the Case Management staff by twenty eight percent (28%) and the staff of the Co-Pay Relief Program by one hundred percent (100%) in FY 2004-2005 to meet the rising need for our services. Thus, the Patient Services Division that administers both case management and the CPR program has grown by forty eight percent (48%) during this fiscal year alone. Consequently, the overall PAF growth rate in FY2004-2005 was an amazing 45%.

Patient Advocate Foundation has also implemented many systems that enhance the capabilities and improve the quality of the expanding financial services. These changes included the implementation of new budgeting process driven by cost allocations for

each of our 17 departments and/or programs, the production of a more comprehensive financial reporting package to include independent monthly financial reporting on the success of the Co-Pay Relief Program expenditures and the addition of a Junior Accountant position that is dedicated solely to the timely financial servicing of patient accounts for the Co-Pay Relief Program. The audited financials found later in this annual report provides a more in-depth look into the revenue sources and expenses for the year, however, I am pleased to report that the actual cash expenses for FY 2004-2005 reflect expenditures 100% within the approved FY2004-2005 budget! Patient Advocate Foundation is extremely pleased with the continued strides that have been made in the financial services department and feel the enhancements will insure the fiscal responsibility and financial stability of PAF.

It is our mission to serve as liaisons for those experiencing chronic, life threatening and/or debilitating illnesses in order to ensure that they have access to healthcare. We feel we have been fortunate to develop long standing relationships with our Partners in Progress, local community leaders, representatives of various national nonprofit organizations, friends and those we consider family, for it is these relationships that enable us to continue to expand the breadth and scope of our services. For these relationships, we are ever grateful and celebrate the empowerment that has been bestowed upon us as a result of this support. Truly, celebration is an appropriate descriptor of what I feel each day as I serve in the capacity of Chief Operating Officer for PAF. Celebration for the staff who is so rewarded by the changes they effect in the lives of those they work with, celebration for the patients whose lives are better because of our interventions, celebration of our Executive Board of Directors who continue to give selflessly of their time, energies and wisdom in order to help shape the future of the Foundation, celebration of our partners who have generously given of their time and resources to support the mission and programs of PAF, and celebration of our mere existence and continued increased demand for our services in the market place, validating the need for PAF to keep working day in and day out to insure that our services are available to all who need them.

With Celebration and Gratitude,

Fran Castellow, MS.Ed. Chief Operating Officer

Fran Castellan

#### A Word from Our Board President

Changes in our nation's healthcare delivery system are occurring at an ever accelerating pace. These changes, both in the public and private sectors, can greatly impact the availability and accessibility of appropriate treatment for patients.

Amid the confusing array of regulations, laws, mandates and payor decisions, the Patient Advocate Foundation (PAF) serves as a resource, beacon and guide to thousands of patients and their families. PAF has met the challenges of the system and the needs of patients for information, advice and direct personal assistance. In doing so, PAF has achieved national stature and prominence as an organization key to the development of policies that affect present and potential users of thehealth care delivery system. Most importantly, PAF intervenes and works on a daily basis on behalf of individuals, as patients, in achieving for them access to the treatments that they need.

On behalf of the Board of Directors of the Patient Advocate Foundation, we salute the leadership, staff, patients and supporters who make up the PAF family. Together, we all contribute greatly to improving the healthcare system for patients whom we serve. Dr. William T. McGivney

President, Board of Directors, 2004-2005

### **DIRECT PATIENT SERVICES...**

# Resolution of Problems through Direct Patient Services

#### Direct Services Provided to Patients at No Cost Include:

- Negotiating pre-authorization approvals
- Providing assistance in expediting the appeals process
- Negotiating resolutions to coding and billing errors
- Resolving debt crisis related to diagnosis
- Mediating insurance appeals
- Negotiating access to pharmaceutical agents, chemotherapy, medical devices and surgical procedures
- Coordinating benefits
- Brokering resources to supplement the limits of insurance and to assure access to care for the uninsured
- Resolving insurance issues in the public

and private sectors

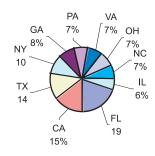
PAF's annual patient contacts increased 85.5% over the same period a year ago, totaling 23,628 unique patient cases handled by our professional team of case managers... Additionally PAF case managers fielded 476 informational requests. Thus, individual requests for direct patient services in FY 2004/2005 totaled 24,104.

The number of requests for assistance received via email experienced phenomenal growth increasing more than fourteen times over last year! This translates into 44,173 requests for information both into and out of the Internet Patient Services division during the fiscal year. We are pleased to share that twenty (20%) of the incoming requests for assistance were generated from a Healthcare Professional, clearly indicating that the resources of PAF are becoming a very valuable tool for other professionals working on behalf of patient access. Total unique website visitors were 324,539 for the year which represents an increase of 8% this year versus last. The total number of

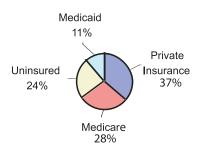
web based views, hits and contacts for specific educational information totaled an additional 3,418,243. In all there were more than 3.8 million requests for direct patient services and educational information via phone, email or website visits during FY2004-2005!

The PAF Resource Department, which supports the direct patient services, mailed out well over 11,000 customized Patient Paks this year to patients with information selected specifically to answer their particular questions. PAF staff also attended over 30 national conferences either as a participant or as an exhibitor. This included conferences such as the Lymphoma Myeloma Conference, Minority Women's Summit, National Diabetes Education Meeting, National Indian Health Board, 19th National Conference on Chronic Disease Prevention and Control, American Society of Clinical Oncology, Association of Oncology Social Workers, Asian American 4th Annual Conference and the Oncology Nursing Society, just to name a few. Additionally, PAF staff members participated in over 1,100 local and regional outreach

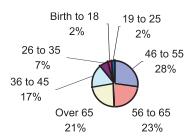
### Top Ten States In Which PAF Cases Originated in FY 2004-2005



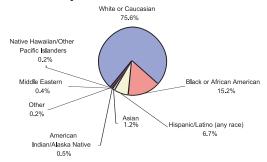
#### Insurance Status of PAF Clients FY 2004-2005



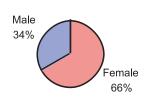
#### Ages of PAF Clients FY 2004-2005

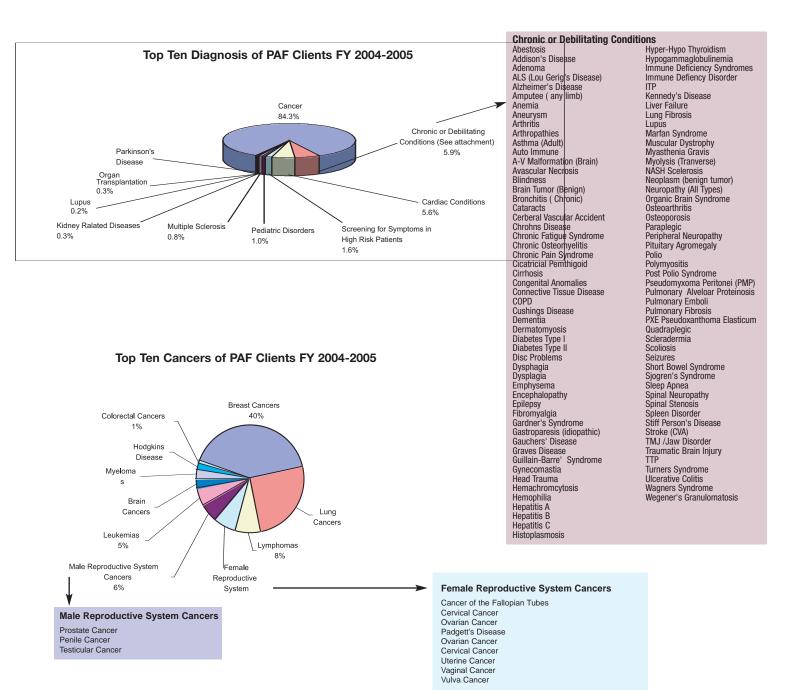


#### Ethnicity of PAF Clients FY 2004-2005



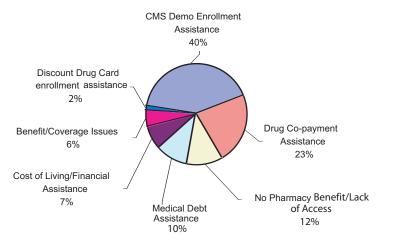
#### Gender of PAF Clients FY 2004-2005

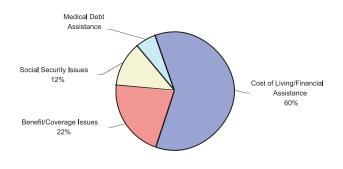




#### Primary Medicare Issues of PAF Clients FY 2004-2005

#### Primary Medicaid Issues of PAF Clients FY 2004-2005





# PATIENT ADVOCATE FOUNDATION CO-PAY RELEEF

# A Patient Assistance Program

Patient Advocate Foundation (PAF) introduced our Co-Pay Relief (CPR) program with a soft launch in April 2004. CPR is designed to provide financial assistance to insured patients who qualify medically and financially helping them with the co-pays for their prescriptions and/or pharmaceutical treatments.

Co-Pay Relief is one of seventeen programs provided by Patient Advocate Foundation to assist patients in accessing healthcare. On October 29, 2004, PAF was awarded its favorable ruling from the Department of Health and Human Services Office of the Inspector General (OIG). The OIG issued Ruling #04-15 provides protection to those donors who participate in CPR. The ruling also approved 27 disease categories that could be serviced by Co-Pay Relief. Currently, CPR provides assistance in breast, lung and prostate cancers, macular degeneration and secondary issues arising from chemotherapy treatment. Additional OIG approved, but not yet funded silos are available in:

- Autoimmune disorders
  - -Crohn's Disease
  - -Arthritis
  - -Arthritic Psoriasis
- Brain Cancer
- Cervical Cancer
- Colon Cancer
- Uterine Cancer
- Diabetes
- Hepatitis A, B, C
- HIV/AIDS

- Kidney Cancer
- Leukemia
- Lymphoma
- Mental Health
- Multiple Sclerosis
- Myeloma
- Ovarian Cancer
- Pancreatic Cancer
- Sarcoma
- Testicular Cancer

To celebrate the one year anniversary of the program, Patient Advocate Foundation announced the Co-Pay Relief (CPR) program to America at a press conference held at the National Press Club in Washington, DC on March 23, 2005. Mark McClellan, M.D., Ph.D., Administrator of the Centers for Medicare and Medicaid Services spoke at the press conference and commended PAF for creating this revolutionary program that provides assistance to insured Americans who are having difficulty meeting their co-payments for medications.



Additional press conference panelists included:

- William T. McGivney, Ph.D., President, Board of Directors, Patient Advocate Foundation; Chief Executive Officer, National Comprehensive Cancer Network
- Nancy Davenport-Ennis,
   President, Patient Advocate Foundation
- Dennis Gastineau, M.D.,
  Director, Human Cell Therapy
  Laboratory, Divisions of
  Transfusion Medicine and
  Hematology, Mayo Clinic;
  Chair, Patient Advocate
  Foundation's Scientific Board
- Alana L. Grajewski, M.D.,

  Director of Pediatric Glaucoma

  at Bascom Palmer Eye Institute;

  Clinical Associate Professor of

  Ophthalmology at the

  University of Miami Miller

  School of Medicine; President

  and Founder of the GL

  Foundation for Pediatric and

  Infantile Glaucoma; COO and

  Executive Director of the

  Miami Ophthalmology Society
- June Dalton, Lung Cancer Patient, Santa Maria, California
- Ann Stewart, Patient Advocate for Commonwealth Hematology Oncology; SHINE Counselor for Executive Office of Elder Affairs

# PATIENT ADVOCATE FOUNDATION CO-PAY RELIEF

# A Patient Assistance Program

We are pleased to report that as a direct result of the national launch in March 2005, many of the disease "silos" have been fully utilized each month, offering maximum assistance to those in need.

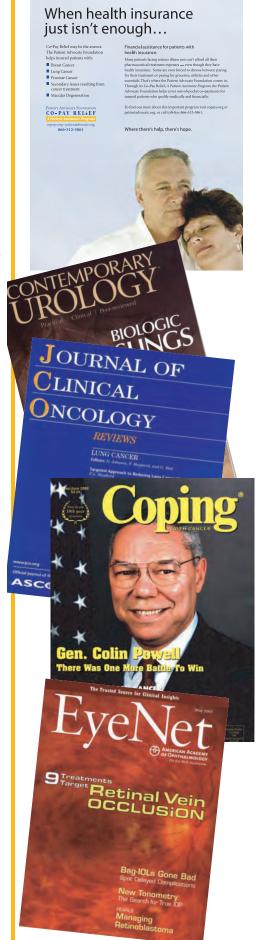
Patient Advocate Foundation has executed an aggressive outreach program for Co-Pay Relief. This year advertisements have been placed in publications including:

- Contemporary Urology
- Journal of Clinical Oncology
- Coping with Cancer
- ASCO Daily News
- Journal of Oncology Nursing
- Ophthalmology Times
- Eyenet

Additionally, PAF's CPR program has been the focus of articles in publications including:

- The Wall Street Journal
- The Houston Chronicle
- The Daily Press (Local paper owned by The Chicago Tribune)
- Oncology Associates Member News
- Hematology Oncology News & Issues
- Savvy Senior
- Santa Maria Times
- USA Today
- Ladies Home Journal

Donations to the CPR program are allocated equally over a twelve month period to ensure that funds will be available throughout the year. Each approved patient is allocated \$2,500.00 per twelve month period for payment of approved co-pay assistance expenditures billed to CPR by treating physician offices or pharmaceutical agent suppliers. Payment is made directly to the providers through debit card transfers or checks. Disbursements are made daily



# PATIENT ADVOCATE FOUNDATION CO-PAY RELEEF

# A Patient Assistance Program

The total number of patients served during CPR's first year of operation which is from April 1, 2004 to March 31, 2005 was 1,259. From April 1, 2005 to June 30, 2005, Co-Pay Relief has provided assistance to 873 patients for a total of 2,132 patients since inception of the program.

The Patient Advocate Foundation Co-Pay Relief program is functioning at maximum efficiency and practicing due diligence with each and every patient account. The average length of time from initial call to approval is 5 to 7 business days. The funds donated to the program are enabling PAF to help patients who are having difficulty with their co-payments and oftentimes may be making decisions to go without treatment, skip payments on monthly bills, or elect not to purchase groceries for the week. But it is the words of those who have been accepted into Co-Pay Relief who can best say how this program has had an impact on their lives.

"I really appreciate your help financially, it will definitely lighten my financial burden."

"I can now focus on my illness and not worry so much about other things."

"Receiving assistance is (a) great burden lifted off my shoulders."

"With out your help I would be still sitting here wondering and worrying about if the doctor would still see me, due to not being able to pay my bills."

We would like to thank the generous supporters of Co-Pay Relief, A Patient Assistance Program.

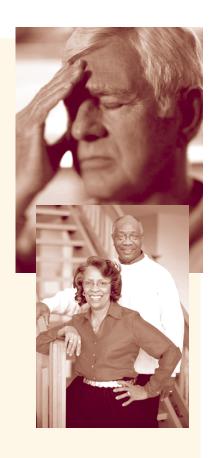












#### 2005-2006 Fiscal Year Forecasting for Co-Pay Relief

- With the advent of additional funding sources entering into contractual relationships with the Co-Pay Relief program, PAF will be expanding its operations into an additional 4,500 square feet of office space in second quarter 2005/2006, bringing Patient Advocate Foundation's total square footage at the head quarters office to 14,500.
- PAF is aggressively pursuing additional funding sources to open additional disease silos within the program.





# 6th Annual PATIENT CONGRESS

June 21-23, 2005 Washington, DC

It was our pleasure to host attendees from around the country for this three day event that included educational addresses by agency, research and political speakers, tours of the Exhibitor booths with 23 in attendance from the advocacy and federal communities, including Lance Armstrong Foundation and CDC's Division of Cancer Prevention and Control, sharing literature and information, being entertained by Roger and Kathy Cawthon, the presentation of our academic scholarship award winners and most importantly, making an impact with elected officials during their Hill Visits. A special thanks goes to our sponsors of Patient Congress: AMGEN, Genitope, US Oncology, Purdue Pharma, Eli Lilly, Lance Armstrong Foundation, sanofi-aventis, Susan G. Komen Breast Cancer Foundation, Oncology Nursing Society and AmerisourceBerge.

Patient Congress VI attendees numbered 211, came from 38 states and the District of Columbia, completed 148 visits to Capitol Hill offices including six constituent breakfasts and enjoyed being addressed by Senator Richard Burr (NC-R), newly appointed member of the HELP committee; Congresswoman Sue Myrick (NC-R), newest member of the Energy & Commerce Committee and cancer survivor; Congresswoman Deborah Pryce (OH-R), Co-Sponsor of the Patient Navigator Program that passed on Wednesday, June 22, 2005 in the U.S. Senate and in the U.S. House of Representatives the week of June 15, 2005 and Congresswoman Lois Capps (CA-D), who is a strong patient advocate and nurse and mother of child that succumbed to cancer. Additional speakers were Mark McClellan, M.D., Ph.D., Administrator of Centers for Medicare & Medicaid Services (CMS) via video, Daniel Schreiner, Medicare Ombudsman, U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services and Janet Woodcock, M.D., Deputy Commissioner of Operations, US Food and Drug Administration. Michael Samuelson, our featured author, Voices from the Edge, shared with us his story of his battle. From the research community, attendees heard from Andrew von Eschenbach, M.D., Director of National Cancer Institute and Susan True, Chief of the Program Services Branch in the Division of Cancer Prevention & Control, Centers for Disease Control and Prevention. We also celebrated Patient Congress's attendees making an impact in Washington, DC as we cruised down the Potomac River aboard the Spirit of Washington.

PHOTOS IN COLUMN R TO L - TOP TO BOTTOM: **Dr. William T. McGivney,** PAF Board President presents the National Humanitarian Healthcare Award to **Representative Lois Capps (D-CA)**; **Representative Sue Myrick (R-NC)** addresses the attendees during the Wednesday Dinner Symposium; **Representative Deborah Pryce (R-OH)** gives remarks after receiving the National Humanitarian Healthcare Award during the Congressional Awards Luncheon; **Nancy Davenport-Ennis**, presents **Pearl Moore, RN, MN, FAAN**, CEO of Oncology Nursing Society with the Advocate of the Year Award during Wednesday's Dinner Symposium; **Dr. Janet Woodcock**, Deputy Commissioner of Operations for the US Food and Drug Administration talks about issues facing the FDA; **Michael Samuelson**, Patient Congress VI featured author, addresses the attendees aboard the *Spirit of Washington*; **Senator Richard Burr (R-NC)**, Keynote speaker during the Capital Hill Briefing and Workshop.

Our attendee's voice in Washington did make an impact and for some, lasting friendships were born. Their stories gave our congressional members faces and hearts to pair with their federal initiatives, which personalized the issue thus, placing a much higher degree of importance on the facts that the attendees brought to their attention.

Our goal is to offer our attendees a conference that is inspiring, educational, and memorable. We feel that we achieved our objectives this year which is stated most eloquently by our attendees themselves:

"Patient Congress is an intellectual, emotional and spiritual experience with compassionate people, leaving you a better person for the effort."

A very extraordinary enriching experience that helped me to know there are congressmen/women who are genuinely sincere, interested, approachable. I am enriched & inspired on a heightened level."

"Meeting so many people from different places with different stories, but each with a similar goal – patient advocacy."

"Just keep up the good work. I cannot express the feelings of satisfaction & very proud to be called a nurse in the oncology field."



# Patient Congress VI Exhibitors



Centers for Disease Control-Division of Cancer Prevention and Control

and Control
The Leukemia and Lymphoma Society
Allergy and Asthma Network
Geriatric Oncology Consortium
Gilda's Club of Greater Washington
Purdue Pharma
Oncology Nursing Society
National Hospice and Palliative Care Organization
PANCAN

Ovarian Cancer National Alliance
Y-ME National Breast Cancer Organization
Lance Armstrong Foundation
Lung Cancer Alliance
The Children's Cause for Cancer Advocacy
Mautner Project
Multiple Myeloma Research Foundation
The Wellness Community
US Department of Labor/ESA/OWCP/DEEOIC
Sarah Lawrence College Health Advocacy Program

A Special thanks goes to our sponsors of Patient Congress: AMGEN, Genitope, US Oncology, Purdue Pharma, Eli Lilly, Lance Armstrong Foundation, sanofi-aventis, Susan G. Komen Breast Cancer Foundation, Oncology Nursing Society and AmerisourceBergen











PHOTOS IN COLUMN R TO L - TOP TO BOTTOM: **Jack Ennis and Nancy Davenport-Ennis**, co-founders of Patient Advocate Foundation; **Susan True**, Chief, Program Services Branch with the CDC's Division of Cancer Prevention and Control briefs attendees on "Comprehensive Cancer Control: From Opportunities to Action" at the Congressional Awards Lunch; **Dr. Andrew von Eschenbach**, Director of the National Cancer Institute discusses the strides in cancer research during the Congressional Awards Lunch; **Nancy Davenport-Ennis** thanks **Kelly Green Kahn** with the American Cancer Society for being a panelist during the Capital Hill Briefing and discussing the Patient Navigator bill; **Attendees** aboard the Spirit of Washington; **Roger and Kathy Cawthon**, Founders, The Cancer Crusade entertained attendees during the Wednesday Dinner Symposium.

# Scholarship for Survivors



The Patient Advocate Foundation Scholarship for Survivors are presented annually during Patient Congress. The scholarships are funded by PAF, however, they are named in honor of Patient Advocate Foundation's Sustaining Partners in Progress who offer outstanding support to patients through their national care-giver and indigent drug programs as well as through their continued support of PAF and our mission. The purpose of these scholarships is to provide support to patients seeking to initiate or complete a course of study that has been interrupted or delayed by a diagnosis of cancer or other critical or life threatening disease.

#### The 2005 Scholarship for Survivor recipients are:

Amanda Valenzuela Oklahoma State Univ.

Benton Brown UT Southwestern Medical School

John E. Schafer II University of Dayton

Drew Fisher University of New Mexico

Kendra Smith Brockport University

Suzanne Day Roberts Wesleyan College Suzanne Day Roberts Wesleyan College

Monica Bowser University of North Carolina at Charlotte

Pam Davis University of Texas at Austin

Andreka Shontae' Boyd Southern University

Henoke Shiferaw University of Maryland



"I would like to thank the Patient Advocate Foundation for supporting my education and well being. I will graduate next year with a BA in American Studies and minors in History and Philosophy. I could not have done it without your support and for that I am grateful." Amanda Valenzuela, Oklahoma State University

"PAF has been by my side throughout many of my experiences and has allowed me to take on new opportunities each and every day.

I appreciate the support and I cannot thank the organization enough.."

John E. Schafer, II,

University of Dayton

"...I knew that (PAF) was behind me and wanted me to succeed. These individuals fight for people like me everyday...I would like to thank Patient Advocate Foundation for being a strong reinforcement during my academic year and in my life." Monica Bowser, University of North Carolina at

"I am extremely grateful for the Patient Advocate Foundation for making my medical education that much more possible!"

Benton Brown, University of Texas Southwestern Medical School

"I just want to thank the
Foundation for their support and
encouragement. It has helped me to
graduate with very manageable
student loans, which has made this
time much easier for me."
Amy Feigenbaum,
2005 Graduate, Wesleyan
University,
a four year scholarship recipient

# National African American Outreach Program (NAAOP)

The PAF National African American Outreach Program (NAAOP) has become more formalized and focused this year. This program is designed to reduce health care disparities and assist consumers in obtaining an improved quality of life within disenfranchised communities by disseminating information to those who are generally unable to receive reliable health care. The program targets diseases that have a higher incidence in the African American community, specifically high risk conditions such as cardiovascular disease, diabetes, hypertension, renal failure, and stroke, along with specific types of cancer, including breast, cervical, ovarian, colorectal and prostate. NAAOP seeks to ensure the patient's rights to adequate healthcare and offers empowerment to improve the quality of life in the African American community. Over 15 percent of the patients served by PAF are African American.

The unique design of NAAOP, which is modeled after PAF's National Hispanic/Latino Outreach Program, provides a proactive and reactive assistance model which focuses on at-risk populations and the prevention of high mortality rates within those populations by improving comprehensive health care awareness, encouraging healthy lifestyle changes, providing information about the value of early detection screenings, and developing partnerships with others who provide annual health care screenings.

Patient Advocate Foundation has hired Dr. Mary T. Christian as a consultant to coordinate the program providing guidance to our staff program coordinator and her outreach team. The Honorable Mary T. Christian, Ph.D., is a former member of the Virginia House of Delegates where she served for seventeen years representing the 92nd District. She is also a Professor Emeritus at Hampton University in Hampton, Virginia. Her experience and community relationships gives Dr. Christian the expertise to advise the National African American Outreach Program. As an African American woman, she is a peer within the targeted community, bringing a level of credibility to the program that is unmatched. She is supported by six case managers who have ties to the African American community and understand the obstacles faced within that community, thus further strengtening the success of the NAAOP.

# Promoting a Healthier African American Community



PAF's Publications Committee has authored a publication this fiscal year specifically for this programs target audience. Entitled *Promoting a Healthier African American Community*, the publication covers those diseases that have a higher incidence in the African American population. These include:

- Stroke and Heart Attack
- Kidney Disease
- Diabetes
- Breast Cancer
- Lung Cancer
- Prostate Cancer
- Colorectal Cancer
- Cervical Cancer

There is a description of each disease, along with the signs and symptoms. There is also a listing of national resources available for more information. Through PAF's relationship with the Virginia Department of Health's Office of Health Policy and Planning, PAF has created a one-page, front and back insert of Virginia-specific resources that is available for use in targeted Virginia outreach.



ENDEUDAMIENTO

National Hispanic/Latino Outreach Program

Patient Advocate Foundation implemented our Hispanic/Latino Outreach Program in 2001 in an effort to bring PAF services to the Spanish speaking population. Our offices located in New York, Florida and California are staffed by bi-lingual case managers who provide Hispanic/Latino outreach initiatives in their respective communities. This program seeks to improve access to healthcare for the chronically and critically ill from the Hispanic/Latino community. PAF is providing case managers specializing in health care access to Hispanic citizens to resolve access to care and funding issues for uninsured, underinsured and insured patients who are diagnosed with chronic, debilitating and/or life threatening diseases and seeking access to hospitals, clinics, pharmaceutical agents, medical devices and psychosocial services that are needed to successfully provide quality healthcare in a timely manner. PAF also provides educational materials in Spanish, including all PAF authored publications which have been translated into Spanish. Since implementation of the program, the number of Hispanic/Latino patients

seeking services from PAF has increased over seven hundred percent since inception and continues to increase each year.

### Senior Services

In July of 2004, Patient Advocate Foundation began enrolling patients into the Medicare Replacement Drug Demonstration (MRDD) Project. Working with TrailBlazers who had been contracted by the Centers for

Medicare and Medicaid Services (CMS) to facilitate enrollment of seniors into the project, PAF was able to enroll in FY 2004/2005 a total of 1,194 patients, more than 12% of the total patients enrolled. PAF's participation in this project was done at no cost to CMS. As a result of the success of PAF's involvement in the MRDD and the relationships forged, and in response to the growing number of seniors seeking assistance, PAF created a formal Senior Services Division in 2005.

For FY 2004/2005, twenty-one percent of those individuals seeking assistance were over 65 years of age. 23% were between 56 and 65 years old. Additionally, 23% were covered by Medicare or Medicare/HMO. PAF also continues to educate and enroll seniors into the Medicare Drug Discount Card program. In anticipation of the 2006 rollout of the Part D Prescription Drug Benefit that is a part of the Medicare Modernization Act, PAF, with the assistance of the Publications Committee, produced a new brochure in the "A Greater Understanding...." series entitled, Medicare Modernization Act of 2003's Prescription Drug Coverage through Part D. This brochure is oversized with large print and provides a summary of the prescription drug benefit, including examples of what drug costs may be under Part D. It has also been translated into Spanish for use in the National Hispanic/Latino Outreach Program.

A Greater Understanding.

Medicare Modernization Act of 2003's Prescription Drug Coverage through Part D



# **Centers for Disease Control and Prevention Grants Update**

# CDC/PAF Hematologic CancerEducation and Outreach Partnership

In September 2004, PAF received notification from the Centers for Disease Control that we were the recipient of a second CDC grant for a period of three years. The National Organization Strategies to Provide Information and Education for Patients. Their Family Members, Friends and Care Givers With Respect to Hematologic Cancers strives to provide outreach and education to patients, their caregivers and family who are dealing with the issues of a hematologic cancer. Project staff attends numerous national events targeting this population and has built many new relationships within the hematologic cancer community. Once a national event has concluded, program staff then provides targeted outreach at the local and regional level while in the area, again to the hematologic cancer patients. PAF has exceeded the quarterly goals of providing direct outreach to 125 patients during the first three quarters of implementation.

#### CDC/PAF Cancer Prevention and Survivorship Partnership

In August 2003, the Patient Advocate Foundation received notification from the Department of Health and Human Services, Centers for Disease Control and Prevention that we had been approved for this five year grant request. This project funds direct patient services and outreach to cancer patients from targeted minority populations and is an integral part of the CDC's Early Detection Or Survivorship of Cancer in Underserved Populations initiative. PAF proposed to increase the survivability of cancer patients and enhance access to medical and social services by removal of barriers blocking access to timely sustained healthcare across the spectrum of disease management from diagnosis to end of life care. PAF is entering into Year 3 of the project and has surpassed all objectives, increasing the number of patients to be served from an initial 100 per month to a current number of 150 per month. This is in light of the fact that PAF is currently serving, on average, 318 patients in this program per month.





During this fiscal year, PAF has developed an exciting partnership with the Lance Armstrong Foundation (LAF) to provide direct case management services to referrals from their LiveStrong Survivor Care call center counselors. Patients who call into the LiveStrong program, if in need of the services provided by PAF, will be directly referred to PAF to obtain those services. This new relationship is one that will open the door for new patients who are in need of PAF services.

Publications

Patient Advocate Foundation's created two new publications during the last fiscal year. The first is for use in the National African American Outreach Program and is entitled Promoting a Healthier African American Community and provides symptoms, risk factors and resources for those diseases that affect the African American community on a more regular basis.

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m edic}_{
m are}$ In preparation for the roll out of the Part Modernization D Prescription Drug Benefit that is a part Act of 2003's Prescription of the of the Medicare Modernization Act in January, 2006, the Publications Committee created the latest addition to the "A Greater Understanding...." series of brochures, Medicare Modernization Act of 2003's Prescription Drug Coverage through Part D. This publication, targeting the medicare population, is oversized with large print and is



Promoting a

Healthier

African

American

Community

 $D_{rug}$  $C_{ove_{rage}}$ 

through

available in both English and Spanish. Additionally, Your Guide to the Disability Process has been translated into Spanish this year.

PAF also updated its Corporate Brochure, along with the corporate logo and accompanying corporate materials. The Corporate Brochure is available in Spanish as well.

# 2005/2006 Fiscal Year Forecasting for Direct Patient Services

- In July of 2005, PAF implemented the Patient Access Partnership Program (PAPP), with a goal of improving awareness and utilization among oncology and hematology patients being treated in the community oncology setting. PAF case managers will work directly with facility staff to assist the practice with payer reimbursement issues, specifically on an individual claim basis and on claims that the practice may be at the point of writing off as uncollected debt.
- PAF is aggressively pursuing participation in the federal contracting arena through the Management Organizational and Business Improvement Services (MOBIS) process and through the Indefinite Delivery/Indefinite Quantity (ID/IQ) process. This is an additional way that PAF is diversifying its income.

# Media Relationships

In 2004/2005, Patient Advocate Foundation and its programs and services, were featured in numerous print and broadcast stories. These media outlets include:

- The Wall Street Journal
- MSNBC Nightly News
- Oncology Associates Member News
- The Daily Press
- Inside Washington Publishers' Inside CMS
- News Pro Net
- Houston Chronicle
- U.S. News & World Report
- St. Louis Post Dispatch

# Patient Advocate Foundation Resource Room

PAF has a Resource Center that works in conjunction with our case managers to educate and empower patients in areas in which they have specific need. Each case manager identifies which publication and/or tapes are most appropriate for the patients to receive from our more than 400 selections; therefore each Patient Pak is customized to the patient. These Patient Paks are extremely beneficial and empowering particularly when partnered with direct service of case management support. Many of the educational pieces are available in Spanish. The PAF Communications Department mailed out over 11,000 customized Patient Paks to patients with information selected specifically to answer their particular questions in fiscal year 2004/2005.





On February 26, 2005, PAF held it's fourth annual *A Promise of Hope Affair* at the Omni Hotel-Newport News. Our 314 attendees had the opportunity to bid on over 175 silent and live auction items, dine and dance the night away to the sounds of Slapwater. Barbara Ciara, anchorwoman from the local CBS news affiliate served as Mistress of Ceremonies for the evening. Funds raised from *A Promise of Hope Affair* support the direct patient services provided to patients. This event also fosters the relationships with local organizations who provide their support.

### Honorary Chairpersons

Barbara Ciara, Managing Editor and Evening News Anchor for WTKR-TV3

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# PAF Receives Federal Appropriation

Through the work of Senators John Warner and George Allen, Patient Advocate Foundation was the recipient of an appropriation in the Federal budget for the second year in a row. PAF received \$148,800.00 to provide support for providing direct patient services. This appropriation is an increase over the appropriation received in 2003/2004.



# Combined Federal Campaign and Combined Virginia Campaign

PAF continues to participate in the Combined Federal Campaign (CFC) which was established by the United States government as a way for Federal employees to support their charities of choice. PAF's CFC number is 1240.

PAF also participates in the Combined Virginia Campaign (CVC), giving Commonwealth of Virginia employees the opportunity to support charities. PAF's CVC number is 1540.

# ForSociety.com and IGive.com

Patient Advocate Foundation is a participant in ForSociety.com and IGive.com. By linking with these sites to do your online shopping and travel, you can designate PAF to receive a donation form the retail vendors who participate. Each shopping site has a different percentage donation and is a perfect way for donors who shop online to donate to PAF.



"My case manager worked diligently to help me resolve my insurance issues.

I think of her as my "friend," not as my case manager."

--Acme, PA

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(as of June 30, 2005)

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# PAF's Cancer Gold Standards

In 2004, the National Institute of Health initiated a program The CEO Cancer Gold Standard that addressed five areas of cancer prevention:

Tobacco Use

Screening and Early Detection

Diet and Nutrition

Physical Activity

Access to Quality Treatment and Clinical Trials

Patient Advocate Foundation embraced this program and instituted our own PAF Cancer Gold Standard Program. PAF became a smoke free workplace and offered smoking cessation programs for the employees. Email alerts were sent notifying staff about local cancer screenings and ensuring that staff insurance coverage contained cancer screening and clinical trial provisions. PAF co-sponsored an in-house 10 week Weight Watchers program along with quarterly healthy pot luck lunches. Three days per week, the opportunity is available for staff to walk outside for 30 minutes and PAF paid for a percentage of a staff members gym membership. And again, the health insurance benefits offered to staff provides access to cancer care at appropriate treatment facilities.



Nancy Davenport-Ennis, CEO, President Founder Patient Advocate Foundation, Inc. National Headquarters Newport News, Virginia



The Patient Advocate Foundation is comprised of three Board of Directors, an Executive Board, Scientific Board, and Honorary Board.

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Richmond, Virginia

#### Honorary Board

The Honorary Board members are either cancer survivors or immediate family members of cancer patients. Their role is to provide support and direction to the patients who seek support from this foundation through networking with programs that we have in place as well as referral to additional national support programs.

Paula Rieger Director, International Affairs American Society of Clinical Oncology Alexandria, Virginia

**Doris Simonson** Mother of Cheryl Grimmel Monmouth, Maine

**Pearl Moore, RN, MN, FAAN**Chief Executive Officer, Oncology Nursing Society Pittsburgh, Pennsylvania

The Honorable Mary T. Christian Virginia House of Delegates Hampton, Virginia Leo Sands Executive Vice President & Chief Administrative Officer US Oncology Houston, Texas

#### Scientific Board

Jeffrey Wolf, MD

Director, Bone Marrow Transplant Unit Alta Bates Comprehensive Cancer Center, Berkeley, California

Dennis A. Gastineau, M.D.
Director, Human Cell therapy Laboratory
Divisions of Transfusion Medicine & Hematology
Mayo Clinic
Rochester, MN

Richard L. Theriault, D.O., M.B.A. Professor of Medicine MD Anderson Cancer Center Houston, TX Lori Williams, RN, MSN, DSN ©, OCN, AOCN MD Anderson Cancer Center Houston. TX

F. Marc Stewart, MD

Professor of Medicine, University of Washington Fred Hutchinson Cancer Research Center Seattle, WA

Robert M. Rifkin, MD, FACP

Director, Rocky Mountain Blood & Marrow Transplant Program Rocky Mountain Cancer Centers Denver, CO

Otis W. Brawley, MD
Professor, Emory School of Medicine
Emory University
Atlanta, GA

Foundation Resources

Corporate Attorney of Record James C. Smith, Jr., Esquire Yorktown, Virginia

#### Patient Advocate Foundation

#### Statements of Financial Position

June 30,	2005		2004
Assets		·	<del>-</del>
Current assets			
General operating cash and cash equivalents	\$ 1,197,904	\$	360,643
Restricted CPR cash and cash equivalents	4,957,855		768,471
Unconditional promises to give	37,574		216,404
Interest receivable	43,913		4,520
Employee receivable	954		-
Due from NPAF	74		-
Inventory	51,539		3,421
Prepaid expenses	17,694		8,040
Investments	 1,750,680		1,753,129
Total current assets	8,058,187		3,114,628
Property and equipment - net of accumulated depreciation	217,071		250,202
Other assets			
Refundable deposits	 10,254		10,084
	\$ 8,285,512	\$	3,374,914
Liabilities and Net Assets			
Current liabilities			
Accounts payable and accrued expenses	\$ 148,513	\$	74,899
Deferred revenue	511,875		-
Accrued vacation leave	84,198		50,197
Current portion of leases and notes payable	-		3,246
Total current liabilities	744,586		128,342
Long-term debt - less current portion	 -		1,291
Total liabilities	 744,586		129,633
Net assets			
Unrestricted	723,400		444,571
Temporarily restricted	4,957,855		984,875
Permanently restricted	 1,859,671		1,815,835
Total net assets	 7,540,926		3,245,281
	\$ 8,285,512	\$	3,374,914

The accompanying notes are an integral part of these financial statements.

Patient Advocate Foundation

# Statements of Activities

Years Ended June 30,								1
		2	2005			2 (	2004	
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Revenues, gains and other support Contributions								
Grants	\$ 3,329,967	\$ 5,711,250	,	\$ 9,041,217	\$ 2,152,777	\$ 1,216,404	\$ 250,000	\$ 3,619,181
Private and public donations	23,741	•	1	23,741	19,429		. '	19,429
Donated services and materials	129,563	1	r	129,563	533,660	1	ı	533,660
Patient Congress	192,255	1		192,255	126,660	ı	•	126,660
Promise of Hope	145,735	1		145,735	88,106			88,106
Special events	134,471		•	134,471	26,000	1	3	26,000
Investment income	101,346	ı	43,836	145,182	4,036	ı	12,766	16,802
Net assets released from restrictions	1,738,270	(1,738,270)	•	ľ	628,460	(581,529)	(46,931)	-
Total revenues, gains								
and other support	5,795,348	3,972,980	43,836	9,812,164	3,609,128	634,875	215,835	4,459,838
Expenses								
Program services								
Patient services	1,968,656	•	•	1,968,656	2,174,331	•	1	2,174,331
Co-Pay relief	2,551,960	1	1	2,551,960	606,926	1	1	606,926
Patient Congress	206,269	1	1	206,269	224,308	•	1	224,308
Scholarships	68,514	1	•	68,514	61,298	1	,	61,298
Supporting services:								
Management and general	636,389	1	1	636,389	493,473		t	493,473
Fundraising	84,731	ı	1	84,731	143,204	1	1	143,204
Total expenses	5,516,519	3	1	5,516,519	3,703,540	ı	1	3,703,540
Change in net assets	278,829	3,972,980	43,836	4,295,645	(94,412)	634,875	215,835	756,298
Net assets - beginning of year	444,571	984,875	1,815,835	3,245,281	538,983	350,000	1,600,000	2,488,983
Net assets - end of year	\$ 723,400	\$ 4,957,855	\$ 1,859,671	\$ 7,540,926	\$ 444,571	\$ 984,875	\$ 1,815,835	\$ 3,245,281

The accompanying notes are an integral part of these financial statements.